



## SUPPORTING PARENTS OF NEURODIVERSE CHILDREN: AN INTERVIEW WITH CORNELIA ELWOOD

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*Cornelia Elwood is a parent support specialist at Mass General Hospital, where she provides trainings for parents of individuals on the autism spectrum. She is the co-author of the book *Take Charge of Treatment for Your Child with Asperger's (ASD)*. NEJRSP editor Jackie Gagliardi interviews her about ways that the family therapists can support parents of neurodiverse children.*

**Jackie Gagliardi:** Hi Cornelia. Welcome and thank you for agreeing to participate in this interview.

**Cornelia Elwood:** Thanks so much for the invitation to participate in the interview! I am excited about it!

**JG:** I am curious about how you became interested in specializing in work with individuals and parents of children on the spectrum.

**CE:** Most of the experiences of my adult personal and professional life have led to my interest in specializing in work with individuals and parents of children on the autism spectrum. I have always been interested in supporting people. As a young professional, I took a two-year life coach training and loved the work. My oldest son, Alexander, was born 22 years ago, and he was diagnosed with Asperger's Syndrome (now known as autism spectrum disorder) when he was four.

I felt that I was ineffective at my most primal and important job...parenting. I was very humbled by the process of parenting and found that typical parenting techniques, such as time outs or getting on Alexander's level to talk through struggles empathically, were ineffective and ultimately led to greater escalation and emotional chaos in our home. I desperately sought strategies to support myself and our family because parenting and home, school, and community life were complex. My search for ways to support Alexander and our family led me to many professionals, including psychologists, speech and language pathologists, occupational therapists, psychiatrists,

and educational consultants who understood autism. When Alexander was ten, I enrolled in a certificate program for autism spectrum disorders to try to make sense of my son's complex profile and to bring greater harmony to our home. Finally, I understood autism and felt empowered to make a difference for Alexander and our family.

For an assignment for one of my classes, I created a parenting guide for home, school, and the community. My guide served as a case management road map for me, an instruction booklet for Alexander, and a collaboration toolbox for the professionals supporting Alexander. I shared this guide with Alexander's educational consultant and the Executive Director of MGH Aspire, Dr. Scott McLeod, and we decided to use the contents to create a book, *Take Charge of Treatment for Your Child with Asperger's (ASD)*, to support other parents. I developed a corresponding training, using the book as the curriculum, and facilitated it a number of times. Supporting parents of autistic children became my mission.

My book trainings helped me realize that I wanted to take my clinical skills to a different level, and I applied to William James College for the clinical mental health counseling program with a concentration in couples and family therapy. My interest in serving this population remained, and I became an ASD specialist for Riverside Community Care and am currently the parent support specialist at MGH Aspire. My life experience shaped my passion for working with autistic individuals and their parents.

**JG:** So interesting and admirable how you were able to utilize all you learned and researched as a parent, and then write a book for parents, so that they had information at hand. As a clinician who specializes in this area, I am wondering what advice or information you can provide to clinicians who are working with individuals on the spectrum and their families.

**CE:** Thanks, Jackie. I could go on and on about this topic, but the three points that I will discuss are: 1. Understand the ASD profile and know corresponding strategies that support each feature and associated feature; 2. Make therapy accessible; 3. Know ASD-specific resources to recommend to clients.

### **Understand the ASD Profile**

First, Autism Spectrum Disorder profiles are complex, and it helps to understand the features and associated features of Autism Spectrum Disorders and the corresponding strategies that support individuals with this profile. The features are social differences, communication differences, restricted and repetitive patterns, interests, and behaviors, and sensory differences. The associated features are motor differences, cognitive differences, and emotional vulnerability. It helps to understand how these features and associated features uniquely present in your clients.

An example of pairing a strategy with a feature or associated feature is working with an individual who struggles with communication and supporting their communication by role-playing,

rehearsing, miming to teach non-verbal communication, video-modeling, and in the moment coaching. You can explain that conversations are like a ping-pong game where you can respond to a question and keep the conversation going by asking a related question back to the conversation partner. The key is to know what strategies are ASD-informed.

## **Making Therapy Accessible**

Here are seven strategies that therapists can utilize with these families.

**1) Provide structure.** Have a visual agenda for the therapy session. I worked for several years with a wonderful eight-year-old boy with an Asperger / autism profile. Every session, we took the first few minutes to preview what we would do during our hour together. Every week, we kept the agenda fairly consistent. I used a time timer to visually show him where we were in each segment of the session. For example:

- Build agenda – 3 minutes
- Check in – 10 minutes
- Discuss topic / practice a skill related to check in – 20 minutes
- Discuss child’s special interest – 5 minutes
- Play game – 5 minutes
- Talk with mom – 7 minutes

**2) Delineate behavioral expectations.** Individuals on the autism spectrum can miss the hidden rules of different environments. It is helpful to proactively explain what the expectations are in writing. For example, therapy lasts 50 minutes. We will not use screens unless for a therapeutic purpose. If using screens for a therapeutic purpose, we will use the center’s computer. It is helpful to clearly establish, particularly for family therapy, that when one person speaks, allow them to complete without interruption. Individuals benefit from therapists clarifying what their role / job is and what the client’s job is in therapy. This explicit information can set the autistic client up for success in participating in the session.

**3) Preview.** Transitions and changes are hallmark challenges for individuals on the autism spectrum. Autistic clients benefit from previews about changes, such as changes in schedule, meeting times, or meeting location. One time I was working with a client, and every week we met in a particular meeting room. One week, after many months, the room was not available and this client and I had to meet in another room. The change in room without sufficient preview made the client very anxious. From that point forward, I reached out to the client, prior to the session, whenever there was a change.

