

AUTISM SPECTRUM NEWS

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INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

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The Autism Community's Response to COVID-19

Cover Up for Safety! Suggestions for Mask Toleration for Individuals with ASD

By Samantha Smith, MEd, BCBA
and Jennifer Croner, MEd, BCBA
Exceptional Learning, LLC

During this difficult and unpredictable time, everyone is faced with new challenges. These challenges may be exacerbated for individuals with Autism Spectrum Disorder (ASD). School and daycare closures and a decrease in employment, among other changes, have caused a significant disruption to daily life and routines. Predictability, structure, and routine are essential aspects of everyone's life. This is especially true for those diagnosed with ASD. Our world continues to adapt and change to the COVID-19 pandemic, and it is important that direct care staff and clinicians continue to keep the best interest of their clients at the forefront of their programming.

The Centers for Disease Control and Prevention (CDC) have continually updated recommendations in order to slow the spread of the virus. One of the latest recommendations indicates that everyone over the age of two should be wearing a cloth mask whenever out in a public area with the exception of those who are un-



able to take the mask off independently, have difficulty breathing, or are unconscious (CDC, 2020). The greatest danger of this virus is in pre-symptomatic and asymptomatic individuals thus the need for everyone to wear a mask. This may pose an issue for individuals with ASD. Mar-

co, Hinkley, Hill, and Nagarajan (2011) report that 96% of individuals with ASD have a hyper- or hypo-sensitivity in multiple sensory domains. Many clinicians and researchers have worked on toleration procedures for a variety of anxiety-inducing behaviors including general medical

examinations, dental procedures, and approaching aversive stimuli (e.g., Cavalari, DuBard, Luiselli, & Birtwell, 2013; Hagopian and Jennett, 2008). Hagopian and Jennett (2008) reported that these procedures generally include graduated exposure, reinforcement, prompting, modeling, shaping, response prevention, and distracting stimuli. Unfortunately, there is limited, if any, research on toleration specifically in regard to cloth face masks. These research studies focus on teaching the individual to tolerate the medical procedure or aversive event. There are currently no recommendations on how to increase toleration of a direct care staff or clinician wearing a medical device or mask themselves; some clients may find this aversive as well. Several aspects of mask toleration are going to be a necessity as the world continues to transition to a new state of normal.

When following these recommendations clients may engage in challenging behavior when they are asked to wear a mask. This also may occur if a direct care staff wears a mask when delivering behavioral therapy. As direct care staff are considered essential workers, they are required to wear a mask

see Mask on page 30

Life in the Time of COVID-19: An Autistic Perspective

By Karl Wittig, P.E.
Advisory Board Chair
Aspies For Social Success (AFSS)

Like many autistics, I have been drawn to science fiction as far back as I can remember. The idea of an epidemic infecting the human race has always been a common theme in science fiction and is probably as old as the genre itself. As such, I have seen and read more stories about pandemics than I could ever count. Still, I never expected to find myself living through the real thing. Yet this is what happened just a few months ago when the COVID-19 virus was first identified and found to spread very rapidly with a frighteningly high mortality rate. Not long after its discovery, the virus had spread to just about every country on earth and led to complete shutdowns of entire societies. By late March of 2020, New York City was under a lockdown where nonessential businesses and public venues were closed, and everyone encouraged not to leave their homes for anything other than necessities or travel for any reason besides essential work.

As a person on the autism spectrum, I had my own ways of dealing with this sit-



Karl Wittig, P.E.

uation and with the uncertainty and anxiety that it could bring. One thing that I have done from the start of the crisis is to watch substantial amounts of news coverage about the pandemic. Although many a typical person would have been (and often was) distressed by this information (not to

mention bored after a while), I found that the better my understanding of what was happening, the less anxiety I felt in the face of such scary circumstances. I later found out that this attitude was common in my local Aspie community.

Having a scientific background, I became interested in the virology, genomics, epidemiology, and medical aspects of COVID-19 and followed as much coverage of these as I could. In particular, the high viral reproduction number (R-zero, significantly greater than 2), in conjunction with its high mortality rate (on the order of 1%), gave me a good indication of the severity of this pandemic – it is basically a form of Russian Roulette with somewhat better odds. The fact that neither of these numbers is accurately known, and are only rough estimates, created even greater uncertainty.

The need to keep our healthcare system from being overwhelmed by more patients than it can handle gave me an appreciation of the need for lockdowns and personal protective equipment, especially after seeing coverage of the situation in Italy, and later Ecuador, where many died because they could not receive care due to limited medical resources. In our own society, these risks were exacerbated by the closing down of hospitals because their high num-

bers of empty beds made them be regarded as uneconomical. These were the reasons for “flattening the curve” (keeping cases requiring attention as few as possible). It was not just a matter of becoming infected, although that is certainly a concern, but of exceeding the capacity of our healthcare system, which would put all of us in great peril. This was truly frightening to me, and I understood what was meant by “we are all in this together.”

Also of value were discussions of policies implemented in response to the crisis, as well as historical retrospectives about previous pandemics ranging from the black death and bubonic plague in Europe, cholera epidemics of the 19th century, and the 1918 Spanish flu (along with a few lesser-known cases), all of which had uncanny similarities to the current situation in spite of the less-advanced scientific and medical knowledge available back then. Once again, this helped me put things more in perspective.

What Could All This Mean for Me?

From a medical standpoint, I was interested in the consequences of being infected

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Interpersonal Relationships and Social Engagement in a Virtual Landscape

By Alissa Cappelleri, MAT
Samantha Curiale-Feinman, MEd, TSHH
New Frontiers Executive Function Coaching

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has identified communication and interaction with others as specific areas of deficit for many individuals with ASD. Difficulty making eye contact, initiating and sustaining a conversation, code switching, and perspective taking are just some of the areas in which individuals with ASD may exhibit skill deficits. A college student described his social communication challenges once as, “I never know what to say to who, and what reaction I am going to get.”

It is important for individuals with ASD to have opportunities to learn and practice social skills. Traditional, research-based instruction in the areas of social communication and language have included a couple key ingredients (Paul, 2008): 1) Interventions that teach skills in a highly structured fashion; and 2) Opportunities for the learner to participate in direct instruction, modeling, guided practice, and corrective feedback. The COVID-19 pandemic, however, has become an obstacle for individuals who need access to the traditional approach of social skills instruction. In person classroom opportunities to learn through direction instruction and corrective feedback, modeling of social interaction skills as demonstrated by peers, and social engagement with classroom teachers and peers have all been put on hold for the time being. Which leads us to the question: How do we find opportunities to develop and maintain social skills in a time when traditional social interaction has been limited?

The Traditional Approach to Social Skills Adapted

In this current climate of mandated virtual interactions, there is a clear need to shift how social skills instruction is being delivered. When it comes to developing an action plan, it is first imperative that the motivation for skill development be identified. While there is a standard baseline of skills that an individual benefits from learning, one’s personal motivators must be considered. Asking the following questions in the context of a social distancing and virtual interactions world, may help to identify one’s driving forces behind building communication skills:

- What do you want to participate in?
- What communities do you want to be part of?
- What do you have to participate in?



Alissa Cappelleri, MAT

- What do you need to be a part of?

Once outcomes have been identified, a Behavior Skills Training model can be employed to break down target skills (Johnson et. al, 2005). Through direct instruction, a description of the skill is presented along with its importance or rationale. The purpose is addressed as well as context. Here now lies an opportunity to provide insight to how one will use the skill in both the virtual world and in person. For example, the skill of joining a group and entering conversation appropriately differs depending on context. When in person, a greeting of some sort is expected to establish participation. However, when commenting online, a greeting is seen as superfluous as each new contribution is linked to content being discussed and not necessarily the acknowledgement of participants.

Modeling and practice are essential to social communication instruction as they allow the learner to rehearse novel skills. The virtual world allows for the opportunity to widen practical applications of skills to a much broader network of people available through online platforms. This expanded audience may not have otherwise been considered as practice partners due to geographical restrictions. However, practice may take on a new form with respect to the delivery of feedback. For those working with individuals to foster social skills remotely, the opportunity to observe and offer direct feedback may be shifted solely to on screen practice and reflective thinking, rather than participating in joint in person activities and outings.

How Do We Practice “Real World” Application Without Participating in the “Real World”?

To promote the generalization of social skills, it is imperative to provide opportunities for practice in the natural environment.



Samantha Curiale-Feinman, MEd, TSHH

However, as we settle into the “new normal” of socially interacting from a physical distance, modifications may need to be considered. What has been traditionally considered an “authentic learning environment” for social skills practice has been categorized by physical space. Historically, one would find ways to physically meet in a location they wished to navigate for practice. Since these spaces are now limited or not accessible, it is essential to shift focus to what is available. The present online space lends exceedingly well to this as there are multiple means of engagement for one to practice skills.

From social media to online gaming, virtual communities are being cultivated. Platforms that gather people around a collective interest encourage participation and serve as a great equalizer. Forums that draw attention to a set subject or a game unite towards a common goal and create an inclusive environment for social skills practice. Once engaged in conversation surrounding shared interests, one may experience the positive reinforcement of successful participation, and further harness that newfound confidence in other communication opportunities.

How Can We Find ORGANIC Opportunities?

It is also essential to create viable and authentic opportunities to engage with peers in a supported environment. An organic opportunity is one where participants are engaging freely. Looking to the “Autcraft community” that has found a home on the online gaming platform of Minecraft, Dr. Kathryn Ringland has been able to observe essential tenets to structured social opportunities that enable room for a naturalistic environment (Ringland 2019).

Having a shared thread for learning, supportive peers, and dedicated community “space” are all essential for structuring practice. Options for leadership and

growth exist as those develop confidence and serve as models to others. For group instruction, all participants are presented with the same visual and auditory access. Methods of direct feedback need to be fleshed out in a way that redirects behavior without pointing fingers.

Preparing individuals to participate in open platforms is essential as unwritten social rules reign supreme. All members of an online community are open and available for scrutiny. There are no edges of the party to seek solace as there are no walls in these communities. The idea of ascribing physical aspects to virtual space is one that the “Autcraft community” has found helpful. In immersing themselves in the culture of gaming has allowed for players to take the confidence fostered there and transfer skills to other platforms. Using this example as a case study, it is clear that other social groups can be established through the idea of community. In this time of isolated living, people are seeking ways to engage beyond. The shared experience creates a universality and evens out the playing field. A culture of care is established that naturally grants opportunities to branch out in developing social skills while still being physically comfortable with what one knows.

Alissa Cappelleri, MAT, Coordinator, and Samantha Feinman, MEd, TSHH, Director, New Frontiers Executive Function Coaching, can be reached at info@nfil.net or 646-558-0085.

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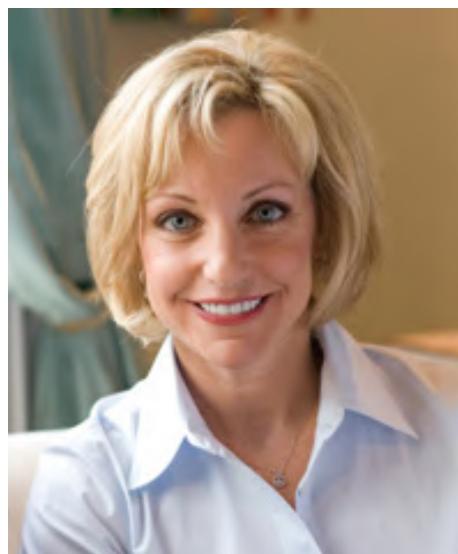
- Chelsea, Parent

You Are in Control

By **Linda J. Walder, Esq.**
Founder and Executive Director
The Daniel Jordan Fiddle Foundation

There is much we, as individuals, cannot control. I am sure you can come up with your own long list of things that are out of your control. During times when you feel out of control, like now during the COVID-19 pandemic when there are so many unknowns and all of the rules of engagement have been turned upside down, I have found it helpful to switch mental gears and focus on the things I do have control over. I hope this idea is inspiring for your own thought process, not only now, but as a life practice. I emphasize that it is a practice and will not come easily at first. I am not a psychiatrist, psychologist or therapist; just a person trying to figure out how to get through difficult times, like many of you.

Several months ago, when we all first learned of the onset of the mysterious and tyrannical COVID-19, many of us were in a state of confusion, shock and fear as our Federal, State and local governments and all of our societal, financial and religious institutions and businesses began to strategize. In each of our homes, we had



Linda J. Walder, Esq.

to strategize and adjust nearly every aspect of our daily lives. For many these changes were and have remained overwhelming, and rightfully so.

Not only do we have to cope with all of the “normal” stressors and challenges but now even our routines and way of life have changed. For individuals diagnosed with Autism and their families these changes can be even more unsettling.

When I started thinking about these stressors and challenges, I felt myself becoming even more anxious. Then I took a step away from the anxiety, a big giant step away, and I saw that my anxiety was largely based on a feeling of being out of control. True, I could not control many things, but I could control my response to feelings of loss, loneliness and uncertainty in the present. I decided then and there to regain some of the power that this crisis and life events were trying to steal from me; that decision was the first thing I could control.

I began a daily practice named “You Are in Control” and began to post once per day on our Instagram page @fiddleautism. My hope is to inspire you to look at your life and focus on the things that you can control and in doing so, take back your power from anxiety, fear and defeatism. I will share a few of my own here with you, and I gratefully welcome your sharing your ideas on @fiddleautism too.

Here are a few of my daily entries:

You Are in Control: You have the power to become more self-sufficient and increase your skill set.

You Are in Control: Isn't it fantastic to admire others for their talents, selflessness,

creativity...and more? Tell them!!

You are In Control: Pamper yourself, take care of yourself, take the time...it's your time to take.

You Are in Control: There is beauty blooming right in front of you and have the power to see it and enjoy it.

You Are in Control: You decide how to play the hand that is dealt to you.

Perhaps the ways we live are changing, and will be changed forever, but you can determine how those changes impact you for better or worse. Remember, you are not alone, your friends, colleagues and family are here for you during this pandemic and beyond.

Linda J. Walder is the Founder and Executive Director of The Daniel Jordan Fiddle Foundation established nearly 20 years ago as an all-volunteer run organization focused on adult Autism. The vision of The Daniel Jordan Fiddle Foundation is for a world of acceptance that values each individual diagnosed with Autism with the hope that each person feels joy and support in attaining meaningful accomplishments throughout their life.

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The Daniel Jordan Fiddle Foundation Transition & Adult Programs at University of Miami- Nova Southeastern University (UM-NSU CARD) has developed a list of resources to assist during the COVID-19 pandemic. The resources were created to support teens and adults with Autism and related disabilities and their families. We hope you will find these resources useful. Feel free to share with other families that could benefit from this support. If you have any questions contact Silvia Gil at s.gil@miami.edu. You can also visit our LinkTree page for a full list of our trainings, support groups and other helpful resources at <https://linktr.ee/umnsucard>.

Teen & Adult Resources

Healthcare Resources

Trainings & Groups for Adults with ASD and Their Caregivers



Unforeseen Advantages of Virtual Learning: Improved Attendance, Participation and More

By Gina Apicella, MS, BCBA, LBA
and Carolyn Gorman, LPC, ATR
Chapel Haven Schleifer Center

Deficits in social-emotional reciprocity, nonverbal communication, and difficulty making and maintaining relationships are some of the barriers individuals with Autism Spectrum Disorder (ASD) face in their daily lives (American Psychiatric Association, 2013). In addition, there are high prevalence rates of psychiatric comorbidities such as ADHD, anxiety, and OCD in those with ASD (Romero, M. et al., 2016). All of these factors contribute to potential difficulties in a learning environment.

Prior to the COVID-19 pandemic, virtual learning was the exception rather than the rule. For adult learners with autism, virtual platforms have served as a way to spend free time, playing video games or browsing through videos and favorite websites. As professionals working with these adult learners, we acknowledge that the virtual world was one where our students had the ability to express themselves, but also one where they didn't necessarily have to practice the social skills we teach and reinforce on a daily basis. When the COVID-19 pandemic presented itself, educational settings were faced with the unplanned, immediate need to create innovative ways to prevent regression and continue to provide ongoing instruction. In many ways, this need turned out to be more of an opportunity to reach students in ways that had not been anticipated. With the use of an online video conferencing service to link all of our students together, everyone has the ability to both see and hear each other and share screens as needed. As you can imagine, there are many disadvantages to online formats over having class in-person; however, in a relatively short time, we have come to realize that there are also many unforeseen advantages.

In programs for adults with ASD, such as the [Asperger's Syndrome Adult Transition \(ASAT\) program](#) at Chapel Haven Schleifer Center in New Haven, CT, instruction is focused on social communication and independent living skills. Instruction is provided in small groups and



Gina Apicella, MS, BCBA, LBA

individually, and typically happens in the natural setting. With stay-at-home orders in place, none of us are doing our usual activities in natural settings, but we are having to create *new* natural settings for our everyday activities such as work, grocery shopping, and socializing with friends and family. This new setting is most often utilizing technology... the same technology many individuals with ASD have enjoyed using in their downtime, and that they have a great amount of expertise navigating.

Navigating the online world is observed to be a natural strength of many of our program participants. There are plenty of times when our students assist our staff with troubleshooting a technology issue in the classroom or introduce the staff to a more user-friendly way of accessing materials online. This skillset can also become the basis of a vocational path for some, which has proven to be a great asset to many employers, ourselves included. In taking this natural strength into consideration, a task that one is accustomed to and comfortable doing typically requires less effort than one that is not within one's repertoire. As with any of us, when our students understand something at the level of being able to help someone else to understand it or explain it to someone else, a sense of confidence is evident. Building on a strength typically leads



Carolyn Gorman, LPC, ATR

to a more reinforcing environment, assuming praise and attention from peers or an instructor are desirable for an individual.

As a participant of virtual learning, it has been noted that some individuals have benefitted from being able to control their surroundings in a way that they know to be most conducive to their learning. For some, this may mean being in a room alone without any distractions, lighting of their choice, seating that feels most comfortable, etc. At times, due to confounding factors such as feelings of anxiety or over-stimulation, some individuals have even requested to join a virtual class, but utilize the option of turning off the audio and/or video in order to "attend," but not have all of the demands of attending. This option has allowed individuals to still access information that they might have otherwise missed if they had only had the option of fully attending (in person or virtually).

Preliminary attendance outcomes tracked by Chapel Haven suggest that in some cases, the barriers that are removed with the shift to a virtual format have had a positive impact on attendance rates of individuals who have otherwise struggled with attendance. One individual who participates in programming with ASAT had an average attendance rate of 50% from January-March

2020, but has a 100% attendance rate, with the exception of a few late arrivals, since shifting to virtual learning. The number of classes the individual is taking each semester has not changed, however, the barriers of in-person attendance are no longer relevant with virtual learning. This suggests that the virtual learning format has mitigated barriers that were negatively impacting this individual's ability to access the programming to allow him to work toward his goals.

Relatedly, it may be no surprise that accessibility has been advantageous in other ways as well. There is an ability to reach a much broader group of students, both in terms of socioeconomic status and physical location. The new virtual offerings of the ASAT program, based in New Haven, CT, have been able to reach students in a range of other states, from New York to Maryland. We have also been able to partner with our sister program, [Chapel Haven West](#), in Tucson, AZ, to offer programming from both campuses to both programs' participants. If an individual is an appropriate fit for participating in our programming, class costs for a six-week semester range from about \$75-\$150, giving individuals who may not have a suitable social network while at home during the pandemic the ability to connect with others and access a robust curriculum and recreational offerings, virtually.

Within our social communicative curriculum, we often have the need to address difficulties with reciprocal conversations, or "turn taking," and the ability to filter thoughts, or knowing when to end a conversational topic. When used thoughtfully, features such as the ability for the facilitator to mute participants and for students to privately chat enable the facilitator and students to learn about and model these social nuances. For example, a student who is repeatedly upset with a peer could be able to quietly resolve the problem in real-time over private chat with the instructor without interruption to the class.

The online format means that most students are taking classes from their familial homes. The virtual teaching format creates a window into the students' home

see [Advantages on page 10](#)

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PROGRAM OUTCOMES

95% of alumni are happy with their level of independence

85% of alumni are employed

89% of alumni are satisfied with their social lives

64% of alumni spend time with friends at least once per week

Unmasking New Opportunities Through Virtual Learning

By **Tarrah Valley**
Special Education Teacher
Shrub Oak International School

The COVID-19 crisis has forced us to face many new challenges while we rethink our ways of teaching and connecting to our students. Despite the difficulties of distance learning and the inability to physically interact with our students, this experience has opened many new doors and has inspired us to become even more innovative than before.

As a special needs educator at [Shrub Oak International School](#), I began this process of distance teaching by thinking of my specific students and the goals I wanted to continue working on with them. I quickly learned that many activities that worked in the classroom were not going to work at home. I turned my attention to new activities that were now a possibility. I had to re-plan my lessons multiple times until I discovered what worked for my students and myself. It was a learning curve as this is an entirely new way of teaching and reaching out to our students. Once I was able to create a lesson format that engaged my students and allowed them to work on their specific goals, we finally started a new normal virtual routine.

As each student has different needs, my lessons had to be individualized for every student. Some of my students that have recently joined Shrub Oak were expected to commence online learning without having built a rapport with me yet. It makes the relationship building process difficult, as I have not had the opportunity to gain their trust or learn about their interests. Through our individual and class sessions, I have been able to get to know my new students on a more personal level as they share their home-life with me as well as their personal interests. Distance learning has been a



Tarrah Valley

wonderful opportunity to focus on these students individually and get to know them in their home environment.

These newer students who had difficulties adapting to the school environment or who had specific sensory needs were now regulated to work on a preferred item, the computer! I now have the chance to work one on one with these students for 20 -30 minutes at a time as we focus on their individual goals. The parents have been wonderful partners as they help their child stay regulated with preparing the computer in a comfortable area, providing sensory tools, and keeping the students focused with redirection if needed. We are working together more than ever as a team to help each student work on their goals and show their full potential. Each virtual session has become a parent-teacher conference and an individualized assessment as we are all working towards the same goals.

As I shared my thoughts with one of the parents, I explained how this experience has given me more insight to the child's specific needs than I could have asked for. As a newer student, it would have taken

the student time to adapt to the school environment, get comfortable with the staff, and adjust to the schedule. Now, I am getting home visits, parental support and insight, and team collaboration all in one. Throughout my sessions, I take notes of all the accommodations that help support my students in their home as these will help make the transition back to school even more successful.

This experience has also allowed my students to showcase all their skills into every-day activities. My students are emailing me daily, being responsible for their assignments, showing up to our sessions on time, and sharing experiences about their days with me. All of these simplistic tasks are goals that we have been working on for months with support. Previously, teaching children to be responsible for homework and show ownership of their work was a challenge. Teaching students to use emails independently with an actual subject in the subject line is also no easy task! These are the small victories that are now part of their daily lives. My students are engaging in social experiences during each session as they share what they have been doing and complete the activities together. At school, they might want, or need, to work individually or with a 1:1, but here, in our virtual class, it is just a couple of peers and myself enjoying our time together. The students are excited to complete the activities with me as we play games, read stories together and work together to solve math equations.

At school, we have a routine and it works well. Needless to say, this has changed our routine and forced us to shake things up. In person, it is easier to motivate my students and get them involved in the activity. Virtually, I have to be much more creative. We are now using more technology and going on virtual fieldtrips, creating online comics, playing educational games, and finding new tasks each week. As I have been planning my online lessons, I have discovered

various new resources that the students love and I will continue to use in the classroom. Many companies have waived their fees or advertised more for distance learning. I have enjoyed expanding my horizons and increasing my knowledge of online resources throughout this experience. I feel that it has improved my teaching skills, as I am more confident in not only project-based learning, but also in teaching remotely and on a digital platform.

Our virtual experiences have given us so much, but it is the small moments that shine the brightest for me. I am fortunate to see their faces and how engaged they are. I am proud to see them use all the strategies and skills that they once needed support with and now demonstrate with independence. Of course, I cannot wait for us to all be together again, but I am grateful for this experience as it has given my students and me many opportunities for more growth and independence.

My advice for other educators would be to enjoy this experience for what it is; an opportunity to learn more about your students and yourself. You have to focus more on your students' interests as you find resources they are engaged with and in return, you learn so much more about them. You get individualized face time with students as you focus solely on them and their individual needs. You get to consult with parents and get their feedback on your student's progress on a regular basis as you work and plan together. As an educator, you are forced to learn an entirely new way of teaching, which is a challenge we have all taken on and are learning as we go. As we celebrate all the wonderful opportunities distance learning has given us, we continue to share our stories and resources in order to help us all grow throughout this experience.

For more information about Shrub Oak International School, visit www.shruboak.org.

Advantages from page 8

environments. Through this window, teachers are better able to understand where each student is coming from and how to address those needs. Within some classes, participation or assistance from parents or family members may be helpful, such as in a virtual cooking class. Parent-student relationships can also be positively affected by virtual learning formats. In some cases, they have given parents the opportunity to better understand what each individual is learning and an ability to help reinforce those areas in the home environment. This has also given the students a chance to be able to generalize previous on-campus learning across settings with the guidance of an instructor.

