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The Communicator

A publication of the Autism National Committee

Introduction

We hope this edition of The Communicator finds you warm in, what for many of us, is a very cold Winter. As usual, we have included a letter from AutCom President Lisa Keller. In it she shares some news about the webinars that we have put on during the last two years. Included in this issue is an excerpt from one of those webinars*: Abundance of Love: Parents of Autistic Children, Teens, and Adults Share What They've Learned*. We were very excited to be able to include an announcement of a new film written and produced by AutCom Board Member Daniel Bergmann entitled *Pointing Fingers*. An article entitled *Enacting Autism*, written by one of the Communicator's editors, describes an approach to cognition that challenges traditional conceptions of autism as a cognitive deficit and the belief that difficulties with social interaction can be blamed on individual social deficits. Also included are our regular columns: *New and Exciting*, *Resources*, and *We Applaud*. Finally, we included a request for contributions to the newsletter from our members. We particularly want to include submissions from autistics in future newsletters.

In This Issue

A Letter from the President

Last year was an interesting and active year at AutCom. We presented three more webinars in our ongoing series. Early in the year, we presented a webinar on employment, entitled “Is Work Working for Us? Autists’ Own Experiences in Seeking, Finding and Continuing Work.” The webinar and transcript are available on our website.

Later in the year, we produced two webinars on themes of friendship and more intimate relationships. In these webinars, we asked a group of autistics, both speaking and nonspeaking, to offer their experiences, and they all did so eloquently. We felt that the prevailing myth of autistics as loners and social misfits needed to be examined and dispelled. Some felt that their differences arose from what Judy Endow (and others) call the “hidden curriculum”, in which their experiences and neurology short circuited their understanding of social cues and learning social expectations. Other panelists, mostly autistics who cannot rely on their voices alone to communicate, described the barriers forced upon them by their apraxia. Apraxia, for those unfamiliar with the term, simply means the inability to make their bodies do what their minds are asking, a body-brain disconnect. They have difficulty forming connections with others, often because their unusual behaviors and lack of speech or limited speech make a poor first impression.

So what did we learn? Breaking news: most people want to have real friends and the chance at an intimate relationship, be it sexual or emotional (and preferably both). Autistics need ways to make friends and keep them. That is difficult in a time when people interact face to face far less than previously, no matter their neurology. Suggestions from the panel to autistics were that if they are in a community with other autistics, consider hosting a live or virtual event with others. Talk to each other, share what’s important to you. Advice to all is to keep all meetings and virtual gatherings respectful, open-minded, and accessible.

My thanks go to all who participated. The recordings of the webinars will be available soon, on our website.

What’s in store for 2025? That depends on what you—autistics and others—are looking for. This is a national organization, and we want to widen our reach, continuing to listen to those with differing viewpoints and experiences. So, if you have something you think is worth discussing, we’re listening. Let us know by sending us your comments and questions to info@autcom.org. Also, we welcome any submissions for our newsletter, from prose to poetry to artwork.

I hope you all had a wonderful holiday season and start to the New Year, and we invite you to work with us to bring the urgency of connection, inclusion, and social justice for all autistics to the forefront in 2025.

Lisa Keller

New and Exciting

Film: Makayla's Voice: A Letter to the World, a new documentary short directed by Julio Palacio (23 minutes). “A teen with autism unlocks a joyous world of self-expression as she shares her voice for the first time using a letter board in this short documentary.” Tribeca Festival Best Documentary Short 2024, Cleveland International Film Festival Best Documentary Short. (Available for a period of time on Netflix.)
https://makaylasvoice.com/

Film: My Name Is Siri – A documentary (25:09). Siri is a college student and jewelry designer who uses a letterboard to communicate. She describes herself as a “REBEL.” Emmy Awards Nominee. (Available to view on Kinema until July 1, 2025.)
https://www.mynameissiri.com/

Documentary in the works: “I Have Been Buried Under Years of Dust,” a documentary based on the memoir of the same name by Emily Grodin, will be produced for broadcast in the USA on public television by Orchard Pictures, Okay Goodnight, LLC and ITVS.
https://valeriegilpeer.com/

Resource: Communicating in Times of Stress. Communication FIRST.
Part One: A Resource for People with Speech-Related Disabilities and Mental Health Conditions.
Part Two: A Resource for Lifeline Workers and Other Allies:
https://communicationfirst.org/communicating-in-times-of-stress/

Book: In Their Words… A documentary novel, by Kathleen Berger. “A documentary novel detailing the history, controversy, and science behind supported typing” that uses “fiction with nonfiction excerpts” and “lays out the facts about the supported typing technique that has changed many lives.”
https://accessingautism.org/product/in-their-words/

Resources

Articles

A Self-Advocate’s Perspective on a Person-Centered Approach to Employment for People with Disabilities by Nicole LeBlanc. August 22, 2024

https://aoddisabilityemploymenttacenter.com/a-self-advocates-perspective-on-a-person-centered-approach-to-employment-for-people-with-disabilities/

Long-term ABA Therapy Is Abusive: A Response to Gorycki, Ruppel, and Zane. By Gary Shkedy, Dalia Shkedy & Aileen H. Sandoval-Norton. Open access. Published: 09 April 2021. Volume 5, pages 126–134, (2021) Advances in Neurodevelopmental Disorders.
https://link.springer.com/article/10.1007/s41252-021-00201-1

Books and other print

The Caged Bird. By Gregory Tino and Ros Webb. The author notes that “It has beautiful illustrations and an important message for people with challenges in their life. Proceeds from book sales will be donated to Inside Voice, where [Tino] learned the Spelling to Communicate method.”

Planning Your Career Through Intense Interests: A Guide for Autistic People. By Yenn Purkis and Barb Cook, autistic advocates, employees and business owners.
https://us.jkp.com/products/planning-your-career-through-intense-interests

A Self-Advocate’s Guide to Safer Sex: What Do I Need to Know About Sexual Assault? By ASAN (Autistic Self Advocacy Network). Two important resources together as a part of their Proud and Supported Series. Both are available in Easy Read and plain language formats.
https://autisticadvocacy.org/resources/proud/

“Snoopers & Sneakers,” a middle grade novel written by autistic advocate Lydia Wayman and Cristina Rouvalis. Orange Blossom Press. Coming in January 2025.
https://www.orangeblossombooks.com/lydia-wayman.html

Square Me, Round World: Stories of Growing Up in a World Not Built for You. By Chelsea Luker, Autistic/ADHDer psychologist from NSW, Australia (and founder of Connect Us Psychology) and Ilustrated by Eliza Fricker
http://www.connectuspsychology.com/shop/

You're Going to Love This Kid!: Teaching Autistic Students in the Inclusive Classroom Third Edition, by Paula Kluth Ph.D. (Author), Paula Aquilla (Contributor), Kelly Chandler-Olcott Ed.D. (Contributor), Christi Kasa-Hendrickson Ph.D. (Contributor), Eileen Yoshina M.Ed. (Contributor). Brookes Publishing Co.

Film and Video

Tilted Thinking, Wanting Ways, Our Neurodiverse Future with Imane Boukaila, Chris Martin, & Adam Wolfond (live feed, 1:37:00; program starts at 0:14:30). “You are invited to an evening of tilted thinking, hydrated languaging, and trespassing truth. In celebrating braided and liberatory new books, Chris Martin, Adam Wolfond, and Imane Boukaila desire greatly to rally and gather, motion and scatter. Meet us here, where ‘the ways of threes are partly laking partly iridescent.’”
https://www.youtube.com/live/oLJhh6m1ux8?feature=shared

Podcasts

My Words are My Voice: the (un) spoken words from individuals within the Autism community. Rich Specht. “Non-speaking autistic individuals have written short stories, poems, profound feelings, philosophical views, and comments on current social events. None of which have been personally verbalized. You will be brought into the minds, hearts, and souls of some very talented, intelligent, creative and remarkable human beings known to be non-speaking. Our world becomes a better place when we all really listen to what's being said.” Monthly podcasts that started in May 2023.
https://open.spotify.com/show/4tvXIdpatYFiu9EdwBoNs0

Support

NEW Free Support - PARA Chutes and Ladders!!! From Autism LevelUP!
“An ‘in the moment’ decision-making framework for support staff who are attempting to provide safety nets and scaffold skills for the learners they support . . . a good solid reference designed to help paraprofessionals to make decisions about what types of supports might be most useful in meeting their student’s support needs in authentic and validating ways. You can download the full support for free -
https://cdn.sanity.io/files/p6bm7moz/production/d4c9e64faa19ccde9932aecf9298f7549271a1d9.pdf

