

The costs of Autism

And what you can do about it

By Brynne Conroy

The incremental costs of supporting an individual with autism in the United States are \$1.4 million over the course of their lifetime according to a 2014 report from leading mental health policy researchers. If the individual has an intellectual disability on top of their autism diagnosis, these costs shoot up to \$2.4 million.

While some of these costs are shouldered by health insurance and school districts, they are also shouldered by individual families. From assistive technology to therapeutic services, the costs of autism can be a very real and visceral part of family finances.

Opportunity costs

Often when we think of "costs" we think only about the items and services for which we shell out money. However, research funded by the National Institute for Mental Health reveals another financial pitfall families should be aware of: opportunity costs.

When a child is diagnosed with autism, one of the parents typically reduces their hours or leaves the workforce completely in order to tend to the child's needs. This leads to a reduction in overall household income. Compared to families of children with other health limitations, households affected by autism see a 21 percent reduction in overall income. They make 28 percent less than families of children with no health limitations.

This dramatic difference most profoundly affects mothers, who are usually the ones to take on care management roles for their children. These mothers are six percent more likely to be unemployed, and if they do work, they earn less and work less hours—seven hours less per week, on average.

Insurance

While combatting a reduced household income, families also have to worry about the costs of services. David Mandell, ScD, leading national researcher on quality care for individuals with autism, reports that we're fortunate in Pennsylvania.

"Pennsylvania has a very generous Medicaid policy relative to other states for children with autism," Mandell says. "Every state has their own Medicaid plan. They can decide how generous they want to be within that plan."

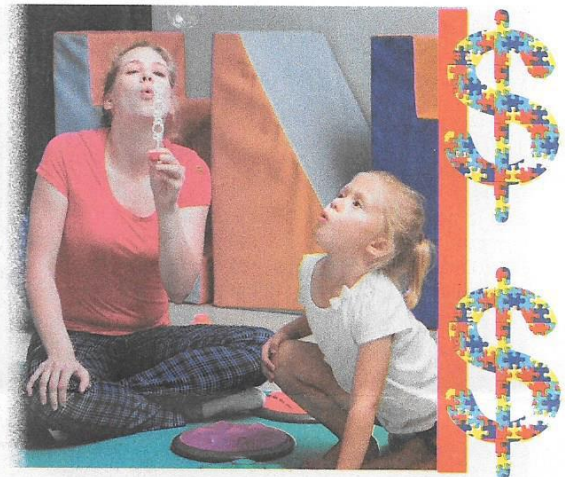
He says that state waivers are often deployed to extend coverage to children with medical conditions that would otherwise render them institutionalized. These waiver programs are limited, either by the amount of people they let in or the amount of money allotted for the cause.

In Pennsylvania, the number of waivers allotted for individuals with autism is comparatively large. If your family's health insurance plan provides only partial coverage for your child's services or does not cover them at all, you can apply with the Department of Welfare for Medicaid as a secondary insurance for your child through the waiver program—even if you don't fall below typical income limits.

Educational supports

Sometimes advocating for a special needs child within your school district can feel like an uphill battle. Mandell suggests treating these meetings as a negotiation session rather than an adversarial match.

"A lot of times what families forget to do is work backwards. 'Where do I



want my child to be when they're 18? When they're 21? Or 30?" he prompts. "We have to have a goal in mind, and everything should be in the service of that goal."

For example, you may be dying for an iPad to help your child communicate and you'd like the district to provide it. Bringing the iPad up immediately is not a good negotiation strategy, though. First, you have to get everyone on board.

If verbal communication is one of your team's goals, but your child has not been making meaningful progress, bring that fact up in the IEP meeting. Ask about alternative strategies that could be implemented since the current one is not working. Someone may bring up assistive technology, like an iPad, but if they don't, you can now inquire about it within the context of your child's IEP goal.

"Think of everyone as your colleague and partner – not your enemy. These are folks that went into this business for a reason," Mandell reminds us. "Sometimes that gets lost along the way, but they have skills and expertise to bring to the table just like you do. Keep them in mind as partners, not antagonists."

Grants & charities

When insurance refuses to cover an item or service that the educational team cannot help provide, families can turn to grant-giving organizations and charities.

Families in Western Pennsylvania can look to these organizations in particular:



ACHIEVA Family Trust Charitable Residual Program - Grants are awarded quarterly for disability-related modifications, medical needs, caregiving needs, products, supplies and camp or recreational tuition. You can learn more by calling (412) 995-5000.

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First Hand Foundation - Grants are awarded worldwide to children who have medical needs not covered by insurance. These needs can include medical treatment, equipment, travel and vehicle modifications. To learn more call (816) 201-1569.



Variety's My Voice Program - Variety is a Wexford-based charity that provides adaptive equipment to children with disabilities. Of particular interest to families affected by autism is its "My Voice" program, which not only provides iPads to children with communication disorders, but also preloads a communication app of your speech therapist's choice onto the device. For more information call (724) 933-0466.

