# SOCIAL AND AFFECTIVE NEUROSCIENCE OF AUTISM LAB



Official Laboratory Newsletter



## **Supporting Families In Times Of Need**

The outbreak of COVID-19 has stopped the world in its tracks. It has been approximately nine weeks since we began sheltering in place here in CT. Schools closed, businesses shut down, and many of us began working from home. The reality of everyday life swiftly changed, and it continues to change as the days go by. For many people, these changes compiled a multitude of already existing stressors, and for others, it created brand new ones. We are all doing our best to get through this, supporting one another virtually, sharing resources, working hard to stay connected, and taking it one step at a time.

During these last nine weeks, many of our team discussions have been focused on the specific challenges that are present for the families we serve – those who have children with Autism Spectrum Disorder and/or other types of developmental disabilities and special needs. We are sensitive to and concerned about what our families are experiencing right now, and we are devoting time, energy, and expertise to understanding what we can do to help support you. During this difficult time, we want you to know how much we value and care about our families' well-being. In the spirit of putting on your own oxygen mask first, in order to better care for those around you, we are featuring self-care strategies in this particular newsletter. We hope that you find it helpful.



Dr. Katarzyna Chawarska is the Director of the Social and Affective Neuroscience of Autism Program and Yale Toddler Developmental Disabilities Clinic at the Child Study Center, as well as the Emily Fraser Beede Professor of Child Psychiatry at Yale School of Medicine. She is a leading expert in research on identifying early diagnostic markers and novel treatment targets in autism spectrum disorders.



Amy Giguere Carney is a social worker in the Yale Child Study Center. She specializes in clinical work with children and families. Amy provides clinical supports to our families during and after their visits with us. She also acts as a liason between families and the community.

### From Our Team

Dr. Katarzyna Chawarska, PhD & Amy Giguere Carney, LCSW

Dear Families, Colleagues, and Friends,

It is our pleasure to present you with the first issue of our SANA Newsletter. In these difficult times of the COVID-19 pandemic, staying in touch is more essential than ever.

We closed our doors and moved to work-from-home mode on March 13th 2020. Within days, our team shifted from providing direct patient care and conducting in-person research protocols to supporting families via tele-health, collecting data via surveys and interviews, and writing manuscripts and grants. We communicate with each other more than ever, albeit virtually, and work to advance our mission, despite challenges of isolation, time divided between work and family commitments, and the sometimes overwhelming uncertainty of what lies ahead. We are pleased to announce two new manuscripts by our scientists, one focused on attentional markers of autism at 6 months (link to JCAAP) and another paper on the role of the value-based learning in atypical attention in ASD (link to JAMA).

Our research fellows Chaela Nutor, Kohrissa Joseph, Nicole Powell, Carolyn Gershman, and Eukyung Yhang will be transitioning to their graduate programs shortly. New young investigators-in-training, Rachel Foster, Emily Diamond, Chitra Banarjee, and Alexandra Boxberger, will be joining us in July and we are looking forward to welcoming them to our lab. We are fortunate to have Hannah Feiner, Diogo Miguel Goncalves Fortes, and Maureen Butler transition into their second year of the research fellowship.

Most importantly, however, we appreciate that these are difficult times for families raising children with developmental disorders. Our clinical social worker, Amy Carney, has composed a guide, titled "Filling Your Own Cup First" reminding us of the importance of taking care of our own needs while caring for others. We present the guide below.

Please stay safe and all the best wishes from our lab to all of you.



#### SELF-CARE STRATEGIES AND PRACTICES

Parenting can be a rich, joyful, fulfilling experience, and it can also be incredibly stressful and exhausting. For families that have children with special needs, parental stress is often increased as time and attention must be divided differently, and tasks are often multiplied. Parents also tend to expend a great deal of energy trying to regulate their own moods and emotions in order to be present for their children. As such, having a bank of strategies and practices to employ can be invaluable. This is especially relevant now, during this time of social and physical distancing due to the COVID-19 outbreak, as families are homebound together and the usual stressors are magnified, while new ones continue to develop.