Webinars – video recordings

Interoception, Physical Well-Being, and Autism with Lindsey Biel, MA, OTR/L. Hosted by CASY - Cultural Autism Studies at Yale, an ethnography project led by Dr. Dawn Prince-Hughes. (1:23:45)
https://m.youtube.com/watch?v=_XLWUaqACdU

Managing Medical Issues in Autism. By Tim Buie, Timothy Buie, MD, Attending Physician, Division of Gastroenterology, Hepatology and Nutrition. “Dr. Buie provides specific behavioral examples observed in-clinic, treatment options, and more so that you are well equipped to provide exceptional care to your GI patients with autism.” (40:48 video) Behaviors in Autism and GI Issues, Boston Children's Hospital
https://youtu.be/bsQ4PAPzmjs

Websites

The Anne McDonald Centre website, which was unavailable during redesign and updating for several months, is now up and running again. The Centre now provides video resources and information to "be helpful for families and friends of people with little or no speech." There are video resources, a "Frequently Asked Questions" section, tributes to Rosemary Crossley and Anne McDonald, and stories.
https://annemcdonaldcentre.org.au/

Excerpts from Webinar: Abundance of Love: Parents of Autistic Children, Teens, and Adults Share What They've Learned

AutCom Presents:

FREE ONLINE WEBINAR: SATURDAY, APRIL 29TH
ABUNDANCE OF LOVE: PARENTS OF AUTISTIC CHILDREN, TEENS, AND ADULTS SHARE WHAT THEY'VE LEARNED

Register Here
Registration in Advance is Required*

11:00am – 1:00pm ET | 10:00am – 12:00pm CT | 9:00am – 11:00am MT | 8:00am – 11:00am PT

Moderated by Lisa Lieberman, MSW, LCSW is an Oregon psychotherapist in private practice with over 45 years of experience.

Marie Giongo
Sara Arshad
Danielle Vauthy
Dennis Mashue
Sharon Koeppl-Medina
Paul Bakeman

Visit www.autcom.org to learn more about Autism National Committee

We are pleased that we can finally release the transcript of this webinar with a parent panel sharing what they have learned, held in 2023. We deeply regret that we were unable to preserve the video to upload to our website, but we have the transcript and hope that it will be interesting and informative. We plan to upload the full transcript to our website in the coming days. Below, we have shared the initial parts of the webinar, with edits for readability, starting with the introductory comments and personal insights by Board Member and host, Maxfield Sparrow, and the responses of the parent panelists to the first two questions:
1. How old was/were your autistic child(ren)/adult child(ren) when they were diagnosed and how old is/are they now?
2. Has your view of autism changed as a result of parenting an autistic person? How? Has your view of parenting changed as a result of parenting an autistic person? How?

MAXFIELD SPARROW, AutCom Board Member and webinar host: Hello everyone and welcome to our second webinar of the year. My name is Maxfield Sparrow, an autistic adult and I have not raised my own children. My understanding of parenting comes largely from having been parented. I want to talk to you for a minute about my dad who was very clearly autistic but never diagnosed because he came from a time when only autistic people with the very highest support needs were recognized.

I learned a lot about parenting by being parented by him. My dad was a very good father and he was a human being who make mistakes. The first thing I want to tell you about that I learned from him is it's good for a parent to apologize to their child. It was hard for him to apologize to me and it was hard to hear him apologize but I accepted it and I treasure the memory of his willingness to be vulnerable with me. Let your children see you being human.

I struggled growing up and my father supported me through many of them but there are other struggles that would trigger something in him. For example, I would hear him shouting in tears over my handwriting. The shouting was his and the tears were mine. My handwriting was awful and all the stress we went through together did not fix my penmanship. It did not occur to me at the time but his handwriting was terrible as well, too. Of course, my cursive writing was even illegible to him. He was getting triggered by me for not been able to do something he cannot do either. That was when I learned the second thing that I want to share about parenting. Parents get triggered because of love and fear. My father loved me, and wanted me to have a better life than he had.

When he saw me having the same struggles he had and making the same mistakes, his fear for my future would grow and sometimes, even affected the things he wanted to do or say from a place of love. No matter what he chose to do, though, I don’t think my handwriting would be great. If I want to write something legible now it's slow and I approach it like I'm drawing the letters.

I wish dad was more patient with my dysgraphia though. He apologized to me in my twenties and for all the battles we had over my handwriting. It was easier to forgive him because all my life, he let me see him as a real, flawed, loving human. Even though I never parented my own child, I tell you what makes for a good parent because I was raised by my daddy.

Listen to your children, believe them, validate their experiences, create a safe place for them to express who they are without fear of being harshly judged. Be willing to be vulnerable sometimes with your children. Be human, apologize when you've gone astray and remember to let your love be bigger than your fear.

The parents we have assembled in this panel will have far more impactful things to say because they have been actually raising children for years. Some of these parents are people I know, and respect deeply. Others are new to me and I'm eager to hear what they have to say because I know I'm going to be developing deep respect for them as well as, too. I know people who invited these parents to be here today, so I know we will hear from some high-quality human beings. I will leave you with this thought: yes, you absolutely must remember to let your love be bigger than your fear.

And love alone is not enough. To parent well, you need love and you need community. Never stop listening to your children, listening to autistic teens and adults, listening to other parents, never stop thinking and learning. No one is born automatically knowing everything they need to know to be a loving and effective parent. Never judge yourself harshly because you did not know something. Keep listening and learning because being the parent your child needs and deserves, is a lifelong journey. Thank you. I will turn it over to Lisa.

LISA LIEBERMAN, Moderator and parent: I'm a parent to a wonderful 34-year-old man, Jordan. He prefers person first language, although that may not be my first choice. He's a man with autism. He is turning 35 next month and for about the last six months I've never been able to say it out loud, and he told me to get over it. Anyway, I'm honoring Jordan by being here today, and I'm also a clinical social worker. I've been in private practice working with people with different kinds of differences on disabilities, which is my specialty. Most importantly, I was on the board of the Autism National Committee for years. My own situation prevented me from continuing to be directly involved, but it's always been close to my heart.

It's nice to see a few familiar faces here. I know there has been a big changing of the guard. We will get started. By the way Max, I love what you had to say. I was taking notes here. Really beautiful points that you made. I took them to heart as well as the parent. Thank you for that. So, we will start with the person who has the youngest child with autism. That would be Danielle Vauthy. So tell us about how old your son was when he was diagnosed and how old he is now.

DANIELLE VAUTHY, Parent panelist: Matteo was diagnosed when he was 12, in the middle of the pandemic. He is about to turn 14. When he was eight he was diagnosed with ADHD inattentive. So, it's been about five years of challenges trying to assess what he needs. When he was 12, he was fully diagnosed with autism.

LISA LIEBERMAN: You haven't had all that much time to get used to the diagnosis, but how has your view of autism changed as a result of parenting Matteo?

DANIELLE VAUTHY: My mom is an augmentative communication specialist. She did her graduate work when I was growing up. I was always with her during that time, so I've been around autistic people in the community since I was little. I also went to her classroom when she was teaching. I had an understanding of it but I didn't live it. So, I understood it from more of the teacher perspective and the daughter of a teacher. It's definitely different when you live it. It's definitely not scary when you live it. When you get a diagnosis of anything it's the unknown that is scary.

I think it's just become a part of his personality and who he is. I definitely do. I have two other children, and we parent children differently based on their needs, whether or not they have a diagnosis. It's just part of his personality, and, being a parent, you really flex. The most important thing is flexing based on what your children needs. I think what's changed is I realized it's part of who he is. And he will have different needs and I will have to be having varied expectations. Just like every child, they all have different needs and expectations.

LISA LIEBERMAN: So, you went to the second part of the question. What I hear you saying is you learned that parenting needs to be very individualized to the needs of our children. That applies for all children. How has your idea of parenting changed in this time? How has your view of parenting changed as a result of parenting your son?

DANIELLE VAUTHY: I think I went into parenting thinking I had all the answers. I thought I could figure everything out. I would describe my parenting style when I first became a parent as defined “by the seat of my pants.” I will address things as they come, I'm smart, I figure it out. I realized with neurodiverse children and all our children for that matter, that being very deliberate and thoughtful and anticipating and setting them up for success are so important. You know, just having structures, expectations, and boundaries which I didn't really have. That was a huge learning curve for me because it really changed the way that I operate in the world. You know, without children, you can kind of fly by the seat of your pants and you can get by but with children, you really need to have a plan. You really need to set up your children for success.