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- **Sign up for the PA Early Education eNews** – this newsletter will keep you up to date on new research on early education and what's happening in Pennsylvania. You can stay up to date with the latest information from the PA Office of Child Development and Early Learning through this monthly e-newsletter which informs early learning professionals, the early childhood community, school district staff, policymakers, community leaders and the public on developments in early childhood education and care in Pennsylvania. The newsletter is free and open to anyone.

Every word, every letter, every action on behalf of quality early learning makes a difference! ■

Patricia Poshard, Editor

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Finding purpose

While these statistics and numbers may seem overwhelming, it should be noted that financial burden or lack thereof is not all there is to life. Mandell notes that through his work, he has met parents that struggled, but have also found their *raison d'être* through those struggles.

"They don't feel hopeless," he relays. "They have found a sense of purpose. That purpose is to take care of their child and to improve the system in which we provide or refuse care. Because the problem is not with the person with autism or their family, but with the system." ■

Brynne Conroy is a Pittsburgh-based personal finance writer. Her work and insights have been featured in media outlets such as Yahoo News, The Globe and Mail, and Bridal Guide.

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- **Attend local festivals** – Arts, collectibles, rocks, literary - whatever she's into!
- **Go out for ice cream cones** – Take walks along a local scenic path or visit a town park.

Shhh! Don't tell them you didn't want to go

I've got a little secret when it comes to daddy daughter dates: I often encourage my husband to take our daughter to places I would rather not go. You know what I mean - those noisy, crowded, high-up-in-the-air places you may not always be all that crazy about either.

The fact is, great daddy daughter date destinations are often raucous, dusty or sweaty places moms might rather avoid. As for when they choose places I enjoy visiting, that's okay. I can take a pass. I'm perfectly happy staying behind so my husband and daughter can have some adventures together that are just about the two of them. ■

Author, journalist and writing coach Christina Katz tries not to dance a jig after her husband and daughter leave for some together time, but she usually just can't stop herself.

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members wear gloves when cleaning up bodily fluids. How are the rooms cleaned that your child will be in? Are cots disinfected? Is bedding washed or sent home with you on a consistent basis? Are the tables and other furniture appropriately child-sized? Are the toilets and sinks? What is the outdoor play area like?

Assess the communication style

How proactive is the daycare with communication? Will you get a summary of your child's day, down to the number of dirty diapers and time and length of her nap? Will you be called immediately if there is a concern? Is the caregiver approachable for questions and discussion?

Understand expectations the daycare has of you and visa-versa

Are you expected to pay for a full-time week over a certain number of days? How do vacations and holidays work? What hours is the daycare open? Will the daycare be able to take your child early or keep her late if necessary? If so, what is the charge for doing so?

Understand the sick policy

Most daycares are specific about what constitutes a sick child or an infection that will not be allowed to be in daycare. A child in my son's daycare came down with the highly contagious conjunctivitis (also known as pinkeye). I was relieved the affected child was sent home immediately and could not return to daycare until a doctor said he was no longer contagious. As a parent you hope the daycare will follow the policies they have in place. Understand that adhering to the

policy is important not only for your child, but others as well. ■

Judy M. Miller is a freelance writer living in the Midwest and a mom to four children, all of whom have spent time in daycare when young. She is the author of What To Expect From Your Adopted Tween and Writing to Heal Adoption Grief: Making Connections & Moving Forward.

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Screen awareness

Video games and other educational devices are not necessarily devoid of benefits, says Seeta Pai, managing director of education and research at Common Sense Media. "Some media may help young kids develop certain 21st century skills that aren't available through other means," says Pai. "But we're talking about well-designed products used in the right circumstances with the right adults."

That means media that takes the place of parental interaction – or serves as a babysitter for busy parents – won't have much learning value, no matter how great the content. Co-viewing and playing video games together allows parents to connect what's happening on-screen to real life, providing the vital context that fuels learning, says Pai. "So after a trip to the zoo, you might play a computer game or use an iPad app about animals and see if you can find animals that your child saw at the zoo." Young kids need parents to help bridge the gap between the screen and real life, she says.

Definitive answers on the educational value of media use for young kids may be years away, says Pai. In the meantime, Common Sense Media offers Learning Ratings, a program that offers "best for learning" ratings and reviews for video games and apps. The ratings (currently in BETA testing) are designed to help parents navigate the confusing world of kids' media and help kids make better media choices, says Pai.

For the Stetners, though, the lesson is clear: electronics can teach, but they can't replace life experience. From learning basics like letters and numbers to life skills like coordination and sportsmanship, Stetner says video games and computers have made her kids smarter. But when the weather's nice, she sends the boys outside to race, wrestle and tumble in real-life dirt and grass – an experience no computer game could ever replicate. ■

Malia Jacobson is an award-winning health and parenting journalist and mom of three. Her latest book is Sleep Tight, Every Night: Helping Toddlers and Preschoolers Sleep Well Without Tears, Tricks or Tirades.