

When to Tell Your Deafblind Child They Are Deafblind

Advice from Lanya McKittrick, PhD.

► BACKGROUND

Experts agree that it is important to tell your child as early as possible when they have a disability. Children who are deafblind are often acutely aware that they are different from their peers and siblings, and it is important to give them language they can use to describe their experiences. By telling your child, you can help them understand the cause of their unique sensory experiences. If left unsaid, children overhear conversations, wonder why they have to go see specialists, and if they do not know why, they may make up a narrative of their own.

► THE BENEFITS OF TELLING THEM EARLY

Telling your child that they are deafblind early has benefits for their development. First, it can help your child manage their unique experiences, which can help them feel more in control of their lives. Second, it can help them feel less isolated and alone. They can develop language earlier to describe their experiences to others and may be able to sooner connect with other deafblind individuals. Finally, telling your child that they are deafblind can help them build self-confidence and self-esteem, as they will have a better understanding of their own strengths and challenges. Telling them allows them to develop age appropriate tools and strategies to be able to answer questions from others about their hearing and vision loss.

► STRATEGIES FOR TELLING YOUR CHILD

There is no one right way to tell your child they are deafblind. However, here are some strategies that may be helpful:

- **Use simple, age-appropriate language.** Your child may not understand complex medical terms, so use language that is easy to understand and appropriate for their age. Take your child's communication abilities into account and tailor the discussion to them. Feel free to use whatever language makes sense to your family. Understand that the word "deafblind" can be scary at first so it may be helpful to find other ways to describe, like "combined hearing and vision loss".

- **Focus on the positives.** Although it can be tempting to focus on the challenges of being deafblind, try to emphasize the positive aspects of their unique experiences and what they can do and how, with support, they can do great things.
- **Encourage questions.** Give your child plenty of opportunities to ask questions and express their feelings. Let them know they can communicate their feelings to you at any time.
- **Be honest.** While it is important to focus on the positives, it is also important to be honest about the challenges your child may face. Make sure your child knows that you are there to support them and that they are not alone.
- **Use visual aids.** Depending on your child's level of vision or abilities, it may be helpful to use visual aids like pictures, diagrams, or videos to help explain the concept of deafblindness.

► CONCLUSION

Telling your deafblind child that they are deafblind can be a difficult conversation, but doing so early has benefits for the entire family. By using simple, age-appropriate language, focusing on the positives, and encouraging questions, you can help your child understand and manage their unique experiences. Remember to be honest, and use visual aids if necessary to help make the conversation easier.

Be patient, empathetic, and supportive, and seek the help of professionals and other families. With the right support and guidance, your child can learn to embrace their disability as just one part of what makes them amazing and thrive in life.

► ABOUT LANYA MCKITTRICK, PhD

Lanya McMcKittrick is Founder of Lane of Inquiry, Deafblind Educational Research and Family Support as well as a mom to four boys, two of whom are deafblind due to Usher syndrome 1b. Visit www.LaneOfInquiry.org for more information.