The other thing that really changed for me is that I stopped looking at parenting as a sprint but really as a marathon. I think initially, I would look at an individual issue that we were having, or difficulty, and I would try to problem solve my way out of it, and so I would miss the forest for the trees. So, we are really seeing my son bloom, and he is really starting to socialize and find his place in the world. I don't know if I would have ever been able to get to that point if I didn't take a step back and take a breath and know this really is a marathon. I'm going to be his mom for the rest of his life and I'm going to be supporting him for the rest of his life. It is not just that one moment. Giving yourself perspective and giving yourself a lot of grace and give your children--your child--grace is so important.

LISA LIEBERMAN: Beautiful. What I am hearing is, I think, is that maybe it would have been less structured, less boundary setting in terms of your comfort level, but this kind of forced you to re-create -- forced you to regrade your parenting style.

DANIELLE VAUTHY: It really did and it was really hard (Laughs)

LISA LIEBERMAN: Next, we are going to go to Dennis Mashue. How old was your son when he was diagnosed?

DENNIS MASHUE, Parent panelist: Tucker was 2 ½ when he was diagnosed with PDD-NOS, because back then, no one wanted to come out right and say autism. About age 4, he got the formal diagnosis of autism.

LISA LIEBERMAN: He old now is?

DENNIS MASHUE: 24.

LISA LIEBERMAN: 24! OK. And maybe you could address how has your view of autism changed in 22 years?

DENNIS MASHUE: One thing that has happened in the 22 years is about 18 months ago, I was diagnosed as autistic with ADHD. What I came to believe, the more that I interacted and met other autistic people, I came to understand that autism is really a positive quality if you can figure out, as my friend Dena put it, we don't grow out of autism, you grow into it. -- Grow into it. I see a lot of positives. ADHD is a little matter that is a little bit more difficult. I learned to see that most autistic people that I know seem to be very intelligent. I think that is a big positive that is not always seen. That would be the biggest change for me.

LISA LIEBERMAN: Of course, we have different definitions of intelligence.

DENNIS MASHUE: Right.

LISA LIEBERMAN: We all know how worthless the IQ tests are for a lot of this population but, I mean, my son has incredible emotional intelligence and sensitivity. OK, and then, how has your idea of parenting changed as you grow into your own autism and your son's?

DENNIS MASHUE: When my son was 14, 15, I was 50. That was when I came to the understanding that there was a genetic component. I came from Michigan, which still is kind of in the dark ages with regard to understanding autism and neurodiversity. It has been a long learning curve. My view of parenting changed and that, I think it is important for parents to get over ourselves when we understand that we have a child with autism. And even if you don't have a child with autism, being a parent is not . . . it is not about us! The goal should be to raise good humans as whatever type of human they choose to be. The way autistics explain it is to meet them where they are, take their hand, and walk beside them.

LISA LIEBERMAN: That is interesting because I am thinking about what Max said earlier about showing our humanness to our children and sharing our errors, and maybe that is not contradictory of what you are saying, maybe it is a different dimension. It is something, when I'm working with parents of autistic kids or autistic adults as well, I coach them to start showing their own human foibles. In that sense, it is not always about the child or the adult with autism. I don't know if that makes sense, so often, they continue trying to parent rather than allowing themselves to go to the developmental steps that we have to go through as parents, in order to accommodate our kids as they develop. There is kind of a balance between, it is not about you and yet at some point, I think it is really helpful for them as they become adults, to become aware that their parent is also a human who makes mistakes and has needs.

DENNIS MASHUE: Absolutely. I think one of the most important things we can learn in that process is, yeah, we are going to make mistakes and after we make mistakes, let's sit down and talk to our child about what mistake we made and that we apologize and we are trying to have better behavior. You know, just like we would expect of them, we need to expect of ourselves.

LISA LIEBERMAN: So, Marie Giongo, tell us about how old your son was when diagnosed and now.

MARIE GIONGO, Parent panelist: Our son, Michael, is 30 years old, and will be 30 in a couple weeks, so if anyone wants to wish him a happy birthday. It is a milestone. He was officially diagnosed when he was 2 1/2 but we had started the journey much earlier, back in the day; fortunately, it wasn't as prevalent a diagnosis as it is today. It took a little while, initially.

I always kind of knew something . . . I was trying to figure out the puzzle piece. Something just wasn't right so I knew, as a mom, intuitively. I guess when he was a little over a year, my in-laws came to us and they said, "Hey, we think he may be hard of hearing." Because they knew a child who was hard of hearing, and Michael was exhibiting the same type of behaviors. He wouldn't turn when we called him, that kind of thing.

We had his hearing checked and eventually that led us to a developmental psychologist. He said, he can't make the formal diagnosis “until I see him at least twice and I’m really tracking his progress versus a one-time snapshot.” So, we didn’t start with him initially, but we did start right away on early intervention, which I am a huge fan of. I think it truly is a gift, to be able to get it the sooner, the better., whenever the diagnosis is made, and then the journey began.

He was officially diagnosed 1-2 weeks before Christmas. You know, I guess I will jump ahead a little bit but for the question where how it changed or your view of autism changed. Sadly, it was almost like we were given a life sentence and that . . . We were literally told, "We were sorry to tell you." We were pregnant at the time and they are like, "We are sorry to tell you that your next child is a boy." Why? He is a gift. We didn't process it that way . . . we don't look at it that way. Yes, it has been a long journey.

To me, autism is a word full stop. It is a way that someone sees the world. I don't care what you call it, it doesn't change the human being who is in front of me. It doesn't change who he is, what his gifts are, what his challenges are. It is the same way for all of us. I just look at it, we look at it as a word, where we needed to do that way.

LISA LIEBERMAN: Was he the oldest?

MARIE GIONGO: He is my oldest.

LISA LIEBERMAN: It takes a lot of parents years to know what you had found at the beginning. It is kind of remarkable, actually.

MARIE GIONGO: It is freeing for me because what some of the other people have expressed. You want them to have the best life, but for us, I think you realize the expectations that are put on you, and then your child, through a societal lens. So, for us, it was freeing, because those expectations kind of went out the door, and it really became focused on we wanted him to be the best. We have to backup our talk and we wanted him to be the best person he could be and help him find his potential.

When he was first diagnosed, we had a quote unquote expert, say to us, when I asked something about college and he/she was speaking about a 2 1/2 year old, and he/she was like, "Sweetheart, you will be lucky if he makes it to high school." Who are you to set his expectations? Now, he is so accomplished. You know, it is amazing! If we had listened to this person, what do they know? For us, it was being able to say, no, we are going to allow him to be the best. He wanted to be the best Michael. He had to figure out what made Michael up. My husband played professional sports so Michael was a big kid and people would look at him and say, "You want him to play football?" My husband was like, no, I want him to talk.

It freed us that way. It freed us for our other children because we were able to translate that to them as well. You know, I really look at it as a blessing. Do I wish the child to have some of the challenges he had? Of course not. I also think it makes them the people who they become. I am so grateful for him. It doesn't define him, it just let me know who he is and where he comes from. I believe we are all neurodiverse. You know? It is really our perspective.

LISA LIEBERMAN: So, you walked into that situation having not been a parent. And having now been a parent. How has your view of parenting changed as a result of parenting Michael?

MARIE GIONGO: I just think as for everything, it is really about seeing each of your children as human beings. I think it translates to the outside world as well. It is about seeing who they are and helping them become the best person they can become. As stated earlier, of course you're going to make mistakes but we always told our children, whenever we made mistakes, we were doing the best with what we knew at that time. We have always had your best interests at heart. It is really about making it about helping them find who they are. It is really about trying to make them the best people and prepare for whatever opportunity life was going to give them or challenges.

LISA LIEBERMAN: That is wonderful. I look forward to hearing from you when we get to the next question. Our next person is Sharon Koeppel-Medina. How old was your son when he was diagnosed?

SHARON KOEPPEL-MEDINA, Parent panelist: Chris had normal development up to 2 1/2, crawled, walked, speaking, and played with other kids and being social. And then all of a sudden, at age 3, things changed. He started losing his language and amounted to having a very limited ability to verbally communicate his wants, needs and thoughts, which was one of the hardest times for me. But I have two children, I was a single parent. I knew that it was going to be up to me to raise my two children. So at age 3, when he attended the screening at his local elementary school, of course he scored very low in expressive language and fine motor skills. But his receptive language was off the charts. I knew he was intelligent. I knew he understood everything that was being said to him, and anything he was exposed to. He was very confident.

I think I said that, but at age 3 he was diagnosed with pervasive developmental disorder. That was pre-autism. Later, at age 5 he was diagnosed with autism. He is now aged 40, just turned 40 this year. When we moved to Vermont, he started attending a preschool half a day. I guess that's when the first signs were noticed, that it was difficult for him to socialize, with other kids. He kept to himself, he loved books, because I read to him all the time--even when he wasn't even born yet. She [the preschool teacher] would find him off by himself reading a book.

