

Horizons Newsletter

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Aging Out: When Kids With Autism Grow Up

Families struggle to find, or invent, good supported living options

Beth Arky

When Susan Senator's son Max was racing toward the high school finish line, he joined the rest of his classmates for the usual rites of passage. He took the ACT and applied to good schools, landing at New York University's prestigious Tisch School of the Arts.

But things couldn't have been more different for Max's brother, Nat. [Senator, a blogger, memoir writer and novelist](#), had to take into account the fact that her profoundly autistic older son, while very competent when it comes to self-help skills like showering and dressing, is also limited verbally, cannot handle money and still doesn't look both ways when crossing the street.

In other words, she knew he needed a 24-hour caregiver to be safe. But because the infrastructure and services aren't in place to create the type of living arrangement she wanted for Nat after he came of age, she joined the growing ranks of parents who are struggling to make short- and long-term provisions, often taking matters into their own hands.

Parents whose children were among the first wave diagnosed with [autism](#)—as well as those with younger children who see the future fast approaching—are confronting new challenges for their kids' adulthood. They're facing the harsh reality that when these children—200,000 of them over the next five years, [according to one estimate](#)—reach 21 or 22, depending on the state, all the educational supports and services they have been receiving under the federal Individuals With Disabilities Education Act (IDEA) will vanish.

Aging out of services

This forced transition, called "aging out," pushes them into the woefully lacking system for disabled adults. And it's not just those with more severely disabled children who are worried. Parents whose children are termed "high-functioning," including

those with an [Asperger's](#) diagnosis, have reason to be concerned that their kids—who may be dealing with things like [ADHD](#), [anxiety](#) and [sensory issues](#) in addition to their [social and communication delays](#)—are not going to magically stop needing support after they reach a certain chronological age.

Liane Kupferberg Carter's autistic son Mickey turns 20 in July and, Carter, who [has written much](#) about the challenges of raising a child on the spectrum, admits to floundering." I don't know how to do this," she says. "When our son Jonathan was preparing to leave home for college, we had a whole shelf of books to guide our family." But there's no such book guiding Carter as she faces the next step with her verbal but cognitively challenged son, diagnosed with [PDD-NOS](#). "We're making it up as we go," she says. Carter is certain of only one thing for Mickey, who likes to camp it up in a pair of Groucho Marx glasses: Due to his cognitive challenges and autism-related epilepsy, which is only partially controlled by medication, he will always need a supervised living situation.

Kristina Chew, whose 14-year-old son, Charlie, is on the more severe end of the spectrum, [proposes that school should continue](#) for the developmentally disabled until they are 25, which would take into account their delays and help families "staring at an abyss" when a child turns 21. "We have learned so much more about autism and the different developments, abilities and needs of autistic individuals in this past decade," she writes. "Let us try to use this knowledge to provide the best outcomes and the best lives for individuals with developmental disabilities at every age."

Planning starts at 14

Senator says parents often begin panicking when their kids hit 14 and [transition planning](#) starts coming up. IDEA requires every state to begin this process for all students with an Individualized Education Program (IEP) by age 16, and some states require that school districts start the process as early as 14. During the annual IEP meeting, the focus shifts to more specific planning and goal-setting for the transition into young adulthood. Goals might include things like post-secondary education, vocational training, and independent living. Autism Speaks also provides a [Transition Tool Kit](#), which offers guidance on everything from housing to Internet safety.

When it came to Nat, Senator created a shared living arrangement. It's like a group home, except that there's a live-in caregiver, which Nat qualifies for due to his level of disability, as opposed to rotating staff. "The idea is that it's just like home," Senator says. "He's got to do the groceries, clean and do the laundry," assisted by another part-time caregiver. Nat shares a house not far from his family with another young man with similar issues; that man's family owns the house and Nat rents from them.

The families secured donated furniture; the rest was paid for out of the two young men's budgets. Friends have been able to watch Nat's story unfold—complete with pictures—on Senator's Facebook page, including their shopping trip to Pier 1 for a pillow, a lamp and a rug. "Nat chose aquas, very wild stuff!" Senator says. "I had no idea!" Other parents have followed the project closely, seeing it as a possible template.

Working with a job coach

Nat works three days a week, sharing a job coach with two other young men. This coach, paid for by a state allocation, looks out for Nat at his job at CVS stocking coolers, making sure he understands what he is expected to do and stays on task. He's also about to start a trial run at a second job retrieving shopping carts at a grocery store. Currently Nat spends the other two days in DayHab, short for Day Habilitation Services, meant to help people with developmental disabilities improve or maintain their independent living skills.

"DayHab is often babysitting," Senator says, "table top activities, coloring, television or sheltered workshops, with very little out in the community, and there's a mixture of disabilities." This isn't true of Nat's program, she says; all of his "colleagues," as Senator terms them are developmentally or intellectually delayed, possibly due to autism or Down syndrome.

