



SHARING
YOUR CHILD'S
diagnosis
WITH OTHERS.

A Guide for Families | Best Buddies Family Support

YOU ARE IN CONTROL OF YOUR STORY.

Learning that your child has been diagnosed with an intellectual or developmental disability (IDD) is a deeply personal experience. Telling others gives them the opportunity to support you. At the same time, you may worry that telling them about the diagnosis will open the door for unwelcome advice or judgement. Sharing the news — with family, friends, co-workers, or your wider community — is entirely your decision. There is no right time, no single method, and no obligation to share more than you are ready to say.

WHERE TO *begin...*



Give yourself time.

Some families share news immediately; others wait until they've had time to process. Both approaches are valid. You decide when you're ready.



Prepare what to say.

Having an idea of what words you will use before you enter the conversation can help. Knowing beforehand how you want to convey the information, request or deflect help, and step away from harmful comments can make it easier to do so in the moment.



Start with the basics.

It's okay to share only what feels comfortable in the moment — perhaps that your child has a genetic condition, that it is progressive, or that it affects certain areas of development. You can always share more details later.



Share in stages.

A simple statement like "We're still learning and will share more when we're ready" is a complete and acceptable response. You do not have to answer every question right away.



Focus on strengths.

After a diagnosis, it is natural to notice challenges first. At the same time, try to look for your child's strengths, interests, and potential. This balanced perspective can help your family adjust to the diagnosis, recognize what your child can do, and identify the supports they may need to thrive.

SUPPORTING YOUR **WHOLE FAMILY.**

Your child: Depending on your child's age and ability, you may want to speak with them about their diagnosis in age-appropriate language. The goal is to provide your child with reassurance and information as you discuss what comes next for them.

Siblings: Brothers and sisters may notice differences and have questions, including concerns about their own health. If the condition has a genetic cause, a genetic counselor can help guide these conversations at the right time and in language that fits each child's age and understanding. This is also an opportunity to reassure siblings that they are equally important in the family and that you will continue to be available for new questions or concerns as they arise.

Extended family: If the condition is inherited, a genetic counselor can draft a family letter summarizing relevant genetic information, allowing relatives to decide how they wish to proceed, on their own timeline.

NAVIGATING THE **WORKPLACE.**

You may have concerns about sharing your child's diagnosis at work. At the same time, you may need to address health insurance, flexible hours, or schedule adjustments. Consider starting with a factual, straightforward approach:

- "This is what has happened."
- "This is what I currently know."
- "This is what I need in order to continue working effectively."

SHARING WITH YOUR **BROADER COMMUNITY.**

Over time, you may choose to communicate with your wider community through:

- A letter or email to close friends and extended family
- Online resources you have found helpful
- Social media updates (if that feels right for your family)
- One-on-one conversations as you feel ready

Some families share openly; others prefer privacy. Both are valid choices. Only you know what is best for your family.

YOU DON'T HAVE TO NAVIGATE THIS ALONE.



Best Buddies Family Support is here to walk alongside you through free programs—offering trusted resources, connection, and a welcoming community, every step of the way.

Call/Text: 786.960.0506

