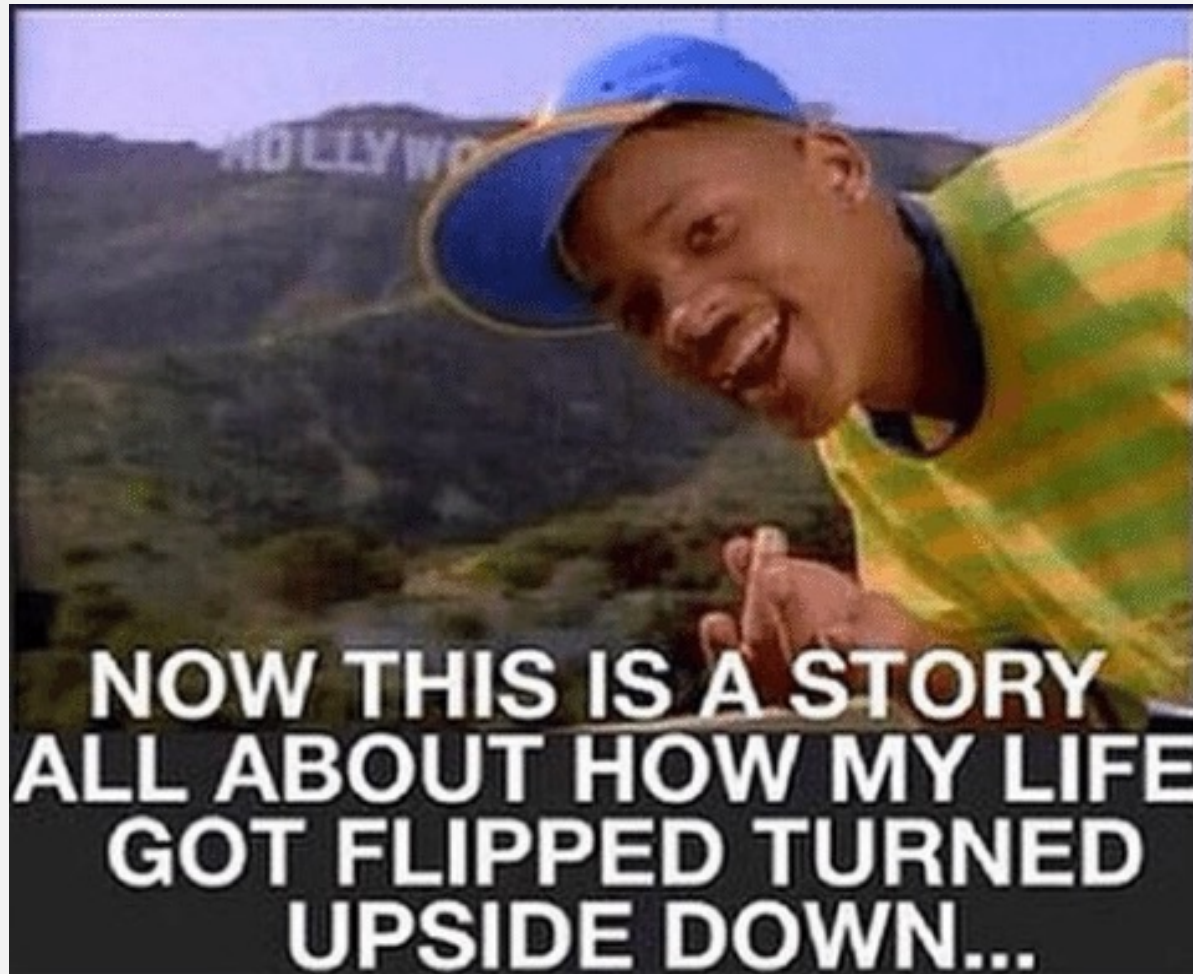


PANDEMIC LOCKDOWN AND DISABILITIES: LESSONS LEARNED WHEN THE WORLD SHUT DOWN

A discussion about what happened, and what to do, when schools, programs and service providers close.



Holly Bortfeld, NAA Conference 2022

**(DON'T) TAKE
NOTE!**

My slides are very heavy in details, but they will be available for download from the NAA website after the conference, so you don't need worry about writing down all this material.

