

Autism Moving Forward: Unexpected Lessons From a WEIRD Year

Ruth Prystash
René DeLoss
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It has been a weird few years for everyone



The pandemic changed life as we knew it.

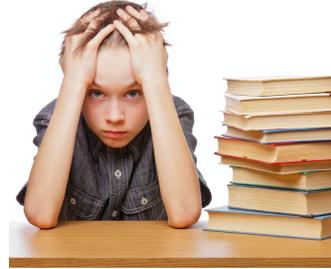
- Changed routines of school, work, and community
- Increased time at home, which was stressful for some
- Financial impact on households
- Stress about a life-threatening disease and the unknown

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Impact on children—what we suspected would happen and what did happen

We suspected:

- Learning would be impacted; children would regress
- Social skills might suffer
- Mental health issues might occur



And we were right. These did occur.

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But what about autism?



We suspected:

- Learning would be impacted and children would regress.
- Social skills would suffer.
- Communication skills would suffer.
- Mental health issues would occur.
- Severe stress would result from the disruption of familiar routines.

And we were right...but not exactly.

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Let's talk about school....



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Schools: What were the negative outcomes?

For students with all levels of need:

- Upsetting changes in routine
- Absence of regular supports and accommodations
- Undifferentiated instruction
- Less explicit instruction
- Parents who were untrained and unprepared for instruction
- More behavior outbursts and meltdowns
- Virtual learning less effective for hands-on learners
- Boredom due to lack of leisure skills
- Regression

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Schools: What were the positive outcomes?

- Better family relationships and quality time with siblings and parents
- Increased flexibility and ability to learn at own pace
- Able to focus on own interests for learning
- Fewer transitions in a day
- Fewer sensory demands and distractions
- Able to learn in a predictable and familiar environment
- ★ **The unexpected: Some autistic individuals and families liked the lockdown.**



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Schools: The upside

"COVID wasn't what I wanted or what I expected. There was stress and anxiety for our family, as there was for others. But for us, there was a rainbow. The new relationship between our children has helped us realize the importance of time at home."



—Bea Moise

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Schools: Making foundational changes

○ Be more flexible

- Give students choices for their schedules
- Focus on social-emotional growth and mental health vs. academics

○ Make the classroom more predictable

- Use schedules and structure

○ Build a relationship and become someone to trust

- Include your students' interests in themes, instruction, and assignments
- Accept them. Accept the messages they convey to you by whatever means possible.



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Schools: Make Emotional Regulation a Priority

○ Move from compliance-driven to regulation-driven

- NO MORE: Look at me! Stop flapping!
- NO MORE NEGATIVE LABELS: attention-seeking, non-compliant

○ Move from deficit-focused to strength-based

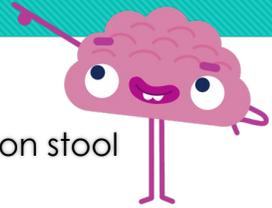
- Focus on what they CAN do
- Interpret behaviors in a positive light

○ CHANGE YOUR PERSPECTIVE!!!



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Schools: Build a sense of sensory safety



Some examples:

- Offer different seating options—stand up, ball chair, stand on stool
- Students may need to move around or stand up to learn
- Provide calming area
- Turn down the lights
- Keep classroom quiet. Offer headphones.
- Provide non-contingent access to sensory activities. Students should never have to “earn” the right to regulate.
- **INDIVIDUALIZE!**

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School: Parents as partners



- Build more opportunities for collaboration with parents and caregivers.
- Provide ongoing parent trainings on practical topics.
- Make IEPs more parent-friendly (NO MORE JARGON!)
- Treat parents as partners.
- Include ALL students in the IEP process. They are IEP team members, too!

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Think outside the box!



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Let's talk about community life....



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Community: What were the negative outcomes?

For adults with all levels of support:

- It became harder (or impossible) to access services—those with severe needs were impacted the most
- Everyday errands, appointments, social events, and work were disrupted
- Difficulty structuring the day
- Social isolation had a negative impact on mental health
- Loss of employment
- Less virtual opportunities for those with more severe needs



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Community: Surviving



“[My son] is a...27-year-old adult male with autism. His most typical demeanor is fun and outgoing....But during this pandemic, we were just trying to survive....

The nights were rough....My husband and I would take shifts, trying to ensure he didn't hurt himself or others, or destroy the house....”

–Lillian Vasquez

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Community: What were the positive outcomes?

- Everyday errands
 - Less anxiety and sensory overload
- Socializing
 - Relief from social pressures (masking)
 - A preference for online socializing
- Work
 - Remote working resulted in fewer sensory demands, more flexibility in hours/schedule, fewer communication issues, less distraction, more focus



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Community: The upside

"I harbored a deep, shameful secret. I loved the lockdown. Never had I felt so certain of my environment or so safe in it."



—Wilma Wake

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Community: Changes we can make now



- **Alternative ways to access** community services need to be offered
- **Virtual alternatives to social events** and gatherings should continue to be offered



- **Improve services** overall for all ages, including adults

- **Provide trainings** for parents, employers, and caregivers



- **Working remotely** should be offered, when possible

- Alternatives include: Sensory-friendly workspace (dimmer lighting, soundproofing or noise-canceling headphones), flexible hours, different communication options (utilizing chat vs. talking in person)

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Now what?



- We don't need to fix them; **we need to fix us.**
- We can't continue to expect them to adapt to neurotypical social norms. **We need to adapt to neurodivergent norms.**
- **We need to provide alternatives** to traditional ways of schooling, employment, and community services.
- If we cannot provide those alternatives, **we need to alter school, work, social, and community environments** to support neurodivergent learners.
- **We need to stop looking at autism as a set of deficits.**

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Conclusion

"Respect is hard to incorporate into a system, but if it happens, it will take each one of us. Person by person, we must build respect into everything we do. Every decision we make, every choice we offer must be guided by respect, by the belief that every person deserves to live a meaningful life and to find their own unique path in the world."

–From *Life After Lockdown: Resetting Perceptions of Autism*