**4) Be sensitive to sensory struggles.** Autistic individuals might have an over- or under-reactive response to sensory stimulation. As a clinician, it is helpful to understand your client’s sensory profile and support accordingly. For example, if your client has a sensory over-reactive

response to touch, it is helpful to ensure that you do not touch your client. For sensory over-reactivity to smell, it is helpful to refrain from wearing scents. If your client is over-responsive to noise, it is helpful to preview loud noises and make sure that the noise in your office is tolerable. If an individual has an under-reactive sensory response to touch, it might be helpful to have fidgets available that can provide tactile input.

**5) Engage through special interests.** Engaging with special interests can be exceptionally rewarding, fun, engaging, and stress reducing for individuals on the autism spectrum. My son's therapist was able to talk about extremely important topics with my son, such as sex, drugs, alcoholism, and relationships by looking at clips of a show, *Bojack Horseman*, which was his special interest. They would watch clips during their session, which addressed these themes and more, and use them as a way for him to access psychoeducation. I have connected with many clients through their special interests. This strategy can lead to engagement and connection with therapist and therapy. That said, it is important to know that transitioning from special interests can be difficult, so make sure that you preview the schedule and support this transition.

**6) Use visual supports.** As mentioned before, it is helpful to have a visual agenda, behavioral expectations list, and previews. In fact, I make as much about the session as visual as I can. For example, when I work with clients virtually. I will often share my screen as take notes on the key take aways from the session and send the list to my clients, so they can review it as often as they would like.

**7) Collaborate with parents and other service providers.** Autistic individuals often benefit from having coordinated support in every environment...home, school or work, and the community. Also, this approach helps individuals generalize skills from environment to environment. When Alexander was younger, his therapist, special educator, speech and language pathologist, and I often worked on developing the same skill, such as whole body listening or using "I-statements" simultaneously in each environment.

### **ASD-Specific Resources**

It is helpful for clinicians to understand what services and resources that are available for individuals on the autism spectrum and their parents. Three that I most recommend are:

**1) MGH Aspire** which provides year-round programming for individuals aged 5 years to adult, including:

- Social groups
- Summer camp
- School vacation camp
- Work-related support
  - Internship program
  - One-on-one career coaching

- Skill-building workshops
- School consultation
- Corporate neurodiversity trainings and workshops
- Parent and caregiver trainings, workshops, and coaching

**2) MGH Lurie Center** which provides the following services for children and adults:

- Neurology evaluations and services
- Psychiatry evaluations and services
- Gastroenterology evaluations and services
- Psychology and educational evaluations and services
- Behavioral consultation and training services
- Speech-language therapy
- Occupational Therapy
- Physical therapy
- Family support services
- MGH Aspire
- Primary care services

**3) Asperger / Autism Network** which provides the following services:

- Information and referral calls
- Coaching for parents
- LifeMap coaching for teens and adults
- Neurodiverse couples
- Coaching in Spanish
- IEP support
- Support groups
- Social events
- Training and education – conference
- LifeNet – Independent living support

**JG:** Thank you for such a detailed response. I am wondering what the impact of Covid had on this population!

**CE:** I did research on this and provided a webinar for parents of children in Aspire programs. There were vulnerabilities and strengths for individuals and families entering the pandemic. The vulnerabilities included:

- Potential for exacerbations of symptoms due to all of the changes and transitions
- Limited access to therapy
- Overwhelming responsibility for caregivers

That said, families of children with ASD are more skillful in adapting to unusual conditions, so they showed resiliency.

There were variable responses to the Pandemic. The benefits for some children with autism profiles included being able to be at home where they were comfortable. They could engage in self-regulating activities without negative social consequences and enjoy a break from social

obligations and expectations. The pandemic birthed new ways of communicating, virtualcommunication, that favored people with autism. The impact of these benefits included reduced stress, positive learning impact, less over-stimulation, less need to mask, more remote social outreach, and a more equal playing field because everyone was awkward remotely.

Some autistic individuals were challenged by the lockdown due to changes in the routines, environments, expectations, and services. Some homes were small, so people had less physical space. Small environments could lead to greater sensory issues. For example, it might be noisier or smells were more present in the space. These challenges led to increased stress, ineffective engagement virtually, regression of communication and self-management skills.

Parents were overwhelmed. They had to be both full-time caregivers and educators. They had to manage and structure daily activities and support their children's therapeutic needs without support or with less professional support. Managing their own jobs became problematic in some cases, and they had to take leave or quit their jobs to manage home demands. Many were contending with potential health threats, social isolation, mounting financial pressures.

Families experienced benefits and difficulties from the pandemic. One significant benefit for the family was increased family time. Many children's verbal behaviors increased due to this increased family interactions. Also, families shared responsibilities more. The difficulties included great stress. Some parents had more conflict with their child. Mental health struggles became greater; at the same time families experienced delays in seeking and receiving care.

As children went back to school and to their extracurricular activities, anxiety heightened in many cases due to the transition and the expectations to refocus on social performance. Many children exhibited increases in externalizing behaviors associated with anxiety, including aggression and defiance. Profile-specific challenges were exacerbated.

**JG:** Thank you, Cornelia, for this wealth of information. If readers would like more information can they reach out to you.

**CE:** Yes, my email is [cpelwood@yahoo.com](mailto:cpelwood@yahoo.com). Please also check out the resources listed below.

## Resources

Beatriz, E., Guarino, A., Beatriz, P.V., (2021, June). *Covid-19 Community Impact Survey: Parents & Families*. Massachusetts Department of Public Health.  
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