#### Strategy #1: Mindfulness and Breathing

Bringing oxygen into your body during times of stress will interrupt your natural physiological stress response and inhibit your stress releasing hormones. So, when you notice yourself in a moment of overwhelm, stress, resentment, etc., press pause and mindfully take 3 - 5 deep breaths. Check in with your body and mind and ask yourself what you need in that moment. If you aren't able to meet that need right then, make a commitment to yourself that you will address it later. Here are a couple of links to help you learn and practice deep breathing techniques:

<u>WEBMD</u> NEW YORK TIMES

#### Strategy #2: Plan Ahead for High-Stress Times of Day

Think about what makes certain times of day difficult (when you are not in the midst of these times), and put buffers in place to help make them easier. During this time when families are homebound, it might be beneficial to create a flexible schedule so that expectations are clear and time is set aside for work, school, play, outdoors, screens, etc. If mornings are chaotic, try having everyone pick out their outfits and/or decide what they will want for breakfast before going to sleep the night before. If kids get particularly restless in the afternoons, perhaps that's the time to plan to be outdoors or to allow for physical activity indoors if the weather isn't cooperating. Even simple games like Simon Says or a home-made obstacle course in a hallway using items you have around the house can help kids get the wiggles out. If the time around dinner prep tends to be stressful, maybe playing calming music, or fun and upbeat music, in the background will help. Or perhaps using that as the time of the day you allow the kids to have screen time so you are uninterrupted would be useful. Maybe chopping veggies or prepping something the night before would ease the burden.

#### Strategy #3: Make a DONE List

As parents, our "to-do" lists are endless. It often feels like there are not enough hours in the day and even when we've done enough to be thoroughly exhausted, we feel discouraged because it didn't all get done. Even when we've planned ahead and implemented organizational strategies, life has a way of throwing a wrench in our plans... maybe a meeting ran late, someone needed extra help with her school work, someone needed more attention than usual because the meltdowns were back to back while you were trying to cook dinner, or maybe you had a splitting headache all day.... The list of ways that life just happens could fill this page. This means that at the end of every day, it's inevitable that there will be things left on our "to-do" lists. This is absolutely 100% ok. At the end of the day, wouldn't it be wonderful to feel empowered by what we've accomplished? Wouldn't it be fantastic to feel like we've been productive, and to remember that every small accomplishment is valid? Rather than focusing on what is left to do on your "to-do list," try drafting a "done" list at the end of the day. There is no doubt you did some important things today, and that is worth celebrating! Give it a go - grab a piece of paper and list 3 things you accomplished today. If you want a challenge, go ahead and write down as many things as you can. Here are some examples to help get you started: breathing through a difficult moment, getting a lunch made (bonus points if it's a lunch for yourself!), calling a loved one, taking a shower, finding that overdue library book, going for a jog, finding someone's shoes, meditating, getting to that work meeting on time, playing catch with the family dog, reading a book to your child... it can be anything at all!

#### Strategy #4: Seek Support

Feelings of isolation can exacerbate grief and stress. Seeking emotional and physical support can help to lessen the burden and keep us feeling more connected.

- Time with friends or extended family (while face-to-face isn't possible during this time, many people find that phone dates or video calls are a solid alternative)
- Individual psychotherapy (many insurance companies are covering telehealth sessions during this period)
- Online support
- Psychoeducation in the form of media, workshops, trainings, and conferences
- Support groups via tele-communication
- Educational advocates and/or parent advocates to help navigate the intervention system
- Note: many families find it helpful to seek child-care or respite care as a way to
  free up time for themselves, time to spend with their partners, time to get together
  with friends or loved ones, or even time to get things completed. While this is not
  possible during this time of social distancing, we have included them in case you
  wish to explore them when restrictions are lifted.
  - College students in the fields of special education, psychology, social work, etc. can be great for this purpose.
  - Young teens and adolescents acting as an extra set of hands while you're also at home can serve as an inexpensive way to get these needs met.
  - o DCF voluntary services has a respite care program

#### Strategy #5: Prioritize and Outsource

We tend to get bogged down with tasks because, as we've already discussed, they are endless! It helps to prioritize and to let things go that aren't absolutely essential. Perhaps the kitchen floor is dirtier than we'd like this week, perhaps the laundry is washed but not folded and put away, perhaps we relax standards or expectations for meals a few times a week... Technology is giving us a lot more options as well – some grocery stores now have an online shopping option with delivery or curbside pickup, which can save families the time and stress of taking children grocery shopping.