Half of Nat's funding comes from the state, half from Medicaid. After he's given a budget for rent, living expenses, transportation and his job coach, the family works with Nat's service provider to "come up with ways to stretch the money," Senator says. The family pays for extras like a recent three-day outing with a social group to New Hampshire.

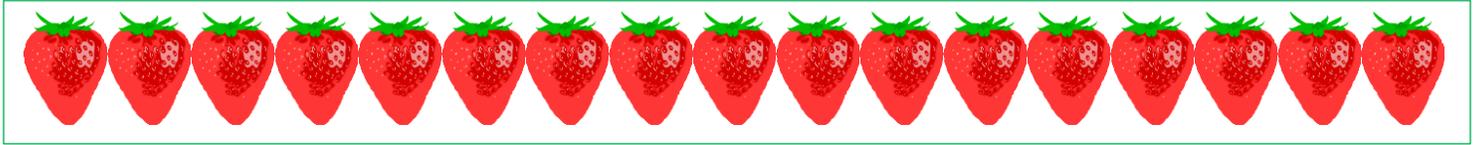
Group homes create families

Barbara Fischkin also helped create a home for her son Dan. She first shared the story of his ["miracle" group home](#)—funded by the U.S. Department of Housing and Urban Development and run by the Nassau County Chapter of AHRC, a nonprofit group—two years ago. Then, she described it as a "newly renovated house on Long Island—a place I call the frat house. Actually, it is a beautiful and smartly designed home that could be a model for such endeavors nationwide. And the guys, who

are in their 20s and 30s, are all at the age when leaving home and family and striking out on your own—even if you need lots of staff to help—is something one yearns to do.”

Two years later, she reports that Dan, now 24, and his three housemates “become more like a family all the time. The guys look out for one another.” Dan is still not verbal and has an aide most of the time “but is making great progress with independent typing.”

Reprint from Child’s Mind Institute



Strawberry Dole Whip

If you have ever been to a Disney theme park, it is likely that you are well acquainted with a Pineapple Dole Whip! Recently added to the menu was a strawberry version, which is just as delicious! Now you can make a clean eating version of these frozen treats at home in minutes, with just a few simple and healthy ingredients!

Ingredients:

- 4 cup frozen strawberries
- 1/2 cup almond milk
- 2 tbsp. Sweetener of choice
- 1 tbsp. lemon juice
- Pinch salt

Combine all of the ingredients in a blender and blend until smooth. Scoop into a plastic bag and freeze for about 10 minutes. Cut a hole in the corner of the bag and squeeze while swirling dole whip into a small bowl or cup.



WEBSITE REVIEW:
Geek Club Books (<http://www.geekclubbooks.com>)
By: Anne Carpenter

Because there are so many websites promoting autism awareness and acceptance these days, it's harder to find one that really stands out from the rest of the crowd. Geek Club Books is one such website that I stumbled upon and it is a treasure trove.

On the Home page, there is a series of interviews with adults with autism who have stood out including Lamar Hardwick, a pastor on the autism spectrum living in Georgia, Haley Moss, an attorney and artist who wrote a book on being a middle school student on the spectrum, and Christa Holmans, a "Neuro divergent Rebel" who lives and travels in her own RV-now, how cool is that?

In addition, there is a section featuring blogs by various individuals with ASD and the site even has its own magazine-ZOOM! Each issue of Zoom is focused on a single topic such as Health in the current issue, family, inclusion, travel, powerful women and trailblazers. This really adds something to this site as the mission is storytelling. One truly unique element that stands out is the set of Bluetooth-enabled puppets called Bluebee Pals that are part of an ingenious TV series called Bluebee TV. It is produced by James Sullivan and Jonathan Murphy, two young men on the autism spectrum who produce clever short videos featuring the puppets on such topics as what autism is, being accepted and the art of friendship. This really plays into the highly visual nature of autism learning and I can't think of a better way to teach autism acceptance to children than this! I loved everything about this website and it should be on the top of everyone's list!

COPING WITH COVID-19
PART II

By: Anne Carpenter

In an earlier article, I wrote about how I felt about living in a pandemic and how I was coping. There have been other strategies I have used to make life more bearable in addition to the wonderful Zoom chats with my sisters every week and the weekly Zoom trivia nights with the Ann Arbor Singles meetup. I have been taking a nap in the afternoon and then taking walks to a lovely local park. Walkers and bicyclists are everywhere and not a mask to be seen. I did wear one, though. I tried a social distancing app called Rex distance that uses the phone's camera to judge distance between people, but one walker was annoyed that I was using it. The fresh air and exercise help me feel less anxious and more restored.

While I haven't been making as many impulse purchases as I used to, I have bought some things from Wish, a popular shopping site that sells items from China so they take a long time to be delivered. I have bought several kinds of humidifiers that use essential oils including tiny USB stick ones in different colors that can be used in a small, enclosed space such as a bathroom. As I write this, I am using a green one with a green light and I put in a few drops of lavender oil so I now have a soothing and fragrant workspace. In addition, I bought a fancy scale that measures BMI, body fat, muscle and water in addition to weight, sets of LED candles, a clock radio with colored LED lights, Bluetooth headphones with LED lights that look more comfortable than the ones I have, shimmery holographic bags, light up USB cables that respond to sound and more items, too! Many of them haven't come yet so I have something to look forward to!