LISA LIEBERMAN: I will interrupt you because I want to note that you had a lot of experience with neurodiverse kids prior, I'm assuming, because you've been a special educator for years. How did your view of autism change after his diagnosis?

SHARON KOEPPEL-MEDINA: I have to say, I worked with a lot of different children with varying levels of abilities. But I'd never worked with a person with autism before. Back then, 40 years ago, they were still saying that the diagnosis for autism, you know, was because of the mother. And then when he was finally diagnosed as having autism, I went to the medical library and read everything I could possibly read about autism. What treatments were, what programs would work and whatever. To be honest, I wasn't pleased with what I was reading. There was no mention of his ability level, only his disabilities.

He went to a preschool program and he was eligible on expressive and fine motor skills in kindergarten. Fortunately, we were originally from the Midwest. My brother was doing a sabbatical at UVM and came to visit when Chris was only about one-year-old. I fell in love with Vermont just like most people do when they come here. Little did I know I would have an autistic son, and little did I know what kind of education setting he would be offered. Luckily, Vermont was always an inclusive state since the closing of the only training school in Vermont.

LISA LIEBERMAN: Is your other child older or younger?

SHARON KOEPPEL-MEDINA: Older.

LISA LIEBERMAN: You had parented a less neurodiverse person and then you had your son diagnosed. How did your view of parenting change as a result of parenting him, after having a child previously?

SHARON KOEPPEL-MEDINA: I had to literally get myself inside his head. Watch all of his movements, see his behavior and speech. What was he telling me to do?

LISA LIEBERMAN: Is it different from what you are doing with your older child?

SHARON KOEPPEL-MEDINA: Absolutely.

LISA LIEBERMAN: How did that evolve for you from who you were as a parent prior?

SHARON KOEPPEL-MEDINA: I still believe I was going to make sure that Chris was offered every opportunity my daughter had. Fortunately, the elementary school was pro-inclusion and he was never in a special class. He was educated alongside his peers K-8. Then the big change for Chris was when he was in second grade, he had an assistant working in his classroom--Alan Kurtz, who I think many of you know. Alan was hired through Washington County services. He had heard about something called Facilitated Communication, Rosemary Crossley from Australia, and her work. He actually invited me to speak with him, to see if I would be interested in this for Chris. And what it could offer him. I could talk for hours about that initial time spent with Alan. But he had literally changed before my eyes.

LISA LIEBERMAN: I know Alan, I was on the board with him for many years and he is really a sweetheart.

SHARON KOEPPEL-MEDINA: It's funny because he came back two or three different times and each time, Chris understood what it was he needed to do. He moved from his finger to his upper arm in three weeks. They invited me to come. I was a teacher as well so I couldn't get off of school.

LISA LIEBERMAN: Thank you, Sharon. We will move on to Sara Arshad. Tell us about when you are child was diagnosed, and how old they are now.

SARA ARSHAD, Parent panelist: Yasmin was born in 1974 so she is 48 right now. She is our third child. Apart from having a grand mal seizure when she was six months old, she was a lovely -- lively, feisty, neuro-typical chatterbox. When she was three years old, she caught a seemingly mild version of the chickenpox along with her siblings who had a far more severe case of it. Of course, she seemed to be doing really well, no fever, no reaction really, until one evening she suddenly stiffened when she was standing on a stool to brush her teeth. She fell backwards. Fortunately, I was there and caught her. But, from that moment, her personality changed. She temporarily lost language for a few weeks. All language. She had temper tantrums for seemingly no reason, and from that day on, she had seizures. We were living in Italy at the time, and the doctors there were completely befuddled.

So we came to Boston, to Children's Hospital, and eventually she was diagnosed with temporal lobe seizures. Then there was a mention of possible encephalitis which may have caused the stiffening of the body. So, at the beginning, we thought we were dealing with a child with epilepsy. We therefore attributed all her behavioral issues to her medications. Eventually when Yasmine was about 5-6 she had a core evaluation and at that time she was diagnosed with pervasive developmental delay. The temporal lobe seizures continued along with continued trial and error to establish which medications would work best.

Then the temper tantrums continued. Eventually, when Yasmin was in her late teens early twenties, she gradually lost the desire to use her verbal language. And her teachers told us that she would not progress intellectually beyond the intellectual capacity of a 12-year-old. And so they basically gave up trying to teach her how to read and write. However, it was not until Yasmin was in her twenties that we first heard the word autism attributed to her.

LISA LIEBERMAN: How is your view of autism changed over the years?

SARA ARSHAD: So, I don't think there's any real singular definition or description of autism. I think the spectrum is so vast and undefinable. But I often think people make generalizations based on characteristics of a specific autistic person they may have met or read about, or seen on TV. In my own case, since the difference between labeling from epileptic to retarded, to pervasive developmental delay, to autistic has made no difference in my daughter's life or mine. So, I've generally tried to ignore these labels.

When her diagnosis was retardation caused by encephalitis, one doctor told me to remember that tardiness, which the word retard was based on, doesn't mean you don’t get there. It just means you get there at a later point. Eventually, the neurologist explained and compared the impact of encephalitis to a short-circuit which may have blacked out certain pathways of the brain, and that the brain would eventually learn new pathways.

I've come to realize that the doctors know very little about the brain anyway. And so, I would say, that sometimes labels are convenient. It was because of her label as autistic that she was invited to be a part of her research on facilitated communication, which gave back Yasmin a voice through typing. Also, an opportunity to show the world what a deep thinker she is. I don't think my view of autism per se has changed as a result of parenting Yasmin. I would put it that parenting Yasmin has taught me patience with a capitol P. What has changed is my willingness and capacity to go beyond that facade.

LISA LIEBERMAN: Is there anything more you want to talk about how your parenting changed? Since she was your third child, I think you said.

SARA ARSHAD: Yes, I would say that I had to give her a lot of focus because her physical needs were terrifying to me. The seizures were really frequent when she was little and she would actually go through periods of time when she was having a seizure every hour and she would be passed out on the couch. This is a four-year old we are talking about. I think my parenting was very different towards Yasmin because her needs were so different from my other two. Over time, I learned that I had to actually accept who she was and actually change my parenting towards her to set the same amount of limits on her that I was setting for my other two kids. That was a hard lesson to learn because I think I had to overcome fear of causing or precipitating a seizure.

LISA LIEBERMAN: Thank you. I am hearing a very overriding theme of, let's not focus on much of the diagnosis, let's focus on who this person is. Not just from you but from several of the panelists. Next, Paul Bakeman. it is really nice to see you. It has been a lot of years. Tell us when Jen was first diagnosed.

PAUL BAKEMAN: It was kind of undiagnosed (Laughs) in a sense. Jen is older. She is now 55 and next month, she will be 56, but not tomorrow—the end of the month. So, we entered the scene when the expert on autism was Bruno Bettelheim. That wasn't a very good expert. There is a very nice book about the creation of Doctor B. It turns out he was a total fraud. He claimed to be a psychiatrist or psychologist or something and set up these prison schools in the Midwest someplace. People thought he was the right guy. He was, you know, a psychotherapist, I think you could call it.

LISA LIEBERMAN: You had a lot of years to think about autism. Your beloved wife of blessed memory, I was with her for many years and I can only imagine how things changed for you. Are you able to articulate your view of autism now from earlier? Once you figured out what it was?

PAUL BAKEMAN, Parent panelist: Initially, you could use the label of autism and get services. We lived in New York State, and if you were labelled artistic, then the educational system wanted nothing to do with you. And they put you in the mental health bucket. They kind of wrote you off. So, it was not good to get a diagnosis of autism at that time. We got clued in by Rosemary Oppenheim, who was in the mental health department and she and her husband were very early proponents of the talking typewriter. It was before facilitated communication, but they used a typewriter machine for people with autism and got a fair number of them to use it. No one would believe it but you know, she steered us away. Jen wasn't officially diagnosed until she was probably six or seven.

LISA LIEBERMAN: Well, that's early for those days.

PAUL BAKEMAN: She was significantly affected, so there was definitely something that wasn't right.

LISA LIEBERMAN: How would you describe autism now versus what you may have thought at that point? I mean, just former than the latter.

PAUL BAKEMAN: At that point, we didn't know too much about it. Really, we really don't know too much about it now, (Laughs) when you get right down to it. The diagnosis was more important along the way. We moved to Vermont when she was 10 and the reason we moved was, one, I was out of a job and the other, we had the choice between New Jersey and Vermont, and Vermont was integrated greater into the school system. New Jersey was not. So we came up here. The diagnosis, etc., gets in the way sometimes and sometimes, it helps. It usually doesn't mean much.