The planning and preparation for classes such as virtual dinner prep have also given students executive functioning modeling

and practice. While they are receiving assistance, they have been required to know what they are cooking week to week and to have ingredients ready for their class times. Virtual classes during a pandemic have also required students to do a bit of problem solving. Sometimes the exact item they need for a class is not available. They have learned to be flexible, to substitute ingredients or art supplies, to adjust to new technology, and have figured out ways to complete a task under less than ideal circumstances.

Given that the virtual format is new and will continue to be modified as outcomes are measured and data is analyzed, the expected challenges have surprisingly been rebutted with unexpected anecdotal and observed advantages. As a program committed to providing high-quality programming to increase the independence of adults with social and developmental

disabilities, the virtual learning format has allowed the individuals we serve to continue to work toward reaching their goals and stay connected with their peers and staff. There are more opportunities to begin the journey toward independence as part of our community than there have ever been, and it has come on the heels of a worldwide pandemic.

Gina Apicella, MS, BCBA, LBA, is Vice President of Autism Services and Carolyn Gorman, LPC, ATR, is Supervisor of the ASAT Program at Chapel Haven Schleifer Center.

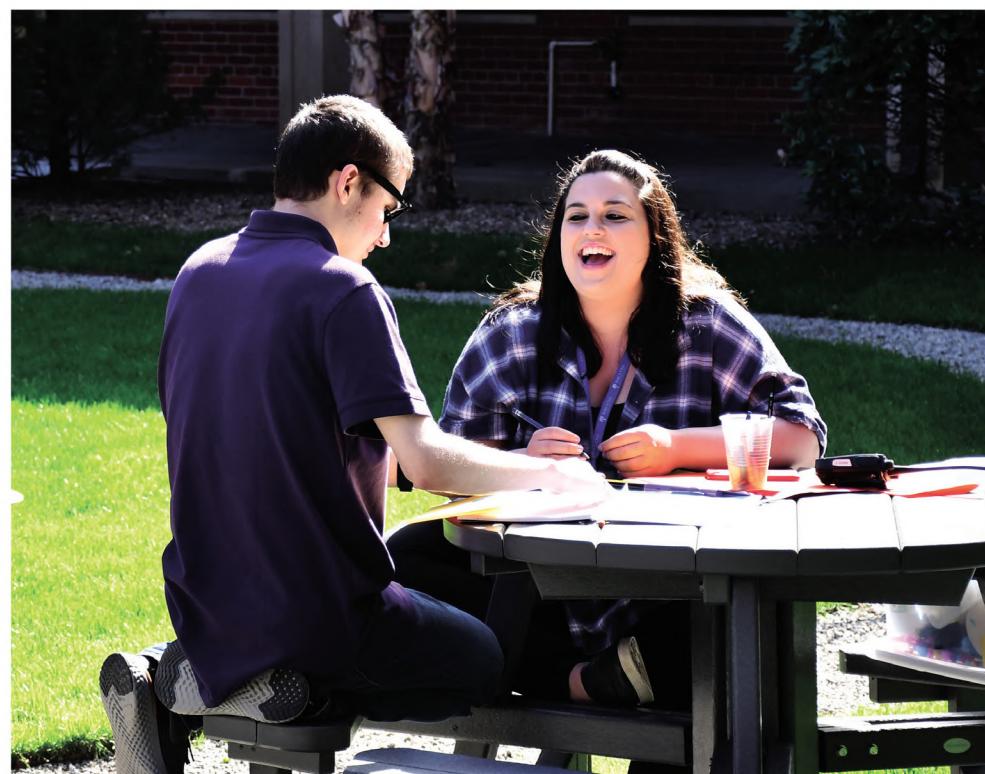
Chapel Haven Schleifer Center is an award-winning, national non-profit dedicated to empowering adults with social and developmental disabilities to live independent and self-empowered lives. Our new distance learning portal, which can be viewed at www.chapelhaven.org/chapel-haven-online/ is available to all adults,

not just those already enrolled at Chapel Haven. Please go online and browse our catalogues! To learn more, contact Catherine DeCarlo at cdecarlo@chapelhaven.org or admission@chapelhaven.org.

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Autism Spectrum News and Behavioral Health News: Supporting the Community During the COVID-19 Crisis

**By Ira H. Minot, LMSW
Founder and Executive Director
Mental Health News Education
Publisher of Autism Spectrum News
and Behavioral Health News**

The current pandemic shows us how difficult social distancing and sheltering in place have been for the general public. It has been especially hard for people with mental illness, substance use disorders, and people on the autism spectrum.

During my own 10-year battle with depression I experienced isolation, social distancing and stigma first-hand. These of course were some of the difficult side-effects of my illness. Now that we are all living with the COVID-19 crisis, my experience provides a unique perspective and understanding of the many issues affecting the behavioral health and autism communities and the organizations that care for and provide services to them.

Following my recovery, I founded Mental Health News, the precursor of what is now Behavioral Health News (BHN). One of the main reasons that drove me to start the publication was that, outside of the few hours a day I spent in out-patient programs, no one was reaching out to me where I lived.

I could have greatly benefited by having a resource like BHN to help alleviate the isolation I experienced in my lonely supported housing apartment. It would have also been helpful to stay informed on the latest mental health information and have access to a roadmap to the many programs, services and organizations in the community that could have helped me during my recovery; programs such as local drop-in centers and support meetings that were being held by organizations such as [NAMI](#), [MHA](#), [NYAPRS](#), and [ACCES-VR](#) (formerly known as VESID - New York's employment program for people with disabilities).



**Ira H. Minot, LMSW
Founder & Executive Director**

MHNE Launches Two New Websites

Mental Health News Education, Inc. (MHNE), the nonprofit organization that publishes [Autism Spectrum News](#) (ASN) and [Behavioral Health News](#), has recently launched two new websites! They are in a totally new format in which articles and advertising are now presented as their own shareable posts. Also, now everything is searchable by title, subject matter and author, going back in time to the first issues of each publication. Now, articles can be easily shared between families and colleagues who will greatly benefit by our award-winning platform of ideas, resources and information.

In addition, each new website has social media integrated for an easy sharing experience to give more visibility to the content. We've seen a dramatic increase in traffic at [BehavioralHealthNews.org](#) and [AutismSpectrumNews.org](#) is now averaging 350 views per day; 11,000 per month; 132,000 per year!

Content That Speaks to the Issues

Through our quarterly print publications, two brand new websites and our social media channels, we are now reaching over 200,000 individuals each year, serving as a beacon of hope for individuals living with autism, mental health issues, and substance use disorders and their families. In just the last year, both ASN and BHN have addressed topics that speak to issues that are compelling and affect the communities that we serve. Here is a snapshot of last year's issues:

ASN Spring 2020 Issue
"Supporting Girls and Women with Autism"

ASN Winter 2020 Issue
"Autism and Neurodiversity"

ASN Fall 2019 Issue
"Autism and Community Engagement"

ASN Summer 2019 Issue
"Supporting Older Adults with Autism"

BHN Spring 2020 Issue
"Housing: An Essential Element of Recovery"

BHN Winter 2020 Issue
"Addressing the Nation's Opioid Epidemic"

BHN Fall 2019 Issue
"Examining Models of Integrated Care"

BHN Summer 2019 Issue
"The Behavioral Health Workforce"

Your Trusted Source

For over 20 years, Autism Spectrum News has dedicated itself to being "Your trusted source of science-based autism education, information, advocacy, and community resources." It has been our masthead slogan over these many years, and this issue accomplishes our mission by devoting the theme entirely to "The Autism Community's Response to COVID-19."

The Current COVID-19 Crisis: The New Normal for Our Community

Consumers, families and the organizations that provide services to them are going through monumental hardships and challenges during the current crisis. In the aftermath of the crisis, many organizations will have had to adapt to the changing times in terms of delivering services and the financial hardships they have suddenly encountered. The dust hasn't yet settled but many organizations that have suffered financial hardship during the crisis may have had to furlough or restructure staff and rethink the many services they can and perhaps can't provide. This new normal will result in a dire need for small organizations to fundraise in creative ways so that they don't have to shut their doors.

Autism Spectrum News Future in Jeopardy

MHNE is a very small organization run by only two people: myself and my son David Minot - my Associate Director and Publisher of *Autism Spectrum News*. Many people think we have a large staff, but we haven't been able to hire support staff due to our small budget. The organizations we partner with are going through their own financial hardships during the COVID-19 crisis, and we've had to cancel our annual Leadership Award Reception fundraising event; we are in a very difficult financial situation.

We will be launching [an emergency COVID-19 Appeal](#) for funding on June 30th, the day when our event would have taken place. Our goal is to raise \$40,000, and we invite you to please give as generously as you can to demonstrate your commitment and help sustain our award-winning publications.

Thank you so much for your compassion and generosity. We stand together and we will get through this as a community.

Mental Health News Education, Inc. Emergency Appeal to Supporters of Autism Spectrum News and Behavioral Health News

**Please Help Us Through the COVID-19 Crisis
Which Has Caused Severe Financial Hardship to Our Organization**

Your Support Will Help Us to Continue Our Vital Educational Mission

I WANT TO HELP NOW!



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- Chocolate Covered Pretzels
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Proud to employ over 40 deserving and capable individuals with differing abilities, comprising 75% of our neurodiverse team.

Receive 20% off your order*
Use Promo Code ASN20



*Designs and Bakes order only

How Spectrum Designs Foundation Pivoted to Support First Responders and Healthcare Providers

By Lee Anne Vetrone
Development Manager
Spectrum Designs Foundation



Lee Anne Vetrone

Six or so weeks ago, when the COVID-19 crisis ramped up and then effectively halted life as we know it, the team at Spectrum Designs Foundation was on schedule to break previous sales records, offer more individuals with Autism paid employment opportunities and open the doors to our anticipated new location in Westchester County, NY. Immediately, thoughts shifted to the safety of our staff, then to sustaining our non-profit businesses: custom apparel, gourmet granola and a boutique laundry. When New York State ordered all non-essential businesses to shut down in an effort to stop the spread of the virus, two of our three businesses were deemed essential - Spectrum Bakes and Spectrum Suds, while the Spectrum Designs' production shop was shuttered. Our staff, 75% of whom are on the spectrum, were sent home and focus turned to providing remote learning opportunities and daily calls to stay in touch. But, what of the business? Spectrum Bakes and Spectrum Suds remained open, operating with a neurodiverse crew of 2-6 individuals.

Once staff was set up with scheduled on-line training and remote work schedules, we pulled together the team to brainstorm next steps, as has always been the norm for our game-changing non-profit. With the larger of our enterprises, Spectrum Designs, closed during the pandemic, how do our still growing enterprises (granola and laundry) rise to the occasion, stay afloat, keep on mission and be of service?

Keeping in mind our limited resources and staff, we created two campaigns for our enterprises that have turned out to be game changers. Spectrum Bakes created the "Snack-in-Place" gift box as a way for people to stay connected to colleagues, friends and families near and far. The boxes have been a hit and have shipped all over the US to much cheer! As a way to give back to a community that has given us so much, Spectrum Suds created the "Free laundry for first responders and healthcare

professionals" initiative, offering to take a "load" off (of laundry) for those who are sacrificing so much for our safety.

Although we were not able to fire up our machines to screen print and embroider custom apparel, we were able to tap into the promotional items end of our business and creatively pivot to procure desperately needed PPE (personal protective equipment) for front line and essential workers, businesses, municipalities and nonprofits. Working diligently, our team successfully sourced ethically priced, certified and vetted items while ensuring a quick delivery for those in need.

The success of these business "pivots" have meant the world to our organization, providing much needed income at an uncertain time, giving us positive, press worthy stories to share with donors and the media, and has secured a place for our staff to learn and work once we are given the go-ahead to come back to work!

Spectrum Designs Foundation is a purpose-driven organization with an important mission - to help individuals with Autism lead full and productive lives through the world of work. As a non-profit, 100% of profits go to advance the mission. Via three separate social enterprises, [Spectrum Designs](#), [Spectrum Bakes](#), and [Spectrum Suds](#), opportunities are created for employment, empowerment and growth.



Jason at Spectrum Suds

Helping Parents Address Challenging Behaviors During These Challenging Times

By **Bethany A. Vibert, PsyD,**
Cynthia Martin, PsyD,
Margaret Dyson, PhD,
and Adriana Di Martino, MD
Autism Center at the Child Mind Institute

There is a clear consensus that children with disabilities are the most vulnerable to both short- and long-term effects of COVID-19 (United Nations, 2020). This is particularly true for children with Autism Spectrum Disorder (here forward autism) for whom the sudden disruptions in educational and therapeutic services have negatively impacted behavior and emotional health (Espinosa et al., 2020; Spark Foundation, 2020). Concurrently, parents have faced the difficulties of being their child's direct care and education providers while also managing their careers (Espinosa et al., 2020). Many parents report inflexible behavior, difficulty with transitions, trouble independently completing tasks, and low frustration tolerance. Here, we briefly summarize strategies to help families support their children.

Behavioral science principles are the most commonly used to decrease challenging and disruptive behaviors (Bearss et al., 2015; Beavers et al. 2013). These evidenced-based interventions establish that, to improve behavior, one first identi-



Bethany A. Vibert, PsyD

fies a specific problem behavior and looks at what happens before (*antecedent*) and right after its occurrence (*consequences*). This will allow to identify the possible function(s) of that particular behavior. Behavior generally has one of four functions: 1) obtain attention, 2) access a tangible object or activities, 3) escape or avoid a task, or 4) seek or avoid sensory stimuli. Once the antecedents, consequences, and function(s) of a behavior are established,



Cynthia Martin, PsyD

a behavioral plan is developed to promote the desired behavior.

Targeting Antecedents

Also called stimulus control or environmental modification, antecedent-based strategies address the environment/events *prior* to a behavior occurrence with the goal of reducing the likelihood that the behavior will occur again (Odom, et al., 2010). One way to modify the environment is to enhance and/or develop a schedule of activities and tasks. Visual schedules facilitate independence, increase on-tasks behaviors, and improve transitions (Banda & Grimmer, 2008; Knight et al., 2014) by making it clear to the child what is coming next. For children with autism, not knowing what to expect can increase disruptive behaviors and trigger emotional dysregulation. Therefore, visual schedules using pictures and/or text to illustrate a sequence of daily activities can prompt appropriate behavior(s) by setting clear expectations (Dettmer et al., 2000). Early reports from areas where strict social distancing responses to COVID-19 were in place have shown that using detailed schedules were effective, even for children who did not require them before (Espinosa et al., 2020).

In constructing a visual schedule, the order of tasks should be individualized to reflect the child's age and abilities. Common strategies for implementing a visual schedule include placing it in a visible central location and reviewing it with the child using both nonverbal and verbal methods such as showing pictures or reviewing the schedule out loud. Using a timer and methods to track activity progress, such as check boxes, moving a picture from a "to do" to a "done" section, and crossing something off, are also helpful practices. In conjunction with the visual schedule the physical environment should also be adjusted to increase attention by removing and/or limiting access to distractions (e.g., storing preferred items away out of sight and reach). Using software applications that limit, monitor, and restrict screen time may also be necessary when media use is excessively distracting.



Margaret Dyson, PhD



Adriana Di Martino, MD

Targeting Consequences/Reinforcement

Addressing consequences of behaviors, such as positively reinforcing a desired behavior, is another important step. Positive reinforcement can be tangible (rewards) or intangible (labeled praise). Rewarding desired behavior increases the likelihood that behavior will occur again. Using a response-contingent model (in that a child has to do a desired behavior to earn a reward) is most helpful. To use strategies from this model effectively, the parent must first identify two things: 1) a desired, alternative or replacement behavior and, 2) a positive reinforcer. Then, a parent only provides the identified reinforcer if and when the desired behavior occurs. It is also helpful to identify a proactive plan for what to do when the child exhibits the undesired or "problem" behavior.

Planned ignoring is one example of an effective strategy for behaviors that have the function of gaining attention or avoiding/escaping a demand or activity. To implement planned ignoring, parents can actively remove attention from the undesired

see *Helping Parents* on page 40



Treatment and Resources for Children With Autism

Children with autism may be having trouble adjusting to distance learning and handling the disruption of their routines. The Child Mind Institute provides remote evaluations and treatment plus resources to support families — wherever you are.

To learn more, visit childmind.org/telehealth or call (877) 203-3452.

Displaying Courage, AHRC NYC Staff Support People with I/DD in Group Homes and Remotely with Technology

By Marco Damiani, CEO
AHRC New York City

Months into our response to the COVID-19 epidemic, we have suffered heartbreaking losses and struggled through many challenges. Through it all, our staff's extraordinary devotion, caring and tireless efforts to support people with disabilities, their families, and each other, has been unprecedented.

No one can predict when the Coronavirus crisis will truly settle down and end. But we can find comfort knowing that we are truly all in this together and, because of that, our bonds will be strengthened as we learn together, plan together and rebuild together.

Staff, who are considered essential workers not only in New York State but across the country, have demonstrated this every day. They are heroes. In many ways, this crisis has brought out the best in our staff at all levels. We can never give enough praise and express sufficient gratitude to our front-line staff. I'd like to share just a few of the many inspiring stories about our front-line staff.

Our First Loss

When Robert Caruso, one of the original residents of an AHRC New York City group home for people with intellectual and developmental disabilities (I/DD) in Howard Beach passed from COVID-19, the impact on his peers and staff was devastating.

Kisha Kennedy-Vanholt, Manager of the home, knew it was up to her team to help everyone recover.

When she told Caruso's roommate, he cried. "I couldn't hug him; that was heartbreaking," Kennedy-Vanholt said.

But this is life under social distancing. Caruso was the first person we supported at AHRC NYC to die from the virus. Unfortunately, with people living in group residences, he wouldn't be the last.

Suffering Broken Hearts

After Caruso's passing, the others in the home stayed in their rooms and stopped eating. They were exposed to COVID-19 and were frightened, but they also likely were suffering broken hearts. "We knew we had to fight really hard to bring life back to the program," Kennedy-Vanholt said.

The word from their primary care physicians was: Don't go near the emergency room or urgent care. Staff tried making favorite foods and finally the individuals began to eat.

"The life is here again," Kennedy-Vanholt said. "You can feel it when you walk in the door."

Adult Day Services Come to Homes

Staff members showed their courage and heart by keeping adult programs open. They knew that providing exercise, art and drama were more important now than ever.

Phurbu Dorgee, a Records Coordinator at one of our [Adult Day Services](#) programs,



Some of AHRC New York City's essential staff at its Fresh Meadow Lane residence in Queens, NY

has been working with Joseph Bell since April 14. They exercise and paint, something Joseph particularly enjoys. "You have to work; you have to take a risk," Dorgee said. "The most important thing is that I'm here for Joseph."

"Painting makes me feel happy," Bell says. "I work hard on my paintings to be an artist."

Melanie Freeman, from our [Manhattan Day Hab Without Walls](#), has been lending a hand at our 95th Street residence in Manhattan. "I try to find things to keep everyone entertained with a focus on mindfulness," she said, adding that she runs a drama therapy group to help individuals express themselves. The group has made sensory bottles, do karaoke, dance and much more.

Telehealth Breaks Through as an Essential Service and Support

The Coronavirus has changed the way we, as service providers, do everything. It has taken us out of our comfort zone. Pushed by COVID-19, technology has become the backbone of many of our services.

As the virus began spreading in New York City, AHRC NYC's partnership in [The Cerebral Palsy Association of New York State's](#) \$13 million grant from the Statewide Healthcare Facility Transformation Program couldn't have come at a better time. The telemedicine equipment connects to [StationMD](#) through a wireless tablet mounted on a portable kiosk. The system delivers virtual health care with a goal of reducing trips to the emergency room and hospitalizations.

People with I/DD are more prone to COVID-19 due to underlying medical conditions such as diabetes, asthma, heart disease, stroke and other disorders.

A 75-year-old Queens man with I/DD who lives in an AHRC NYC group residence was ill with a fever and chills. Staff thought it might be Coronavirus. Rather than expose him to urgent care or the emergency room, they used StationMD. The StationMD doctor reviewed the man's history and observed the man. The doctor

prescribed Keflex for a urinary tract infection, and the man was better in three days.

"I'm a believer in helping the person where they're at, in their own home with people who care about them," said Marcia Richman, an AHRC NYC Registered Nurse and Residential Health Care Coordinator and Home Care Director of Patient Services.

Supporting Our Staff

In times of crisis, everyone is anxious. We must make sure we "hear" and respond to our staff's anxieties. So when our clinicians began making virtual mental health visits, through [doxy.me](#) with people with disabilities and their families, we were able to use a similar platform to connect with staff facing increased stress during this pandemic.

"Some people need more support than others," said Dr. Richard Cohen, Director of Clinical Services, referring to individuals with disabilities and their families. "We are always assessing how much may be needed to meet individual needs. We're looking at what resources are available and what additional support may be helpful.

"Our goal is to keep people safe in their own home and minimize unnecessary exposure to emergency rooms for mental health care. AHRC NYC Clinicians work to address the myriad of stressors associated with this pandemic. The impact of social isolation and disruption of life routines are significant, and supports are essential."

Distance Learning

Remote learning is new for our preschoolers, school-age and college students,

see Courage on page 32



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Utilizing Digital Media to Enable Continuity of Autism Services

**By Howard Savin, CCO,
Matthew Hess, CEO,
Cindy Conley, Clinical Director,
Ellen D'Amato, School Psychologist,
and Jay Cohen, Program Supervisor
First Children Services**

For over a decade there has been an abundance of professional articles and seminars on the potential of telehealth and distance learning services. Outside of the medical world, the movement of state licensing bodies and insurance payers to permit use of telehealth services by licensed behavioral health clinicians and BCBA's has been glacial. In March 2020 we witnessed the rapid, crisis-driven implementation of telehealth and related development of transformative educational interventions for consumers of our services. This article will describe the rapid mobilization of **First Children Services'** (FCS) telehealth ABA, mental health interventions and distance learning to sustain continuity of care for special needs children.

First Children provides ABA and mental health services through clinics, in-home and school settings. FCS also operates a special needs school, a therapeutic education program for youth with severe anxiety and supports children in New Jersey district homebound programs. The emergent COVID-19 crisis jeopardized the continuity of our clients' autism and related educational services.

The Clinical Team made the difficult decision to close FCS' clinics but determined to continue providing exceptional ABA services to prevent regression of learned skills or the reemergence of problem behaviors. After learning how to implement telehealth ABA services, clinically informed individual decisions were made about continuing care via telehealth or by providing in home ABA treatment. Parents were mostly on board with this plan while a few of our families elected to suspend services until current COVID-19 restrictions are lifted.

Training on CDC guidelines commenced with a review of safety requirements for continued in-person services such as temperature checks, PPEs, hand washing and social distance. Subsequently, staff were provided PPEs, and it was decided to reduce staffing to one Registered Behavior Therapist (RBT) in one home per day. BCBA supervision proceeded via telehealth to minimize risk. Next, parent and employee agreements were prepared which outlined expectations for continued social distancing, reporting potential exposures, and compliance with CDC guidelines for in home services.

Clinical leadership spent two weeks attending ABA telehealth webinars and reading relevant literature to gain telehealth competency. The CASP organization (**Council of Autism Service Providers**) was noteworthy in disseminating comprehensive support to First Children and other ABA providers to enable timely telehealth competency.

Clinical leadership then conferenced with each BCBA regarding modifications of treatment plans, materials, or behavior interventions while planning for the effec-

tive implementation of telehealth services. RBTs were also trained to deliver instructions, collect reliable data, modify materials, provide reinforcement and respond to problem behaviors via telehealth.

Respective BCBAs held parent/caregiver meetings to review expectations, complete the telehealth consent forms, test home technology and address any concerns. RBTs then conducted 2-3 pairing sessions with clients via telehealth. Once ABA telehealth sessions were initiated, some RBTs began with 15-minute sessions and session lengths were increased towards 60 minutes, as clients adjusted to telehealth services.

Within two weeks as telehealth providers, BCBA's found that individual ABA telehealth services were not as effective as in person services. Our team believes part of this could be due in part to lower utilization of telehealth hours compared with in person therapy. Telehealth ABA services does seem effective in preventing some skills regression. In contrast, parent training appeared to be more effective via telehealth. The increased engagement of parents observed is likely due to the convenience of engaging with a provider in ones' home - with or without their children present. Clinical leadership is enthused by the potential of telehealth and expects to continue providing parent training telehealth after the of COVID-19 threat has subsided.

First Children's Transitions program addresses the needs of 34 school avoidant middle and high school aged students who suffer from anxiety and other emotional disorders, including autism. Academic instruction is provided in a classroom setting and both group and individual therapeutic services are integrated into programming with the goal of maximizing school attendance.

Novel methods of delivering distance learning services were devised following the onset of the COVID-19 crisis. Laptop computers and printers were delivered to all students in need. Supervisors used Microsoft Teams to guide the teachers in developing specific written and live virtual contact which enabled delivery of meaningful and engaging assignments that met the specific needs of the students.