WHAT WE'LL DISCUSS TODAY

- Schools
- Inflation and staffing shortages
- Housing and HCBS
- Work and day programs
- Building a home program
- Behavior at home
- Health services
- Basic necessities
- Prepping for special needs
- Resources and links

LOCKDOWNS

- In March 2020, the whole world changed drastically. What was introduced as a short-term shutdown, has languished into years. However, no other community felt the lockdown quite like the disability community.
- All the years spent fighting for funding, services, IEPs, ISPs, etc. all came to a screeching halt, overnight.
- While lockdown was absolutely an inconvenience for everyone, explaining – and enforcing - lockdown to our kids, who thrive on rigidity of schedule, was almost impossible.

WHAT THE FUTURE BRINGS – OUR NEW NORMAL

Along with the dearth of services over the last 2 years, you survived mandates, masks, gloves and social distancing. And So. Much. Hand sanitizer!

Unfortunately, there have been several formal warnings from government that this won't be the last pandemic in our lifetime.

This will also be applicable for you if you've been shut out of society for exercising choice. Or maybe you are just tired of how the world is acting and want to live quietly and ignore the nonsense of society.

Since there will be more, how can we, as families and friends, support our kids and our community now and in the future?

By being as prepared as we can.

This won't be a like-for-like presentation because life just isn't that easy, but this is a "Lessons Learned and How to Adapt as best you can" sort of presentation.



Holly Bortfeld, NAA Conference 2022

SCHOOLS

Schools closing (pre-k through college) had an immediate effect on most families and left a huge hole in the lives of our kids. Losing almost 2 years of education is bad enough, but some of the ancillary school services lost were:

- Meals for low-income children
- Socialization
- Childcare – before and after school, as well as the coverage for parents to work during the day
- Therapies
- ESY (Extended School Year, aka Summer School)
- Exercise, sports, music, art
- Transition services
- Graduation
- A safe place to go

ALTERNATIVES FOR SCHOOL

For the education side of school, some of the options used during the shutdowns:

- Homeschooling (parent, family member or hired person, online)
- Co-ops (joining one or forming your own with other local parents)
- Cyber schooling
- Online-only colleges
- Websites like KhanAcademy, MasterClass, SkillShare, Youtube and many others have online classes that may help you in your current or future job, life skills such as personal finance and college prep, hobbies, etc.
- Later, the DOE allowed for one extra year to the age-out plan so if a student wished, or didn't pass, they could stay in school until 23, instead of finishing by their 22nd birthday. PA Bill 664

ANCILLARY SCHOOL SERVICE ALTERNATIVES

- In most states, meals for low-income children were still provided by schools through a drive-through program and food banks increased the food in family packs to make up for the change.
- Socialization was replaced by zoom meetings and online gaming.
- Childcare had no replacement, someone had to stay home with the kids. Many kids were sent to live with relatives if the parents were “essential workers” until restrictions were lifted.
- Therapies – some therapists offered telehealth sessions, some sent exercises/homework for the families to do at home to limit regression. Families also bought apps and programs to use at home.
- Exercise, sports, music and art classes were done online or just in the home.
- Graduation was done online, drive through or the students were brought in one at a time.



INFLATION AND IT'S EFFECT ON WAGES

- Before covid, finding and retaining staff was tough but not impossible. Then the push for \$15/hour came, and now with rising inflation in 2022, even unskilled labor jobs are starting at \$24/hour, which no state can match for basic support staff.
- Schools are using parents and substitutes (subs are in critical shortage too) as teachers and sharing 1:1 aides across multiple students and classrooms. Individual therapies have been stopped or moved to group sessions.
- Programs are having to hire untrained staff that have run out their unemployment but maybe aren't suited for this work.
- Many group homes have been closed due to lack of staff.

STAFFING IN THE “NEW NORMAL”

- If we can't find staff willing to work for the low wages the state pays, what are our options? Well, as usual, the answer is 'families'. The states have been dumping the responsibility and costs onto families for decades and it's only getting worse.
- Some parents are offering a room in their house along with free rent/utilities to get staff since housing is also in short supply.
- Life Sharing programs are being touted by states but it's basically adult foster care, where the individual gives up self-direction, LRE, ISP goals, may have to move away from friends/family/job and can be forced out at any time.
- PA has started allowing one parent to be paid to stay home to care for their child through some of the waivers. (My other talk today is on Waivers). It's still low pay, and likely lower than the parent would make in another job, but the states are not keeping up with inflation or the market, so it's become a common option. Unfortunately, waiver slots having a LONG waiting list.

HCBS HOMES

In the past 10 years, there has been a massive shift in service models from institutions to community-based living in the USA.