LISA LIEBERMAN: You have other kids?

PAUL BAKEMAN: Yes, Eric. He is three years older than Jen.

LISA LIEBERMAN: Did your parenting change after you became aware that something was different?

PAUL BAKEMAN: Oh yeah. It had to. (Laughs) The major things that helped us in our early years were friends we gained while we were in Vermont and who had a child that was Jen's age. He also had autism. They were very helpful and we got some early speech therapy from a person who was down in the Albany area. I can't remember what agency she worked through, but she always had faith in Jen, and she could see the spark in there. Jen was not speaking at the time. You know, her first words were probably when she was five or maybe six. She speaks now but limitedly.

LISA LIEBERMAN: I remember Jen sat in board meetings and danced to the beat of her own drum and delighted in it…

PAUL BAKEMAN: She likes people! She likes to hang out in the back of the room and know everyone there. (Laughs)

LISA LIEBERMAN: Well, I'm just going to share a little bit about my situation because that is the most important issue here. Jordan was also diagnosed at the age of 2 1/2 with PDD-NOS. Probably for the same reason. We had just moved to Portland, Oregon from Yakima, Washington. I called the pediatrician and he said, “of course it is something that is much milder." The first time I heard the word autism, I ventured back in my mind to the psychology classes where you see a person just rocking in their own little world. Of course, I was devastated. It took me three years from the time I wanted to have a child to the time that he was actually born. I had a lot of infertility issues, I was 38 at the time. The diagnosis was a huge blow at that point in time. Of course, my view of autism has changed so much just in the spectrum of neurodiversity, I will say that. And I do want to say one thing. We are very lucky because the first person we ever saw told us two things and he couldn't have told us better things.

One of them was, this child has had optimal parenting thus far. He honored us as parents. And then the second thing he said was, find out what his strengths are and build on them. I couldn't have asked for better information or better message from that person. At that point, I had just learned that my husband had earlier stages of multiple sclerosis. He is now completely quadriplegic with MS. and has been a very different journey for me. I said to people, "I'm going to find out about this thing called autism and I will be back." I ended up specializing in disability and differences in family from that point on and that was 32 years ago.

I am so glad I discovered Autism National Committee. I had a friendship with—and some of you will figure out who that is—and she was initially on the board and she told me that it was something that fit with my philosophy and it definitely did. I became aware of the fact that I really thought I knew about autism and when I got on that board and began being around people in learning about FC, I became a neophyte and all of those people became my teachers.

My son, I have said, was my greatest sorrow initially and my greatest teacher ultimately. All my dreams for who I thought he would be died early on and yet, I had visions of us singing together, performing together. I am Jewish and I had visions of him becoming a bar mitzvah and of course, all of the other milestones--graduating from high school, going on to college, developing a career. All of those things kind of blew apart and I think for me, I did not have an open mind view of parenting, and I fortunately had some friends who were older parents and I viewed them and I learned so much about honoring the person and honoring the individual. I would say the biggest thing that happened for me, is rather than seeing behavior on the part of a child as a “won't”, I began to see it more as a “can't”.

And that he really was doing the best he could. That was quite a process for me. I had to get help. By the time Jordan was nine, we became partners. Up until that point, it was a very, very difficult transition for me. He is now 34. He moved out a year ago into an apartment with support. It is a building for people with developmental challenges who are into the arts. By the way, Jordan and I have performed many times together. He has a driver's license, he has been working now for about 10 years, part-time, grocery stores and the gym. He is contributing.

He is a very social justice minded person, a deep, deep thinker. In the end, he has been such a tremendous blessing and I to have come around as seeing autism and neurodiversity as a continuum. And my view of parenting just did a 180 in terms of what was necessary. I don't know about you guys, but I feel if I could start all over again, I could maybe parent any child because of what he has taught me. I am very grateful for that at this point.

********* End of excerpt.

We thank all the folks who have attended this and other webinars with us. The full transcript will be on the website soon (autcom.org). We have also uploaded some of our other webinars (video and transcripts) to the website, and we hope in the future to have many more for you to view there and to share.

Enacting Autism

By Alan Kurtz

For decades, researchers have considered autism primarily to be a cognitive disability. The so-called "core" cognitive deficits were said to include a lack of *theory of mind*, *weak central coherence* (difficulty seeing the big picture), and difficulties with *executive functioning*. Researchers struggled, however, to explain the co-occurrence of these differences or how exactly they produced the constellation of characteristics we call "autism."

More significantly, cognitive explanations did not account for how autistics experienced the world differently from neurotypicals. Sensory and motor differences were either ignored or attributed to underlying cognitive issues. Presumptions about the cognitive origins of autism made it impossible to examine seriously how interaction with the environment by people with unique ways of sensing and moving could result in different ways of experiencing, understanding, and interacting with their world.

Disability studies theorists are increasingly turning to e*mbodied* approaches to explain disability. I argue here that a particular theory of embodiment, *enactive mind*, can help us understand autism both as having biological origins and as being a product of individually embodied and environmentally embedded experience. Perhaps more importantly, it has significant implications for how we support one another.

Enactive Mind.

Varela, Thompson, and Rosch (1991) coined the term *enactive mind* in their book, *The Embodied Mind.* In it they articulated an alternative to traditional theories of cognition. The foundations for their theoretical perspective were later expanded in Evan Thompson's (2007) *Mind in Life* and have since been elaborated by other researchers in the fields of neuroscience, cognitive science, human development and philosophy.

Cognition is our capacity to think, understand, acquire new knowledge, or as enactivists say, *make sense* of the world. For enactivists cognition is a complex dynamic process that is not confined to the brain. Instead, it is a whole-body phenomenon that emerges from our interaction with the larger world as physical, feeling, moving, socially embedded, and historically situated beings. It stands in stark contrast to theories of cognition that regard cognition as a symbol-manipulation process taking place entirely within the skull. In the introduction to the revised edition of *The Embodied Mind,* Thompson defines cognition simply as the "exercise of skillful *know-how* [emphasis added] in situated and embodied action."

What do enactivists mean by "skillful know-how" as opposed to "knowledge"? Let me provide an example. If you were to ask me what my friend Jay's manual sign is for "garlic bread," I would probably not "remember" it. When I am making a spaghetti dinner and Jay signs "garlic bread," I recognize it immediately. My know-how is tied intimately to the task at hand, my ongoing perceptions and actions, and my history with Jay. Context and history make this “knowledge” accessible to me in ways not possible through sheer mental effort. Similarly, I cannot tell you the combination of my gym locker, but I have the know-how to enter the right combination when standing at my locker.

Imagine pointing to the letter "t" on a keyboard, letterboard, or some other device. I cannot do that without thinking about how I would move my left index finger. When thinking about it I can even feel my finger begin to move. Regardless of whether you are typing with two hands, pointing with one finger, or using eye gaze, you probably cannot think about selecting a letter without experiencing the subtle beginning of the movements required to make your choice. For most people, knowledge of a letter's location seems inseparable from their embodied memory of physically accessing it.

For enactivists, most thinking does not occur as an abstract “off-line” activity. Instead, it is tied to our ongoing *embodied* interaction with our physical and social environments as well as our history of interaction within those environments. Thompson (2007, pp. 10-11), puts it this way:

> cognitive processes emerge from the nonlinear and circular causality of continuous sensorimotor interactions involving the brain, body, and environment. The central metaphor for this approach is the mind as embodied dynamic system in the world, rather than the mind as a neural network in the head.

Building on a foundation in *dynamic systems theory*, enactivists reject the common notion that causality flows top-down, with the brain simply directing the body’s behavior. In other words, they do not believe that our brains act as computers that tell our bodies how to move. Instead, they argue for a much more complex and nuanced understanding of the relationship among various bodily systems, personal history, perception, action, and movement. For enactivists, the individual who emerges from these complex, dynamically interacting components constitutes an *autonomous*, *self-organizing* system that is irreducible solely to either genetic or environmental influences.

Enactivists do not believe the world we experience is one that exists as an objective reality that is identical for everyone. Instead, it is one that reflects our unique ways of perceiving and acting as well as our unique history of interaction with our environment. Enactive mind theorists argue that we *make sense* of the world through participation in ongoing *perception/action loops*. We move to perceive, and we perceive to move. In doing so, we choose what aspects of the environment to which we attend and with which we interact. This is what enactivists mean when they say we *enact* our world. Rather than simply responding to and processing incoming sensory information, we constantly choose those things to which we pay attention to and how we will move in the various contexts in which we have chosen to interact. As Thompson (2007, p.15) says, the mind “discloses and presents the world.” This is not to say: “the mind creates the world." Rather, it means that the world we experience is a function of our ongoing movements and perceptions as we act and sense in real time. (Of course, people enact or make sense of autism based on their own experience and history, the ideas expressed here being no exception).