Concurrently, tele-behavioral individual and group therapy services were adopted and provided to students on their scheduled basis. In situations where students were acutely struggling with the stress of their COVID-19-related circumstances, licensed staff clinicians, in concert with CDC guidelines, provided intensive in-home therapeutic support.

First Children also provides traditional homebound services in New Jersey under the direction of Susan Goldman, M.Ed. These services quickly transitioned to a distance learning model via Instructor's use of Skype, Google hangouts, Zoom, Instagram and Facetime to connect with students. This enabled continued work on classroom assignments, projects, essays, and labs while keeping students on target with their counterparts in "regular" district classrooms.

The First Children School serves over 100 students with multiple disabilities for whom distance learning and remote clinical servicing was unimaginable when the pandemic hit. Most students receive multiple therapies including speech, occu-

pational, and physical therapy. Many students are blind, visually impaired, or deaf. Some children require behavioral support including one-to-one intervention. Accordingly, a variety of factors were considered before adopting specific methods for delivering educational and therapeutic services adopted during this time.

Parents have always been active members of the IEP team but have become truly key partners with the teachers and therapists in identifying needs and the best means of providing educational and therapeutic services within their homes. Staff have engaged the families and students in both familiar and new ways. Ongoing communication between our teachers and therapists provided families with coordinated plans that included activities, vocabulary, and strategies to be embedded into a student's daily routine and natural environment. Initial communication with families helped to identify preferred means of contact, accessible equipment and materials and a description of the home environment. All are important components in the design of a distance learning program that would meet the needs of the students and their families. While bringing students, families and staff together has been the school staff's best practice, social distancing was not. Thus, new, and comfortable ways of bringing everyone together were created such as daily video conferencing with teachers, therapists, nurses and virtual IEP meetings.

The needs of our families were as unique as the needs of our students, and the Team needed to learn how to individualize. Thus, staff proceeded to identify the essentials of these natural environments and plan accordingly. A major task was practicing these new ways of access. The team's favorite phrase was "keep it simple." Staff also had to consider the needs of the new instructors, as parents provided them with clear and appropriate guidance. The overarching goal was to create an environment of support to enable staff and families to "ask for help" as well as "provide it." Most of all we needed to continue with the familiar into the future when we return to school without totally abandoning new ways of connecting via Microsoft teams, Zoom and virtual instruction. We continue to celebrate the engagement of our families in these new and exciting ways. The school's staff have learned a lot over the past six weeks and will continue to grow and change.

COVID-19 will not be the death knell for traditional models of behavioral health and special education. Going forward, schools, offices and clinics will re-open and providers will succeed by embracing a blended model that incorporates telehealth and distance learning services. This flexible approach will help insure good outcomes for clients regardless their physical locations.

For further information on First Children Services please contact Matt Hess at mhess@firstchildrenservices.com.

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Maintaining Best Outcomes for Students in a Congregate Care Setting Amidst a Pandemic

By Rita M. Gardner, MPH, LABA, BCBA, Helena Maguire, MS, LABA, BCBA, Jennie Labowitz, MS, NCSP, BCBA, Silva Orchanian, MEd, BCBA, LABA, and Mary Jane Weiss, PhD, BCBA-D Melmark

CCOVID-19 posed immediate and unprecedented challenges to organizations providing intensive behavioral services in a congregate care setting to children and adolescents diagnosed with autism and intellectual/developmental disabilities. The evolving discoveries about the novel virus and how to combat its spread created daily, real-time triage needs at every level of human services organizations.

Congregate care settings have been particularly affected, prompting leadership teams at organizations like Melmark, which serves individuals with autism and intellectual/developmental disabilities, often accompanied by medical fragility, to strategically develop adjusted standards of care. In addition, the need for some individuals to now be served primarily at home, with others remaining in their residential placements, was a significant challenge requiring procedures to directly engage learners in a variety of environments. The sudden change in educational setting and delivery, need for remote caregiver



Rita M. Gardner, MPH, LABA, BCBA

support, and development of telehealth support structures posed unique challenges to education and residential staff.

Closing Day Programs

One of the earliest steps in mitigation was to close day programs (school and adult day) at all of Melmark's service divisions in Massachusetts, Pennsylvania and North Carolina. This created new sce-



Helena Maguire, MS, LABA, BCBA

narios for education professionals as they worked to ensure the continuity of services to all individuals. Melmark's senior leadership team enacted many layers of change to support health and safety protocols and to provide services to all individuals, regardless of their physical location, in evidence-based, best practice ways.

A Multi-Layered Approach for Home Instruction

For students whose instruction would now take place in a home environment, radical changes in service delivery were immediately needed. Some parents were thrust into primary instructional roles, if their child was not responsive to instructors via video. Students who could participate in remote instruction had to learn the nuances of interacting with their teachers in a virtual environment. Teachers learned to provide instruction and coaching remotely. Despite the abrupt onset of these changes, education teams provided a measured and methodical implementation of individualized telehealth/tele-educational services. Each member of the education team collaborated to ensure best outcomes, both for the students and staff.

1) Addressing issues of access - Staff and families were assessed for their access to and familiarity of use of computers and tablets. Organizational Zoom accounts were made available to departments and to individual employees so that telehealth/tele-educational services could be delivered in a secure online setting. In some cases, equipment was provided to families to ensure communication could occur. In other cases, collaboration with school districts secured devices for use. Finally, the organization purchased cameras, laptops, and hotspots for families and for staff in need.

2) Training of staff in the technology for and the provision of remote support - Staff members learned how to use new programs and applications to support families in instruction. In some cases, staff directly provided telehealth/tele-education to



Jennie Labowitz, MS, NCSP, BCBA



Silva Orchanian, MEd, BCBA, LABA



Mary Jane Weiss, PhD, BCBA-D

the individual served. In other cases, family members provided that direct support to the individual in partnership with staff, who trained parents on the use of technology and provided instructional coaching.

3) Check-ins with families - All families received check-ins multiple times per week, regardless of the format of remote

see Best Outcomes on page 33

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Silver Linings: Potential Benefits of “the New Normal” for Individuals with ASD

By John Bryson, MS Ed, CESP
Sr. Manager, Corporate Consulting
NEXT for AUTISM

COVID-19 has presented new challenges for individuals with ASD and their families, starting with curtailed access to essential services and rippling out to potentially life-altering changes. Everchanging stay-at-home orders have led to ongoing uncertainty for health and safety, as well as a positive outlook for the future. The impact of social distancing on mental health is an ongoing concern, as are the negative effects on the economy and permanent changes to health and safety measures. The “normal” way of life may never return, yet despite these significant issues, there is the potential for positive change for individuals with ASD.

Consider the explosion in telecommuting over the last few months. The world has seen a record number of employees working remotely. Countless companies have transitioned their businesses to virtual platforms and project management software. Some companies, experiencing remote work for the first time, are learning its many benefits: increased productivity, performance, engagement, retention and profitability (Farrer, 2020). A friend of mine, who is on the spectrum, works for a company that is new to telecommuting,



John Bryson, MS Ed, CESP

An active advocate for disability rights, he recently shared that thanks to his current remote situation, he is happier than he has ever been. He feels more motivated, more productive and less stressed. He also reported a decrease in anxiety and depression symptoms. He feels optimistic that his option to work remotely will become permanent and these health and wellness benefits will continue.

When companies reopen, many will likely maintain remote work options, whether

as an accommodation for certain employees or a universally adopted practice. Individuals with ASD, who need or prefer to work in a more individual setting and use technology to work from environments tailored to their needs, may find that employers are more willing than ever to meet these needs. The embrace of remote work opportunities for all employees will create a more generous space for employees with autism to receive the supports necessary to truly thrive.

Another acquaintance with ASD worked in a communal job environment for 25 years, masking the characteristics of his diagnosis from his colleagues. The demands of daily social interactions became overwhelming, and hiding his symptoms daily had a profoundly deleterious effect on his wellness. Eventually, he was diagnosed with Post Traumatic Stress Disorder (PTSD) and was unable to continue working. Reflecting on his career path, he believes that had he been supported to feel comfortable about disclosing his disability rather than masking it, he would not have experienced the stress that caused him to lose his job. Greater awareness of how flexibility can contribute to the success and wellbeing of employees with disabilities will translate to more positive work environments for all employees.

Universal design - designs for the disability community that can be widely generalized - will likely see an uptick in the

areas of health and safety. More spacious workplaces, which have been a necessity for some people with disabilities, will now be required for all due to social distancing. Social norms like handshakes, hugs and pats on the back, which were avoided for people with autism who are sensitive to touch, will become common for all. There will be fewer people in stairwells, hallways and elevators, as companies and buildings try to minimize the possibility of a surge in COVID-19 cases. Flexibility and support will be absolute necessities for any company wishing to retain a healthy workforce, and individuals with ASD will benefit.

Many companies will have to rebuild their customer base. Post-COVID-19, consumers are likely to spend cautiously and favor value-specific services, like curbside pick-up, or health and safety over brand loyalty (Bhargava, Buzzell, Sexauer, & Charm, 2020). Competition to regain consumers and attract new ones, using every strategy, will be fierce. In this scenario, I believe that disability-inclusion hiring strategies are a post-COVID-19 business solution. A national survey in the US found that 92% of consumers felt more favorable toward companies that hire people with disabilities (Siperstein, Romano, Mohler, & Parker, 2006). When companies reevaluate their labor needs, hiring individuals with ASD and other disabilities will renew

see *Silver Linings* on [page 41](#)



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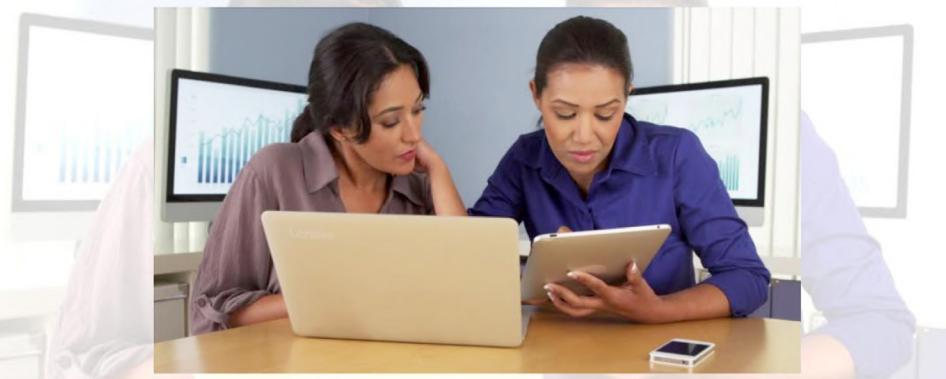
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Help for Parents Managing Challenging Behaviors for Children with ASD During COVID-19

By Rebecca Schulman, PsyD, BCBA-D and Rory Panter, PsyD
Behavior Therapy Associates

The last several weeks have resulted in significant changes for families, as parents and children are now spending most of their time together in the home. Many parents are trying to balance work, child-care, and distance learning for their children, while also trying to manage children's challenging behaviors. It is common for many children with Autism Spectrum Disorder (ASD) to exhibit behavior difficulties during transitions or times of stress. One of the common diagnostic characteristics of ASD is "Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior; e.g. extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat the same food every day" (American Psychiatric Association, 2013, p. 50). The impact that COVID-19 has had on families has resulted in likely one of the biggest transitions for children in their lifetime. Children with ASD may be experiencing a variety of emotions, such as fear, confusion, anger, anxiety, and boredom, which may influence the develop-



Rebecca Schulman, PsyD, BCBA-D

ment or exacerbation of challenging behaviors. Using several important behavior strategies, parents can better address their children's challenging behaviors and make this time at home run a bit more smoothly for everyone.

First and foremost, it is important for parents to set realistic expectations for themselves and their children. Families are now forced to juggle more roles and



Rory Panter, PsyD

responsibilities than ever (e.g. parent, teacher, play mate, etc.). Therefore, it is essential for parents to be realistic regarding what they and their children can accomplish each day, particularly as parents' attention must be divided. Families can decide together on their core values during this time at home and have open discussions about these values (Harris, 2019). For co-parents, all adults involved should

be sending the same message to their children about behaving in accordance with these values. Consistency among parents/guardians is the key to creating a cohesive family (Clark, 2017).

Following routines and structure are important for all children in order to help provide order to their daily lives. For children with ASD, it can be especially important to structure the home environment in order to create a safe and predictable environment for them, reduce overall levels of anxiety, and increase their skill development. By setting up specific home schedules and routines, parents can help their children adjust during this time of uncertainty. For example, creating and sticking to a regular schedule will help children understand that they are not simply on vacation. The schedule can be similar to a school day schedule, alternating periods of academics, play, and activities of daily living and changing activities at set time intervals. If possible, children should wake up, eat, and go to bed at their typical times. Consistency and structure help children know what is going to happen and when, which can help to reduce anxiety, as well as increase compliance. Having children contribute to their own daily schedule can make this task a more interactive and fun activity.

see Help on page 29



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Services for the UnderServed (S:US) is pleased to announce the following appointments to leadership positions within the Developmental Disabilities Division. Congratulations!

MONICA SANTOS
Chief Program Officer



Monica joined the S:US family in March 2020 as the Chief Program Officer, Developmental Disabilities Division. Monica started in the field as a DSP and held increasingly responsible positions at AHRCNYC where she has spent the last 25 years of her career. Her most recent position is Vice President, Residential Services and Housing Solutions. In this capacity, Monica oversees \$92M in residential services for 700 people with I/DD. Monica holds an MA in Disability Studies from the School of Professional Studies, Graduate Center, CUNY. She had a stint in Botswana from 1988 to 1990 as a Peace Corps volunteer, which has helped to shape the person she is today. Monica's personal philosophy is that "every life is of infinite value." She looks forward to sharing her vision for the people we support.

COURTNEY MORGAN, MBA, BSN, RN
Senior VP, Health & Clinical Services



Courtney returned to S:US in February 2020 as the Senior Vice President, Health & Clinical Services, Developmental Disabilities Division. Courtney had previously been a member of the S:US family serving as the Director of Medical Services, DD Division, 2005-2014. For the last six years, Courtney held the position of Chief Health Administrator at The Head Injury Association. In addition to her Bachelor of Science degree in Nursing, she holds an MBA in Health Care and Information Systems from St. Joseph's College. Courtney is excited to be returning home and looks forward to bringing to us all that she has learned during her time away.

Understanding and Mitigating Challenges Faced by the Healthcare System When Treating Children with ASD and Problem Behavior

By Alexis Pavlov, PhD, BCBA-D
and Colin Muething, PhD, BCBA-D
Marcus Autism Center

Meeting the healthcare needs of the heterogeneous population of children with autism spectrum disorder (ASD) poses a unique set of difficulties for an already burdened healthcare system during a pandemic such as the current COVID-19 crisis. Children with ASD experience the same childhood illnesses as typically developing children but are also at increased risk for a host of other medical conditions such as gastrointestinal issues, neurologic issues, and psychiatric conditions (Liu et al., 2017). As a result, children with ASD often require increased specialty healthcare compared to children without ASD such as increased time spent in acute, inpatient settings (Croen et al., 2006). Children with ASD are more likely to be hospitalized for routine injuries and visit the Emergency Department (ED) more often compared to typically developing children (McDermott, Zhou, & Mann, 2008).

Complicating the challenges of meeting this increased need for medical care is the fact that children with ASD present with symptoms, such as restricted and repetitive interests, difficulty with routine changes,



Alexis Pavlov, PhD, BCBA-D

and deficits in social communication that may impede the delivery of this care. These symptoms can negatively impact medical appointments and can lead to increased use of restraint or sedation to complete routine medical procedures (Croen et al., 2006). However, the availability of guidance regarding the use of behavioral strategies to work with patients with ASD has increased in the literature (Riviere, Becquet, Peltret,



Colin Muething, PhD, BCBA-D

Facon, & Darcheville, 2011; Stuesser, and Roscoe, 2020). Consultation from a behavior analyst (i.e., Board Certified Behavior Analyst, BCBA) or someone with training in implementing behavioral interventions with this population can dramatically reduce the difficulties presented in medical settings by children with ASD. For example, de-escalation strategies such as providing access to preferred items/activities

or attention and reducing demands can eliminate triggers for problem behavior or reduce the likelihood of problem behavior escalating into a crisis. Additionally, when triggers can't be avoided and problem behavior results, practitioners trained in the use of effective physical management strategies can use blocking and redirection to maintain the safety of both the caregivers, patients, and clinicians providing care.

The advanced training in applied behavior analysis and understanding of behavioral principals that are part of the training for BCBA's can equip them to assist healthcare providers in identifying potential triggers for problem behaviors. These include gathering direct and indirect data to identify the underlying causes of challenging behavior and the application of reinforcement-based procedures to increase adaptive replacement behaviors such as compliance or tolerance. Common triggers to problem behavior include the restriction of preferred items or activities, restricted or diverted attention and escape from demands or aversive situations (Beavers et al., 2013). Identifying the specific triggers that are most likely to evoke a particular child's problem behavior guides a behavior analyst's recommendations regarding individualized strategies for eliminating or

see *Healthcare on page 30*

Examining the Challenges Service Providers Have Faced as a Result of COVID-19

By Arthur Y. Webb
Executive Director
New York Integrated Network for
Persons with Intellectual and
Developmental Disabilities (NYIN)

COVID-19 has had devastating consequences to people and communities: tragedy at its worst; consequences beyond measure; and anxiety and uncertainty exceeding our grasp.

The purpose of this article is to highlight the challenges that providers of care for persons with intellectual and developmental disabilities have faced since onset of this horrible virus. They have had to use a "do it yourself" method without the direct support of government like find and buy PPE and medical supplies; close programs; provide staff incentives; follow CDC and state guidelines on quarantine and isolation; and negotiate with hospitals for access. The issues continue to mount like the lack of priority for testing staff and persons being served and the unreimbursed expenses related to managing the crisis.

The most tragic outcome of this crisis is the high rate of infections, hospitalizations and deaths for people living in licensed residential settings in New York City like group homes and including staff. The early data on infection and death rates showed that persons with intellectual and developmental disabilities had 3-5 times the rates



Arthur Y. Webb

in New York City residential group homes compared to general population rates.

One of the more profound impacts of the COVID-19 crisis is that leaders in the nonprofit, human service world are living with competing priorities and moral dilemmas all day long. Some of these competing priorities can bang against each other in harsh ways but then require immediate resolution and action. Sometimes these are diametrically opposing priorities.

Why is this relevant to the crisis caused by COVID-19 for both the public health

and economic crises? The challenge has been dealing with competing values and strategies even in the face of evidence. For example: providers want to protect the clients at all cost even though it might undermine the fiscal viability of the agency; they insist that staff come to work even though they have not been tested; and insist on staff coming to work even though they have family obligations due to the crisis. There are many other conundrums that executives have faced during this crisis.

For persons with intellectual and developmental disabilities (IDD) including those with mental retardation, cerebral palsy, Down Syndrome, epilepsy, neurological impairment, and autism are being directly impacted by COVID-19. The very thing that is a hallmark of the IDD field - integrated community living - is now creating an additional vulnerability in being exposed to COVID-19 - living in a group home.

New York Integrated Network for Persons with Intellectual and Developmental Disabilities (NYIN) is a 501(c)3 nonprofit organization which formed a data collaborative project headed and facilitated by one of the member CEOs over a year ago. Its purpose was to build a database on the activities of the members since the state Office for Persons with Developmental Disabilities (OPWDD) was not producing information to measure quality, costs, or outcomes. However, the data collaborative started to focus on collecting data on COVID-19 in early February. Once again,

the state was not doing this in any meaningful way. The Collaborative expanded it participants to include two other larger agencies in NYC (see below). Our goal was to track rates of infection, hospitalizations, and deaths. This was designed to help track trend lines, identify hotspots and advocate for priority attention from public officials. The data was a subject of an article in Crain's Health Pulse in early April.

This Collaborative is collecting data on over 4000 persons living in licensed group homes in NYC or over 30% of all residential settings in NYC.

One would think that data gathering is a neutral activity but as a Collaborative, we have learned that data can get public officials, advocates, staff, and families all upset and concerned. The issues start with questioning the data gathering methodology, and then moves to using it to criticize the field. This is a no-win proposition even though providers are doing everything to protect the staff and the persons they serve.

I actually believe that leaders learn to hold two contradictory ideas, values, and priorities at the same time and still effectively lead. In psychology, they call this cognitive dissonance, which can and does create mental stress and discomfort. We constantly look for evidence, best practices and lessons learned to reconcile this dissonance. We also see, what sometimes is called cognitive immunization, where even

see *Examining on page 34*

Stress and the COVID-19 Pandemic: Paying Attention to Your Cortisol Level in Challenging Times

By **Sam Goldstein, PhD**
Assistant Clinical Instructor
University of Utah School of Medicine

The COVID-19 pandemic not only worries us about our health but our very survival as a society. We all can identify with the emotional, physical and cognitive impact of stress on our bodies and minds. In stressful situations we struggle to concentrate, remember and learn. We are more prone to headaches, nausea and contracting illnesses. We are also more likely to experience thoughts and behaviors consistent with mental health conditions such as anxiety and depression. In this article I present valuable information about cortisol and your body, and then offer some practical suggestions to help you stay in control of your body's stress reaction.

What exactly is the underlying biological, neurological and physiological response in our bodies that is not only a consequence of stress but in and of itself fuels further stress related challenges. The culprit is a steroid hormone known as cortisol. When used as a medication it is known as hydrocortisone. Hydrocortisone as a topical agent can reduce swelling, itching and redness. However, within our body cortisol has far more reaching effects. Cortisol



Sam Goldstein, PhD

is produced in many animals, primarily in the adrenal glands. It functions to increase blood sugar, to suppress the immune system and aid in the metabolism of fat, protein and carbohydrates in our bodies. It also decreases bone formation. Think of cortisol as nature's built in alarm system. It is your body's main stress hormone. Once released into your bloodstream, it in-

teracts with multiple systems in the brain and body, impacting mood, motivation, fear and learning. Cortisol can be found in your saliva and hair. Cortisol is perhaps best known as fueling your body's "fight-or-flight" system, such that in a crisis you are more likely to survive. It regulates your blood pressure. Cortisol also controls your sleep wake cycle and under times of stress boosts your energy.

We know that moderately elevated cortisol is a good thing in times of stress. However, we also know that prolonged and significant elevations of cortisol in the body, as the result of ongoing stressful experiences, turns an important protective system into a powerful, adverse force capable of causing a broad range of emotional, cognitive, behavioral and physical problems.

Over the past forty years research studies across the life span from infancy to geriatrics have demonstrated the adverse impact of extended and highly elevated cortisol levels. Elevated cortisol is found in infants living in chaotic environments. Not only that, extended levels of elevated cortisol in young children has been associated with delays in the development of abilities such as executive functioning. This has also been found true in adult's ability to effectively problem solve. Studies completed well before the current COVID-19 pandemic have demonstrated that average

levels of cortisol across the life span are higher today than ever before. In light of the current pandemic it would not be unexpected that all of our cortisol levels at this time are significantly elevated. Let's briefly discuss more of the science.

Infants exposed to postnatal maternal depression have been found to experience higher levels of cortisol as adolescents. This suggests that early adverse experiences might even alter later cortisol and related steroid levels. Maternal depression can be added risk for depression in children. Alterations in cortisol level long term might be the link between early life events and later mental health challenges. A number of researchers have demonstrated increased cortisol levels during the day among toddlers in childcare, in particular for children with long hours in childcare but not children at home.

It has also been demonstrated that memory tends to be better for emotionally charged than for neutral information. Evidence from human and animal studies finds that when low doses of cortisol are administered in research study and participants are exposed to pictures designed to produce varying levels of emotional arousal, incidental memory for these pictures, particularly those representing significant

see Stress on page 34

Why Is There Laughter During the COVID-19 Pandemic?

By **Monica E. Carr, PhD**
Autism Specialist and Research Fellow
University of Melbourne, Australia

At the time of writing, a Google search for "COVID-19 funny" returned some 880,000,000 results. Similarly, at this time the novel Coronavirus SARS-2 has affected all but 12 countries around the world, and despite testing limitations some 4,256,579 positive cases have been reported worldwide ([COVID-19 Worldometer](#)). With no vaccine, no clinically proven anti-viral treatments currently available, and a reported global death toll of 287,354, many people may wonder why COVID-19-related humor has been so prevalent during this pandemic. The role and use of humor at this time could be even more confusing for people on the autism spectrum.

Currently a diagnosis of Autism Spectrum Disorder (ASD) is made based upon the presence of persistent impairment in reciprocal social communication and interaction and also restricted, repetitive patterns of behavior, both present from early childhood (DSM-5, 2013). We live in an era where social communication and interaction may take various forms other than direct speech. Typical daily interactions in our schools and workplaces, or amongst our family and friends, may include a multitude of in-person or virtual exchanges of texts, pictures, or videos. Appropriate-



Monica E. Carr, PhD

ly developed social skills are integral to achieving these social communication and interaction tasks successfully.