#### Strategy #6: Exercise

The Anxiety and Depression Association of America (ADAA) states that "Exercise and other physical activity produces endorphins - chemicals in the brain that act as natural painkillers - and also improve sleep, which in turn reduces stress. Scientists have found that regular participation in aerobic exercise has been shown to decrease overall levels of tension, elevate and stabilize mood, improve sleep, and improve self-esteem. Even five minutes of aerobic exercise can stimulate anti-anxiety effects." It can be hard to find or make the time for this one but science backs it up! Be creative about how to work it in. A walk during lunch break? Running around in the yard with the kids or the dog? Waking up 30 minutes early to squeeze in a workout a couple of times a week? Here are a couple of links to quick workouts you might want to try:

## NEW YORK TIMES SELF

Especially when you've had to push yourself to exercise, take a few minutes afterwards to note how you feel and give yourself credit for taking care of you.

#### Strategy # 7: Meditation

Meditation and deep breathing can also cause your body to produce endorphins. In addition, meditation allows us time to slow down and practice mindfulness, and to have a better sense for our bodies in space.

Over the years, I have worked with people who say they aren't good at meditation because they can't clear their minds of thoughts or they can't stay still long enough. I encourage them to give it a try and to let go of the idea that one can be good or bad at meditation. It takes practice to settle your body and mind, and to practice observing our thoughts rather than judging them. It can help to start small. Here is a link that provides free guided meditations for beginners, from 1 to 20 minutes in length:

#### **INSANITY-MIND**

There are several apps available to help learn techniques and offer guidance as well - Headspace, Calm, and Breathe are a few of them.

#### Strategy #8: Journal

Journaling can be a great way to process your emotions and to get your thoughts out of your mind. It can act as a release, it can be a source of digging deeper, or it can be a way to vent the things you don't feel comfortable saying out loud to anyone so that you don't have to hold it in. And when we read these entries back down the road, it can be a powerful way to see growth and change. I sometimes hear from clients that they are afraid that writing something down will make it more "real" and we process that together. Sometimes the act of holding onto something gives it more power than it deserves. It's important to remember that thoughts are not facts, and feelings are not facts. Sometimes writing things down is a wonderful way to gain perspective on it. It can be a way to challenge the thought, to reframe it into a more positive thought, to better understand it, or to let it go.

#### Strategy #9: Look for the good and practice GRATITUDE

The field of positive psychology has provided us with lots of empirical evidence that practicing gratitude decreases negative affect and helps us cope with difficult situations. This can be done in whatever way works best for you:

- Keeping a gratitude journal is a wonderful way to see many positive aspects of your life in one place. Try jotting down 3 things you are grateful for each night or each morning (or whatever time of day works best for you!) or keep a small notebook with you and jot them down as you go about your day. Many people find that they are pleasantly surprised at how their lens changes throughout the day. When you are on the lookout for positive things, you tend to see more of them.
- This is about mindfulness as well rather than postponing joy, it helps us to be present in the moment as we seek out things for which to be grateful. Try using your senses throughout the day and see what's out there waiting to be appreciated. Be specific.
- A few examples: Sitting at a stoplight, you might notice an older couple walking hand in hand and take in the sweetness of that; you might witness someone doing something kind for a stranger; your child might say a new word and you might joyfully cheer; your coffee or tea might smell and taste particularly wonderful one morning; you might unexpectedly hear a song you love... these moments are everywhere. The more you look for them, the more you'll see them.

#### Strategy #10: Be gentle with yourself

Practice self-acceptance and self-forgiveness. Talk to yourself the way you'd talk to your best friend. Remind yourself that you are doing the best you can.



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#### **Featured Resarch**

Yale Autism Center of Excellence

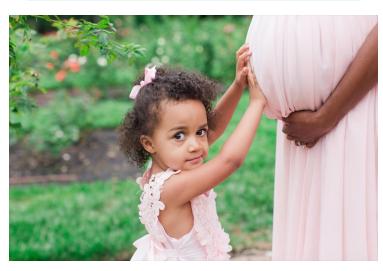
Prenatal and Neonatal Studies

This Autism Center of Excellence (ACE) study will help our understanding of the fundamental changes that occur in the brains of fetuses and newborns with high and low familial likelihood for ASD.

We are recruiting mothers (24 weeks pregnant or fewer) with older children who have and do not have ASD. Participation includes two MRI scans during pregnancy, one MRI of your infant at 4 weeks of age, and follow-ups through 24 months that assess social, adaptive, cognitive, language, and attentional development in your child. If you are over 24 weeks pregnant or have just had your baby, you can still participate in the neonatal portion of the study!