Pandemic shutdowns have shown how fragile HCBS disability services are: how underfunded, understaffed and unprepared the states are to have the most vulnerable citizens living in the community when supports drop off.

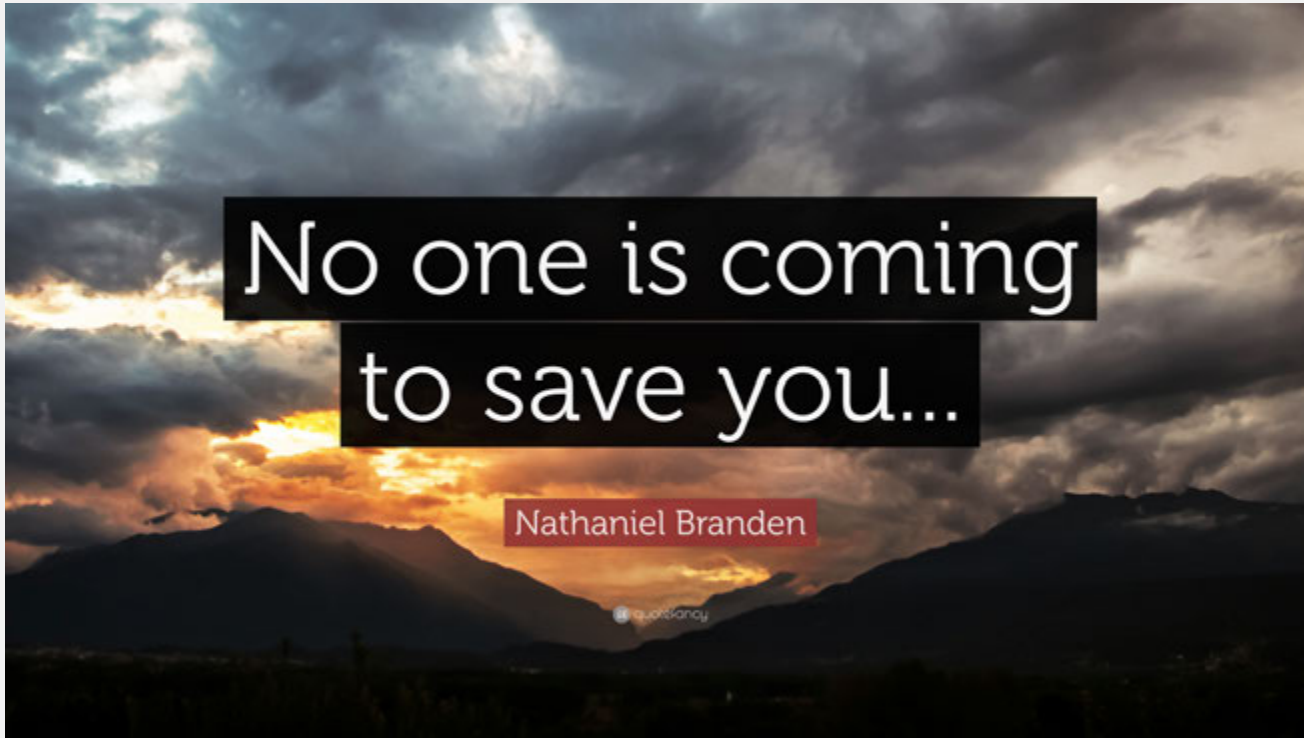
Continual reports of community home staff quitting, leaving the residents unattended to fend for themselves. We also saw many group home companies close the houses, telling families to take their kids and the rest were dumped at the ER.

Restrictions for visitors meant parents didn't get to see their children for weeks or months.

HCBS ALTERNATIVES

How some of the issues can be lessened:

- Teach Zoom/Facetime skills and how to use an iPad/phone. Keep the skills generalized.
- If the residents can't go into the community, the home staff should teach them leisure skills and keep them generalized.
- Make sure the group home has or creates a backup emergency plan that includes enforceable, agreed upon failure sanctions and contingency options. Use a lawyer.
- Get a few parents together to buy and own your group home (with succession backups) so you aren't reliant on a company who may abandon their responsibility.