Orpinas and Horne (2006) defined social competence as "a person's age-appropriate knowledge and skills for functioning peacefully and creatively in his or her own community or social environment" (p. 108). Research has posited that the judicious use of humor may be an important social skill in itself and may contribute to other social competencies, such as the ability to initiate social interactions, provide emotional sup-

port, and manage conflict (Yip and Martin, 2006). It has been reported that humor may function as a mechanism for coping with stress (Lefcourt, 2001). Humor may also be viewed as an important emotion regulation mechanism. Prior research has noted the relationship between humor and a positive mood (Martin et al., 2003), and in maintaining a cheerful perspective in the face of adversity (Lefcourt, 2001; Martin, et al., 1993).

During the COVID-19 pandemic, humor has been widely used by people in all walks of life, including city Mayors, national television entertainers, comedians, and internet content creators. Humorous content has been widely shared on social media platforms by children and adults alike, posing a confusing message as to how joking and laughter share a place with grieving and solemnity during this unprecedented period. Social skill deficits and developmental delays that are prevalent amongst many people on the autism spectrum further contribute to questions about why is this meme or video funny, or why we should laugh at the moment? Such questions are completely valid, and it is of utmost importance to provide appropriate explanations and guidance surrounding the use of humor.

COVID-19-themed humor has been used in various ways, including to send important messages to promote behavioral change for government mandated initiatives such as social distancing, increased

frequency of hand washing, the necessity of temperature screening and contact tracing when entering public venues, and in many locations the compulsory wearing of face masks. Humor may serve as a useful delivery mode to clearly convey important messages to a wide audience, while reducing the stress associated with sudden behavioral changes. Humor may also promote solidarity and a sense of inclusion, relieve aggression, and alleviate boredom that may be particularly challenging for people with ASD as a result of unanticipated changes to daily living routines.

Many styles of humor exist, and what is funny to one person may not be funny to another. Consequently, some people on the autism spectrum who experience challenges attributed to an undeveloped sense of humor, or the inappropriate use of humor, may be placed at a distinct disadvantage in their social interactions. Yip and Martin (2006) reported that two humor styles - affiliative, and self-enhancing - are thought to be potentially beneficial to relationships and emotional well-being. Further, two humor styles - aggressive, and self-defeating - are believed to be potentially detrimental to relationships and well-being. Importantly, Martin et al (2003) highlighted that the absence of maladaptive humor styles may be equally as important as the presence of positive humor styles.

Social skills training can help develop

see Laughter on page 38

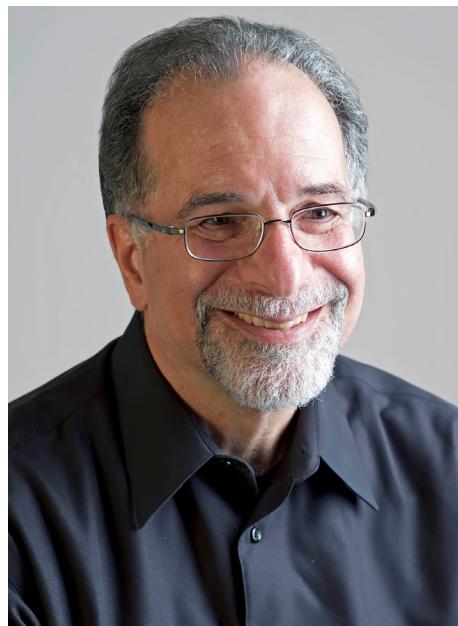
Stronger Than We Think: The Advantages of Neurodiversity in the Face of Adversity

By Robert Naseef, PhD
Psychologist
Alternative Choices

COVID-19 presents huge challenges and added layers of vulnerability for children and adults with autism and other special needs and their families. Some experience more adversity than others because of race and social class. However, it is my belief that neurodiversity has some built-in advantages for families with neurodiverse members. It is in that sense that we may be stronger than we think. On April 9, 2020, I spoke about this on a [Facebook Live](#) event for the Autism Society of America. Here are the highlights of that conversation.

We know the emotional ups and downs of life with neurological differences. Some children and adults find distance learning and working from home to be easier than predicted because of less pressure to socialize. Others are lost without their routines. Far too many are also devoid of access to the technology that helps folks to function under these conditions.

Children and families with neurodiverse members are resilient. It's been baked into our very beings by the challenges we have faced over and over. It's been a process in which we've learned lots of coping skills



Robert Naseef, PhD

that help us to face adversity and bounce back. Let's reflect on the challenges our families understand very well and take a deeper look.

- We know how to face loneliness and alienation. We have a lot of practice at from the moment of diagnosis for parents, and often from playground expe-

riences for children and teens. Self-isolation and sheltering-in-place are not totally new for us.

- We have to be very careful as parents because our children often don't understand danger, so we have lots of practice at being alert to danger. Now we all need to be careful about everything we touch, wash our hands frequently, and avoid touching our faces. Families of children with rare diseases and others who have a compromised immune system have lots of experience with this. Reinforcing safety and health with our children is a constant.
- We have learned to adjust expectations, and we have practiced celebrating whatever we can do. Right now, instead of focusing on what little we can do as we shelter-in-place, we focus on all of the things we can still do.
- We have learned to face our fears and regulate our emotions again with lots of practice. Now we need to deal with our emotions while also dealing with the fear of being infected with COVID-19. It's harder, but it's a struggle we know well.
- We have learned that we do not have control, and we have learned and practice acceptance which includes working hard

to do our best with what's in our control. Right now, that means staying safe and learning how to live during this time.

- We do better with schedules and routines. We have a lot of practice at that. Now we have to make new schedules and new routines to meet the present challenges. The transition to new routines may be hard, but lots of us are good at creating routines and sticking to them.
- We have also faced setbacks, and we have practice at persisting and moving forward despite our disappointments. Science tells us that neurodiverse children and adults can continue to learn and develop through the lifespan. We will persist and move forward.
- We have learned to go easy on ourselves because this is another issue we cannot fix with hard work, but we must step up and work hard.

People with autism have been saying for some time that things that would benefit autistic people at home, work and school would also benefit everyone else. Children need routines in lives that have been disrupted; varying levels of routine helps all

see *Neurodiversity on page 36*

The Effects of Stress Are on a Spectrum Too: Why I Can't Think

By Marcia Eckerd, PhD
Licensed Psychologist

To say that stress and anxiety are issues these days is to state the obvious. I have been having trouble doing my long-term work. I couldn't focus on anything that wasn't immediately tangible like a zoom meeting or writing a blog. Autistic and neurotypical friends were having the same problems. Even those who didn't usually have executive function problems were having trouble with executive functions: keeping organized mentally and with things, initiating work and getting distracted. I wasn't alone.

I'm not worrying about getting sick with COVID-19 all the time. I'm practicing the recommended precautions. I work from home and stay busy. But the constant background of the pandemic is stressful. The world as I knew it is upended and I do everything differently. A neighbor's dog ran across the street to me and his 20-year-old son alarmed me by not wearing a mask and what seemed like yelling at his dog in my face. I take walks in serpentine tracks to keep social distance. This can't help but affect me; I'm always aware that we're in this pandemic, that safety is an issue and I have to rethink how I do what I do. I feel threatened and that does make me anxious.

In fact, the difficulty I'm having thinking is due to the automatic stress response of my brain. The point of a stress response



Marcia Eckerd, PhD

is to kick the body into gear (via the serotonergic system) to deal with a perceived or real threat. The problem when there's an ongoing threat there is likely to be a stress response that's also ongoing - a pathological stress response - which impacts us emotionally, cognitively and physiologically. Our negative emotions can be obvious: anxiety, sadness, anger, frustration.

Thinking and decision making are among the cognitive processes affected by stress. The hippocampus and amygdala (to simplify this) kick the pre-frontal cortex partly offline, so to speak, depending

on how activated we are. Putting it simply, when our bodies (and minds) are scanning for threat, we're not using the thinking part of our brains as effectively. We're not necessarily in the present - we may be in what just happened or what might happen, the past and the future. We're not grounded in right now when perhaps nothing is actually going on.

Not everyone is feeling stressed to the same degree. Some autistic people* welcome working from home without the social and sensory demands of the office environment. They are comfortable being alone. I know both neurodiverse and neurotypical friends who have found this to be a time when they can garden, read, work and do things they never had time for. They are focusing on enjoyable things, and their activities are bringing them into the present moment. Many feel this way AND still have that background trouble with thinking when not engaged in specific positive activities.

Now that we face "opening up" there will be new challenges: keeping track of changing rules, changing "facts" defining what's happening, changing social demands navigating the rules and how people observe them. People who felt comfortable at home might be less comfortable and more anxious when they feel expected to be "out" in work or community environments.

There are also both autistic people and neurotypicals who are much more vulnerable to intense anxiety or depression. This

emotional reaction can be due primarily to stress, or it can be ongoing and intensified by the stress response. For those overwhelmed by the sheer number of demands in their lives, by fear of illness or isolation or by anxiety dealing with the fluidity and lack of predictable parameters for what's going to happen, anxiety can be over the top; they are suffering badly. Ideally, they can reach out to others who can be of support. A few might even be suicidal.

My suggestions below are to help those struggling with stress, anxiety or depression at any level. For those who need it, teletherapy services are available. Insurers are now covering codes for teletherapy and telemedicine. Positive psychology, CBT and experience have a lot to offer.

1. Create a structure to your day - Get up at a time you decide. Have actually scheduled times for different tasks so you'll feel more organized and in control. I have to set alerts for what I schedule, especially involving meetings, since time seems to blend together.
2. Practice good self-care - This is an important time to take care of yourself. Eat well and get sleep. Try to maintain a consistent sleeping schedule. Exercise. Walk, and there are plenty of online exercise classes; some like [Daily Om](#) let you pay what you can.

see *Can't Think on page 35*

A Unique Program to Support Autism Educators During COVID-19 Distance Learning

By Aubyn Stahmer, PhD,
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Allison Nahmias, PhD,
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Robin Stewart, LCSW,
Bibiana Restrepo, MD,
Amber Fitzgerald, MA, BCBA,
and Heather Maurin, BCBA
UC Davis MIND Institute

The COVID-19 crisis has led to unprecedented school closures and a rapid transition to distance education which severely disrupted educational services for students on the autism spectrum. Distance learning will likely continue beyond the acute crisis as social distancing efforts persist. The Federal Department of Education issued guidance that schools are required to ensure that students with disabilities have equal access to distance learning. This massive and sudden shift in routine education services provides a unique challenge for educators working with students on the autism spectrum.

IDEA (USDOE, 2004) clearly stresses the importance of family-school collaboration. Research supports improved school outcomes when parents are involved in educational planning and intervention delivery (e.g., Iavannone et al., 2003; Moes & Frea, 2020; Sheridan et al., 2009). Par-



ent-educator partnerships are considered best practice for students with autism (National Research Council, 2001). However, educators do not receive formal training in how to successfully partner with caregivers (Murray et al., 2011).

Parent involvement is essential for distance learning. It is heavily influenced by school support and therefore collaboration will be key in this context (Bebson, 2008). Early studies of online learning for students with disabilities suggest that parents take on a greater role that is similar to that of a

teacher, involving structuring the educational day, using recommended interventions, and modifying activities to meet their children's needs (Smith et al., 2016). Parents reported an increased need for effective parent-teacher communication and collaboration during online learning. Educators need immediate support in partnering with families to achieve educational goals through this new distance instruction method.

In an effort to support educators as they transitioned to distance education, we adopted the Project ECHO (Extension for

Community Healthcare Outcomes) model as a platform for teaching educators how to best support students with autism and their families. Project ECHO aims to build a community of practice for complex medical conditions such as autism, increase system capacity, and disseminate evidence-based practices to rural and underserved areas.

Mazurek and colleagues adapted and tested ECHO Autism (www.echoautism.com) by developing virtual learning networks of providers with access to interdisciplinary autism expertise (ECHO Hub) to increase provider confidence in providing autism services (Mazurek et al., 2017, 2019). The Autism Center for Excellence (ACE) at the MIND Institute has an Autism ECHO team who partnered with the UC Davis Center for Excellence in Developmental Disabilities (CEDD) and the California Autism Professional Training and Information Network (CAPTAIN), which is the statewide initiative funded by the California Department of Education to build educator expertise in autism.

This team established the *Special Edition: Autism Tele ECHO for Educators* that aimed to equip school providers with tools, strategies, and resources to use a distance coaching model to assist families in setting

see *Unique Program on page 36*

Maximizing Virtual Visits to Maintain Essential Touchpoints in Autism Care

By Kristin Sohl, MD, FAAP, Associate Professor, Department of Child Health, University of Missouri School of Medicine, Executive Director, ECHO Autism

The Coronavirus Pandemic brings much uncertainty to our lives but one constant remains: access to your medical teams. While it is critical to socially distance and stay healthy and safe, medical teams around the world are adapting and meeting the challenge to care for people through telemedicine.

Telemedicine has been utilized for several decades in its more traditional sense with patients going to their local clinic and the specialist virtually seeing from a distant location. Now, with COVID-19, policies have been adjusted to allow physicians and practitioners to see patients directly in their home. This allows the clinician and the patient to receive care for their concern and limit their risk for infection.

Virtual visits are being done through many ways, called platforms. One of the most common options is Zoom but there are many others. Phone (audio only) visits are also a form of virtual visit being used to connect right now. I would like to provide some important tips to maximize your virtual visits.

First, let's talk about the professional and what they need to do to be ready for the visit. All professionals using telemedicine need to get comfortable with the technolo-



Kristin Sohl, MD, FAAP

gy and practice the key elements like connecting, muting and unmuting audio, turning on and video and sharing their screen. Professionals also need to know how to handle common problems like converting a video visit to an audio only or phone visit if the connection is lost, helping the patient connect and working with non-English speaking patients.

The professionalism and caring demeanor used in person should be used in virtual visits. Be sure to introduce yourself, obtain consent for the virtual visit by explaining the benefits and risks of a virtual visit compared to in person and engage with the pa-

tient as you normally would in person. One important addition with a virtual visit is to check for understanding with the patient since they won't have the same "check-out" paperwork they usually receive when seen in person.

Now, let's talk about the patient or client and what they need to do to prepare for the visit. It is important to determine what device you will use to connect with your provider. You can use a smart phone, webcam on your computer, or tablet. These are the ideal devices for connecting with video and audio and make for the best visits with your clinical team. If you don't have access to one of these, audio only options can work like a telephone or traditional cell phone. Once you know which device you will use, look at the instructions your provider gave you for connecting. This may be in your email. Call the clinic or office if you need help. You may need to download (install) a program on your device to be able to connect for the visit. Once this is complete, practice. Practice turning on and off your video (camera) and connecting to audio (sound). Check the lighting in the room where you will do the visit to make sure it is not too bright or too dark. Test to make sure you can see your full head and shoulders in the camera image. Set a reminder for the day and time of your visit so you can be ready. Write down your questions for the doctor so you will be ready. Have a list of medicines that you take with you.

When it's time for the appointment, connect to the visit using the instructions from your provider's office (clinic). Here are some more tips for a successful visit. If you are seeing the provider with your child, let them be with you. Make sure they are awake and ready to participate like they would if they were going to the provider's office. If your child doesn't want to sit on camera, that's okay, have some toys or preferred items nearby so they can be comfortable while you talk with the provider. It will be important for the provider to visually see your child when possible. It is also helpful to have your child's most recent weight in case the provider is monitoring specific things for your child.

Individuals with autism and their family members as well as the professionals who support and serve them are navigating uncharted waters together. Innovations like rapid adoption of virtual technology for longitudinal medical follow-up care, initial evaluations, parent trainings, support groups, therapies, early interventions, special education and more are stretching our collective ingenuity to meet critical needs.

Professionals and people with autism alike are finding that virtual visits are a unique and refreshing way to connect that seem to reduce the perceived demands of traditional social communication and open up channels for novel opportunities to support the therapeutic relationship. It is

see *Touchpoints on page 38*

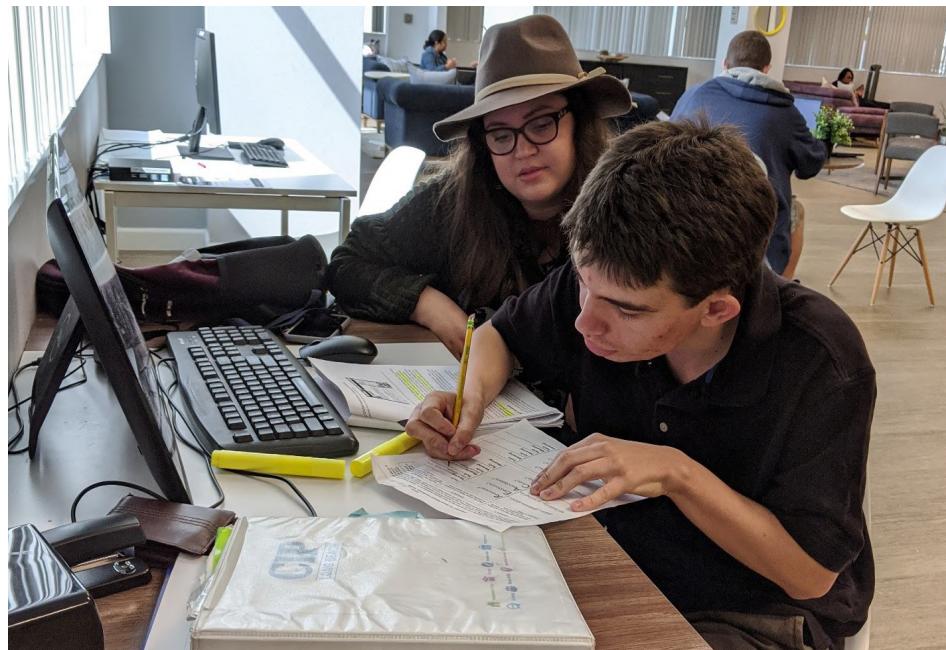
Coping During COVID-19: Strategies to Reinforce Executive Functioning Skills During Times of Change

By Crystal Hayes, MEd
College Internship Program

As the world enters a perpetual state of “new normal” due to the COVID-19 pandemic, previously developed routines and coping skills may not be readily accessible - or may not work at all.

Along with the closing of many schools and workplaces, drastically changing societal norms, community restrictions, and frequent fluctuation in how everyday tasks are to be conducted have made the world an overwhelming place to navigate, especially for individuals with autism spectrum disorders (ASD). Individuals with ASD often find change difficult to manage, particularly when the parameters are not clearly defined. Studies indicate that nearly 40% of young people with ASD are estimated to have at least one anxiety disorder (van Steensel, Bögels & Perrin, 2011). According to the Centers for Disease Control and Prevention (CDC) (2020), increased levels of anxiety and stress as a result of the pandemic can lead to fear, changes in self-care patterns, difficulty sleeping or concentrating, and worsening mental health conditions.

Stress can impair the most basic executive functions, including short-term



College Internship Program (CIP) student and staff work together to organize assignment tasks and schedule study time

memory, planning and self-regulation. Ackerman (2020) describes coping as “cognitive and behavioral strategies that people use to deal with stressful situations or difficult demands, whether they are internal or external.” While many people develop trusted coping strategies that help

to self-regulate in times of discomfort, many of these strategies are short-term solutions. Examples of coping strategies include listening to music, deep breathing exercises, drawing, dancing, or even playing video games. A focus on the development of the following executive function-

ing strategies will reinforce habits that lead to better coping skills.

Organization

Take inventory - Taking inventory of coping strategies that have worked in past times of uncertainty is a good starting point. Make a list or create a visual toolbox of each coping strategy paired with associated situations or specific feelings. Reach out to teachers and direct support professionals to assist in recognizing coping strategies that have worked at school and in the community. Visually outlining coping skills will help to provide a simple tool for accessing strategies when stress or anxiety are elevated.

Organize Personal Space - Creating predictability in the physical environment can be a powerful proactive coping strategy. As much as possible, identify dedicated spaces for sleep, school/work, leisure, meals, etc. Separating these spaces helps to compartmentalize certain parts of the day that may cause higher levels of stress. For example, the bed should be a place of rest and relaxation. Studying for an exam while lying in bed allows for a stressful task to diminish the importance of self-care.

see Strategies on page 37

Top 6 Teletherapy Questions Asked by SLPs During COVID-19

By Lisa Moore, MS, CCC-SLP
Director of Clinical Operations
TeleTeachers

As an educational community, many of us are venturing into an unknown world of distance learning and are adapting to meet family and student needs on the fly. School districts are expanding to an online instructional model where students are attending speech and language sessions from their new learning environment, *home*. Naturally, this can send everyone involved into an information-seeking frenzy to guide practices through this time of transition. We are here to help.

What are the key components of a successful workspace?

Establishing an optimal workspace within your home will lead to a greater sense of productivity during your workday. Carving out space where a physical boundary can be created such as a closed-door will prevent our beloved but possibly shirtless children and furry friends from popping up during therapy sessions and meetings with parents and colleagues. Don't have an extra room to shut that door? That's Okay! *Be creative*. Dedicate a table and decorate it with pictures just as you might within an office space to simulate “time for work.”



Lisa Moore, MS, CCC-SLP

When choosing your space make sure to consider your backdrop. The simpler the backdrop the better for your students. This will ensure your students are focusing on you and not your children's pile of toys or your pile of laundry. No one wants to see your skivvies over your shoulder. Even though we are all managing through this work-from-home crisis, ultimate professionalism should still be the goal. It's okay if every session isn't perfect. Authenticity is the ultimate connector.

Think about the lighting. Set yourself up in an area that will allow you to close

blinds or curtains when the sun is shining directly into your space reducing the glare on your face or presented materials. Make sure your students have a clear picture of the visual cues and therapy materials you are presenting to them.

Put me in coach! Be prepared with your technology setup to the best of your ability. Telepractice requires a few essential players: a laptop or desktop, an internal or external webcam, and reliable internet with a minimum 4.0 Mbps download and 2.0 Mbps upload (can vary pending platform used). Check your speeds at speedtest.net to make sure you are meeting the internet speed requirement. Being hardwired to your internet source (vs. using a wireless connection) will also decrease your chances of disconnection throughout your sessions.

Additional tools include: headsets for reducing environmental background noise (fans, humming appliances, conversations, etc.), a document camera to easily share books and the use of manipulatives, and my personal favorite, a SECOND MONITOR. This is a sanity saver and a great way to organize your session. Organizing your therapy activities on one screen to drag over to your shared screen when ready is one of the greatest things ever! Did I mention, ever?! Don't have a second monitor? Grab a TV that may not be used in the house that has a USB plug and VOILA! You have yourself a second screen. Trust me, you will never go back.

What is an acceptable HIPAA and FERPA compliant platform for telepractice?

Our national team of educators have quickly come to our rescue:

“We are empowering medical providers to serve patients wherever they are during this national public health emergency. We are especially concerned about reaching those most at risk, including older persons and persons with disabilities.” - Roger Severino, Director, Office for Civil Rights.

Please visit the [U.S. Department of Health and Human Resources-Acceptable Platforms](https://www.hhs.gov/health-care/acceptable-platforms/) webpage for further clarification.

Overwhelmingly, we are seeing Zoom as the [most popular option during this crisis](#), and they are providing it [free for schools](#).

How do you plan for and handle students who do not show for sessions?

Before beginning your online sessions, reach out to the parents or facilitator for the student and discuss your expectations. Setting attendance expectations upfront will reduce the number of nonattendances or late arrivals that will arise. When a student does not attend your agreed upon session day and time, the standard wait time is 10-15 minutes. During this timeframe, you as the therapist will need to actively be reaching out to the student to encourage attendance via a phone call and an email.

see SLPs on page 37

Thriving During COVID-19: Transitioning to Virtual Programming for Individuals with Disabilities

By Becky Lipnick
Vista Life Innovations

In this ever-changing health crisis, the world has been altered. Our daily patterns have been changed and the ways in which we connect with and support others has shifted. For those with a disability, maintaining a sense of community and human connection is more important than ever. Organizations that serve those with disabilities have had to adapt to the current circumstances while continuing to support their members. Particularly since members may have temporarily relocated, virtual programming has become an integral tool to continue to provide support. Vista Life Innovations, a service provider for those with disabilities along the Connecticut shoreline, has shifted from in-person supports to virtual programming when necessary and seen tremendous results.

The transition to virtual programming happened faster than expected. Vista began its internal planning, and as with many other organizations and businesses, by mid-March was conducting the majority of its internal meetings virtually using the Zoom platform. After learning who would remain in the local community and receive in-person programming and who would be temporarily relocated to their family homes,



Program Specialist Linalynn Schmelzer (top left)
instructing several Vista members during one of her classes

Vista was able to reimagine delivering their core programming virtually. After some preparation, the next step was to test - and then implement - this virtual programming for Vista's students and members.

Tod Van Kirk, Vista's Vice President of Programs, Services & Organizational Development, believes that offering virtual programming has been critical for the ongoing success of Vista's students and members. He observes, "We have learned a lot regarding our internal operations and in our service delivery - both in-person and virtual. For one, we learned that the power of human connection cannot be overstated.

For many of us who are more isolated than normal, 'seeing' people - even in a Zoom meeting over the internet - is extremely important."

