



# CONVERSATIONS IN CARE

## Quick Guides for CHWs and Care Teams

Practical Tools Rooted in Trust and Respect

### Autism Spectrum Disorder (ASD)

#### Why It Matters:

For many families, learning their child has Autism Spectrum Disorder (ASD) can feel overwhelming. The diagnosis may bring a mix of emotions, such as confusion, grief, relief, fear, or uncertainty, and families may cycle through these feelings as they begin to understand what the diagnosis means for their child and their future.

The way providers respond in these first conversations can make a lasting difference. Leading with empathy, patience, and clarity helps families feel supported rather than isolated. By listening without judgment, answering questions in simple and clear ways, and offering reassurance, providers can help families process information at their own pace.

This conversation guide is designed to support providers in creating a safe, respectful space where families feel heard and understood. With compassion and clear guidance, providers can empower families to take the next steps in supporting their child.

#### Before the conversation:

- Create a safe, respectful environment.
- Ask about what the family already knows or believes.
- Acknowledge that different words, beliefs, or traditions may be different, and that it is okay.
- At first, listen more than speak.

### Questions Parents May Have About Autism Spectrum Disorder

#### What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder, often called ASD, is a developmental condition that affects how a person communicates, learns, and interacts with the world around them. Because it is a “spectrum,” it looks different for every child – some children may need a lot of support, while others may need less.



**Tip:** Emphasize that ASD is not caused by something parents did or didn't do. Each child is unique, and early support can help them grow and thrive.

## Why is it called a “spectrum”?

Autism Spectrum Disorder, often called ASD, is a developmental condition that affects how a person communicates, learns, and interacts with the world around them. Because it is a “spectrum,” it looks different for every child — some children may need a lot of support, while others may need less.



**Tip:** Tip: Emphasize that ASD is not caused by something parents did or didn't do. Each child is unique, and early support can help them grow and thrive.

## When do signs of autism usually appear?

Signs often show up in early childhood, usually by age 2–3, though they may be noticed earlier or later. Every child develops differently, so it's important for families to share what they observe with their provider.



**Tip:** Encourage families to trust their observations. Early conversations can lead to helpful support sooner.

## Can children with autism learn and make progress?

Yes. With therapies, supportive services, and encouragement, children with autism can continue learning, building skills, and thriving.



**Tip:** Reassure families that progress is possible. Connect them to early intervention programs, therapy services, and parent support groups.

## Did I do something wrong that caused my child's autism?

No. Autism is a natural variation in brain development. It is not a punishment or a result of something parents did.



**Tip:** Acknowledge that parents — especially mothers — often feel guilt. Remind them that this is not their fault.

## Is God punishing us or testing our family by giving our child autism?

Many families grapple with these deep spiritual questions. While some see life's challenges as tests or opportunities for growth, from a medical view, autism is simply a different way the brain develops. Your spiritual beliefs are important, and it is okay to consider that this journey might come with lessons, not punishment.



**Tip:** In some faith communities, parents question whether the diagnosis is a divine punishment or test of faith. Respect spiritual beliefs while also reinforcing that autism is not a punishment.

## Could my child be cursed or under the evil eye?

In many cultures, explanations like a curse or the evil eye are a common way to understand hardships. Medical research shows autism is related to brain development, but cultural traditions for protection and healing can still bring families comfort.



**Tip:** Parents from certain traditions worry that autism might be the result of an evil spirit or curse placed on the child. Honor cultural practices while also guiding families to evidence-based supports.

## What will people in our community say? Will they blame us?

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## We don't have a word for "autism" in our language. How do I explain it to relatives?

Sometimes, language fails to capture every new concept. Autism describes a different way of processing information and experiencing the world. It might be helpful to think of it as a unique developmental style rather than a flaw, much like how different cultures celebrate their unique traditions and strengths.



**Tip:** Many immigrant parents have limited exposure to autism; without a cultural reference, they struggle to understand it themselves and to help extended family accept that it's a real condition and not anyone's fault. Support families in finding simple, culturally meaningful language to explain autism to others.