Enactivists often use the term *sense-making* to describe cognitive processes. Sense-making, according to Hanne De Jaegher (2013, p.5) is "the way we make sense of the world by moving around in it and with it (sense-making is thoroughly embodied)." We cannot separate the way a person makes sense of the world from their history of moving and perceiving within it.

It is easy to see how differences in embodiment could make a difference in how we make sense of the world. A person with congenital blindness, for example, cannot use visual imagery to navigate their environment. Likewise, a person with typical mobility may regard a particular set of stairs as an efficient way to enter a building while a person using a wheelchair may conceive of them as an obstacle. The way we make sense of something can change with *context* and *experience*. If a ramp exists as an alternative to stairs, a person using a wheelchair will probably not regard the stairs as an obstacle. Similarly, a blind person who spends time in a particular environment may develop the know-how required to navigate that environment – but with a know-how that is very different from that used by a sighted person.

Differences in embodiment can also have significant implications for social interaction. For example, Shaun Gallagher (2020) discusses the negative social consequences resulting from the bilateral facial paralysis characteristic of Mobius Syndrome. Social development is impaired not by an innate problem with social interaction, but by the failure of others to respond to someone in whom they see no facial response. The difficulty with social interaction noted in this population has more to do with their history of embodied interaction with others than to a biologically based "social deficit." More subtle differences in the way someone moves or perceives, such as those experienced by autistics, can also profoundly affect the way they make sense of various physical and social environments, the way they act within them, and with how others perceive and make sense of their actions.

Unfortunately, differences in the way someone moves and perceives are often thought to indicate intellectual or social deficits. Professionals supporting autistics often operate from this assumption and design interventions to reduce or eliminate these differences. Self-stimulation or "stimming,“ for example, is sometimes considered something that must be reduced or eliminated, even when it makes sense to a the person stimming or when it helps them cope with the demands of the environment.

Participatory sense-making

De Jaegher and Di Paolo (2007) used the term *participatory sense-making* in their explanation of soci*al cognition* (how we process, remember, and make sense of social situations). Gallagher (2010, p.12) defined participatory sense-making as: “our ability to understand the world through our interactions with others.” Essentially, participatory sense-making refers to the process through which both individual and shared understandings can emerge from social interaction.

Building on their concept of participatory sense-making, De Jaegher and Di Paolo (2007, p.493) formulated the following enactive definition of *social interaction*:

> Social interaction is the regulated coupling between two autonomous agents, where the regulation is aimed at aspects of the coupling itself so that it constitutes an autonomous organization in the domain of relational dynamics, without destroying the autonomy of the agents involved (though the latter’s scope can be augmented or reduced.)

In other words, social interactions, just like individuals, are autonomous dynamic systems. These systems can support or limit the autonomy of the individual participants. Those acting within these interpersonal systems participate with others in making sense of the world, but with one or more individuals often influencing the interaction more than others. Systems made of interacting participants often constrain individual behavior. In other words, there are things we are less likely to do in some social situations than when we are in another social environment or alone. They can also be very creative - allowing new possibilities for understanding and action to emerge as participants interact. If we take participatory sense-making seriously, neither emergent social interaction nor the social breakdowns that can occur can be explained by the behavior or skills of a single participant.

It is important here to clarify what enactive mind researchers mean by “autonomy” - whether they are applying it to a single individual or to a group. The term can be confusing because people often consider it synonymous with independence. Of course, no living beings are completely independent. On a very basic level we need to exchange material and energy with our environment to survive. According to De Jaegher (2013, p. 5) the autonomy of living systems:

> … lies in the fact that they self-generate, self-organize, and self-distinguish. That is, living systems are networks of dynamical processes (metabolic, immune, neural, sensorimotor, etc.) that generate their own identity by self-sustaining and distinguishing themselves from their environment, while at the same time constantly exchanging matter and energy with the environment. An autonomous system is composed of several processes that actively generate and sustain an identity under precarious conditions.

A person is considered to act autonomously because neither their behavior nor the way they make sense of the world is pre-programmed or determined solely by outside forces. Instead, individual autonomy unfolds as a person attempts to survive and thrive. This emergent perspective makes it impossible to locate cognitive functions in isolated neurological modules or even solely within the brain.

As autonomous beings, we come to value some things more than others. Varela, Thompson, and Rosch (1991, 2016) explain that as the result of our interaction with the physical and social environment we bring forth *domains of significance*. Creating these domains of significance is essential both for preserving our existence and living satisfying lives. Values thus emerge as we act in our physical and social environments as beings with unique bodily makeups and unique personal histories.

It would be incorrect to conclude, however, that what we value is merely the product of our cultural background or an adaption to the demands of the physical environment. From an enactive perspective, we continually choose what we attend to, what we act upon, and the environments in which we act. Our participation in making sense of the world with others can actually lead to changes to the culture and to how we structure the physical environment. From an enactive mind perspective, it makes more sense to say that we participate in our culture's co-evolution than to say we simply adapt to it.

Enactivists also describe the interpersonal systems that emerge through participatory sense-making as *self-organizing*. The state, or the order self-organizing systems, arises from the internal dynamics of the system itself. This is true for many types of systems including physical, natural and social ones. In these systems it is usually impossible to identify single causes for the overall characteristics of the system at a given moment. Similarly, disruptions in the order of the system can seldom be attributed to a single cause. Regarding social interaction, it is usually impossible to trace the characteristics of the system to a single factor or individual action, since those actions are modified over time by the self-organizing interaction itself.

The theory of enactive mind and the concept of participatory sense-making thus raise significant challenges to the belief that difficulties with social interaction are an individual problem. Both successful social interaction and social breakdowns can be understood as properties that emerge in real time from the interaction of all participants. The unfolding social whole, in other words, is more than the sum of its parts. From this perspective, it makes little sense to blame difficulties with social interaction on an individual's "social deficits."

Practitioners who focus on improving social skills by teaching autistics to better understand social norms or by changing individual behavior often neglect the extent to which social behavior emerge from the dynamics of the interaction itself. Likewise, researchers seeking to locate social deficits in individuals are probably using the wrong unit of analysis.

We know from multiple autobiographical accounts that autistics often struggle to understand what is going on in social situations. It would be a mistake, however, to infer that these struggles result from an innate social deficit. Social learning occurs as we move, perceive, and synchronize our actions with those of others. Clearly, any differences in the way a person moves or perceives could affect how they learn about social interaction and how they make sense of it. With movement and perception playing such key roles in the development of social cognition, it makes little sense therefore to trace perceived social deficits to underlying innate cognitive deficits.

It should be no surprise that people who move and sense in ways considered atypical have different ways of understanding the world. It should also be no surprise that social interactions taking place without accounting for these differences can limit the full participation of people who perceive and move atypically.

Enaction and Autism.

It is quite natural for enactivists to turn their attention to autism. This is due in part to their rejection of Theory of Mind, or the belief that successful social interaction can occur only when social actors can theorize about what others are thinking. Enactivists generally reject the idea that a Theory of Mind plays a significant role in most social interaction or that its absence provides a satisfactory explanation for autism. (e.g. Gallagher, 2020; De Jaegher, 2013). Indeed, the belief that we need to consciously understand or theorize what others are thinking to interact successfully with others is fundamentally at odds with enactivism.

The limits of Theory of Mind become clear if we imagine suddenly seeing a car coming towards us on a two-lane highway. Most people respond in this situation in an instant, with the know-how developed from years of practice. They do this without consciously theorizing about what the other driver is thinking. In fact, theorizing before acting in this scenario is inefficient, dangerous, and potentially deadly. They may consider afterwards what was going on in the other driver's mind, but not before acting. Enactivists argue that most social actions take place without participants first theorizing what others are thinking. Some enactivists propose that most people typically perceive others' intentions more directly (Gallagher (2001, 2004; 2020; De Jaegher, Di Paulo & Gallagher, 2010). Conscious reflection before each social act, in fact, is an incredibly tedious and inefficient process – raising questions about the effectiveness of programs designed to improve social interaction by teaching "social thinking."

Klin (2003) and his colleagues were perhaps the first to apply an explicitly enactive theoretical perspective to autism. They found that autistics tend to look at a person's mouth instead of their eyes during social interaction. This unique way of perceiving others, they argued, could lead to difficulties with effective real time social interaction and social understanding over time.