Guarin, one of the students in our residential transition program, describes how he values "seeing everybody - my friends - when I can't see them in person. I can see them on the screen at least and feel connected." Seeing other people helps maintain bonds and helps to serve the need to be connected with each other. Those at Vista continue to observe this powerful concept in programming with students and members and in internal operational gatherings.

Instead of simply "surviving" during this crisis, Vista's students and members are inspiring others by continuing to build their skills. Another student who is temporarily located away from the Vista dormitory, Andre, describes the virtual programming by saying, "We're learning the skills we would be learning there [in the dormitory]. Now that we're learning it here, virtually, we can better our skills when we go back... We can reconvene where we left off, but with better knowledge."

With ingenuity, a wide variety of classes and trainings that were formerly offered in-person have transitioned to virtual instruction. Vista students and members can take art, wellness and even medical training through Zoom. Lead art instructor, Samantha Smith, guides participants in private and group art classes. Smith admits to being uncertain about teaching virtually at first, but says, "the experience has exceeded my expectations. Even though the members are all in different places and not with me, the work they are producing is amazing! It is a pleasure to see them flourish in these unusual circumstances."

Smith is not the only one to see individuals adapting to virtual programming. Program Specialist Linalynn Schmelzer sees the smiles of participants of her wellness

see Thriving on page 38

Transitioning an ABA Company to Telehealth Service Delivery Model

By Marina A. Azimova, EdM, MSW, BCBA
Executive Director of Clinical Services
ABA Services of Connecticut, LLC

Working for a company that provides Applied Behavior Analysis (ABA) services, we were always tied to insurance companies' untouchable rule: if you are not with the client face to face, you are not entitled to reimbursement and your time is not valid as service delivery. As Executive Director of Clinical Services of ABA Services of Connecticut, I was always one of the "enforcers" of the concept. However, as a consultant for many international projects (some of which were developed through coaching sessions), I always wondered why these remote approaches could not be utilized here in the United States.

Over the last ten years, several studies were published to address this possibility. Telehealth-based interventions for Autism Spectrum Disorder (ASD) have been studied with ABA programming/strategies with acceptable reliability and effective treatment of behavior problems (Suess et al., 2013; Lindgren et al., 2016). Further, telehealth IEP consultations for ASD have been noted to improve IEP quality and educational results (Ruble et al., 2013). Additionally, a recent pilot study used telehealth to deliver an adapted manualized CBT (Cognitive Behavior Therapy) for co-occurring anxiety with ASD ("Facing



Marina A. Azimova, EdM, MSW, BCBA

Your Fears") that seems to be effective in reducing anxiety symptoms (Reaven et al., 2012). Researchers also found satisfactory feasibility rates as noted by the high session attendance (94%), and mean satisfaction ratings for both parents (93%) and children (89%), and adequate fidelity from clinicians (92%).

In the field of ABA, utilizing a telehealth format could help with remote service delivery, but there are many variables to take into consideration. For example, ensuring

clinical programs are set up accurately and securely as well as guaranteeing that providers are compensated despite the change in delivery format.

The Coronavirus pandemic caused many insurance companies to change regulations and requirements (including remote service delivery). However, providing ethical services with a high standard of care became a business challenge and a clinical nightmare, including unpredictable circumstances and unclear expectations, for many providers.

Our company enacted the following strategies to confront the challenges presented to us:

Prior to starting the remote service delivery model, we established approval by the insurance companies with which we worked.

Once approval was established, we conducted interviews with all our clients/families to determine if they are open to a telehealth delivery format. A special consent form was designed and then signed by the families that were willing to utilize remote ABA therapy. Out of 41 active cases involving clients with ASD, 25 families were willing and able to receive remote services.

After the number of families that required services was established, the amount of certified and non-certified personnel needed to fill those hours was clear. In addition, the training needed to prepare the staff became evident. These staff required a new set of skills to provide remote services, and therefore immediate and intense training was conducted.

Next, the development of "the blueprint" of how programming would be modified to fit a new format was established for our clinicians (5 BCBA's - 3 full-time and 2 part-time, 1 BCaBA). Each staff member needed to sort through each of their client's programs and establish which needed to be prioritized and/or modified. Prioritization took into account which behavior goals and associated protocols were not suitable for remote delivery. The following steps were used in this process:

- Can the program be delivered visually? If not, could it be modified to deliver essential assessment-based skills?
- Do we need to change mastery criteria as a result of proposed modifications? To what extent? Will it still bring the client to the desirable results?
- How much time will our modifications require? Will they impact data collection? Will we have to redesign our data collection paperwork?
- How much training will our therapists and caregivers need to implement these changes? How fast and effective could our training be provided?

We spent almost ten full days resolving these questions, evaluating results, and

see Transitioning on page 35

What Do Change in Schedules, Virtual Meetings, and Face Masks Have in Common?

By Heidi Hillman PhD, BCBA-D
Eastern Washington University

The coronavirus pandemic has disrupted daily life for almost every person around the world; especially daily routines. Routines are a good thing, since the predictability can be comforting. For many, changes to routines are frustrating; but are usually seen as positive, creating novel changes. But for autistics, daily life without routines is challenging. Autistic individuals live in a chaotic world, constantly trying to make sense of their environment. Routines act as powerful rudders, creating order out of the cacophony of stimuli. Predictable routines become mundane for many, but autistics thrive on routines and dislike uncertainty. In the world of autism, predictable routines are used to calm and self-regulate anxiety, making it is easier for an individual with autism to effectively interact with their environment.

So, what do change in schedules, face masks, and virtual meetings have in common? They all can introduce chaos and unpredictability. This article began as an outline of how to maintain routines during this disruptive time. I, however, started experiencing anxiety and frustration with my daily life and wanted to



Heidi Hillman PhD, BCBA-D

know why. Being a researcher, I began collecting data on my daily life, turning my chaos into research. The research project turned into great teaching moments; and I thought if I am charting an effective path through my disrupted daily life, my results may help others chart their own path. Here is what I learned so far about three areas - routines, virtual meetings, and face masks.

Change in Daily Routine

Individuals with autism thrive on routine; we not only seek out specific routines in everyday life, we crave it; appreciating the comfort it provides. Hence, you can imagine the overwhelming change the coronavirus pandemic brought upon most autistics and their families; it is what I call the ultimate routine crusher.

One week I was working at an office, the next week I was told to work from home. While my colleagues looked forward to working from home, I feared it; because it was different, and I clung to my previous routine even though it did not exist. I tried keeping the same hours at home as I did at work, doing similar tasks at similar times; and I failed - miserably. It was not until I viewed my situation as what routine works best in the home environment, was I able to move on. That was a big "aha!" moment for me. Since I prefer visuals, I developed a chart of "tasks" to complete in the day and put them in the order (not time) I needed to complete them. The chart helped me visualize when to complete each task, but with flexibility. This chart morphed my pre-pandemic routine, based on time, into a flexible, yet predictable, schedule. My second teaching moment was incorporating activities I normally did not do during the day; working in the garden, completing my

work in the afternoons while having more down time in the mornings, and running at night when the world is quieter. My third teaching moment was maintaining a similar bedtime while allowing flexibility with the time I wake up. After a few weeks of quarantine, I was more tired and grumpy than before; after observation I realized that my bedtime was slowly moving further and further away from my normal bedtime, which wreaked havoc on my sleep schedule, which wreaked havoc on my day schedule. I learned I can be flexible with my wake-up time, but I have to stick close to my 10pm bedtime. The overarching theme I learned - flexibility with my routine led to a more effective one.

Video Meetings

With social distancing in full force, video (e.g., Zoom) meetings became the "new normal." However, for an autistic the stimuli in video meetings are greatly amplified; making it hard for me to grasp the "big picture." It is not so much all the attendees' faces staring at me, but all the stimuli going on behind them that leads to an overwhelming flood of information, activating my anxieties. For example, in a video meeting one of the attendees had a

see *Schedules on page 39*

How We've Always Done It

By Becca Lory Hector, CAS, BCCS
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Iremember the day exactly. It was an unspectacular Sunday and I was headed to the last job I would ever take working for somebody else. It was a low-paying, hourly, management position for an animal nonprofit and just about the only benefit of the job was that I was in charge of making the schedule. This Sunday, like most Sundays, being at work was my norm. Since days off need to be used for chores and errands, tasks that I only dare to complete during the weekdays, I worked every weekend to ensure that I could take off two weekdays for my dreaded adulting. That was my only "accommodation," but that was about to change. That Sunday, I would ask for what I needed. After all, I had gone without any true accommodations for the requisite first 90 days. In that time, I had not only done the job required of me, but I had reformatted the tasks of the role to increase profits over \$14,000 in those three months. To be sure, asking for some flexibility now would be greeted with a resounding YES. All I wanted was one remote workday a week to do admin and data entry tasks in the quiet of my own home. I mean, I proved my value through my performance, right? WRONG! I could not have been more wrong.



Becca Lory Hector, CAS, BCCS

I think we would all like to imagine that my experience was a rare occurrence, a blip in the radar of the otherwise kind and caring world of work. Alas, it wasn't even a rare occurrence for me. It was definitely not the first time that I have been open, honest, and upfront with an employer, only to be told no, "that it was against company policy." Or maybe that, "nobody gets special treatment." Or perhaps, "if we do it for you, everyone will want it." Or my favorite, "this is how we have always done it." GRRRRRR! Never has a more counter-in-

tuitive statement be made in business than that! And yet, if I had a nickel for every employer...But, I digress.

The reason for telling this story isn't to show you the inane thinking in American working environments. I am telling you this story because, as I sit here typing this, the world is making its way through an "unexpected" pandemic, and in the middle of all this chaos, most American businesses went almost fully remote in less than a week. Yes, you read that correctly. Less than a week. The very same accommodation that so many of us have asked for time and time again, only to be told no because a brick-and-mortar existence is how "we have always done it," became a reality before our very eyes. Imagine our surprise when, almost miraculously, businesses across the country, big and small, closed their doors and said, "we can make this remote thing work." Many of us sat back, mouths agape, and speechless because, after the resentment passed, this could mean the possibility of sustainable work for millions of autistics, and the entirety of the disability community.

Think about that. As long as remote work has existed, disabled people across the globe have begged for remote work and flex schedules to be made available so that work, and all of its benefits become a realistic possibility for many of us. And now, after years of rejection, the world just turned around and poof, businesses have caught up to the opportunities that tech

provides. Not to mention what disability advocates have been saying all along, all in under a week. Truly a "festivus" miracle.

Now this is not to say that remote work is for all autistics. How could it be? It's not a fit for all humans. There are many for whom the type of work that can be done remotely isn't a fit for their strengths. Others of us, like all humans, are actually extroverts and miss the human interaction. Still more of us, specialize in the kind of work that must be done in person, like construction. But for a good chunk of us, remote work is a perfect fit, and, up until now, it was the forbidden fruit. It only took a global pandemic for businesses to see the value in it.

When employers give the option of remote work, they are also opening themselves up to some really great benefits. First off, roughly 53 million American adults live with a disability (CDC Press Releases, 2020). If only a quarter of them are qualified and could be accommodated by remote work, we are talking about 13 million human beings who want to be working but could not in pre-COVID-19 America. Think of that potential! Oh, and did I mention that those 13 million individuals will be some of the most productive and loyal employees to ever be hired. For those of us who benefit from remote work, landing a job you can sustain is like finding out you have a golden ticket in your Wonka

see *Always on page 39*

COVID-19: Tips for Working From Home (And Finding Relief) With Your Children Out of School

By Amy Kelly, MBA, MNM
National Director of Family Engagement
Devereux Advanced Behavioral Health

For many parents and caregivers, working from home during COVID-19 (while your children are out of school or day care) can present unique challenges, especially if you are caring for a child with emotional, behavioral or cognitive differences.

As a mother of three children, one with autism and intellectual and developmental disabilities who requires intensive 24/7 supports and yearlong special education, I admit I am feeling the pinch of juggling home-schooling and daily routines, while trying to work full-time.

While this is no easy feat, there are steps parents and caregivers can take while trying to adapt to these new changes and find some relief along the way.

Create a schedule for everyone: Set expectations for the day so your family knows what to expect. Try to [model the day](#) according to your children's pre-COVID-19 schedule/school day. [Schedule](#) meals and breaks for the same time every day.

Divide and conquer: [Work with your](#)



Amy Kelly and her daughter Annie

[spouse/partner](#), or other family members living in your house, to take shifts to split up home-schooling time and work time. This may provide needed flexibility to get your work done *and* keep the kids on track.

Create a home workspace: [Get creative](#) – your home workspace doesn't necessarily have to be a separate room but, perhaps, a

corner of a room with a divider and noise cancelling headphones.

Consider hiring a caregiver: Companies like [Care.com](#) will match your family with a highly-trained caregiver who is qualified to meet your child's unique needs. (*Note:* You may be able to hire a caregiver who is designated strictly to your home to ensure

safety during COVID-19.) In addition, consider hiring a family member to help out while you work for a couple of hours if he or she is able.

Look into your state's public assistance programs: Learn about [eligibility requirements](#) and how to apply for medical assistance programs and/or [social security income](#). Your child may be eligible for assistance because of his or her disability. Look for supports such as [respite](#), [home healthcare](#) and [waivers](#).

If possible, take time off from work: The [Family Medical Leave Act](#) (FMLA) allows employees to take time off from work if they are ill or caring for an ill family member. (*Note:* Not all companies offer this opportunity. Please check with your human resources department.)

Most importantly, take things in stride: Be forgiving and kind to yourself – and your children. We are all trying to adjust to this new normal. For a good laugh, watch this [BBC News reporter](#) give a live broadcast while trying to juggle working from home alongside his kids – it happens to us all!

see Relief on page 34

Using Telehealth to Create a Virtual Community for Adults with Autism

By Kara Constantine, PhD, NCSP,
Kate Langston-Rooney, MEd, BCBA, LBS,
Amanda Duffy, MEd, BCBA, LBS,
and Sasha Birosik, BA
Devereux Advanced Behavioral Health

During March 2020, many community-based programs for adults with Autism Spectrum Disorder (ASD) needed to make the difficult decision to suspend in-person services for the safety of all stakeholders. The unexpected interruption in daily operations led to an immediate concern for the overall quality of life for participants, since so much of their daily routine and social interactions depend on services. Families were also abruptly left with limited support while trying to cope with their own anxiety and stressors surrounding COVID-19.

Typical programming for adults with Autism consists of reducing challenging behavior and teaching adaptive skills (e.g., social communication, functional living skills) in natural settings. Teaching procedures and strategies should be rooted in Applied Behavior Analysis (ABA), which remain the only evidence-based interventions for adults with ASD (National Autism Center, 2015). Although symptom severity often decreases over time, social skill deficits tend to persist (Schall & McDonough, 2010) and are related to difficulties forming friendships, increased loneliness, anxiety,



depression, decreased life satisfaction, and lower self-esteem (Mazurek, 2014). Therefore, programming should include targeting skills in community-based settings to support individuals in developing meaningful relationships and natural supports.

Immediately after the disruption of services and in order to ensure continuity of care, providers looked to transition to remote services. Programs had to quickly answer one question, "How do you make a community-based program virtual while continuing to deliver evidence-based practices?" The following information will discuss the research surrounding the use of telehealth for adults with ASD and review

one program's response to a major public health crisis.

Telehealth

Met with uncertainty, many practitioners turned to existing research regarding telehealth to inform treatment decisions. Telehealth broadly refers to "the use of communication technology to assist in education and treatment of health-related conditions" (Ferguson et al., 2019, p. 583) and is associated with many benefits including increased access to services at a lower cost (Lindgren et al., 2015). Many medical and mental-health related disciplines incorpo-

rate telehealth into their practice; however, the application of telehealth to the ABA field has been less researched (Tomlinson et al., 2018). Systematic reviews of the literature suggest that telehealth has been used to successfully teach interventionists (e.g., caregivers, support staff, teachers, other professionals) how to conduct functional analyses and preference assessments, as well as implement functional communication training, naturalistic and incidental teaching, behavior support strategies, and comprehensive training packages to children with ASD (Ferguson et al., 2019; Tomlinson et al., 2018).

Although the research is promising, previous studies lack the scientific rigor needed to establish telehealth as an evidence-based practice for ASD (Ferguson et al., 2019; Tomlinson et al., 2018). Moreover, no known study has assessed the efficacy of delivering ABA strategies via telehealth directly to adults with ASD. Despite limited empirical guidance, many providers of community-based adult services were encouraged to utilize virtual options in order to ensure continuity of care for participants as seen in the following case example.

A Case Example of Virtual Programming

After suspending in-person services, the [Community Adult Autism Partnership](#)

see Community on page 32

The Impact of COVID-19 on Families

By Taveesha Guyton, BSW
Founder and CEO
We R Famile

COVID-19, also known as the Coronavirus, has impacted us in many ways. Financially; there are millions of people unemployed due to the impact of this virus. Mentally and emotionally; individuals have isolated themselves due to stay-at-home orders, only going out for the essentials to places such as grocery stores, pharmacies, and banks. With social gatherings limited in capacity and many events being canceled due to social distancing practices, this isolation has impacted everyone in various ways. Some people have transitioned to working from home. Schools have closed their doors and have transitioned from a physical classroom to virtual school. The Coronavirus has impacted how we live, work, and play. Now that families are staying home more, how does that affect them? If you are a family with an individual with autism, what are the impacts of our new normal and how do we help families cope with staying home?

How to Explain Coronavirus

Our children may have a lot of questions now that the world is going through a pandemic. Why are people walking around



Taveesha Guyton, BSW

with face masks and gloves? What does it mean to social distance and when can we go back to school? These are all valid questions. How do we as parents explain what is going on and how do we help our children cope? Explain to your children in clear, concise language what is going on and how it will affect their lives. According to [Kidshealth.org](https://www.kidshealth.org), "Find out what kids already know about the virus." Ask them, "What questions do they have regarding what is going on?" This helps weed out any inaccurate information and also keeps

the line of communication open. It is okay if the child does not want to discuss what is going on. Assure them that their feelings are valid and you are there for them when they are ready to discuss what is happening. Explain the new rules the family will be following during this pandemic such as increased hand washing practices, the practice of social distancing, and wearing protective gear while out in public. This explanation can be from simple YouTube Videos, a social story you have created, or news from other sources such as [The Autism Society](https://www.autismspeaks.org) or the [Center for Disease Control](https://www.cdc.gov).

Staying Safe at Home

Routines are very comforting and keeping the same routine helps provide some kind of normalcy. Things such as a bath and bedroom routine will help your child while the world is transitioning. Give children choices. We all like to feel like we have some kind of control in our lives as we comply with restrictions, giving children choices will bring a sense of autonomy. This can be something as simple as what they want for lunch, what they want for a snack, or what clothes they will wear for virtual school. The use of a visual schedule could be a useful tool for the house. This helps children know what they are to be doing at certain times of the day. This schedule helps keep children on task

as well as helps parents keep tasks in order. The children can have individual schedules to carry around with them, checking items off as they are accomplished. The schedule can be placed in a central location so the whole family can see it. Make sure you section out time for family dinner, family exercise, and family time in general.

Since most of us are operating school, work, and family life at home, the use of a timer can be helpful, too. The timer can be used to indicate moments of transition. In [this article from Kids Health](https://www.kidshealth.org), they state, "Visual schedules and to-do lists can help kids know what to expect, while timers and 2-minute warnings can help with transitions." Taking breaks can also help with this transition. According to [Autism Speaks](https://www.autismspeaks.org), "Free time could be broken up into time for: books and puzzles, arts and crafts, table top activities, etc. Try to include some outdoors and exercise times in your child's schedule, weather and safety permitting."

Managing Screen Time and Incorporating New Activities

According to the [Autism Speaks](https://www.autismspeaks.org), "Limiting screen time can be one of the biggest challenges for a family during breaks. It helps to set clear limits before the day begins and to review these limits with your child often. You can do this by scheduling

see [Families on page 32](#)

How to Recover Financially From a Crisis When You Are Autistic

By Andrew Komarow, MSFS, CFP®
Founder
Planning Across the Spectrum

Being an autistic adult has many challenges and, obviously by this point, we are well aware of them. We constantly talk about the [high unemployment rate for autistic adults](#) and how a majority of Americans are [unable to cover one month of living expenses](#).

That all being said, I believe there are some unique struggles that many autistics deal with that we can turn into strengths when it comes to dealing with money. Like the majority of the adult population, we were very likely never taught how to handle money well, to save, and to be financially prepared when things take a turn.

When a crisis that causes a sudden change in finances like what we are currently experiencing with COVID-19 occurs, it can be life-altering in so many ways. Not only are you struggling with the loss of your usual routine in the outside world, but many of the basic necessities you depend on for your day to day life are up in the air as well. I believe there is a [huge case for working with a disability](#). Unfortunately, many have lost their jobs or at least have had their hours cut, making it incredibly challenging to navigate how to handle your finances.

Right now, it just is not helpful to look at



Andrew Komarow, MSFS, CFP®

the past and all the mistakes we may have made in the beginning of our financial journey. Thinking about how you should have prepared more is something I think many are grappling with. That just is not helpful to you or anyone else. These types of thoughts only lead to anxiety and add to the sense of feeling overwhelmed. There are so many articles being pumped out from the "experts" about emergency funds, savings, retirement, etc. - trust me, I get it. I am one of those people who is constantly being educated on all of those things but even I know, right now that is just not helpful! It's just like someone telling you

that you should have had collision coverage on your car after you got into an accident. We're in a crisis and it just isn't the time to start talking about what we should have done. We need to talk about what we can do right now.

Now is the time to step back, look at where you currently are and think about where you would like to be. Where do you want to go? From that point, we can move one step at a time to get there in small chunks. Small, incremental steps with a set out plan are often the answer to helping settle the anxiety in our autistic brain.

For example, imagine that you have just lost your job. This is a problem because you relied on your job for income to pay your rent. What is the end goal here? Being able to pay your rent! Now that we have a beginning and an end, let's plan out the middle!

Financial Advice During the Crisis

- Find out what benefits you qualify for and act quickly. Nothing is wrong with seeking more support and more services when they are at your disposal. If you once received benefits that you haven't received since being employed, you may be able to re-qualify for them now. Appeal decisions that don't work in your favor.
- If you have an "emergency fund," now is the time to dip into it. This is what it

is there for. If it helps, try to reconsider your emergency fund as more of a "reserve fund." This is money you have reserved for a time you need it. You are not setting yourself back by dipping into your reserves, you are using it in the way it was intended.

- If you qualify, your stimulus check will likely have come through by now. If it hasn't, you can check the status of it [here](#).
- This might be a good time to borrow from your retirement accounts if you have them. That being said, avoid taking from accounts that have harsh penalties. If you have an ABLE account, that can be a great place to start (and if not, add that to the list of things we talk about when we are in a better position)!
- Look into your credit on free sites like [creditkarma.com](https://www.creditkarma.com) to make sure that everything looks as it should in terms of all of your credit balances and that you are up to date on what is being reported.
- Look at your current spending and accounts. If there are recurring expenses like subscriptions to things that you aren't using, cancel them! Is now the time to cut everything way down and completely decimate your quality of life? Absolutely not. That being said, there

see [Financial Advice on page 33](#)

Mobilizing to Maintain Continuity of the Yes She Can Training Program

By Lesli Cattan, LCSW
Director of Training Programs
Yes She Can

Yes She Can provides a job skills training program for young women with autism and related social and learning disabilities. The program is implemented at [Girl AGain](#) boutique where clinical professionals and business managers coach trainees in all aspects of running the business. It has been a fundamental component of the program to have trainees working in the retail store, engaging with each other and with customers.

On March 3rd, 2020, the first case of COVID-19 was diagnosed just 3 miles away from our program in Westchester County, NY. A week later our management team began making plans for a virtual experience. It wasn't a question of whether we would shift to an on-line job skills training program but how. Nine weeks into making that shift, the Yes She Can's job skills development program has actively engaged all trainees in coaching sessions and meaningful skill development. All of our previously enrolled trainees remained with the program, and now new trainees have joined the program while others are in the referral process to begin during the summer session.



Lesli Cattan, LCSW

The plan to provide an on-going, consistent program to our trainees has evolved during the 9 weeks we have been training on a remote basis. Within 1 week of shutting down the Girl AGain store site, our first iteration of the training program had transferred to a remote platform and was focused on providing structure, on-going social connections and emotional support during these uncertain times - to both the young women we serve and their families. A shut down of life as we knew it was both unfathomable and worrisome as we consid-

ered the impact of the pandemic on the lives of our trainees, their families and staff.

In a recent podcast, Doreen Marshall, PhD., Vice President of Programs with the American Foundation for Suicide Prevention reiterated the importance of taking care of the basics during traumatic periods of time. Because all but one of our trainees live at home with their families, we knew that basic shelter and support was not in question. While there were and continue to be clear stressors, none of our trainees' families would be in such financial distress so as to not be able to feed themselves. Basic life necessities would be provided.

Transferring the Yes She Can training program to a remote platform required an assessment of the technology available to each trainee in her home. There was a distribution of our Chrome Books to those who needed the equipment to successfully participate. There was an initial rush to download and teach ourselves how to use the needed software and subsequently teach the trainees and their parents. The coaches often felt just barely a step ahead of our trainees.