## What caused my child's autism? Was it vaccines, something I ate, or our new environment?

Scientists believe that autism arises from various factors — genetic, environmental, and developmental. There is no single cause, and nothing a parent did causes it. This isn't about blame; it's about understanding that autism is a natural variation in human diversity, not the result of any specific action.



**Tip:** Parents often search for a cause, with common beliefs including fears about vaccines, genetics, or environmental factors. It's important to gently address myths (such as those regarding vaccines) while focusing on providing support and moving forward.

## Did raising my child between two languages confuse them?

No. Children can thrive in bilingual or multicultural environments. Autism affects how children communicate, but being exposed to more than one language is not harmful.



**Tip:** Some immigrant parents worry that speaking their native language at home might have hindered their child's development, leading them to stop using it in hopes of reducing "confusion". Encourage families to keep their home language as it supports identity and strengthens family bonds.

## Can autism be cured or outgrown?

Autism is lifelong, but with early support, children can develop important skills and flourish.

Autism is not something that needs to be cured in the same way a sickness might be treated. It is a lifelong difference in how the brain works. With love, understanding, and early supportive interventions, your child can develop skills to flourish. Every child's path is unique, and many do very well as they grow."



**Tip:** After diagnosis, many parents hold onto hope for a cure or that the child will "grow out of it," sometimes turning to prayer for a miracle. Reframe hope around growth, progress, and thriving.



## Should we seek traditional healers or only follow doctors?

It is completely understandable to feel caught between traditional healing and modern medicine. Families can honor both. Traditional healing and spiritual practices may bring comfort, while medical therapies provide developmental support. Both can work together.



**Tip:** Parents may feel torn between following recommended therapies and pursuing cultural or spiritual remedies (prayer, herbal medicine, rituals), trying to reconcile traditional beliefs with Western medical advice. Respect cultural healing while encouraging evidence-based services.



## How can we get help here?

Navigating services in a new country can feel overwhelming. Providers can guide families step by step, connecting them to early intervention programs, therapy services, and community groups.



**Tip:** Acknowledge barriers like language, cost, or immigration concerns. Offer concrete referrals and ongoing guidance so families know they're not alone.



## Am I capable of being a good parent to a child with autism?

Absolutely. Asking these questions shows your love and commitment. Parenting is a journey of learning, and you are not alone in it. Parenting is one of the most challenging and rewarding journeys. You are doing your very best, and no parent is perfect. With support and guidance, you will continue to learn and grow in your parenting.



**Tip:** Mothers and fathers often question their parenting skills, wondering how to handle their child's needs, behaviors, and education, and fearing they're not prepared for this new parenting journey. Reassure families that their efforts matter. Encourage self-compassion and support networks.



## Will my child talk, make friends, or play with other children?

Many children with autism find ways to communicate and connect, though it may look different. With support, they can build relationships and enjoy play in their own ways.



**Tip:** Especially when a young child isn't speaking or interacting typically, parents ache to know if their child will ever communicate with them or socially connect with peers. Validate parents' hopes for connection. Highlight alternative forms of communication as real and meaningful.

## Will my child go to school, work, or have relationships one day?

Many autistic people go to school, have jobs, and build meaningful relationships. Each child's journey is unique, but their potential is real and wide-ranging.



**Tip:** Looking to the future, parents worry about their child's long-term prospects – whether they can succeed in school, find work, or have relationships, or if autism means a different path in life. Balance honesty with hope – focus on supports that open possibilities.

## Who will care for my child when I am gone?

This is a common and painful fear. Planning ahead with family, community, and services can help ensure ongoing support and build independence where possible.



**Tip:** This heart-breaking fear weighs on many parents: they wonder what will happen when they grow old or pass away, who will love, support, and protect their child. Provide resources for long-term planning and support. Normalize this concern as it weighs heavily on many families.

## Will my other children – or a future baby – also have autism?

Genetics can play a role, but every child is unique. Providers can help monitor development and connect families with supports as needed.



**Tip:** Parents may worry about future children. Offer reassurance, monitoring, and family-wide support.

**Note:** These questions and responses were gathered from community members and developed with their voices and cultural insight.