WORK AND DAY PROGRAMS

- As most businesses closed or reduced their hours, many lost their jobs either temporarily or permanently.
- OVR and other job coaching services shut down so those who used these services couldn't report to work, even if their job was open.
- Day programs, where the person spends the day but doesn't live, also closed down.
- Because of the uncertainty of the "end" of restrictions, most people just waited and didn't start trying to replace programs, but as time went on, it became clear that something had to be done rather than let our kids sit and rot, endangering everyone's mental health further. But how do you replace programs when you can't go anywhere or bring anyone in? You get creative.

WORK AND DAY PROGRAM ALTERNATIVES

- If you believe your child will go back to the same or a similar job when restrictions are lifted, run practice drills daily to keep the skills alive and generalized. Work on any weak spots they may have or add new skills for a future promotion.
- Work on life skills such as cooking, painting, laundry, ADLs, cleaning, any projects around the house/yard that need to be done.
- New hobbies like drawing, investing, birdwatching, collecting, puzzles, animal fostering, yoga, tai chi, coding/programming, chess, etc.
- One good thing about covid was that countless thousands of online classes, virtual tours, webinars and programs, most of which were free. (See the resource slides at the end)
- Volunteering is always a great option. Whether it's going to a place, helping an elderly neighbor, cleaning up your neighborhood, making care packages for charities, coloring and sending cards to retirement homes, or whatever your child can do, there are always something useful to do.

HOME PROGRAMS

If you have never had a home program or haven't had one in a very long time, don't fret. Just start and keep going.

- You are probably asking, "Where do I start?!" **Start with a schedule.** Visually lay out what you want to work on each day and remember the acronym "**KISS**" (Keep it simple!). The schedule does not have to be pretty, or even laminated. A handwritten schedule will do just fine.
- Build in **choice** into the schedule. For any hope of compliance, your child should dictate order completion. **End with a positive**—What is your child most interested in? Example: fun app, tv show, Youtube as a reward.

*Copied from and continued at
<https://howtoaba.com/resources-for-children-with-autism-during-covid-19>*

HOME PROGRAMS (CONT.)

- Keep things simple and attainable – especially in the beginning. Only put a few activities on the schedule to make it doable. Goal is to have both you and your child feel successful. If it's too daunting, it won't get done.
- To set yourself up for success, ask yourself the following questions and be truly honest with yourself:
 - What are the most doable items?
 - How much time do you have to interact with your child?
 - Are you working from home and actually have to get your own work done, or can you dedicate some time to your child/children?
 - Do you have other children that require lots of your attention?
 - Can you do some group learning with some/all of your children at once?

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<https://howtoaba.com/resources-for-children-with-autism-during-covid-19>*

LIVING WITH AUTISM

Holly Bortfeld, NAA Conference 2022

When you find out your normal
daily lifestyle is called “quarantine”



BEHAVIOR AND SAFETY

- During lockdown, most emergency behavior (aka “Crisis”) programs closed, and are still closed 2 years later, leaving just the ER for emergencies. Unfortunately, the ER was mostly inaccessible due to covid patients and reduced staffing, so they would sedate and send the child home without treatment.
- Simultaneously losing their rigid schedule, staff, programs and everything that keeps them centered, caused many kids/adults to take out their frustrations on the only people they had to vent on – their family.
- Discuss emergency medications with your child’s doctors and keep a script on hand.
- In preparation for future needs, parents should work with BSC/therapists or school staff to learn how to implement a behavioral intervention plan at home.
- Families and staff/supports should build and generalize leisure skills like board games, especially things that don’t require internet. Boredom for our kids can be dangerous. Keep them engaged to keep everyone safe.

ACCESS TO MEDICAL CARE

- In the early days of covid, hospitals denied parents or support people for patients with disabilities, even if they were nonverbal. After much outcry and a few lawsuits and AMA removals, one parent was allowed in with a person who have a disability.
 - NOTE: If you don't have guardianship (and provide proof) of your adult, you may be barred temporarily or longer and have no input on care or even to help keep your child calm.
- Stay in good standing with your doctors (you must go in person 1x year for a doctor to be able to legally prescribe for you).
- Books and a **good** first aid kit.
- Make sure the police and fire departments where you live know you and have your contact information. Use Smart911 or other similar programs.
- Refills of all meds (write meds and dosages on paper to hand to police or ambulance) and a PRN med.
- Good stock of basics like vitamins, water, pain reliever, anti-inflammatories, sleep aids, blood pressure/pulse-ox, nebulizer, humidifier, electrolytes, etc.