We anticipated certain autism-specific responses to the current health crisis and planned around those concerns. We expected that our trainees would be stressed by the changes to their routines. We expected there would be a range of understanding about the pandemic, of anxiety-based responses, as well as expression of their

fears and concerns. Therefore, our initial focus was to provide more emotional support rather than coaching job skills. Our work-from-home plan initially included 2 weekly group meetings where trainees were encouraged to share their concerns verbally or via the chat function on Zoom with each other and with the coaches. We emphasized developing daily routines, the need to continue to practice good self-care and maintain connections. These needs correspond with our program goals to improve workplace social skills, to practice self-care including good physical care and hygiene, emotional regulation and self-advocacy.

During the twice weekly group meetings, we scheduled time "just to talk" (surprisingly requested by the trainees), to do enjoyable and low stress activities together including art projects and virtual tours, producing a list of recommended shows available on-line, offering calming, social connections and providing structure. We added a weekly 30-minute yoga class to support both the trainees and staff and provided an avenue to practice coping and calming strategies for everyone.

When we ran our program at Girl AGain, we had up to 4 trainees working together, with two coaches for 3-hour training sessions. It was clear very quickly that 3-hour coaching sessions would not be practical or effective on a remote platform. We quickly

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Help from page 19

Children can help select which fun activities to include, as well as the order in which they would like to complete certain tasks. Providing children with choices increases their sense of control and has been shown to reduce challenging behavior in children with disabilities (Shogren, Fagella-Luby, Bae, & Wehmeyer, 2004). Incorporating novel activities into the routine, such as games, exercise videos, and cooking may also help to keep children engaged. It may be helpful to review the schedule as a family each morning. For a child who is a more visual learner, pictures can be added to improve comprehension of the schedule. Using timers can also increase predictability, informing children when activities are about to end, which can help children calmly transition from one activity to another. Activity schedules have been shown to be an effective strategy to help children with ASD perform tasks and activities with greater independence (i.e. without direct prompting and guidance from parents) (McClannahan & Krantz, 2010).

Although parents should try to stick to the schedule and routines as much as possible, flexibility is also needed during this time. It is inevitable that something will not go as planned each day (e.g. a conference call runs longer than predicted). It is important to remember not to panic. Children will be taking their cues on how to behave from the adults in their lives so parents should try to remain calm and engage in a problem-solving activity to remedy the situation. This glitch in the plan could serve as a great teachable moment to work

on problem-solving skills with children.

Social Learning Theory posits that we learn behavior from observing the behaviors of others (Bandura, 1977). There are bound to be times when children become upset and raise their voices at their parents. The key is how the parents respond. If, in frustration, parents raise their voices toward their children, they have taught them that yelling at each other is acceptable behavior. Modeling the appropriate behavior helps children to learn replacement behaviors (Asher, Gordon, Selbst, & Cooperberg, 2010). Parents should also model ways to appropriately manage emotions, such as uncertainty, fear, frustration, and anxiety, during this stressful time. It is okay to validate for children that this is a stressful time and that adults too are experiencing similar feelings. However, rather than demonstrate excessive worry in front of children, parents can model the ways that they are in control of the situation (e.g., thoroughly washing their hands, social distancing, etc.) and staying calm (e.g., taking a break, taking deep breaths, going on a walk, reaching out to a friend virtually, etc.).

When children are then observed demonstrating appropriate behaviors, parents should provide reinforcement (Wong et al., 2015). Parents should let their children know that they are watching and noticing all the good things they are doing. Verbal praise is an excellent and quick way to let children know that their efforts are appreciated. Parents should let children know that they are proud that they are completing their work, playing nicely with their siblings, or how they remembered to

calmly ask for more snacks. Behavior-specific praise identifies the correct behavior, such as "I love how you two are playing together" or "Thank you for remembering to ask before you took more chips."

Parenting a child with ASD is a demanding job and can present many unique challenges, especially during times of change and stress. Parents who are experiencing ongoing difficulty in their interactions with their child may wish to seek out professional assistance. Parent Management Training (PMT) (Kazdin, 2008) or Behavioral Parent Training (BPT) are methods of intervention and support in which a therapist teaches parents how to more effectively manage their children's challenging behaviors. The therapist works directly with the parents to provide them with both intervention strategies and prevention skills. Parents then act as the agent of change as they use the strategies they have learned with their own children. The best hope for more consistent and stable behavior changes in a child rests in modifying their environment.

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while they are providing services. When creating programs to increase an individual's tolerance of wearing a mask, many of the procedures may transfer to increasing toleration of a direct care staff wearing a mask. These procedures are likely to occur simultaneously to ensure the health of everyone during service delivery. Procedures that may assist in increasing toleration are providing the individual the rationale for wearing a mask; model how to put the mask on and take it off on yourself, caregivers, or preferred items (e.g., stuffed animals) noting that the mask will keep others and themselves safe; when first targeting mask toleration, incorporate graduated exposure into preferred activities to increase the likelihood of compliance; and provide corrections when the individual removes the mask during required times.

An excellent opportunity to include choice and preference during these procedures is to include the individual in choosing the mask design. You can also have them decorate the mask themselves, but you should be careful that modifications do not decrease its effectiveness. Another important aspect to include is reinforcement for wearing the mask but ensure that the reinforcement is functional! Based on recent observations many individuals are attempting to escape the demand of putting the mask on or avoid the sensory stimulation. Therefore, removing the mask for periods of time following an appropriate request after they hit the targeted duration would increase the future likelihood of them wearing the mask for a lengthy amount of time (i.e., shaping). When removing the mask make sure to move six feet from the individual to ensure social distancing is followed when they are not

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protected by the mask. It may also be beneficial to provide other preferred items following the target duration or items that you may save for particular procedures that are of very high value (e.g., if they have a preferred snack or toy only provide access after they keep the mask on for the target amount of time and slowly increase the amount of time they are wearing it as they are successful).

The nature of our work requires that we are close to our individuals when providing instruction with physical prompting, blocking challenging behavior such as self-injurious behavior, engaging in play behaviors, or when providing physical attention as a reinforcer. Therefore, the toleration of masks on both the client and the clinician is imperative. Many of the individuals we work with also require specific prompts to engage in a correct response that involve using our mouths such

**Jennifer Croner, MEd, BCBA**

as when teaching an individual to move their mouth in a particular manner to emit speech or modeling an open mouth when brushing their teeth. It is important to determine the ethical considerations in removing some of these programs for a short period of time or finding alternative ways to prompt such as video modeling.

Overall, the safety of our clients, direct care staff, and clinicians is of the utmost importance during this time and vital to ensuring the ongoing service provision to those in need. With the hope that the need for this level of protection is short-lived, clinicians must recognize that swift and immediate action is imperative. Other helpful programs to include as part of your client's program during this time include thorough hand washing, wearing and safely removing latex gloves, using hand sanitizer, using lotion, covering coughs and sneezes using their arm, disinfecting

surfaces, and understanding how to engage in social distancing. These procedures may assist in maintaining a healthy, safe lifestyle until the dangers of this virus subside.

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reducing the adverse aspects of an encounter with a medical provider. Additionally, supplemental education for providers is available via crisis management training programs. These training programs can be completed via live didactic instruction to teach users how to safely prevent, manage, and de-escalate crisis situations displayed by children and adolescents with developmental disabilities. Some specific curricula have been designed that focus on ASD and train users to face the unique challenges of working with this population. For example, in our own hospital system we have provided training to nurses and nurse managers, rehab specialists, sedation specialists, technicians, paramedics, and security officers. With the support of trainers, users such as these can learn to independently implement crisis management in their practice settings to reduce the reliance on chemical or mechanical restraint.

The challenges faced by the healthcare system when providing medical care to children with ASD and challenging behaviors are exacerbated when that child is also diagnosed with an infectious disease. As a recent example, a 17-year old male diagnosed with ASD presented in our ED after displaying symptoms of a viral infection and was later diagnosed with COVID-19. Upon admission to the hospital, the child began eloping (i.e., bolting) from the iso-

lation room to which he had been confined as an infection prevention measure. Elopement is particularly difficult to manage in the hospital due to constraints on staffing and the inherent limitations of the environment. Hospitals are less than optimal settings for managing problem behavior due to tight confined patient rooms, large open hallways, the presence of potentially dangerous or expensive medical equipment, and sterile or over-stimulating environments. These limitations can prevent effective physical management and increase the likelihood of a crisis situation often resulting in more intrusive strategies. In this case, elopement was particularly dangerous due to the increased risk for spread of exposure to Coronavirus. For this patient, case consultation provided by behaviorally trained professionals included working directly with hospital staff to engineer the environment and increasing the staff to patient ratio so that elopement attempts could be blocked by individuals wearing personal protective equipment. Interviewing the patient's caregiver and conducting observations established that the patient primarily engaged in elopement to access preferred items and to escape from environments he found to be aversive. This information was in turn used to further inform strategies aimed at preventing elopement attempts, which included enriching the patient's environment by adding preferred items and activities to his hospital room. Following

implementation, elopement attempts decreased and the patient was able to remain in isolation to prevent further exposure for staff or other patients.

Caring for the medical needs of children with ASD can be further complicated by the presenting symptoms associated with this developmental disability. However, healthcare professionals and behavior analyst or behaviorally trained practitioners can work in concert to develop a plan of care. By considering both their medical and behavioral health needs in amalgamation, we are able to provide continuity of care and ensure individualized treatment for these patients.

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by this virus. The majority of patients experience mild symptoms, or else have illnesses comparable to a nasty flu. Only a small fraction even require hospitalization, and only a fraction of those need intensive care (ventilators in the worst cases). Even then, many of those survive the ordeal. The mortality rate of around 1% was not as scary as it might have been because I had faced similar odds several years ago from the surgical risks of a prostate reduction. As to hospitalization, I prepared myself for such an eventuality. Should I develop any of the well-known symptoms, I would immediately call my primary care doctor to inform him of the situation, and, if necessary, get myself to the nearest emergency room, which is within walking distance. In extreme circumstances, I would call 911 and have an ambulance take me there.

A more likely possibility was that I would become sick and need to stay home for several days. I am actually well-prepared for this, because I always keep several weeks' worth of nonperishable food, personal, and household items (I hate shopping for anything other than my special interests and do it as infrequently as possible). Because I live alone, this makes the prospect of being confined at home much more bearable, as I have nearly everything I need on the premises. A scarier possibility is that I develop a severe case, because I once had such a flu when I was about 30 years old, and I was so weak that I did not even feel like watching my favorite television programs. The thought of such an illness at twice that age is indeed worrisome.

As scary as the prospect of contracting the disease is, I am even more frightened by the societal effects of this pandemic. We have seen how easily supply chains are disrupted for essential items, ranging from hospital ventilators, masks, gowns, and swabs, to household paper products and disinfectants and more recently meat products. This is very disturbing when I realize that the use of "just in time" production with few storage inventories, a practice that was adopted for our economy with little controversy, in conjunction with the offshoring of most of our manufacturing (particularly of essential products), renders these supply chains vulnerable to severe disruption in the event of a rapid spike in demand (this has also happened for webcams and laptop computers with the dramatic increase in teleconferencing). Serious disruptions can also result should significant numbers of workers in

the manufacturing or distribution of these products become infected with the virus. The result would be massive shortages of essential goods and the social turmoil that would follow. I dealt with this possibility by filling my stores of essential items to capacity. Given the small size of my studio apartment, refrigerator, and cabinets, this hardly qualifies as hoarding!

Even scarier is the disruption of such essential services as healthcare, police, and firefighting should large numbers of their providers become infected. This happened in my local post office, and mail deliveries were stalled for days at a time; fortunately, I do not receive any essential medications by mail-order, which would have created a serious situation for me. I sometimes have visions of society itself breaking down because of this and wonder if such fears are realistic or just the result of too much bad science fiction!

In addition to the above-mentioned benefits of staying informed, there have been some practical ones as well. Prior to the lockdown, I saw a news report that one NYC suburb had ordered barbershops and hair salons closed. I immediately went to the nearest barber and got my overly long hair cut. Fortunately, the shop was still open, and I asked for a shorter than usual trim. This turned out to be a good idea because the NYC lockdown happened shortly afterwards. Of far greater significance, however, was the discovery that, by the time many COVID-19 patients arrived at a hospital, their blood oxygen concentration was dangerously low, which necessitated putting them on ventilators and resulted in less favorable outcomes (including death) that might have been avoided had they been treated sooner. Upon learning that this can be measured by a consumer-grade pulse oximeter, available at most pharmacies, I visited several large drug stores, which were all sold out, until I found a local one that miraculously still had some in stock. Clearly, this was a good investment on my part.

How I Spent My COVID Vacation

Living under lockdown as we currently are is one of the few situations where being on the autism spectrum can actually be of help. I realized this when I learned that, in the general population, the single greatest source of anxiety resulting from the lockdown is the limitation on socializing with friends and relatives that it creates. As with most Aspies, my social life was never exactly prolific, so that this is not as great an

issue for me or, as I soon found out, for many other Aspies in my community.

As with much of society, however, the most-affected autistics are those who live independently and have lost their income because they work in non-essential occupations. For them, stimulus payments and unemployment benefits (when they can get through to the agency), along with moratoriums on evictions for non-payment of rent, have been of paramount importance. Those who live with parents or family, or who receive disability or other benefits, have not fared as badly. As for me, I am more thankful than ever to be retired!

Finding myself primarily at home, I decided that the best use of my time was to take care of essential tasks that had been put off, such as cleaning my apartment, filing tax returns, sorting and purging personal records and other documents (I filled several large bags with shredded and recycled paper!), and updating my computers with the latest software and security (I have a few spares, and can now use any of them should my main machine break down – a necessity in these times). Taking care of such things not only kept me occupied, but also reduced anxieties about work that needed to be done. I strongly recommend this to other autistics who have any neglected or unfinished tasks pending, especially those living independently.

Having resolved not to touch them until essential tasks were finished, I also have plenty of special-interest paraphernalia to keep me occupied. This largely consists of old electronic and scientific equipment that I repair and restore (radio, audio, laboratory instruments, etc.), which I have done most of my life. As such, I have enough items to keep me busy for some time. I also have plenty of books, video lectures, and documentaries about my interests to keep me occupied for as long as is necessary.

Keeping the Community Connected

Ever since I was diagnosed on the autism spectrum almost 20 years ago, support groups have been a regular and consistent part of my life; I have attended, facilitated, and helped organize them during all this time. With the lockdown and banning of gatherings, however, the groups I participate in were not able to meet. Thanks to online teleconferencing, though, these groups have continued through the crisis and even thrived. In fact, some have had higher attendances than their in-person meetings ever did.

Aspies For Social Success (AFSS –

www.nyautismcommunity.org, also on Facebook and Meetup), which has organized support and social groups for the past decade, now hosts weekly Zoom teleconferences (mostly on Wednesday evenings), facilitated by Steve Katz; these have shattered previous attendance records. Initially, we experimented with text-based meetings using software designed by two group members. Although AFSS decided to use Zoom, which provides any desired combination of video, audio, and text chat, for our teleconferences one of these members, Mona Pereth, has been hosting online text-chat groups for Queens, NY-based Aspies (<http://autisticnyc.org/queens/>). In New Jersey, long-time Aspie facilitator and NYC group member Daniel Szyper has been hosting his group, Central NJ Aspies 4 Social Success (www.meetup.com/NJ-Aspies-4-Social-Success/) every Sunday afternoon. Thanks to online technology, peer-run Aspie support groups, which for many autistics are a primary (sometimes the only) social connection, are alive and well and thriving more than ever. Additionally, AANE and Spectrum Services of NYC, which have provided, among their many offerings, free professionally-run adult support groups for many years, facilitated by Kate Cody, Psy.D., Pat Schissel, LMSW, and Dena Gassner, MSW, are continuing to host their monthly NYC adult and women's groups on Zoom (www.aane.org/events). I have regularly been attending a number of these groups, and those who facilitate them are among the "front line workers" of our community to whom we should all be grateful.

These developments have made attending Aspie groups easier and more convenient for those who travel considerable distances. More significantly, many autistics have never learned to drive. For those who do not live in areas with good public transit, this has made groups accessible to many who previously could not get to them. Also, many of us in the Aspie community have long advocated for greater interaction among groups in different regions; once again, these technologies will make this more viable than ever.

Finally, many of us wonder what the world will be like after this pandemic has subsided, and the crisis ended. While this is impossible to predict, it is almost certain that the autism community will in some ways be affected by these changes. We can only hope that they will be for the better.

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their parents and teachers. No one was quite sure what to expect when our schools were forced closed. We were fortunate to have such dedicated teachers, who weren't too sure how distance learning would work with their students.

"It's a very technically advanced way of teaching children," said John Goodson, Assistant Director of Educational Services and Program Development, adding that the staff has worked diligently to make this work in all the schools. "We're teaching students and training parents on using different techniques to drive ABA (Applied Behavioral Analysis). We're coaching parents to be the primary clinicians and now they are."

Vanecia Murphy is a Behavioral Trainer at AHRC NYC's Brooklyn Blue Feather Elementary School. "For me, the experience started off rough," she said. "I had to prepare everything, and I wasn't sure what to expect of the students and their parents. How were we going to get parents and students on board?"

Now, she loves remote learning because



Marco Damiani

her students, to her surprise, are cooperating. While she conducts a one-on-one session with the student and the parent, by his/her side, she will deliver verbal praise, as

will the parent, by sitting nicely and complying. Parents are encouraged to have stickers or edible reinforcers nearby.

To break up her routine, Murphy took her students on a virtual field trip to the aquarium. It was such a success that she shared the idea with her colleagues.

As with our telehealth program, our timing to partner with STAR Autism Support, which provides curriculum, was opportune. The company began remote learning for children with autism when COVID-19 developed in China. Goodson visited a Long Island preschool in 2016 and decided to pilot it in three preschools.

Pride and Thanks Do Help, But Funding is Needed

I could not be more proud of our staff and the people they support. They have gone above and beyond in every possible way.

Like other providers across the country, AHRC NYC has incurred large and urgently needed additional expenses in staffing costs. We've also had to purchase huge amounts of Personal Protective Equipment (PPE) to keep our staff and the individuals they support safe.

The House has recently passed another COVID-19 relief bill, which included dedicated funds for Medicaid home and community-based services, PPE and our workforce. Congress must include people with disabilities, their families, and direct support professionals in the next COVID-19 relief bill.

Medicaid-funded disability providers have not received any emergency relief funds from the federal government. If you haven't already, please write to your members of Congress and tell them that Medicaid service providers who support people with I/DD need funding now.

Thank you to all the parents, direct support professionals and other caregivers supporting people with disabilities. You are providing care under unprecedented conditions and are the key safety net for individuals with disabilities. Indeed, you are essential.

Marco Damiani is CEO of AHRC New York City. He has 40 years' experience in the field. Marco was recently appointed to the Mayor Bill de Blasio's Sector Advisory Council on Public Health and Healthcare.

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Program (CAAPP) implemented significant modifications to transition entirely to telehealth. Logistical steps included identifying a HIPAA compliant platform (e.g., Zoom), securing confirmation that services delivered via telehealth would be supported by funders, ensuring that staff and participants were able to access and navigate the technology, and obtaining informed consent for telehealth services from clients and their families. The team developed and scheduled virtual trainings using behavior skills training (BST) to prepare staff to use the technology, document services, and embed their sessions with evidence-based practices and meaningful goals. For example, staff have been able to prompt participants through routines and daily living skills while also displaying task analyses and visual materials on the screen. Staff were especially encouraged to utilize BST and were able to enhance their training by incorporating video models of skills.

Telehealth allowed participants to maintain structure, socialize with peers, and continue to work on skills in a new virtual format. To provide a sense of familiarity, virtual social groups (VSG) were scheduled multiple times per day and were designed to mirror those previously offered in-person (e.g., arts and crafts, exercise, cooking). Team members frequently consulted with participants and staff to invite feedback about groups and make needed

changes. For example, groups have been adapted to meet the needs of a wide range of skill levels and included suggestions for substitutions when materials were not easily accessible.

Groups that were most successful included visual supports, structured activities, opportunities to model skills, and incorporated advanced video conferencing features (e.g., reactions, private and public chats, breakout rooms, etc.). After developing a consistent VSG schedule, the team embedded opportunities to practice skills and work on projects related to groups during individual sessions. For example, participants met in smaller groups to practice conversational skills with peers following a more structured social skills lesson.

Participation in VSGs illuminated unforeseen benefits. Staff were able to provide prompts utilizing private chat features without interrupting the natural flow of conversation. Numerous participants reported feeling more comfortable engaging in the virtual platform and some individuals began attending groups for the first time. Many have taken more ownership of their programming, including advocating to plan presentations and lead groups.

Conclusion

Although utilizing telehealth with adults in community-based program models is still largely uncharted territory, times of

crisis often inspire unique opportunities and creative solutions. Direct services and virtual groups have been vital in helping participants to continue their programming, maintain structure and consistency, and increase opportunities to socialize with familiar peers and staff during tumultuous times. As the world slowly readjusts to whatever new normal lies ahead, many people living with ASD will be armed with a new set of valuable skills to help them navigate an increasingly technological world. The benefits of telehealth have been outlined previously including increased access to supports and cost-effective service delivery. However, there might be additional benefits to utilizing telehealth with adults with ASD that need to be further explored. Although many are eager to reconnect in-person, it presents an opportunity to bridge the new virtual community with the brick-and-mortar one.

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screen time at specific times of day and only allowing screens during these times. You could also allow your child a specified amount of screen time (e.g., 1 hour) and keep track of it throughout the day. Using visual timers (there are many apps for this) can be helpful for setting these limits." If screen time must be limited, then something should be put in its place.

Families are coming up with more creative ways to cope while being at home. This may include enjoying the back yard more or playing games such as I-SPY,

which helps with color, object recognition and the use of imagination. Another game can be hopscotch, this helps with gross motor skills and counting. How about more help in the kitchen? Cooking is a life skill. Cooking new meals together is a cool creative way to break up the monotony of staying at home. Cooking involves math and science and helps children learn about sequencing and following directions. It helps with focus, seeing a project to completion, gives children active roles and the best part, families get to eat the fruits of their labor. Children can be given duties to include measuring

ingredients, ensuring there is adequate space in the refrigerator for the food, and clean up and break down of dishes and tools.

Managing Challenging Behaviors

As we transition to safer at home orders, continue to work from home distance learning with virtual school, maladaptive behaviors are sure to be on the increase. There may be more noncompliance, tantrums, and physical and verbal aggression. These things are to be expected as we are living a more restrictive life. When children

know what to expect, it takes the element of surprise out of life. This can be as simple as setting up realistic expectation for your children and explaining to them in clear concise words what is expected as the family transitions. Create and follow a behavior model using "if/then" statements. For example, "if you finish your math homework, then you can play a game." Setting up and sticking to a schedule and routine helps children know what to expect. Model the behavior you want to see. In the article [Managing Children's Challenging](#)

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educational support. This enabled discussion about behavioral challenges, skill programs that were posing difficulties, general concerns, and safety concerns. It also provided a context for educational staff to share information about the use of schedules and visual cues, pacing of instruction, and favorite activities. Scripts and task analyses were created to help families understand the structure of each educational session.

4) Individualization of approach for active instruction - Perhaps the greatest lesson was the need for individual solutions. Every individual and each family required individualized and tailored plans. An analysis of goals and programs was a fundamental first step. From a skill development perspective, prioritization was given to the maintenance of skills, to ensure that abilities would not be lost in the transition from active on-site programming. Given the propensity for individuals with ASD to lose skills in the absence of practice, it was important to identify the skills that would be consistently reviewed. It was also important to identify programs or skills that might be modified or placed on hold until the resumption of the on-site educational program. For example, it might not make sense to continue working on skills that would evoke challenging behaviors or on skills that were not going smoothly. Examples of goals that might be modified in light of safety concerns included things such as the introduction of novel foods to a selective eater. Initial instructional goals

included rapport building, eye contact, and attending/responding to a virtual teacher.

Motivation was another element of individualization that was essential to address. Teachers and instructors worked diligently to share information about how the individual was motivated in the school/program environment. In this way, parents could ensure those reinforcers/preferences (or similar ones) were available during remote learning time.

Teachers integrated new goals into many learners' lessons. In the beginning of the stay at home period, teachers provided visual information about school closure, and addressed newly needed skills such as attending to virtual instruction. Over time, instruction embedded more focus on health and safety skills. These included: the proper wearing of a face mask, toleration of prolonged periods in a mask, thorough hand washing, appropriate social distancing, and engagement during virtual communication.

5) Flexibility in considering how education is delivered - Families were navigating other stressors and adjustments in addition to the changes in instruction for their child with autism. Many families were working from home or staying home to care for young children; some were juggling both. In many homes, other children were also receiving remote instruction from their schools. Parents' ability to provide instruction or coaching was sometimes limited by these demands. To ensure continuity of education for all students, staff designed individualized programs

for each family. In some situations, it was easier to integrate instruction into activities of daily living or into recreational times. It was also necessary to support families in realistically assessing what was possible, given all of the other variables and circumstances impacting the family.