In her dissertation, De Jaegher (2006) adopted an enactive perspective, examining the role of *interpersonal synchrony* in autism. She argued that difficulty autistics often have in getting into synch with others can have a profound effect on ongoing interaction.[1]

De Jaegher (2013, p.9) expanded on her original work on enactive mind and autism, identifying additional embodied experiences that might affect autistics including:

> hypo- and hyper-sensitivities, over difficulties with the timing, coordination, and integration of movement and perception, painfulness of certain stimuli, muscle tone differences, rigid posture, movement, attention, and saliency problems, to differences in bodily coordination during social interactions.

More importantly, De Jaegher described how breakdowns in social interaction could result from difficulties with the participatory sense-making process required for the emergence of social interaction and its sustainability. As noted above, the interaction among two or more people can be considered an autonomous dynamic system. This fact led De Jaegher to conclude that, in considering the social difficulties that autistic individuals may experience, we should focus on interaction *as such*. As De Jaegher (2013, p.4) pointed out: “the interaction process, in its extra-individual dimension, influences, modifies, and in part creates the intentions of those engaged in it.”

De Jaegher’s approach to autism, and that of other enactivists such as Shaun Gallagher, contrasts with traditional cognitive explanations that have largely ignored the role of interaction. It also calls into question the use of therapies focusing solely on modifying individual behavior or on increasing a person’s social understanding,

Gallagher and Varga (2015) also provided an explanation for autism that focused on differences in “bodily aspects of social interaction” that might affect social cognition. These include motor, sensory, and timing issues. In contrast to Theory of Mind explanations, they argued for “interaction theory and enactive accounts of cognition that put more emphasis on embodied processes in social interaction and the direct perception of some mental states” (p.130).

More recently, De Jaegher (2023) argued that we should invite the participation of autistics through a process she calls “letting be”:

> I have a particular meaning in mind of *letting be*. I do not mean by it an invitation to disengage. On the contrary, letting be refers precisely to the existential engagement that is at the heart of all our

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[1] This is entirely consistent with the fact that self-organizing dynamic systems are made possible, in part, by the synchronization of their constituent parts. A rich body of literature shows the importance of interpersonal synchrony to the formation of human dyads and small groups. Interestingly, research shows that difficulty participating in synchronized action with others is common among autistics. The studies are summarized in a recent systematic review and meta-analysis (Carnevali, Valori, et al., 2024).

> interactions—an engagement that involves us deeply, and that is as transformative of the being and becoming of whom we engage with, as it is of our own being and becoming (p.13).

Thelen and Smith (1994) articulated groundbreaking theory for human development based on dynamic systems theory. With their emphasis on the critical role of movement, perception, and experience in development, their work helped form the foundation for modern theories of enactive mind.

I believe that Thelen and Smith's theory also has implications for how we make sense of autism.[2] They contend that human beings, as with other dynamic self-organizing systems, develop *attractors*. These behavioral and cognitive attractors evolve as we move and perceive in real time and are strengthened with experience. They increase the probability that learned patterns of movement or ways of thinking will emerge in real time as we adapt to various contexts and respond to the immediate demands of the environment. Through the course of development, increasingly complex attractor topographies emerge. The individual set of attractors we develop make the probability of some actions more likely than others. The way a person holds a fork, for example, is not something that is innate or natural. Instead, a child learns to use a fork as she moves, perceives, and participates in eating with others. As this "fork holding" attractor is strengthened through practice, it ultimately comes to feel natural and automatic. Few people need to consciously plan how they will grasp and use a fork. The expansion of a person's set of attractors facilitates more automatic behavior and flexibility in responding to the environment. I believe that autism may be described, in part, as the development of attractors that tend both to be stronger than in neurotypicals and fewer in number. This may help us make sense of some of the characteristics associated with autism – characteristics such as an enhanced ability to focus on a topic or activity, a range of interests that might be fewer in number than for neurotypicals, reliance on rituals and routines, a need for consistency in the environment, and difficulty in developing new motor responses.

Researchers studying autism are increasingly turning to a theory of enactive mind to explain the results of their empirical studies. The studies are too numerous to list in a newsletter article. The results of this research have done little, as far as I can tell, to impact practices on the ground. In the last 20 years practitioners have begun recognizing the importance of embodiment, however. Ideas related to embodiment and autism are now generally accepted. These include beliefs about the effect of sensory and motor differences on learning, action, and subjective experience. Concepts associated more specifically with enaction, such as participatory sense-making and

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[2] Interestingly, Esther Thelen developed a keen interest in autism at the end of her life, even serving as a keynote speaker at an early AutCom conference. She was particularly interested in how movement differences might affect the developmental trajectories of autistics.

autonomy, however, appear to have had little effect on professional practice. I find this unfortunate because the implications of these ideas for understanding autism and for creating more inclusive environments are profound.

Implications.

A theory of enactive mind has a number of implications for the way neurotypicals and autistics interact. This includes the various ways professionals such as teachers and therapists provide support. I list a few below.

First, neurotypicals need to recognize that autistics exhibit autonomy and that they should support the achievement of goals consistent with autistics' own interest and desires. Much of what is done for (or to) autistics is based on the belief that their actions are unreasonable. In fact, actions that others find problematic may make perfect sense to an autonomous person seeking to live the best life they can. Gallagher (2020, p. 222) contends that "social and cultural practices, institutions, and the narratives that support them" can extend or limit individual autonomy." Our goal, then, should be to work with autistics in developing inclusive social practices and narratives that support and extend their autonomy.

Each autistic person, like everyone else, makes sense of the world in a unique way. These ways of making sense are a function in part of their own individual embodiment and their history of interaction. Individual behavior reflects this uniqueness. Instead of simply eliminating behaviors considered by some to be "abnormal," it is important to consider the meaning they have for the autistic and how that behavior has emerged over time as a reasonable response to the demands of the environment.

Second, when addressing difficulties in social interaction or social breakdowns, we need to focus on the interaction itself. Social connections emerge in real time and provide a context in which people participate in making sense of the world. If our goal is to enhance social interaction, we need to first examine how the actual interaction evolves, breaks down, and is restored over time. We need to focus as De Jaegher said, on interaction *as such*. Again, this calls into questions "therapies" designed to improve social skills by changing the individual autistic's behavior or social understanding.

Third, teachers and therapists need to work from the assumption that the characteristics of autism emerge from the ways a person moves and perceives. As De Jaegher (2013) says:

> Therefore, interventions for autism – w.r.t. [with respect to] social difficulties, cognition, affect, and sensorimotor capacities - need to pay special attention to interactional coordination, rhythmic capacity and participatory sense-making. (p.13)

Fourth, we need to support the routines that autistics use in making sense of their world. I think of the complex rituals that I have observed in the relationships among autistics and close family members. These rituals emerge over time and have meanings not easily discernable to observers. It is vital that we avoid eliminating these routines. Instead, we should support them and, when invited, participate in the co-development of rituals that help us to make sense of and cope with the world together.

Fifth, we need to examine how various environments afford autistic individuals with opportunities for participation and learning. Enactivists, building on Gibson's (1966) ecological approach to psychology and perception, often refer to his concept of *affordances*. Much of what we do, we can do because the environment *affords* us an opportunity. Stairs, ramps, escalators, and elevators, for example, afford people opportunities to more effectively move in a vertical direction. In the case of autistics, quiet locations at events afford opportunities for some to attend events they might otherwise find overwhelming. As we consider the supports needed for autistics to pursue their goals, we need to consider the opportunities various environments afford. Likewise, instead of focusing on simply changing a person's behavior when they are struggling, we need to explore how we can alter the environment in ways that ensure success.

Finally, we need to celebrate those unique attractor topographies described by Thelen and Smith (1994) that emerge as autisics (like everyone else) act and sense over time. They result in a rich diversity of abilities and forms of know-how that enrich our society. In other words, we need to support neurodiversity, just as we have come to support diversity of other kinds.

Toward a Principle of Freedom

In concluding, I want to introduce into the conversation a concept seldom mentioned in the professional literature on autism. That is the concept of *freedom*.

In their book *The Dawn of Everything: A New History of Humanity*, anthropologist David Graeber and archeologist David Wengrow (2021) identify three forms of human freedom. The first is the "freedom to move away." The second is the freedom to "disobey" and the third is the freedom to "create new forms of social life."

I believe some limited progress has been made in supporting the first two forms of freedom for autistics. There is certainly a greater focus on "choice" than in the past. But even the choices provided often remain quite limited, especially for those perceived as having more significant disabilities. Professionals tend to establish the range of choices available with little or no input from autistics. The third form of freedom, creating new forms of social life, thus remains elusive for most autistics and for people with disabilities in general.