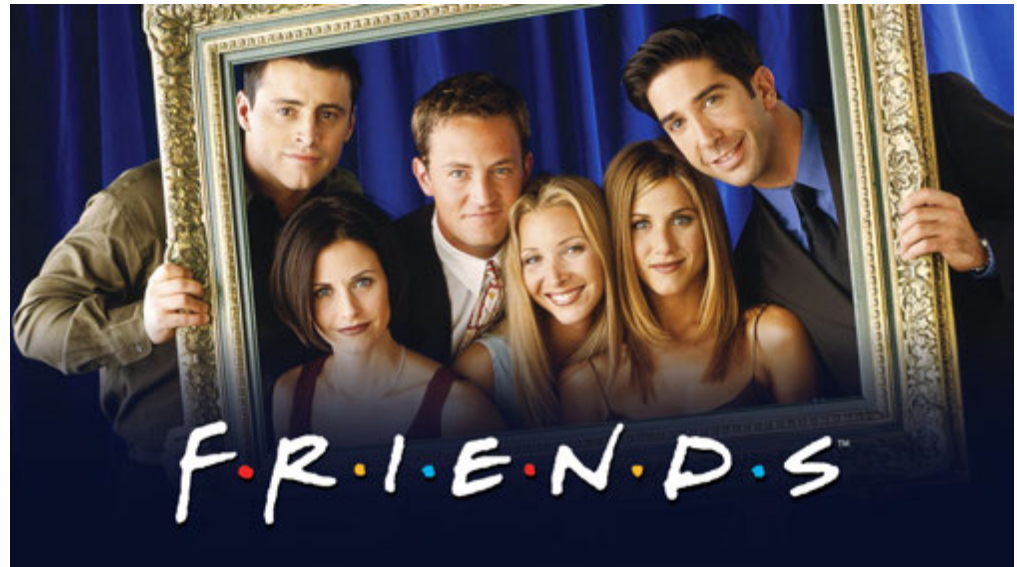
DEPRESSION AND ISOLATION

- What happened – 2021 saw a 51% increase in suicides in teen girls as well as 28% of anxiety and depression in children under 17 (that's 8 MILLION American children).
- **Importantly, there was also a 28% reduction in physical exercise, which is one of the top treatments for depression.**
- As reported in a September 2020 review article published in *Cell*, loneliness “may be the most potent threat to survival and longevity.” The article explains how social isolation lowers cognitive development, weakens the immune system, and puts people at risk of substance use disorders. the UK saw a 77% increase in pediatric referrals for such issues as self-harm and suicidal thoughts during a 6-month period in 2021.
- While Telehealth has its problems, including the inability to be exhaustive when intensive interventions are needed, it can bridge the gap until restrictions are lifted.

DEPRESSION AND ISOLATION (CONT)

- Staying busy is a key to mental health stability. Find a new hobby: read all the Classics, learn a new language, declutter your house, finally put all those pictures into photo albums, cook your way through the Julia Child cookbooks, start a garden.
- Plan a trip. Experts say that people with depression benefit from having something to look forward to.
- Adapt your exercise and activities to lockdown as best you can.
- Online social groups are hit and miss. Find groups that you have things in common with – other than location – and you'll generally find a better fit.
- Almost 20% of Americans adopted or acquired a new pet during lockdown.

**DON'T
FORGET
YOUR
FRIENDS!**



LET'S GET PHYSICAL

- While we don't know what the next pandemic may be, we know that 95% of people who died or suffered severe reactions to covid had multiple comorbidities, namely hypertension, Type 2 diabetes, and respiratory diseases, such as COPD. All of which are preventable, caused by lifestyle choices.
- Dietary, exercise and lifestyle changes can help you safeguard your family against many diseases.
- Companies like Peloton, Mirror and Tonal sprung up as they offer both in-home equipment with online social opportunities.
- The YMCA created YMCA-360 and many other local orgs also offered their own version of online fitness classes. Most still offer them.
- Start with a functional medicine eval, make needed adjustments and MOVE!
- I know I'm old, but Wii Fit still rocks.

BASIC NECESSITIES

- According to the US Dept. of Labor, 41 million Americans received unemployment since the lockdown began. The US also implemented many other plans such as stimulus checks, Medicaid and SNAP (food stamps) for the unemployed, PPL funding for businesses and eviction moratoriums. These programs were enough for some people, but not all and may not exist in future emergencies. Let's talk about some programs you may not know about:
- Program for renters or homeowners with disabilities. It sets aside 50% of the renter's SSI/SSDI income, and rebates are \$500-650 per month.
<https://mypath.pa.gov/> / <https://www.revenue.pa.gov/>
- Food banks have initiated new programs in PA to encourage farmers to sell wholesale to them directly. PA is also one of the top gleaning states.
- If you/your child has Medicaid, you can qualify for lower rates for Amazon Prime, Cell Phone and internet, utilities, tax prep and more (links in resource section).