Guiding Principles

Perhaps the greatest lesson amidst COVID-19 has been the reinforcement of our foundational roots of individualizing our instructional goals, providing support to families, and ensuring that staff members are prepared for and skilled in the delivery of services. In the future, we will have the lessons of COVID-19 to guide us in planning for remote instruction and for prolonged periods of at-home stays. The experience of COVID-19 has reinforced the importance of collaboration, communication, and flexibility when providing support to families.

Summary

COVID-19 continues to challenge the care of the most vulnerable. The need to provide ongoing services for students with autism and intellectual/developmental disabilities with medical fragility and/or behavioral challenges necessitates a constantly evolving response. Action plans must continue to be considered for all levels of the organization, with the best interests and safety of the individuals served remaining top priority.

The lessons of COVID-19 have prepared

us for the continuation of care during public health threats and during other crisis situations. It has also stretched organizations to provide services, trainings, and supports in remote contexts when possible. In this way, services were uninterrupted, maintenance of skills was assured, and families were supported in managing these unprecedented changes in the schedule, location, and instructional context for service delivery.

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Deadline: December 2, 2020

Summer 2021 Issue:

“Autism and Employment”

Deadline: June 3, 2021

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Financial Advice from page 28

are often expenses we are paying for monthly that we forgot about or that we don't use or need anymore.

- There is currently forgiveness on payments and interest on all federal student loans owned by the Education Department. No interest will accrue during the administrative forbearance period. There are two sides to think about here. If you do have the funds to make payments on your loan now, your loan will be paid down slightly quicker due

to there currently being no interest. However, if you cannot afford to make payments right now, you don't have to. Several private loan companies are also offering forgiveness, so research all of your options.

- Some utility companies have promised not to terminate service of those who cannot currently pay their bills due to being impacted by COVID-19. The full list can be found [here](#).
- Tax filing has been extended by 3 months to June 15. You do not have

to file a return or make payments until that date.

- Beware of shady sales pitches. There are **lots of scams right now** offering to “help” with financial relief for those affected by Coronavirus. Skip them and talk to your financial planner first.

Try and remember that this is a setback. It happened quickly and it can be devastating. That being said, this is just temporary; it will get better, we will come out of this. Create your lists and your steps, and check things off bit by bit. Use this as an oppor-

tunity to learn so that you can start to build a better financial foundation that will leave you in a better place than you ever have been when this is all said and done! There will be a next time - and next time, you are going to be prepared.

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Examining from page 20

in the face of overwhelming evidence we hold on to certain beliefs.

Cognitive dissonance is not a small or trivial matter facing leaders because it can and does create situations where leaders ignore facts; hold on to beliefs after they have been debunked or considered irrelevant; avoid making tough decisions and avoid conflicts; refuse to change the course of action; fail to listen to competing thoughts; rationalize their actions; and follow the herd because it is easier and is a path of least resistance.

Let us work through some examples for executives in the human services sector where beliefs bang against evidence:

Most executives who are managing agencies heavily dependent on government funding constantly complain about lack of flexibility to use resources or reform program models but when given a chance to reform, they stick with what they know. An example is sticking with a fee-for-service (FFS) model because the whole agency is wrapped around making FFS work versus given the opportunity to take risk under global budgets or managed care to flexibly

use finite resources.

Another example is the use of licensed group homes for people with disabilities. There is a strong belief that the essence of community living is having access to group homes of four persons or less. Families, advocates, providers, and government agencies hold on to this model because they believe it works. There is no real evidence that this model is better than independent living or living in non-certified housing in terms of quality of life or well-being. New housing models are slow to enter the policy realm because of these strong beliefs around group homes.

High performing executives and leaders are often good story tellers about themselves or their agency. At a personal and professional level, stories help create a narrative that unifies the disparate pieces of their lives. In order to deal with the reality of cognitive dissonance, leaders weave together a coherent story that gives meaning to their life and role.

All of this has become quite pronounced during the dual crises of dealing with COVID-19 and the economic fallout from revenue loss and expense increases.

Here is an opening line that gives us

insight into the world of cognitive dissonance for executives and insight into the crises that could fundamentally change the way organizations operate.

A Tale of Two Cities by Charles Dickens:

It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of Light, it was the season of Darkness, it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us, we were all going direct to Heaven, we were all going direct the other way - in short, the period was so far like the present period, that some of its noisiest authorities insisted on its being received, for good or for evil, in the superlative degree of comparison only.

Crises tend to reveal many things about people and organizations. What I have seen is that executives have stepped up and demonstrated leadership in managing the dual crisis of COVID-19 and its economic fallout. We are fortunate to have

these leaders.

Data Collaborative Members are: NYC AHRC, YAI, Access: Supports for Living, ANIBIC, Birch Family Services, CP Unlimited, Westchester Jewish Community Services, Human Care Services for Families & Children, IAHD, LifeSpire, Services for the Underserved, Brooklyn Community Services, The Jewish Board of Family and Children's Services, HeartShare Human Services of New York

Arthur Y. Webb was the former commissioner of OMRDD (now OPWDD) from 1983 to 1990 and Executive Director of Division of Substance Abuse Services (now OASAS) from 1990 to 1992. Mr. Webb has held several senior executive positions in government and the nonprofit sectors. For the last ten years, he has been a consultant working with numerous nonprofits to translate public policy into innovative solutions. Presently is the Executive Director of the New York Integrated Network for Persons with Intellectual and Developmental Disabilities (a nonprofit collaboration of 12 providers). Contact: arthur@arthurwebbgroup.com or 917-716-8180

Stress from page 21

emotional challenges, are enhanced.

In an extensive review of cortisol, stress exposure and mental health in humans in the Journal of Psychoendocrinology in 2012, researchers Sabine, Staufenbiel and colleagues in the Netherlands concluded that exposure to chronic stress was significantly demonstrated in hair cortisol levels. The authors concluded after this extensive review that the dysregulation of the hypothalamic-pituitary adrenal axis as it relates to cortisol in the development and/or maintenance of psychopathology may be subtle but clearly present in chronically stressed populations. The combination of endocrine, genetic and psychological paradigms is a pre-requisite to an integrated approach that aims to understand the specific role cortisol plays in shaping physical functioning.

Researchers have demonstrated that in an analysis of young children that preschoolers exposed to high levels of concurrent maternal stress had elevated levels of cortisol. These children also had a history of high maternal stress exposure in infancy. Finally, preschoolers with high levels of cortisol exhibited greater mental health symptoms in first grade. Elevated levels of cortisol have also been found to contribute to the diagnosis and severity of late life Generalized Anxiety Disorder.

The current levels of social distancing, staying at home and even quarantine also serves to increase stress levels. Being deprived of interactions with others is a significant risk factor to develop mental health problems at all ages. For example, newborns of all species deprived of a consistent caretaker with whom they bond

develop marasmus or failure to thrive. Further, a recent research trend is the investigation of the comparative effects of social isolation and loneliness in older adults. Depression and cardiovascular health are the most often researched outcomes, followed by well-being. Emilie Courtin and Martin Knapp in the Journal Health and Social Care in 2017 found a consistent trend in research demonstrating the detrimental effect of isolation or loneliness on health. It is likely that these mental health problems are in part mediated by elevated cortisol.

Moderating Your Cortisol Levels

There are no specific medication treatments to lower cortisol level nor are there any medications one can take in a preventive way to reduce the likelihood of seriously elevated cortisol levels in stressful situations. However, the following eleven suggestions may help moderate your cortisol levels:

- **Manage your stress.** Be sensitive to your body. Get enough sleep. Eat well. Stick to a routine each day.
- **Manage your diet.** Some foods may be effective in helping control cortisol levels. These include dark chocolates, bananas and pears, black or green tea, yogurt and other probiotics. Drinking plenty of water avoids dehydration which may also help lower cortisol levels.
- **Stay calm.** Spend some time each day in a relaxation activity such as meditation, mindful thinking or even a simple breathing exercise. Take a hot bath or sit in a hot tub if you are fortunate to own one.

- **Engage in a hobby.** One study found that gardening led to decreased levels of cortisol.

- **Unwind.** Spend time each evening unwinding before bed. Read or play solitaire. Don't watch the news before bed!

- **Stay connected.** Seek humor. Have fun and enjoy the company of others even if it is remotely through social media. Laughter releases a cascade of protective hormones. Share a favorite recipe or a post a picture from a past trip.

- **Exercise.** Aerobic exercises that increase your heart rate for at least twenty minutes to a half hour per day are beneficial. My colleague, Dr. John Ratey, has well demonstrated the benefits of aerobic exercise in his book Spark.

- **Watch what you drink.** Avoid caffeine late in the day. Limit your alcohol consumption.

- **Maintain a bedtime routine.** Studies have demonstrated that cortisol levels rise after a disagreement with your spouse before bedtime. As noted, children living in homes where there is regular conflict at any time of the day demonstrate high cortisol levels.

- **Spend time with your pets or get a pet.** One study measuring cortisol level in children undergoing medical procedures found that the presence of a canine lowered children's cortisol levels. Another study found that contact with a canine was actually more beneficial for reducing cortisol levels in a stress-

ful situation than a supportive parent or friend.

- **Consider supplements.** Supplements such as fish oil and the Asian herb known as ashwagandha for example, have been demonstrated to reduce cortisol level in your bloodstream.

In these unprecedented and broadly stressful times we should all pay attention to our stress and cortisol levels. I expect that that psychological studies over the next five years examining the effects of the COVID-19 pandemic will demonstrate the significant impact our experiences have on our minds and bodies for many years to come. I urge you regardless of your age to be proactive. Pay attention to your mind and body. Pay attention to your cortisol level.

This article is reprinted with permission. The original article, published on April 7th, 2020, can be viewed [here](#).

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Relief from page 27

These are challenging times, but with planning and patience, you and your family will be able to successfully navigate the maze of working, home-schooling and scheduling – together.

Amy Kelly, MBA, MNM, is the mother to Danny, Annie and Ryan. Annie is diagnosed with moderate to severe autism, verbal apraxia, intellectual and developmental disabilities and general anxiety disorder. Amy is the National Direc-

tor of Family Engagement for [Devereux Advanced Behavioral Health](#), one of the nation's oldest and largest nonprofit providers of behavioral healthcare, and serves as a family representative on several special needs boards in the community, locally and nationally. In addi-

tion, she participates with other patients and families in efforts supported by the American Board of Pediatrics Foundation and the Autism Speaks Autism Treatment Network to address children with special needs and the importance of quality care.

Transitioning from page 25

shaping the new structure for our telehealth services. Most cases required modifications and some additional material development. Data collection was changed minimally with a couple of new forms added. Training took little time for the therapists and certified personnel who had a lot of experience in utilizing different learning software. For less computer-savvy staff, training took a longer time, but the overall level of clinical skills kept all our active cases afloat.

One meaningful finding during this analysis/preparation time was a clear understanding that we needed to develop a company protocol with spelled-out, step-by-step directions for remote services delivery. We also understood that this additional knowledge would need to become an essential part of our standard employee training in the future so that all staff could provide remote services when necessary.

Once staff was trained and programs were modified, sessions needed to start remotely. Although our company incurred expenses during this “trial and error period” (reimbursement for the time our employees spent putting structures in place for our clients), it was a valuable investment into understanding this process.

Because we were utilizing a new for-

mat, we decided to start cautiously to ensure small successes that we could build upon. We wanted to test how our clients (and caregivers) would respond to the new learning format, regarding medium and endurance. We started with evaluating fifteen-minute sessions for the first couple of days. The evaluation included asking the following questions:

- How do we evaluate if a session was successful?
- How do we adjust the session times based on the client/caregiver behavior?
- How should we manage billing if insurance reimbursement for some companies is in 30-minute intervals?

Criteria for success was established individually for each client, and based on that criteria, session time was gradually increased. Frequent and ongoing communication with staff and caregivers was essential for successful increases in time. In the few cases that required small increases in time (less than thirty minutes), a combination of direct services with a child were provided for 15-20 minutes (with a caregiver involved), and a coaching/discussion time with that caregiver as a follow-up completed the 30-minute block.

Essential to the development of successful remote sessions were the following components:

- Certified personnel trained our staff to recognize clients’ tiredness and frustration before problem behavior surfaced.
- Staff encouraged therapists and caregivers to ask for additional training or coaching sessions when needed.
- Observations of online sessions were scheduled frequently.
- In tough behavior situations, our certified clinicians did not hesitate to take a lead if they felt that therapist was losing control of the session.
- Equipment was tested prior to use.
- Utilization of “gamer headset” for privacy and confidentiality. Furthermore, these headsets significantly reduce feedback.
- Staff were positioned in a private room where work was not interrupted and/or overheard.
- Because of the time delay in communication over a remote platform, staff was

taught to talk slowly and allow longer pauses between sentences.

- Staff was encouraged to use the mute button to reduce extraneous noise in the sessions, especially when in a supervisory role.

We have been utilizing this model for two full months now. We are collecting data and planning to do more analysis moving forward. However, our clinicians are seeing skills acquisition happening, mastery criteria being reached, and (according to all our BCBA’s) much higher level of parental involvement and understanding.

So, hopefully, readers will benefit from our learning experiences as well.

The COVID-19 pandemic has led to considerable amount of problems for ABA services consumers. It also effectively demonstrated that under the pressure of overwhelming consumer needs, no “carved in stone” rules of insurance reimbursement can stay untouched. We faced challenges that we were not prepared for. Nevertheless, these challenges helped us to learn and build new set of clinical skills, new capabilities for problem solving, new repertoire of strategies for effective service delivery.

For more information, please visit www.abaservicesofct.com.

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Can't Think from page 22

3. Unstick yourself if you are stuck on a thought - If one is stuck on negative thoughts, use a pattern interrupt. Take 10 deep breaths, sing, do jumping jacks, walk outside or just change what you're doing. Focus on a positive thought, a way in which things are working OK. A thought like, “I can make it through this, so many are in the same boat” is honest.
4. Meditate - If you haven't had a meditation practice before, this is a great time to start with an online app such as [Headspace](#), [Calm](#) or [Insight Timer](#). Meditation is scientifically proven to create structural change in the brain that makes you more stress resilient.
5. Practice mindfulness - Many of our worries are about the future; try to get back to the present moment. Do mindfulness exercises where you focus on your sensory experience of breathing, holding an object and noticing all its details, letting a mint melt in your mouth noticing every detail of each moment. Even washing dishes can be done mindfully.
6. Reach out - People are getting creative about using Zoom, FaceTime, Hangouts, Google Duplo and other apps to see friends and family and spend time

together, whether with friends, groups like book groups; any meaningful connection. Find a support network and use it.

7. Take advantage of what's online - Think of things that were interesting and you had no opportunity or time for them. Everything is online, from developing creative art skills to touring museums and national parks. This can be a time to grow. I have a friend taking her cello lessons online. There are short and long courses, podcasts, all kinds of projects. Try a yoga class or learn to juggle or anything that might interest you.
8. Do some things simply for pleasure - Binge on a TV show or find other opportunities to enjoy yourself. This is the time to indulge – mystery novels? Sci-fi movies? Do whatever you will enjoy, without feeling guilty you're not doing something “worthwhile.” One meme said, “This is the only time in history when you can save the world by doing nothing and watching TV. Don't mess it up.”
9. Limit exposure to media - Keep up with developments in what we're directed to do but monitor how much time you spend upsetting yourself.
10. Focus on what's positive - While many resist writing things down, a gratitude

journal helps. Take a moment to be grateful, even writing down a single gratitude each day. I'm grateful that I am OK, that today the sun was out, and my tulips are blooming.

11. Be a problem solver rather than a complainer - Reframe difficulties as problems to be solved and explore logical alternatives. Look outward for resources. Prioritize.
12. Give up perfectionism for a while - Cut yourself some slack. With all this stress, perfectionism isn't going to work. Good enough is going to be the goal for a while.

For those in need of help, there are teletherapy resources and multiple hotlines you can use.

Teletherapy

Psychology Today: <https://www.psychologytoday.com/us/therapists/online-counseling>

<https://www.cnet.com/how-to/how-to-find-a-therapist-online/>

Talk or Text Hotlines

24-Hour Helpline to talk: 1 (800) 537-6066

Crisis Text Line: Text HOME To 741741

Suicide Hotlines

National Suicide Hotline: 1-800-273-8255.

[Suicide prevention live chat](#)

We can make it through this time taking care of ourselves and helping each other. The bottom line is that despite our differences, we're all going through challenges together.

* I use identity first language instead of person first language at the request of autistic friends.

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Unique Program from page 23

up new learning routines for students with autism during home-based instruction. The program built on:

1. the ECHO Autism format, including didactics and case-based learning;
2. the AFIRM modules (<https://afirm.fpg.unc.edu/afirm-modules>), which provide instructions for using evidence-based autism practices; and
3. evidence-based parent engagement and distance coaching strategies (Haine-Schlagel et al., in press; Vismara et al., 2012; Wainer & Ingersoll, 2013).

We began with a foundational session about best practices in distance coaching (technology trouble shooting, session structure), partnering with parents (collaborative goal setting; understanding context) and building parent engagement. The rest of the curriculum supported building a program in collaboration with caregivers that improved learning readiness, increased student engagement, and reduced behavior challenges. Specific topics included:

1. use of visual schedules and an activity matrix for embedding instruction;
2. strategies to support new learning routines and positive behaviors;
3. using positive behavior support to address challenging behaviors; and
4. strategies for building self-regulation to reduce anxiety.

The ECHO Hub was comprised of an interdisciplinary team with experience in public education including: Behavior Analyst, Speech Language Pathologist, Education Specialist, Social Worker, Parent, Developmental Behavioral Pediatrician, School Psychologist and Clinical Psychologist. The Autism Tele ECHO team limited enrollment to approximately 20 people to encourage discussion and community building. Response to Autism Tele ECHO was high, therefore we offered two sessions of each topic. On average, 19 educators (including special education teachers, behavior analysts, and speech language pathologists) participated in each session. Sessions included case-based learning and mentorship to promote participation during ECHO virtual learning. Educators shared challenges ranging from student refusal to attend distance classes with peers to supporting youth with co-occurring mental health conditions and limited resources. Participants also shared the results of implementing recommended strategies. For example, the strategy suggested for the student who refused to participate in distance classes began by recording his participation, slowly building a tolerance to distance learning. The result was that he started to participate in activities with his peers. Another participant supported

a teenage student with autism and mental health concerns, significant elopement, and aggression challenges with a single parent. Through co-development of a plan prioritizing parent concerns and focusing on a small number of functional skills targeted during daily routines, behavior began to improve. Overall educators learned to support parents in embedding instruction naturally into daily routines so that home learning did not feel so overwhelming.

Following each session, participants completed an evaluation using a 5-point Likert scale (1=strongly disagree to 5=strongly agree). Average ratings for the usefulness and relevance of the didactic lesson were 4.7 ($SD = 0.61$). Participants agreed or strongly agreed that their knowledge of each topic increased (mean = 4.4, $SD = 0.73$) and felt the case presentations and discussions were applicable to their current needs (mean = 4.6, $SD = 0.71$). Educators reported that they “loved the parent-teacher collaboration that was being established.”

The participants also commented on their experience with the program. One participant said “it is very valuable to hear the case and think through the challenging situation. I like the process of hearing from the different team members and their perspective from their experience and expertise.” Another participant shared, “I liked that the group was small enough for all of us to speak, introduce ourselves and ask questions. I feel more confident entering the world of remote online learning and being able to support families at home during this global pandemic.”

Sara Lighthall, Preschool Teacher at Elk Grove USD, commented that “The Echo training was so relevant to the dramatic change in teaching right now. The platform was perfect to allow teachers the space to take in information, ask thought provoking questions, then give and receive recommendations that could be used immediately to help our families. This training has been the highlight of my learning during Distance Teaching and am so thankful I was able to be a part of it.”

The ECHO Autism format is a promising method for providing distance support to educators. One main advantage for this program is its just-in-time support to those who need it, especially during a national crisis such as COVID-19 pandemic. The didactic portions of the sessions (publicly available at health.ucdavis.edu/mindinstitute/education/echo/echo-special-edition.html) have received over 1,500 views thus far.

Our team was heartened by the educators’ interest and commitment to learning new ways to partner with families during this crisis. IDEA regulation 34 C.F.R. 300.34 enables educators to help parents learn new skills to support a student in reaching educational goals; however, during usual education, teachers report needing additional time, structure, and support to build relationships with families (Jivanjee et al., 2007). The necessity of distance learning provides an opportunity to develop a new framework for partnership between educators and families.

Recently, researchers have developed

training and consultation models that successfully build family-school partnerships that can lead to improvements in child outcomes at home and at school (Azad et al., 2018; Ruble et al., 2010). Distance education may increase communication and interaction between parents and teachers and enhance the collaborative parent-teacher relationship (Smith et al., 2016). We are hopeful that this model and educator experience partnering with parents will promote interdisciplinary collaboration and refine families-school partnerships.

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Neurodiversity from page 22

of us. We need safety and predictability. We can and must meet the challenges of COVID-19. We are living through a period

of both danger and opportunity. We don’t control the outcome, but our efforts make a difference.

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and father of an adult son with autism. His latest book is *Autism in the Family: Caring and Coping Together* (2013) by Brookes Publishing. He can be contacted at RNaseef@altenativechoices.com, and

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Strategies from page 24

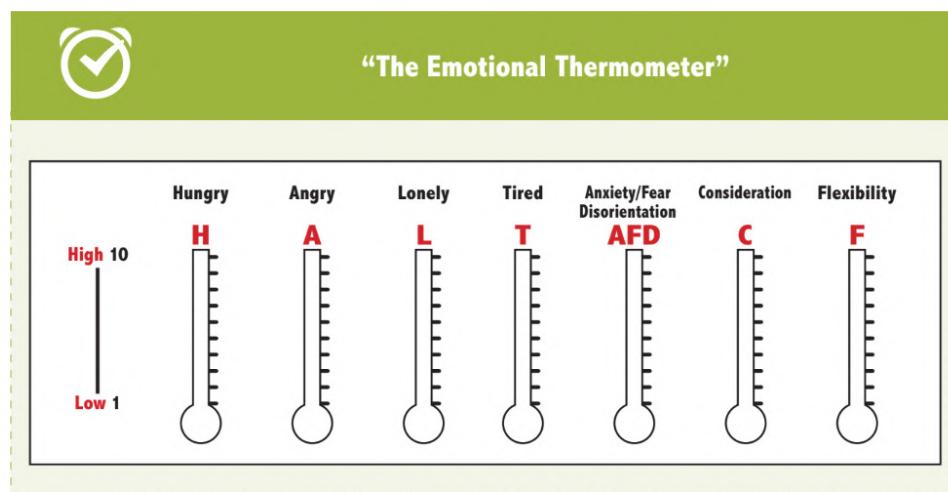
Planning and Time Management

Most people had established routines and structure in place prior to COVID-19. This ranges from morning hygiene routines, to transitioning between classes at school, to eating dinner at a certain time. Understanding that a change in routine will be a challenge for most, it is important to maintain as much of the original routines as possible. Plan times throughout the day for self-care and coping strategies in order to prioritize personal wellness.

Build Morning and Evening Routines - While unexpected changes in schedule may occur throughout the day, maintaining a consistent morning routine can influence a more positive response to adversity. Utilize a calendar, white board, bathroom mirror, alarms, or other preferred prompts to track each task. Young adults receiving post-secondary transition supports at the College Internship Program (CIP) have reported that pairing music with their routines helps with motivation as well as self-monitoring the time allotted for each task.

Evening routines are essential for regulating sleep patterns and promoting healthy sleep habits. Begin evening tasks early, reduce screen time, and limit tasks that require elevated energy levels close to bedtime. In addition, allot time during the evening routine to reflect on the day and look at the schedule to prepare for the next day. Consider pairing a preferred task with morning and evening routines. For example, include drawing or reading as a precursor to preparing for bed.

Anticipate Change - Support cognitive flexibility and preemptive use of coping strategies by taking the time to anticipate potential changes in expectations or rou-



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time. Take note of things that have the potential to change within the structure of the day, week, or month, and discuss reasonable reactions prior to the change occurring. Unexpected change removes control from the person and places control on the environment. Utilization of coping strategies allows a person to control the way they respond to the change.

Set SMART Goals - Setting goals for the future can feel like a daunting task when the future is uncertain. For this reason, it is important to set goals that are Specific, Measurable, Attainable, Relevant, and Timely. Goals that can be completed in an hour, a day, or a week are all acceptable, and completion of these goals can increase self-efficacy and confidence in the ability to move forward despite uncertain circumstances. For example, an individual seeking employment may set a personal goal to complete and submit two job applications by Friday afternoon. This type of specific goal setting allows a person to set their own parameters and maintain a sense of control over their own actions.

