



If you love someone with autism who needs lifetime, 24/7 care, then you may have experience with things like:

- Seizures
- Self-injury
- Obsessive Compulsive Disorder
- Gastrointestinal Issues
- Insomnia

These are just some of the conditions that people with profound autism often struggle with.

Few answers or resources are available. Why? Because people with profound autism aren't generally included in clinical research. This means solutions that are helpful for them aren't even part of the conversation.

### **It's time to change that.**

Recently, the [federal committee](#) that makes recommendations to Congress about [autism](#) [asked to hear about](#) these types of experiences.

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*“January 3 - February 14, 2024, the Interagency Autism Coordinating Committee (IACC), the National Institute of Mental Health (NIMH) Office of National Autism Coordination (ONAC) requested public comments to assist the IACC in identifying priorities related to physical and mental health conditions, and other related conditions, that commonly co-occur with autism. The IACC requested public comments on the impact of these co-occurring conditions, as well as research, services, and policy needs to that may be helpful to consider in addressing issues related to these conditions.”*

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After reaching out to stakeholders in the profound autism community, the Profound Autism Alliance submitted the following feedback to the IACC, directly referencing our community's experiences.

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### Question 1

*What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory & motor challenges)*

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*Because people with profound autism can't provide written comments to requests like this, we've attempted to convey their experiences through caregiver feedback.*

"It's challenging to determine what will help your children when they can't tell you exactly what is happening with their digestive systems. We have been through several specialized diets & supplements & have finally settled on what we think is helping them, but both have struggled with chronic constipation."

"They dismissed my concerns because he wasn't celiac, but chronic constipation during early development prevented potty training; at 14 years old, he's still in pull-ups."

"My kid used to sleep for 4 hours every 3 days. Almost 30 years into this, she sleeps 4 hours daily, sometimes in several pieces. Staying up through her insomnia has been soul-shattering & brutal. My health has deteriorated, as I was left to monitor her during all waking hours plus figure out how to work while sleep deprived."

"It is hard to find a dentist who will adapt to sensory & behavioral issues & if you need sedation dental work. My son went without for years, & then when we found a dentist, he had to get 5 teeth removed at one time due to decay."

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### Question 2

*What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)*

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"Self-injury is so damaging to his body & mind. He will hit his head until his temples are swollen & blood vessels burst on the surface. He bangs the bridge of his nose & has

created a bump. He has scars all over his hands, arms, & legs that are remnants of self-injury episodes. He picks his skin; he slams his hands to his chest; he has callouses from biting areas repeatedly; he has left me with scars on my hands & arms; he pulls hair so hard that my scalp throbs; he scratches, pinches, & is unpredictable. He has always had self-injury & aggression. However, as an adult, it is very life-altering. It affects services & his quality of life. I don't understand how services won't accept people who have behavioral challenges."

"Aggression towards others & herself- Biting, scratching, hitting, putting pressure on people with her hands or other body parts), hitting herself in the head, picking at her skin, bending her body into painful contortions, throwing herself down, using objects as weapons, breaking her teeth on objects, pulling out hair."

"OCD - Constant ritual behavior, verbal ticks that must be completed (some of them involve other people doing the next part), hoarding objects like receipts or empty boxes, shrieking at high levels at all times of the day & night if something doesn't go according to ritual, triggering violent episodes, tons of laundry because she can't stand anything that looks like it may be dirty, hand washing until she has severe eczema."

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### Question 3

*What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?*

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"Health care is generally difficult, so many adult providers do not understand how to interact or communicate with your children. My children are young adults now at 21 & 23, & they still struggle to tolerate basic medical exams--blood pressure cuff, otoscopes, thermometers, much less injections. Both boys have had to be sedated in the hospital to undergo what would normally be outpatient procedures: dentistry & dermatology, for example. My younger son just had to be sedated, which was a long, stressful process in the local hospital because the anesthesia professionals were not trained to work with this population. The reason? He needed to have plantar warts removed, which you would

normally do in the podiatrist's office with a local anesthetic. My older son has a suspicious lesion on his scalp that I suspect is basal cell skin cancer, so we're getting ready to have to go through a similar procedure with a dermatologist. Our lives have been shaped by special education, & both of their challenges with communication & behavior have severely limited their opportunities. They could not participate in sports except for a few special needs opportunities. They could not participate in clubs or pursue any hobbies, & they had no friends in the conventional sense. It creates a sense of loneliness & isolation for parents that is very hard to describe. Attending church & religious services of any kind has been difficult.

"Other issues, such as ingrown toenails or cavities, should be considered, too, since these are normally minor occurrences, but for someone who is non-verbal & doesn't communicate very well, they can lead to infections."

"Prompt dependency gets in the way of authentic communication."

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#### *Question 4*

*What additional research is needed to help address co-occurring conditions for autistic people?*

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Autistic people who require round-the-clock care throughout their lives experience unique challenges that require targeted research. Additionally, a renewed focus on the meaningful inclusion of people of all ages with profound autism in clinical research is critical, as currently, they are severely underrepresented.

Specific areas of focus that would benefit those with profound autism include:

- Research specific to communication as it is currently minimal at best.
- Research focusing on intense behaviors that people with profound autism experience, frequently resulting in injury and isolation.

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#### *Question 5*

*What could be improved in autism services and supports to help address co-occurring*

To improve health and connection, it is critical that clinical practice guidelines specific to profound autism are developed and implemented. Additionally, enforcement of protections under federal mental health parity law should be a priority.

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"Every hospital that receives federal funding (all of 'them) should be mandated to have a designated ER & inpatient care coordinator on staff for all patients with ID (including profound autism) & other disabilities. It doesn't need to be a separate position. The role can be a (trained) regular staff member. Hospital rules & procedures may need to flex for various reasons to improve the quality of care for our community, & management will need to approve changes. For example, a caregiver in the room overnight, dispensing regular (Dr approved) meds, consolidating scheduled tests & procedures.

"He can never ever ever be left alone. That doesn't sound like a big deal compared to the myriad of other issues we've faced in the past and that other families grapple with now, but it's pretty major when you're talking about 66-year-old parents and a nonverbal 38-year-old guy who would not be accepted at any of the nonprofit residential programs in the area and is still on the waiting list for the most appropriate community-based Medicaid Waiver funding."ID (including PA) & other disabilities. It doesn't need to be a separate position. The role can be a (trained) regular staff member. Hospital rules & procedures may need to flex for various reasons to improve the quality of care for our community, & management will need to approve changes. Ex, caregiver in the room overnight, dispensing regular (Dr approved) meds, consolidating scheduled tests & procedures.