LIHEAP

- The Low-Income Home Energy Assistance Program (LIHEAP) is a state benefit program that assists eligible low-income households with their heating and cooling energy costs, bill payment assistance, energy crisis assistance, weatherization and energy-related home repairs.
- To find out whether you are eligible to receive LIHEAP benefits, contact your state or tribal LIHEAP office.
 - <https://www.acf.hhs.gov/ocs/map/liheap-map-state-and-territory-contact-listing>
- For help applying for LIHEAP benefits, you may also call this toll-free number: 1-866-674-6327.

LIHWAP

- The Low-Income Household Water Assistance Program (LIHWAP) helps PA families pay overdue water bills. LIHWAP is a temporary emergency program to help low-income families pay overdue water bills. LIHWAP is a grant. You do not have to repay it.
- LIHWAP crisis grants may be available if you have an emergency situation and are in jeopardy of losing your water service. You can receive one crisis grant for your drinking water service and one crisis grant for your wastewater service, up to \$2,500 each.
- **Crisis situations include:**
 - Past-due water bills.
 - Termination of utility service.
 - Danger of having utility service terminated (received a notice that service will be shut off within the next 60 days).
- To find out whether you are eligible to receive LIHEAP benefits, go to <https://www.dhs.pa.gov/Services/Assistance/Pages/LIHWAP.aspx>
 - For help applying for LIHWAP benefits, you may also call this toll-free number: 877-395-8930

HOME INTERNET

- If a member of your household had their work or schooling moved to an online format but cannot afford home internet access, the following providers offer affordable options:
- [Emergency Broadband Benefit](#) is an [FCC program](#) that will provide a discount of up to \$50 per month towards broadband service for eligible households and up to \$75 per month for households on qualifying Tribal lands.
- Affordable Connectivity Program <https://www.fcc.gov/acp>
- [Access from AT&T](#) is a low-cost home internet package for qualifying individuals and households.
- [Comcast Internet Essentials](#) is a similarly priced package for qualifying individuals and households. Due to COVID-19, it is currently available for free for the first two months.
- [Mediacom Connect 2 Compete](#) offers internet access to students at a reduced rate.
- [Verizon Lifeline](#) provides reduced-fee internet services at a 3-tier level for low-income customers.
- [EveryoneOn](#), through partnerships with local internet service providers, is able to offer free or reduced home internet service in 48 states and the District of Columbia.
- If you have an existing provider, they may be making special accommodations in response to the pandemic. Visit their website or contact them via phone for more information.

PHONE SERVICE

- **Lifeline** is a Federal Communications Commission (FCC) program. It helps low-income individuals and families get discounted landline or cell phone service. Some people also qualify for a free phone.
 - <https://www.fcc.gov/general/lifeline-program-low-income-consumers>
- Lifeline can also provide internet service discounts for low-income households. Individuals can apply for either a phone or internet discount, but not both.
 - <https://www.fcc.gov/lifeline-consumers>

ARE YOU READY TO BECOME A SURVIVALIST?

No, you don't need to become a survivalist like Richard Proenneke, who got fed up with women and went to Alaska and lived there alone for 30 years. (PS he was amazing!)

But we can certainly get some basics covered.



PREPPING FOR EMERGENCIES: DISABILITY EDITION

- **Supplies**
 - Stock up during sales. Get items in packaging that will last the longest. Shelf stable items will generally last years longer than their “best by” dates.
- Build, and keep up to date, a basket/box of toys, games, books, cards, snacks, whatever keeps your kid busy.
 - My son is 26 and his basket contains protein-laden shelf stable GFCFSF snacks, water, a solar charger and cable for his ipad and phone, 2 star wars books, 5 travel-sized games, batteries and LED flashlight, socks and his fav fidget toys.
- Have a copy of your child’s care plan/letter of intent and medication list in each car, bug out bag, and emergency kit.

