Autism, Parenting, and Self-Care

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Agenda

- Background: ASD and Caregiver Stress
- Parenting During a Pandemic
- Why Self-Care? How?
- Questions
ASD Diagnosis on the Rise

- In 2012, it was estimated that approximately 1.47% (or one in 68) of children under the age of eight have ASD (Christensen, Baio et al. 2016).

- In 2014, the rate was approximately one in 59 in eight-year-old children (Baio, Wiggins et al. 2018). In comparison, a recent study in Shanghai found that roughly 1 in 1200 children between the age of 3 and 12 met the criteria for ASD (Jin, Yang et al. 2018).
Parents of Kids with Autism: A Growing Need

- More familiarity and awareness of Autism in post-industrial countries, and more services available to families with a child with ASD (Maguire 2013)

- As we create these additional supports for children and teens, it is essential that we keep parents in mind as both caregivers and individuals with their own sets of needs
Stress of Diagnostic Process

- Parents deal with lengthy waitlists, travel, and often a significant financial burden while going through the evaluation process.
- A recent survey in the UK found that 61% of families were dissatisfied with the information provided to them following the ASD diagnosis. They also found that the average length of time from first contacting a health professional to diagnosis was over 3.5 years (Crane et al., 2016).
Diagnosis & the Added Stress of Racism

- Mandell, Listerud, Levy, and Pinto-Martin (2002) found that Black children were diagnosed a year and a half later than Caucasian children; they also required triple the number of visits over a length of time three times longer than that of Caucasian children.

- Mandell, Ittenbach, Levy, and Pinto-Martin (2007) also found that African-American children were 2.6 times less likely to receive an Autism diagnosis than Caucasian children on their first specialty visit, and if they were not given an Autism diagnosis, the diagnosis they were most likely to receive was ADHD.
When Hispanic and Asian children present with cognitive impairments, clinicians are less likely to continue assessing for other developmental delays such as Autism (Mandell et al., 2009). These differences may be explained by healthcare disparities for children with ASD.

Bishop-Fitzpatrick and Kind (2017) examined nine studies related to healthcare disparities and ASD. Seven of those studies examined healthcare disparities and race, and six of those studies found evidence of racial disparities in quality and access to healthcare for Latino and African American children with ASD (Bishop-Fitzpatrick & Kind, 2017).
Finnegan (2014) interviewed seven parents of a child with ASD and found that receiving a diagnosis was often a relief, as it gave answers and helped to alleviate feelings of guilt and confusion. The same study also found that the most difficult years were reportedly often the years following the diagnosis due to difficulty obtaining services.
Post-Diagnosis

- Setting up services
- More waitlists
- Educational advocacy
- Legal advocacy
- Childcare
- Coping with own feelings about the diagnosis
- Deciding whether/ how to disclose to child/teen
Parental Experience of Internalized Guilt/ Shame

- “Is this my fault?”
- “Did I pass this to him/her?”
- “I’ve failed him/her.”
- “I should be doing more.”
Case Example
All of this was difficult before 2020...
And now parents are also coping with Covid-19.
A study early in the Covid-19 outbreak in China found that the psychological impact had been moderate to severe for 53.8% of respondents; 16.5% reported moderate to severe depression symptoms; and 28.8% reported moderate to severe anxiety symptoms (Wang, 2020).
Parenting During Covid-19

- Home schooling
- Advocating
- Setting up and help facilitate remote occupational therapy, physical therapy, Zoom psychotherapy, ABA therapy, potentially others
- Explaining a pandemic
- Creating a routine
- Working, caring for other children, caring for parents
- The list goes on!
With all these things to worry about, why add “self-care” to the list?
Why Self-Care
Self-Care: Feeling Like Yourself

- Physical
- Emotional
- Spiritual

- Practical/
  "Taking Care of Business"
- Mental
- Social
Many of my clients find that it’s helpful to have self-care ideas for different amounts of free time. As we begin planning, you may want to think about activities that fall into these categories:

- 60 seconds (activities that can easily, frequently be completed with minimal planning)
- 5 minutes
- 10 minutes
- 30 minutes
- 60 min
- Several hours (less frequent, higher value activities that can be completed less frequently with more planning)
# Planning Self-Care

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<th>Day</th>
<th>Morning</th>
<th>Afternoon</th>
<th>Evening</th>
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<tr>
<td>Monday</td>
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<td>Parent group @ 8:30. Planning required: start Sam’s bedtime at 7:30 pm.</td>
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<td>Tuesday</td>
<td>Go for a walk (30 minutes, no planning needed)</td>
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<td>Favorite salad for lunch. 15 min. Planning required: add ingredients to grocery list, prep night before.</td>
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<td>Saturday</td>
<td>Hectic day. Remember to practice deep breathing (60 seconds)</td>
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Physical Self-Care

