

WHAT CAREGIVERS WANT YOU TO KNOW ABOUT THEIR AUTISTIC CHILD

“I wish my child’s pediatrician was more familiar with the complexity of autism and the phenomenon of ‘masking,’ especially in girls.”

Autism in girls. Masking, or “camouflaging,” refers to behavioral adaptations that individuals with autism use to conceal symptoms during social situations. Particularly common in females, masking may lead to delayed diagnoses, misdiagnoses, and other mental health challenges.¹

“I wish our pediatrician recognized that caregivers need as much support and guidance as their children.”

Caregiver mental health. Parents of children with autism often experience higher levels of stress, social isolation, and poor mental health compared to parents of typically developing children as well as those with other developmental disabilities.²



“I wish my pediatrician would have looked for physical illness first when there was a change in behavior with my non-verbal son, instead of assuming, ‘That’s just autism.’”

Co-occurring conditions. Co-occurring physical and mental illnesses are common in people with autism (e.g., gastrointestinal disease, epilepsy, anxiety, depression). The presence of co-occurring conditions can exacerbate the symptoms of autism, interfere with therapeutic interventions, and lead to missed or incorrect diagnoses. It is critical to recognize other conditions early and provide timely referrals to specialists, as needed.³

“Please consider yourself as part of our team, and work with our other specialists so that we may all work together to help our child.”

Collaboration and coordination of care. Increasing family awareness and understanding of the medical home can promote partnership of the parents and primary care provider in planning and coordinating the child’s care and advocating for their needs.⁴

“Pediatricians can and should diagnose autism in clear cases. The years-long wait lists for diagnosis by specialists are heart-wrenching, future-stealing and, in many cases, unnecessary.”

Diagnosing autism. Although most children will need to see a specialist, such as a developmental-behavioral or neurodevelopmental pediatrician, psychologist, neurologist, or psychiatrist, for a diagnostic evaluation, general pediatricians and child psychologists comfortable with application of the DSM-5 criteria can make an initial clinical diagnosis.⁵

“I wish our pediatrician’s staff had better training on how to treat patients with autism. I can’t tell you how many times a staff member would come into the exam room and ask, ‘What is wrong with him?’”

“Please speak directly to my child. Presume competence. Take time to explain and show my child what you are going to do.”

Staff training. Visits to the pediatrician’s office can be difficult for autistic patients, their caregivers and office staff. However, with some thoughtful preparation and simple accommodations, pediatricians can create a welcoming and supportive environment to ensure a positive experience for both the patient and their family.⁶

“Trust the family in their observations and advice. We know our child best and spent countless hours observing our child.”

Patient and family-centered care. Caregivers are key partners in the diagnostic and ongoing care process, given their deep understanding of their child's unique behaviors and development. Encouraging open communication and validating caregivers’ concerns fosters a collaborative approach to care, which can lead to more accurate assessments and timely interventions. Respecting the caregiver’s expertise also builds trust and strengthens the pediatrician-caregiver relationship, ultimately enhancing outcomes for the patient.⁷

¹ Camouflaging in Autism: Examining Sex-Based and Compensatory Models in Social Cognition and Communication. *Autism Research: official journal of the International Society for Autism Research*. <https://doi.org/10.1002/aur.2440>.

² Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*. <https://doi.org/10.1177/1362361309105658>.

³ Autism Spectrum Disorder and Co-occurring Developmental, Psychiatric, and Medical Conditions Among Children in Multiple Populations of the United States. *Journal of Developmental & Behavioral Pediatrics*. https://journals.lww.com/jrnldb/abstract/2010/05000/autism_spectrum_disorder_and_co_occurring.1.aspx.

^{4/5} Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. *American Academy of Pediatrics*. <https://doi.org/10.1542/peds.2019-3447>.

⁶ Tips for a Successful Office Visit. CASP.

⁷ Patient- and Family-Centered Rounds: Partnering to Improve Care. *Pediatrics*. <https://doi.org/10.33546/bnj.2350>



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