An exception to this may be seen in the growth of organizations and conferences run by and for autistics. In these groups, autistics participate in creating new forms of social organization that make sense to them. Few opportunities, exist, however, for autistics, at a broader community or societal level, to fully participate with others in making sense of, fashioning, and re-creating the larger social world. Autistics are largely excluded from the participatory processes from which new forms of social life emerge.

Unfortunately, the focus of “treatment” for autistics has remained on teaching them to behave and think like neurotypicals. Others have asked, and even demanded, that autistics adapt to a *normal* that they have had no role in constructing or defining. Professionals have largely ignored the way autistics make sense of the world, instead requiring them to act in ways that only make sense to others.

With its focus on autonomy and participatory sense-making, I believe a theory of enactive mind has much to say about enhancing the freedom of autistics. This is especially true for the third form of freedom – freedom to create new forms of social life. Enaction recognizes that each person is unique and that each person enacts their own domains of significance. It recognizes that each person, with a unique body and unique history, has their own way of making sense of the world, valuing aspects of it, and acting within it. At the same time, it recognizes that human sense-making is, at a very fundamental level, social and participatory.

I believe that we may elicit from the theory of enactive mind a *principle of freedom* that can guide us in creating new forms of social life. Such a principle moves beyond the provision of simple choices and protection from abuse, neglect, and exploitation (as important as these issues remain in their own right). Freedom, from this broader enactive perspective, consists of the full participation of each person *with others* in making sense of the world. A society embracing such a principle would facilitate the emergence of new forms of interaction that remain authentically social while respecting the inherent autonomy of each person – autistics and neurotypicals alike. Supports provided consistent with this principle would ensure that autistics participate fully in the processes whereby our communities (and society as a whole) evolve.

To be clear, I do not advocate a laissez-faire approach (everyone does whatever they want). That is obviously inconsistent with the concept of participatory sense-making. Embracing freedom, as conceived here, does mean rejecting traditional top-down systems of support that require autistics to conform to a stultifying and static normality. Instead, the autonomy of autistics must be respected by supporting their participation in the continual process of creating and re-creating new forms of social life.

In the interest of supporting participatory sense-making, I encourage people to contact me with any thoughts, suggestions and criticisms they may have of the ideas expressed in this article. kurtz@maine.edu

References Provided on Request

We applaud . . .

CANDOR (Chronically Ill Autistic Neuro-Eclectic Disabled Organization for Reclamation (formerly Autism Support and Advocacy Center) in Durham, North Carolina, for their 2024 virtual conference, “Transgressing Neuronormative Relationships.” It was “designed by Autistic people and center[ed] own-voices presenters,” including presenters who type or spell to communicate, David James Savarese and Danny Whitty. The conference focused on the critical importance of community as an “integral aspect of the survival and thriving conditions of disabled individuals.”
https://www.candornc.org/

U.S. Secretary of Education Miguel A Cardona, Ed.D., for issuing the Secretary's letter on Restraint and Seclusion, January 8, 2025, to Governors, Chief State School Officers, Administrators of Lead Agencies, School District Administrators, and Early Childhood Program and School Leaders.
Excerpt: “The U.S. Department of Education (Department) remains concerned that children continue to be subjected to restraint and seclusion practices even though these practices are harmful to children and despite the lack of evidence that these practices are effective strategies to respond to a child’s behavior or that these practices reduce the occurrence of behaviors that interfere with learning. The use of restraint and seclusion practices is inconsistent with our shared goal to ensure every child is treated with dignity and free from abuse. The most recent publicly available data shows that more than 50,000 public school students were restrained or secluded in public schools during the 2020-2021 school year.[i]
Restraint and seclusion practices can have a lasting and negative impact on children. There is ample evidence of significant harms to students due to these practices, including serious physical injury, emotional trauma, and even death.[ii] Schools and early childhood programs should do everything possible to align their practices to ensure all children are educated in learning environments that are safe, supportive, and responsive to their unique needs.”
https://www.ed.gov/laws-and-policy/key-policy-letters/secretarys-letter-restraint-and-seclusion

Upcoming Webinar on Movement and Sensory Issues

The Autism National Committee is please do to announce that we will be conducting a webinar on movement and sensory issues in autism entitled: *Sensory and Movement Dilemma: The Autism Paradox.* The webinar will be broadcast sometime in late March or early April. Check out our website for updates!

Board Member and filmmaker Daniel Bergmann has some exciting news!

We are excited to announce that AutCom Board Member and film maker Daniel Bergmann is currently producing and starring in a fiction film, for which he also wrote the screenplay, entitled *Pointing Fingers*. Some of you may have met Bergmann through AutCom's recent webinar series on relationships, in which he was a panelist. He is now sharing a glimpse of his film project, with a plot teaser and some insights into the production process itself, in a video short that also features his co-star Emily Grodin (link below).

Pointing Fingers – A young couple in love. A murder mystery. The silence of autism. A fiction film written and produced by Daniel Bergmann, starring Daniel Bergmann and Emily Grodin.

Excerpt from the video short: "In *Pointing Fingers*, Francis and Claire are a couple with minimally-speaking autism who have taken the bold step of living together with Daisy, their aide who helps them with communication and everything else. It turns out that Daisy has a past that Claire and Francis didn't know about, and one morning, they awaken to find that Daisy was murdered in the night. Enmeshed in a crime they had nothing to do with, they must now, despite all their challenges, but with the help of an online community of minimal speakers, solve the murder and bring the killer to justice."

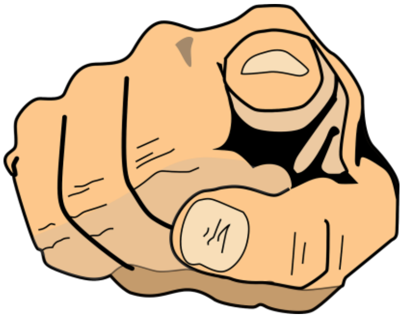
See this link for a video short about the film project.
https://vimeo.com/965846222/fe352ffa46

Update on Advocacy to FDA to Help End Harmful Practices

AutCom has opposed the use of electric skin shock and other punishment procedures since its founding, along with many organizations and individuals. Thanks to ASAN for taking the lead in writing this letter to the FDA, which we joined nearly 200 organizations in signing.

ASAN Letter Urging FDA to Release Final Rule. November 26, 2024 - “In the fourteen years since this issue was first raised to the FDA, some of our nation’s most vulnerable people have been subjected to unbearably painful electric shocks for such harmless behaviors as getting out of their seats, interrupting, whispering, slouching, swearing, or failing to maintain a neat appearance. As the previous rule recognized and the proposed ban continues to note, disabled people are experiencing dramatic short and long-term harm from this abusive treatment every day. They cannot afford to wait any longer. We the undersigned urge HHS and the White House to prioritize and take all actions necessary to ensure this critical rule is immediately finalized and implemented.” https://autisticadvocacy.org/2024/11/asan-letter-urging-fda-to-release-final-rule/

We Want Your
Poems, Articles, Book Reviews...



We know that AutCom members have a lot to share . We would love to receive your articles, poems, book reviews, or announcements of events that would be of interest to AutCom. We are especially interested in hearing from autistic members. Please let us know if you have something you would like to share in future newsletters.

Autism National Committee

www.autcom.org

The first autism advocacy organization dedicated
to "Social Justice for All Autistics"
through a shared vision and
a commitment to positive approaches

Principles of the Autism National Committee

As a member of the Autism National Committee, I endorse for all autistics and those with related disabilities the development of high-quality community services, including education, residences, jobs/job training programs, and of individualized support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communication and social needs; of adequate supports to every family to assist them in maintaining their family member with a disability in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individuals' behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no need or any justification for using painful and abusive procedures.

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AutCom Annual Membership Form

Join any time (specify the membership year). Renew each January (except for Lifetime Members).

For the Membership Year _______________ (January 1-December 31, except for lifetime membership)

Name ____ **Date:** ___________________

Address ____

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Phone _______________ **Email** ____

I prefer to receive the newsletter ____email ____print if available (Note: print is not always available)

I want to ____ Renew my membership ____ Become a Member ____ Become a Lifetime Member

I am a/an _____ Autistic _____ Family member _____ Friend

_____ Student _____ Professional (field) ______________________________

Enclosed is my membership fee of: _____ $10.00 (autistic person - annual membership fee)

_____$30.00 (nonautistic person annual membership) ____ $10.00 (student annual membership)

_____$75.00 (supporting annual membership) ____ $500.00 (lifetime membership)

Donation: I am enclosing an additional $________ donation to speed up the good work!

As a donor, I want to be ____ listed by name ____ anonymous.

Send this form or a copy and a check payable to Autism National Committee to

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