- Exercise
- Food
- Water
- Deep breathing
Senses

5 things you see
4 things you hear
3 things you feel
2 things you touch
1 thing you taste
Deep Breathing

In a 12 week study, participants who participated in slow breathing exercise training experienced decreases in heart rate, blood pressure, and perceived stress (Naik, Gaur, & Pal, 2018)
Learning to Breathe Deeply
6 Minute Guided Relaxation
Emotional Self-Care

- Therapy
- Writing/ Journaling
- Creative outlets

❖ You can create these habits with family members as well!
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[www.child-behavior-guide.com](http://www.child-behavior-guide.com)
Feelings Wheel: Adult Version
Spiritual Self-Care

- Church
- For some, yoga and art might fall under this category
- Time for reflection
Spiritual Self-Care, Book Recommendation

Happier Now: How to Stop Chasing Perfection and Embrace Everyday Moments (Even the Difficult Ones)
Nataly Kogan, Author of “Happier Now”
“Taking Care of Business” Self-Care

- Organizing
- Finishing a project
- Running an errand
- Completing something that has taken up “mental real estate.”
Right now, can you think of one thing you haven’t had time to do, something that would take less than 10 minutes to complete?

Jot it down!
Mental Self-Care

- Reading a book for fun
- Crossword puzzle
- Researching something interesting
- Learn a new hobby
- Practice reframing unhelpful thoughts
Reframing Unhelpful Thoughts

- Thought: “I’m always behind on things, and there’s never enough time.”
- Feeling: Inadequate, defeated
- Action: Shut down

- More Accurate Thought: “Sometimes I’m behind, and I have a lot on my plate, but I’m creating a plan. Many people are struggling right now.”
- New Feeling: Motivated, less alone, less stigmatized
- Action: Try to implement new plan
Social Self-Care

- Phone call with friend or loved one
- Socially distanced get together with a friend
- Support group or peer support group
Telehealth

- A recent study examined the impact of a parent skills training for veterans via telehealth, finding that this modality had potential for reducing depression and parenting stress, and improving family functioning (James Riegler, Raj et al. 2020)
- Parent support groups can be an amazing way to connect with others
Troubleshooting

- Who can cover for me?
- Can I ask for help?
- Where in my calendar can I choose ONE THING for myself?
- Others?
- Try to keep one promise to yourself each day.
What’s in your control today?
RESOURCES: Parent Groups

- **Social City:**
  [https://www.socialcitynyc.com/about](https://www.socialcitynyc.com/about) - parent workshop on August 19th on school year uncertainty

- **Cope with Schools NYC**
  Virtual parenting group starting this fall - [https://www.copewithschoolnyc.com/parent-counseling/](https://www.copewithschoolnyc.com/parent-counseling/)

- **Child and Family Institute**
  Virtual parent support and behavior support group - [www.childfamilyinstitute.com](http://www.childfamilyinstitute.com)

- **New Frontiers in Learning**
  [www.nfil.net](http://www.nfil.net)
  Parent Forum on Thursdays: [https://attendee.gotowebinar.com/rt/2517071693600938254](https://attendee.gotowebinar.com/rt/2517071693600938254)

- **Tech Kids Unlimited**
  [www.techkindsunlimited.org](http://www.techkindsunlimited.org) parent workshops. I run a free virtual “parent share” one Thursday/month.
RESOURCES: Videos

- Breathing Exercise:
  https://www.youtube.com/watch?v=0Ua9bOsZTYg (laying down)
  https://www.youtube.com/watch?v=52qgs9MhGbQ (sitting/ standing)
- Progressive Muscle Relaxation
  https://www.youtube.com/watch?v=1nZEdqcGVzo (6 minute guided relaxation)
  https://www.youtube.com/watch?v=PYsvvRNZfxE (10 minute guided relaxation)
- Ted Talk on Yoga:: https://www.ted.com/talks/krishna_sudhir_what_yoga_does_to_your_body_and_brain
- Ted Talk on Drawing: https://www.ted.com/talks/shantell_martin_how_drawing_can_set_you_free
- Ted Talk on Perfection:
  https://www.ted.com/talks/thomas_curran_our_dangerous_obsession_with_perfectionism_is_getting_worse
- Ted Talk on Connections During Quarantine:
  https://www.ted.com/talks/priya_parker_how_to_create_meaningful_connections_while_apart
Resources: Client-Approved Books

- Nataly Kogan, *Happier Now*
- Rick Hanson, *Hardwiring Happiness: The New Brain Science of Contentment, Calm, and Confidence*
- Lori Gottlieb, *Maybe You Should Talk to Someone: A Therapist, HER Therapist, and Our Lives Revealed*
- Jen Sincero, *You Are a Badass: How to Stop Doubting Your Greatness and Start Living an Awesome Life*
References


References