I also ordered from Amazon, but primarily essential items such as kleenex, two packages of masks, one of which I plan to donate to the VA Telehealth office in my apartment building lobby, toothpaste and other necessities. I have been avoiding the grocery store and ordering groceries from Whole Foods. Trying to make the best of a bad situation, I will buy some fun and enjoyable things once in a while, but will hold the line for now and enjoy the neat things coming my way!

Autism:

Safety Skills & Community Skills to Help Promote Independence

Safety Skills:

- Understanding what an emergency is and how and when to call 911
- Memorize their home address, how to verbalize it and how to write/type it out
- Memorize their phone number
- Internet safety rules to help keep them safe on social media
- How to be safe crossing the street and in parking lots
- Kitchen Safety with knives
- Kitchen Safety with fires
- Kitchen Safety with the stove and microwave
- How to navigate their local community (how to read road signs, how they could get back home if they were lost)
- How to talk to strangers/neighbors if they are in trouble or need help
- Who to call if they need help
- What to do if there was a fire in the house
- What to do if a stranger is at the door of the house
- How to identify “safe people” (such as police officers, fire-fighters, or friends)
- Understanding potential hazards with household products and chemicals
- Safety around pets and animals
- Understanding basic first aid skills
- How to stay safe in the home and not wander
- Pool safety skills (teaching them how to swim)

Community Skills:

- How to navigate stores to make purchases
- How to create a list of items they need to purchase
- How to purchase your items at the checkout lane
- Navigating parking lots safely
- How to read community signs
- Ask for directions
- Able to use an app or electronic device for directions

What Does it Feel Like to Have

TACTILE DEFENSIVENESS

LEARN MORE AT [HTTPS://WWW.THESENSORYTOOLBOX.COM/](https://www.thesensorytoolbox.com/)

ITCHY SHIRT TAGS DRIVE ME CRAZY

I can always feel that the tag is there. I'd prefer shirts without any tags that are made out of a soft material. Sometimes I like to wear long sleeves so that my arms don't touch anything.



I DON'T LIKE TO GET MY HAIR CUT

There's a lot of light touch when I get my hair cut, which overwhelms my sensory system. I need a lot of deep touch pressure before and after.

TICKLING CAN BE OVERWHELMING AND PAINFUL

I get so much tactile input from tickling that my nervous system gets overwhelmed. Instead of laughing, I may start crying.



I DON'T LIKE TO EAT CERTAIN TEXTURES

Some foods feel really strange in my mouth, which makes me nervous to eat them. I like to eat foods that all have similar textures that I'm comfortable with.

I LIKE TO KEEP MY HANDS CLEAN

When my hands are dirty, there's any number of textures and substances that my brain is fixated on. This stops me from playing, especially with messy activities.



LEARN MORE AT [HTTPS://WWW.THESENSORYTOOLBOX.COM/TACTILE-DEFENSIVENESS/](https://www.thesensorytoolbox.com/tactile-defensiveness/)



TITLE: Practical Communication Tools for Autism: Using Visual Strategies for Lifelong Success

AUTHOR: Hodgdon, Linda and Bryant, Marianne

SUBJECT AREA: Autism-Education-Visual Strategies

PUBLISHER: QuirkRoberts

PUBLICATION DATE; October 27, 2019

By: ANNE CARPENTER

I was over the moon when I discovered this new book by Linda Hodgdon as she hasn't come out with new material for some time. This is a little gem that takes the teacher or parent on a journey through the life of Caity Bryant, a child with autism who had many challenging behaviors and meltdowns.

Linda Hodgdon worked with Caity's mother, Marianne to see if visual strategies would get through to her and help her work through the many challenges she experienced. Despite initial skepticism, Marianne decided to take the plunge and try it out anyway. Each chapter documents Caity's life from preschool to elementary school to high school and beyond through a travelogue of visual supports that were used at each and every step of the way.

Each chapter describes how Marianne used visuals for everything from helping her daughter get dressed in the morning, to getting ready for school, managing and regulating her emotions and much more! Every stage of her life, from early childhood all the way up to adulthood and everything and anything that can be supported by visual means is covered and I do mean, covered complete with examples in full color of the visual tools used. I was delighted to see these in color as so many books like this use black and white photos in the name of economy, but the use of color is so much more effective. This adds real "oomph" to the concepts at hand and nobody can do this like Linda Hodgdon!

The book is written in easy to understand language free of jargon so busy parents and teachers can easily read this in one sitting. The book is organized in such a way that one can go back to a chapter for reference if one is unsure about a visual tool to use to help a student master division, for example. This one is a real winner but it is only available in a Kindle edition-I hope that there will be a print version soon!



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