**PREPPING FOR
EMERGENCIES:
DISABILITY EDITION
(CONT)**

- Emergency Plan – can your child cope in a LOUD emergency shelter?
<https://www.ready.pa.gov/BePrepared/PlanSpecialNeeds/Pages/Pennsylvanians-With-Disabilites.aspx>
- When you arrive at a Red Cross shelter, just tell them you have a SN child and they will do what they can to accommodate.
- Not every family can afford a certified service animal but emergency shelters don't accept others.
- <https://www.ready.pa.gov/BePrepared/PlanSpecialNeeds/Pages/Pets-and-Livestock.aspx>
- <https://lowincomerelief.com/looking-for-free-or-low-cost-veterinary-care/>

WHEN ITS
OVER

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**BEFORE THE
LOCKDOWN**



**AFTER THE
LOCKDOWN**



RESOURCES

- Home Program Resources for autism
 - <https://howtoaba.com/resources-for-children-with-autism-during-covid-19/>
- 211.org or dial 211.
 - Referrals for food, housing, medical and mental health, disasters, utilities and more.
- Free printable guide on food prepping
 - <https://extension.usu.edu/preserve-the-harvest/food-storage>
- Special Olympics
 - <https://www.specialolympics.org/>
- Volunteering
 - <https://tacanow.org/family-resources/volunteering-opportunities-for-people-with-asd/>

MORE RESOURCES

- The National School Lunch Program
 - <https://www.fns.usda.gov/nslp>
- The School Breakfast Program
 - <https://www.fns.usda.gov/sbp/school-breakfast-program>
- Find your local food bank
 - <https://www.feedingpa.org/>
- Social story for covid
 - <https://theautismeducator.ie/2020/03/11/corona-virus-social-story/>
- In Home Therapy
 - <https://tacanow.org/family-resources/in-home-therapy-programs/>
- Homeschooling
 - <https://tacanow.org/family-resources/homeschooling-your-child-with-autism-spectrum-disorder-the-basics/>
- TACA Webinars
 - <https://tacanow.org/events/>

READINESS RESOURCES

- Smart 911
 - <https://smart911.com/>
- PA Premise Alert
 - <https://papremisealert.com/us/>
- PA Yellow Dot Program
 - <https://www.penndot.pa.gov/TravelInPA/Pages/Yellow-Dot.aspx>
- SHTF group
 - <https://www.facebook.com/groups/commonsensesurvival>
- Readiness in PA
 - <https://www.ready.pa.gov/>

MORE RESOURCES

- Many gyms have low-cost or free memberships
 - Start with your local YMCA.org and ask for a referral if they don't offer it. <https://ymca360.org>
- Leisure Skills
 - <https://www.autismsociety-nc.org/leisure-skills/>
- US national parks are free to those with disabilities
 - <https://www.nps.gov/subjects/accessibility/access-pass.htm>
- Many museums, zoos, theaters, theme parks, or other activity centers offer reduced rates for Medicaid card holders and free admission for their aide.
 - <https://www.art-reach.org/>
 - <https://museums4all.org/>
- Organizations That Help People With Disabilities Get Discounts
 - <https://capitaloneshopping.com/blog/free-stuff-for-people-with-disabilities-bc5e48cf50c4>
 - <https://dealhack.com/blog/disability-discount-guide>
 - <https://lowincomerelief.com/pa-food-stamps/>

HOMESCHOOL CO-OPS

- <https://howtostarthomeschooling.net/how-to-start-a-homeschool-co-op/>
- <https://raisingarrows.net/homeschool-co-op-covid/>
- <https://learning-center.homesciencetools.com/article/how-to-start-a-homeschool-co-op/>
- <https://hslida.org/post/tutors-co-ops-private-schools-better-check-your-state-laws>
- <https://www.caller.com/story/news/education/2020/08/04/families-turn-home-school-pods-covid-19-risk-continues/5559490002/>
- <https://hslida.org/community/grants-for-homeschooling>

FREE ONLINE RESOURCES

Free online/virtual tours, activities, plays, live music and more

- <https://mommypoppins.com/virtual-and-online-guide-for-family-fun>
- <https://freedomhomeschooling.com/virtual-field-trips/>
- https://docs.google.com/document/d/1SvldgTx9djKO6SjyvPDsoG1kgE3iExmi3qh2KRRku_w/preview
- <https://artsandculture.google.com/partner?hl=en>
- <https://www.playbill.com/article/15-broadway-plays-and-musicals-you-can-watch-on-stage-from-home>
- <https://storylineonline.net/>
- <https://www.amazingeducationalresources.com/>