We are currently accepting new referrals to any of our studies. However, given prevailing guidance and in the interest of participant safety, our on-site visits are on hold for now.



#### What is an MRI and is it safe for my baby?

An MRI is a safe imaging technique that uses a magnet --no radiation or contrast dyes. MRIs have no known side affects for mom or baby.

#### What is the MRI like for my baby?

Before the MRI, you will feed, swaddle, and rock your baby. This way, during the scan, your baby will simply sleep!

## Other Studies Currently Recruiting

In addition to our ACE prenatal and neonatal research, we are recruiting for several other studies. If you have a child in these age ranges, you may be eligible to participate!

- 14-30 month-olds with ASD, or who are typically developing
- 4-5 year-olds with ASD, with or without symptoms of anxiety, with developmental concerns, or who are typically developing
- 7-17 year-olds with ASD, who have an older sibling with ASD, or who are typically developing children

## **INTERESTED IN PARTICIPATING?**



## For the Little Ones:

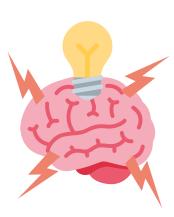
## Find the Words

E	R	S	D	N	Ι	Н	W	S	V	K	В	G	Ι	Е
Q	E	Z	Y	Н	F	D	С	V	N	L	P	В	W	S
U	K	P	R	S	D	I	D	Z	M	L	0	Х	D	Z
E	V	R	Т	N	E	М	Р	0	L	E	V	E	D	N
L	С	Z	A	N	N	G	С	L	R	X	U	J	M	V
В	U	A	Т	Т	I	E	Н	A	В	N	R	W	U	P
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R	Q	A	U	S	R	Z	N	I	M	W	Т	W	M	С
Р	В	M	Y	L	K	В	V	I	W	R	С	I	Н	L
Y	U	L	I	В	Z	0	N	0	E	L	A	Y	0	F
X	K	P	Z	F	М	W	В	K	Χ	J	Y	U	М	N

We do a lot of things in our lab! On the right there are 11 words about what we study. Can you find them all? (Hint: some of them may be backwards)

BABY
BRAIN
CHILDREN
DEVELOPMENT
EMOTION
FACE
LAB
MOVIES
PUPPET
SCIENTIST
YALE

## Did You Know...



... that your brain actually produces enough electricity to power a light bulb?

Ever see a picture of a person with a light bulb over their heads? Well, this fact sheds a whole **new light** on those pictures!

## It's Coloring Time!





"It takes away my worries and my anxiety and my wondering because I don't have to wonder. I'll know just as any signs (of ASD) are evident."

Melissa Patao, Autism Center of Excelence Parent

## **Resources for Parents**

Here are some resources which families and caregivers might find helpful during social distancing:

Should you like to learn more about the <u>COVID-19</u> <u>virus</u> and ways of <u>protecting yourself and others</u> <u>from its effects</u>, please take a look at two ingenious guides to COVID-19 created by a first year graduate student at the Yale School of Medicine.

The <u>Yale Child Study Center</u> has compiled ASD-specific resources for COVID-19.

Help is in your Hands is a free website for families of very young children with social communication challenges. It includes narrated video lessons with suggestions for activities parents can try. Strategies are based on the Early Start Denver Model. More information can be found here.

## **Family Corner**

#### **Parent Support Group**

Dr. Kelly Powell's monthly support group has gone virtual! The meeting takes place the **4th Tuesday of every month at 6pm**, with additional meetings scheduled depending on need and interest. Please email Kelly directly, at kelly.powell@yale.edu, if you are interested in participating!

#### We Want to Hear From You!

Let us know how your family is doing! You can send us updates, pictures, and cards to:

Yale Child Study Center
Developmental Disabilities Program
Social Neuroscience Laboratory
300 George St. Suite 900
New Haven, CT 06511

New contact info? Let us know with an email to sanalab@yale.edu

"It has been a pleasure being a part of the ACE prenatal and newborn studies. The staff and clinicians are extremely knowledgeable, kind, and helpful. The visits get more and more fun for my son as he gets older, and I find it interesting to learn about his development at each visit."

Deanna Macris, Autism Center of Excelence
Parent

## **Connect with Us**







## **INTERESTED IN PARTICIPATING?**