Self-Regulation

Self-Assess - Referred to as the "Emotional Thermometer" in Autism and Learning Differences: An Active Learning Toolkit (McManmon, M.P., 2016), this tool helps individuals to recognize and identify emotions and respond accordingly. Utilizing this tool daily can help improve self-awareness and build healthy habits. By focusing on specific behaviors that affect emotional regulation (i.e. eating breakfast, talking with a close friend, getting a full night's rest), individuals can learn to make positive changes that affect themselves and those around them. Other methods of self-assessment include daily journaling, creating a self-monitoring to-do lists, and asking trusted sources (such as a parent, friend, or teacher) for specific feedback.

Conclusion

Individuals with ASD may face challenges coping with stress and uncertainty associated with the COVID-19 pandemic. In tandem with trusted coping strategies,

development of executive functioning skills can promote flexibility and increased ability to cope in times of change and adversity. Provided the necessary support, positive reinforcement, and consistency, this time can be an opportunity for growth and development for those with ASD.

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SLPs from page 24

Make sure to note your contact attempts and the student absent within their log note. Typically, these minutes are surrendered to the school when this occurs. As always before implementing this plan, make sure it is consistent throughout your SLP team and that your school's administrators are on board.

Do I need consent from parents in order to hold group sessions via teletherapy sessions?

In general, teletherapy does not have regulations that require signed consent to hold group sessions. SLPs follow the service delivery model that is stated on the Individualized Educational Plan (IEP). Medicaid reimbursement regulations per state can drive this model as in some states Medicaid will not reimburse for group teletherapy sessions. During this time of transition to distance learning, many districts are requiring either verbal or written consent from parents/guardians regarding group sessions. They are also providing letters or legal documents to inform families of the change in service delivery during this time. It is always best practice to defer to the direction of your district's administration regarding parental/guardian consent and current state rules and regulations regarding Medicaid reimbursement.

How can I involve parents during the sessions with their child?

Reach out to the family prior to the start of your session when possible and discuss expectations of support during your sessions. Provide parents with tasks that you would like for them to engage in during your sessions such as hand over hand assistance for activities. If you give them a role in therapy from the beginning, they are more likely to be present to help during the session. Although not encouraged, if a parent is not able to sit next to the child to facilitate engagement, encourage an adult to be within the same room or within earshot of the child who is attending on the computer.

Help the family think outside of the box. Possibly grandparents, siblings or even neighbors may be available to help attend to other children or attend to the student that's receiving the services virtually. If the appropriate level of support is not able to be provided, it is our ethical duty to let our administrators know and call an IEP team meeting to remedy the situation.

Do I need to purchase ready-made, telepractice specific materials for my sessions?

In one simple word, NO! Although there is a tremendous amount of exceptionally made materials by a variety of talented

SLPs on the market, get creative! Think outside the box! Scan and upload materials you already have to share via your preferred platform, incorporate physical activity, utilize manipulatives or toys readily available in your home or the student's home, collaborate with your team of teachers on an academic lesson or even just google free worksheets. Get those creative juices flowing while running on your treadmill, walking your dog or even playing with your own children or grandchildren. Materials that you use during your on-site sessions can easily be adapted to your new virtual classroom.

What are resources that will keep me apprised of the ever-changing regulations and closures during COVID-19?

- [ASHA Telepractice Portal](#)
- [ASHA State-by-State](#)
- [Map: Coronavirus and School Closures](#)
- [COVID-19 Information and Resources for Schools and School Personnel](#)
- [FERPA and the Coronavirus Disease of 2019](#)
- [U.S. Department of Health and Human Resources-Acceptable Platforms](#)

Stay positive fellow SLPs! You've got

this! Through the trials and tribulations this may bring for you, you are learning new techniques and tricks for your future in-person sessions OR your continued teletherapy sessions. You are learning more about how to help your students by getting a glimpse into their daily environments outside of the classroom. You are engaging parents and family members who may not have ever thought to support their child's communication within the home increasing your student's progress and overall success.

Keep your chins up! You are all rock stars. I believe in you. We at TeleTeachers believe in YOU!

This article has been reprinted with permission. The original post can be found at <https://blog.teleteachers.com/top-6-questions-asked-by-spls-during-covid-19>

Lisa Moore, MS, CCC-SLP serves as the Director of Clinical Operations at TeleTeachers. She has over 13 years school-based SLP experience. For the past 8 years, Lisa has worked within the teletherapy environment diagnosing and treating school-aged students in the states of Arizona, California, Colorado, Indiana, Ohio, Missouri, and South Carolina. She has been a Supervisor of SLPs and support to Special Education Directors and educational staff nationwide in creating and growing effective teletherapy programs.

Thriving from page 25

classes every day. By incorporating music and dance into her classes, even individuals who “don’t like exercise” begin to brighten up and dance along. Schmelzer has added more dancing to her programming as a way for members to move together, de-stress and be creative with their dance moves.

In addition to these group classes, one-on-one education is still taking place. Shift Supervisor Norm Collins virtually works with students on their medication training. Collins walks students through a set of questions about what medications they are taking and the quantities, but the conversation goes beyond that. “The goal is for each student is to understand their health needs and to self-advocate for their well-being,” explains Collins. “It is also to have an individualized system that allows them to independently take their medications.” Collins is proud that students are continuing to achieve higher medication independence level statuses during this time.

At first, Vista’s virtual programming was meant maintain structure and routine,



Becky Lipnick

so many of the offerings mirrored their traditional programming. However, Van Kirk notes how, “Soon after we started virtual programming, individualization and creativity came into our collective consciousness. We are fortunate to have an unbeliev-

able team of staff – and our students and members are just as unbelievable – together they are driving our efforts into new areas. From a daily ‘Friend Time’ group that meets, to a ‘Day Is Done’ group, to a ‘Vista Family Dinner’ – the creativity we are seeing is endless...and the impact continues to be powerful.”

For example, Day Is Done is a constantly evolving group that supports Vista’s students and members emotionally. One student, Nicole, describes, “Day Is Done means to me that I get to see everybody’s faces... I get to see the people in the dorm.” Participants in this group share a high and low point of their day, but the conversation is also an opportunity to laugh and bond. Day Is Done often ends with the group singing and dancing along to a well-known song. For Ashley, another Vista student, seeing everyone at Day Is Done is the highlight of her day. To Andre, “It’s all about that new beginning – it’s a new start. We start our day and we end our day together.”

While everyone would like to return to normalcy as states experiment with reopening, it is possible to provide impactful

virtual programming that keeps individuals connected as friends, colleagues and part of a greater community. No one can predict the future, but it is important to continue to provide programming that is fresh and meaningful to individuals with disabilities regardless of the circumstances. At Vista, this means constantly seeking and trying new things... constantly changing and evolving.

We are all in this together.

“Today is another day... There are some people who are alone. This is an opportunity to reach out to them and see how they’re doing... There’s hope at the end of the rainbow...”

- the words of several Vista students and members

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Laughter from page 21

social competence and is an important aspect of treatment for many people with ASD. Miller, Vernon, Wu and Russo (2014) conducted an extensive review of social skills group training and reported that research evidence for social skills development in youth with ASD has largely targeted social competence. Additional components such as social cognition, theory of mind skills, conversational skills, emotional expressiveness, social and emotional perspective taking, understanding non-verbal communication, self-determination, and symptoms of anxiety have also been included in social skills interventions (Miller et al., 2014). Further, they reported that the majority of social skills programs took place weekly for 10 - 16 weeks and were based upon group discussion and/or rehearsal opportunities and role-plays (Miller et al., 2014). Their research suggested that several months of weekly group intervention may be the minimum amount of time necessary to reliably improve participants’ social skills.

While facets of humor are reflected in these skill sets, humor is currently an un-

der-researched area in social skills development for people with ASD. Nonetheless, it is possible to incorporate explicit teaching of humor styles, social cognition, theory of mind, emotional expressiveness, and social and emotional perspective taking using a variety of comedic materials as the topic of group discussion and role play in social skills training.

Ideally, people may gain experience in social skills training in a group setting as part of their overall support program. While this is not always possible because of geographic isolation or funding complications, families, peers, teachers and other instructors in community settings may also use discussion and role-play to help develop an understanding of humor and the requisite social skills to use humor to promote social interactions, manage mood, and alleviate stress. As with many other types of social interaction, knowing when to end a humorous exchange is also an important skill. Teaching an individual with ASD to read their communicative partner’s queues that signal loss of interest in a conversational topic, or the absence of laughter when sharing humorous exchanges, can

provide the scaffolding necessary for people with ASD to successfully use humor in a positive and socially acceptable manner.

In summary, while there is certainly nothing funny about the COVID-19 pandemic, there are constructive uses of humor when navigating the associated challenges as the pandemic continues to unfold.

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Touchpoints from page 23

likely we will look back on our traditional, in-person visit methods and wonder what we could have applied with 2020 hindsight.

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bar. It's a major win for all involved. And if that doesn't appeal to you, how about the hidden benefits like lower overhead and less paid sick days. But again, I digress. That's a business discussion for another article.

So, what happens when this pandemic passes, and we attempt return to normal?" Here we are, having witnessed a global "festivus" miracle, and word on the street is that the very convenient remote work option is not going to stick around. According to the Society for Human Resource Management, "All but 5 percent [of businesses] said they expect their workforce to return to pre-crisis levels [brick-and-mortar] within six months" (Maurer, 2020). While we might not be returning to "pre-crisis levels" in as soon as six months, it lets you know that, despite remote work saving all of them from having to declare bankruptcy, and all of its now proven potential, the goal for most of American businesses is to head right back to how we

"have always done it." There are exceptions, however. Some, like Twitter (Twitter Announcement Heralds "New Normal" of Permanent Remote Work - Virtualization Review, 2020) and Square, (Square announces permanent work-from-home policy, 2020), have already announced that a remote work option is going to be a permanent policy.

Here we sit, a few months into the pandemic with no end in sight. Remote work has been implemented and none of the worries employers had about remote work happened. People didn't kick back, take their paycheck, and sit home unable to control their urge to watch tv on the clock. Productivity didn't drop, and it turns out that most of those in-person meetings really can be emails. Yet the discussion surrounding remote work continues. Will it be taken away when we attempt to return to "normal" or will this pandemic kickstart a new age in employment? I am certainly hoping for the latter. While it is too late, and too traumatic, for me to ever imagine working for anyone but myself, there are so many

that can benefit from a remote work option being a permanent facet of employment, and there are even more who could benefit from the business mindset shifting from the way we have "always done it." None of us knows how long the pandemic will affect our way of life, but we are all walking through it together. Let us take the time to pause and pay attention to what the pandemic is teaching us about how we have chosen to live and work as a society. We owe it to humanity to do better because we CAN do better.

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Schedules from page 26

Zoom background of a beach with waves crashing onto a beach. I was focused on the background, waiting for the waves to change or something to cross the sandy beach. In another meeting, an attendee's child started playing in the background; that was all I could focus on. Hence, attending to the discussion, rather than the extraneous stimuli, is mentally and physically exhausting! To help me concentrate, my strategies include positioning my laptop sideways or looking away from the computer screen and focusing on the voices, turning off the Gallery View to reduce the visual barrage of information, and using fidget toys (the most effective coping strategy I have found) since it allows me to engage in a repetitive behavior that calms my anxieties.

In addition to stimuli overload, interpreting non-verbal behaviors in video meetings requires more focus than face-to-face chat, since I am only seeing the top quarter, if that, of a person. I must make sense of non-verbal cues like facial expressions and tone and pitch of the voice, which are difficult to interpret over video. For example, most people have "upset" looking faces when they are at rest, or when connectivity issues occur the congruence between facial and verbal behaviors breaks down. Ways I cope include taking sensory-breaks mid-session for meetings longer than 50 minutes, switching my view so I just focus on the speaker, and limiting video meetings to those that are absolutely necessary.

A topic that involves both stimuli overload and non-verbal cues is not knowing

who is in the virtual meeting room until I enter the meeting, which causes me distress. This may not cause panic in others, but for me the uncertainty of who is in the virtual room causes anxiety. When walking into a traditional meeting room, I can peek in the room before entering. Whereas with video meetings, boom! I just appear and must quickly acquaint myself with who is in the room; and then if a person starts conversing with me right when I enter, I panic. To cope with this, I am one of the first attendees entering the meeting, then I mute my microphone followed by finding an activity to engage in (rather than looking at the computer screen) while waiting for the meeting to start.

Silence is something I usually relish, but with video meetings silence causes me to panic. Interesting, I wonder why? It took me a long time to figure out why; I assumed there was a technical connectivity issue. With in-person conversations, silence is a natural pause, but with video meetings silence means something is wrong, provoking panic. Wouldn't it be nice to have a silent video meeting?

No wonder when I finish a video meeting I am agitated and exhausted! I found engaging in low sensory, repetitive activities (running, walking, napping, yoga) rather than higher sensory activities (TV, watching a movie or playing a computer game) is more beneficial.

Face Masks

I did not know why I felt so fearful around certain people in the grocery store

until I realized they were wearing face masks. With face masks, I am not able to effectively "read" the person's facial expressions thereby limiting my ability to predict how I should act, which gives me pause when interacting. For example, I relax more in the presence of a person smiling and when a person frowns, I realize I said something wrong. With a face mask, I do not receive that feedback and it makes me anxious. At first, I thought it was the added stimuli of the face mask that made me nervous, not able to recognize the person. It was not until I conversed with a person wearing sunglasses that I learned a very interesting thing - I do not read faces, I read mouths! And I do not think I am the only one. Through repeated interactions with people wearing face masks, I learned I interpret social cues from mainly their mouth area. Did you know, when a person is upset, happy, or mad the eyes stay about the same? It is the eyebrows and mouth that change with their emotions. I had to learn to focus on a different part of the face when interpreting social cues - the eyebrows. A person's eyebrows provide me more information about a person's emotions than their eyes. For example, the inner part of the eyebrows dips down when a person is mad or frustrated, they lift slightly up for happy emotions, and eyebrows really lift up when the person is excited or surprised.

Another interesting conundrum with face masks, my ability to multi-task decreases. I believe it has to do with the fact my sensory processing is working overtime evaluating social cues in addition to the emotional toll of entering panic mode. I recently noticed

when out shopping alongside people wearing face masks I do not concentrate well and cannot fluidly carry on a conversation. I lose track of what I am saying, it is difficult for me to follow multi-step directions and I find it difficult to recall small things such as a short list of items to purchase at the grocery store. To cope, I write my entire shopping list down and take it with me to the store, I focus on 4-by-4 breathing techniques (inhale for four counts and exhale for four counts) to calm my amygdala, when conversing with a person wearing a mask I maintain short, polite conversations, and with those I know well I encourage them to be expressive with their eyebrows. What does this mean for families with autistic kids? Be gracious. Be patient and allow more time to complete directions, try not to place multiple demands when you are around those wearing face masks, make your shopping trips short, and understand anxiety levels may increase.

In conclusion, autism comes in many different forms, so my experience by no means applies to all individuals, but it may reveal insights that have broad applicability for those experiencing similar experiences. It is important for families to find coping mechanisms that work for them to help successfully transition and chart a new path during this pandemic. I remind myself, even though this unprecedented time brings about unpredictable environments, it also offers the opportunity for change and flexibility.

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Helping Parents from page 14

behavior, and only attend to appropriate, desired behaviors. For instance, if “whining and complaining about schoolwork” is an undesired behavior, when the child complains about schoolwork, the parent remains silent and does not change their facial expressions or demeanor. When the child engages in schoolwork without complaints, the parent positively reinforces by using labeled praise. Labeled praise is when the parent explicitly describes what they like about what the child is doing. A parent might say, “Awesome job moving on to the next row of math problems!” to use labeled praise as positive reinforcement during schoolwork.

When implementing a behavioral management plan, parents should expect extinction bursts. An extinction burst is when a behavior occurs more frequently and intensely because the reinforcers for that behavior are removed. It is essential that these behaviors are not inadvertently reinforced when a burst occurs. Parents may often think it means the behavior plan is not working when it means the opposite. If the behavior is not mistakenly reinforced, extinction bursts ultimately end with extinction of that behavior (Wong et al., 2015).

If using antecedent and consequence/reinforcement-based strategies do not help to improve your child’s behavior, then consider consulting a professional for additional intervention. More broadly, behavioral specialists can help in guiding parents to develop, monitor, and adjust an individualized plan based on the child’s response over time. A number of telehealth approaches have been developed for this purpose (The Council of Autism Service Providers, 2020) and are available in centers across the United States, including ours. Although implementing behavioral strategies can be effective in reducing challenging behaviors, in situations in which safety is at-risk, parents should always reach out for professional and/or emergency support. In these instances crisis lines (Text HOME to 741741), as well as autism specific, personalized information is available (Autism Response Team by Autism Speaks).

During this COVID-19 crisis, parents have reported that professional support related to their child’s special needs has been helpful (Toseeb et al., 2020). Autism treatment programs aimed at increasing social communication and daily living skills have been adapted into telehealth formats (Bearss et al., 2018; Ferguson et al., 2019;

Ingersoll et al., 2016; Sutherland et al., 2018). In response to COVID-19 broader implementations of telehealth interventions are increasingly more accessible (Autism Response Team or Child Mind Institute).

While effective strategies for supporting children are important, parents’ own management of stress and incorporation of self-care is essential. Especially in these difficult and unprecedented times, finding ways to help oneself so that one can help their child has never been more important. Social support, and engagement in solution-focused strategies, mindfulness-based programs, keeping healthy diet, sleep, and exercise routines (Cachia et al., 2015; Pottie et al., 2009; Saha & Agarwal, 2016; Zaidman-Zait et al., 2016; World Health Organization, 2020) are all evidenced-based ways to help parents cope with these inherent stressors. Other strategies for parents include maintaining frequent and regular contact with a child’s teachers, special educators, and treatment providers. Staying in touch with friends and family and asking for help when needed (e.g., having friends deliver groceries or other necessities) is also recommended.

Although the COVID-19 crisis has brought stress and challenges for all families, many also underscored that more family time is an incredibly rare and valued benefit of this unprecedented time. We hope the suggestions discussed above can help families to take advantage of this opportunity and improve the quality of their time together.

Bethany A. Vibert, PsyD, Cynthia Martin, PsyD, and Margaret Dyson, PhD, are Clinical Psychologists, and Adriana Di Martino, MD, is Research Director at the Autism Center at the Child Mind Institute.

To learn more about the Autism Center at the Child Mind Institute, visit www.child-mind.org/center/autism-clinical-center.

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validate their feelings. Children, like parents want to know they are being heard, listened to and understood. We all are experiencing different emotions, and sometimes these emotions are in forms of maladaptive behaviors such as verbal and physical aggression. According to the article, “Praise the appropriate behavior. Don’t just save the reinforcement for the end of the day; give it out in small increments throughout the day. Let your kids know that you are watching and noticing all the good things they are doing. Verbal praise is an excellent and quick way to let your children know you are proud of them and you appreciate their efforts. ‘Catch them being good!’”

Self-Care is the Best Care

Parents continue to wear multiple hats;

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Behaviors in the Mist of Coronavirus (Covid-19): Help for Parents written by Rory Panter, PsyD, and Rebecca Schulman, PsyD, BCBA-D, they state that “There are bound to be times when your children become upset and raise their voices at you. The key is how you respond to your child. If, in frustration, you raise your voice toward your child, you have taught them that yelling at each other is acceptable behavior. If you say to your child, in a raised voice, ‘Don’t yell at me!’ you are sending a mixed message. Modeling the appropriate behavior will help your child to learn the more appropriate behavior. So, instead, take a deep breath and say in a calm and even tone of voice, ‘We can talk when you are using a calm voice like mine.’” Also, be sure to

it is very easily to lose one’s self, especially in days and times such as this. Self-care is more important than ever. What that looks like varies, but it is important. Self-care can mean reaching out to friends and family. This can be a weekly call and or check-in via various meeting platforms. This can be an end of the day check in with self as well, identifying small wins and victories. Self-care can include taking baths, writing in a journal, doing yoga, being intentional about spiritual practice, mindful breathing exercises, and dancing to music. Self-care can also be asking for help from your support system. This may include family, friends and any mental health professionals. Self-care can be something as simple as lying in bed and taking deep breaths and being grateful you survived the day.

This pandemic has made people aware we are facing a “new normal.” It is uncertain when and if the world will go back to how it used to be. There is not a rule book on how to survive a pandemic. As families are staying home more, it is imperative that we stay strong. Staying at home is difficult for various reasons. Having families stay strong during this pandemic is crucial. Creating a routine for the family to follow, developing coping strategies such as giving children as well as parents more understanding during the unprecedented times is critical. Thinking outside of the box and maintaining self-care practices will help children and parents cope while staying at home.

Taveesha Guyton is a social worker who works with autistic children and adults. For more information, please visit Werfamilie.org.

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switched to 1.5-hour coaching sessions with well thought-out dyads based on trainee's skill level, interests and personality. Given the shorter but more intensive coaching sessions, the coaches needed to change the way information was chunked and adjust expectations about the pace of skill development and acquisition.

Our initial experience indicated that trainees' increased anxiety actually interfered with their ability to recall processes they had learned and mastered while on-site. Generalizing knowledge from the Yes She Can training setting at the store to their home setting was challenging for trainees, requiring re-teaching or prompting of skills. For those whose thinking patterns include negative self-talk, we saw an initial spike in statements like, "I can't do this," "what am I doing wrong," "am I the only one who can't get on-line?" Some of the business processes had to change which required trainees to be more flexible and willing to re-think how to complete particular tasks differently. Not surprisingly, it proved to be a very challenging time for both trainees and staff.

Shifting the training program on-line also required us to take into consideration the demands placed on Yes She Can coaches and staff. In addition to the gen-

eralized anxiety people experienced early in March, like many others, our staff have personal demands of caring for and now home-schooling young children, spouses and/or older family members. It was important to acknowledge the stressors staff were dealing with and to remain as flexible as possible to support their needs.

However, over the past 2 months, Yes She Can staff has observed trainees settling into a new norm, albeit not without ongoing challenges. The initial learning curve around technology has subsided and clearer instructional processes have emerged. Coaches encouraged trainees to use calendars to enhance their independent functioning, but for some it is not enough. Our weekly email outlining the weekly schedule of small and larger group meetings provide necessary reminders and help trainees to plan their week and maintain a routine. We are impressed to see that trainees have been able to transfer skills to a home-based work site and that trainees are learning and using new business processes with more ease. Their sense of mastery is returning, although an internet or zoom glitch can easily cause everyone's frustration levels to shoot up.

Despite these difficult times, there are nuggets of positive progress and unexpected gains. We have observed some advantages to video coaching, especially in

content delivery. Over the past 9 weeks, we have made revisions to the program and have taken opportunities to add curriculum content including teaching marketing strategies and tactics, career exploration and job search skills.

Our trainees are understanding the rational behind needing to shift our retail store to a positive on-line shopping experience and are learning new skills to support making that happen. They are thinking through their own recommendations, synthesizing their research and past experience. As the trainees are now more able to focus on the business needs, their group discussions have turned to generating creative marketing ideas rather than perseverating on the health crisis. Trainees challenged by interpersonal connections and communication are finding the experience of learning from home, less stressful and in fact are thriving using other written communication tools. Some trainees are developing stronger bonds with each other and are learning new ways to support each other. Other trainees are showing signs of improved self-advocacy.

While we recognize the priority of health and safety and the significant challenges other service providers have faced in this current pandemic, we are pleased to be able to provide continuity and meaningful learning opportunities in a virtual setting

for the autism community. Yes She Can!

Lesli Cattan, LCSW, is Director of Training Programs at Yes She Can Inc., based in White Plains, NY. For further information about the Yes She Can training program, contact Lesli at lesli@yesshecaninc.org or visit www.yesshecaninc.org.

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Silver Linings from page 18

their workforce and appeal to consumers. Disability inclusion is an innovative solution to post-COVID-19 business growth.

The saying "don't let this crisis go to waste" has been a commonly used phrase recently. For individuals with autism, the silver lining to this crisis may be greater understanding and accommodation of their needs, which have become universal needs

for all of us. If this shared experience has taught us anything, it is that when backed into a corner and united, humanity will innovate and create radical new ways - or expand existing paths - of living to survive and thrive. Rather than going back to normal, let's strive for a new and better normal.

Contact John Bryson by e-mail at jbryson@nextforautism.org or by phone at 212.759.3775. NEXT for AUTISM can be

found on the web at www.nextforautism.org.

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Our mission is to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives.

**For more information, visit the website www.aane.org or contact the facilitators:
Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com**

Socialization and Life Skills Group for Adults with an Asperger/Autism Spectrum Profile

This support group, Opening Doors, is now in partnership with the Asperger/Autism Network (AANE). This group is for adults who have an Asperger or similar autism spectrum profile. Learn, socialize and receive support from others who share common experiences. Focused on: Socialization, Mindfulness, Creativity, Self-Advocacy, Health and Well Being, Career Counseling, Relationships and Fun!

For more information, contact the facilitators:

Anna L. Nasci, OTR/L, MS, NCC, LMHC | Masako Hashimoto, MS, NCC, LMHC - OpeningDoorsWestchester@gmail.com

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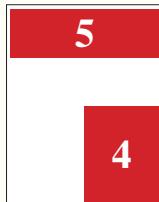
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