

3 Tips for Teaching Children

- 1. Using the illustrations, explain that many children with rare diseases or disabilities can look different.** Their bodies, faces, or skin might look different from their own, or they may need assistive devices.

Instead of pointing, staring or talking as if the child or adult with differences cannot see or hear them, children can:

- ⇒ **Smile!**
- ⇒ **Say hello and wave hello.**
- ⇒ **Say something nice.**
- ⇒ **Say, “Can I ask a question about a difference I notice?”**

- 2. If children ask questions about the assistive devices, give them simple yet factual and objective responses.**

“What are those things next to his head?” (when noticing to the child whose wheelchair has head supports)

You can say: “Some wheelchairs have head supports for children who have a difficult time holding their heads up.”

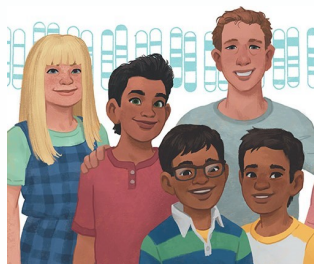
- 3. Model and practice saying something nice to the person who is physically different or asking permission to ask a question about a difference you notice.**



Why Read A Book about Rare Diseases to All Children?

This book is written for children with rare diseases, However, all children can benefit from reading this book.

- * Encourages acceptance of diversity
- * Helps children cultivate their own self-worth
- * Increases emotional intelligence in children
- * Takes action against disablism through education



Reading the Book *Extraordinary!* to Children without Rare Diseases



A Guide for Teachers

by Kara Ayik
Educator, author, speaker,
and parent.

Notes for Educators



Principles that apply to all children:

1. We are all unique, one-of-a-kind individuals who have purpose and value.
2. All children have preferences for the types of activities they like.
3. All children have differences in their appearances, even identical twins.
4. All children have their own ways of expressing themselves.
5. All children have gifts (talents or abilities) which they may or may not be aware of.
6. All children have the potential to develop their character qualities.

Special notes for the teacher of a child with a rare disease:

1. Privately offer the child an opportunity to share information with classmates about his or her rare disease. Asking or suggesting that s/he do so may make the child agree out of obligation or a desire to please the teacher.
2. Ask the parents/caregivers if there is something about your student's health that they would like you to know about.
3. Be observant and take action against bullying, exclusion, and disablism.
4. Children with rare diseases may need your efforts to help them feel included, but take care not to make these efforts obvious. Learn about your student's gifts and the activities the student enjoys and try to build on them.

Seven Ideas for Teachers

1. Explain to your children that even though they do not have a rare disease, they are also extraordinary for the same reasons that Evren and his friends are. They have a unique identity and a positive purpose in this world. There is no one else like them in the entire world, and that is what makes each human being special.

2. Children with rare diseases and disabilities may need "tools" that help their bodies work better. Use the book as a tool for teaching the names of assistive devices.

Tools can help people move more easily, like wheelchairs and walkers. They can also help them to see or hear better, like glasses or hearing aids, or breathe better like oxygen or tracheostomies (often pronounced "trake.")

Note that two children in the book are wearing helmets to protect their brains in case they fall down during a seizure, which happens when the brain has a condition called epilepsy. The brain, which keeps us awake, may stop working like it usually does for a short time.

3. Children with rare diseases and disabilities still like the same kinds of fun activities that all children do. Talk about fun activities and ways all children can participate.

4. Explain that some children with rare diseases have to take medicines regularly. Even very young children can identify with having to take medicine. Almost all children have had shots, for example. You can explain that some children have to take medicines on a regular basis, and that these medicines can be given in different forms.



If they ask if the needles hurt or the medicines taste bad, say that probably yes, but the children become used to it, and that they really like the way the prescribed medicines usually make them feel much better.

5. Use the book to open a conversation about what to do when children see someone with a physical difference or disability. Pointing, staring, or talking about and not to the person with physical differences hurts feelings. (See "3 Tips.")

6. Use the book as a teaching opportunity to talk about values and character qualities.

All children benefit from learning about character qualities. Use the book to open a door for talking about qualities like kindness, honesty, and patience. Help them learn empathy for people with differences.

7. You may need to explain that rare diseases are not contagious.

Sometimes children do not express their fears out loud. It is possible that they may wonder if they might have or can catch a rare disease. Explain to children that a rare disease is not like the flu or a cold but something some children develop before they are born.

If they ask about pediatric cancer, then you can encourage them that Evren says that they should (1) make healthy choices about food and exercise; and (2) think instead about learning and having fun and adventures.

You might also state in a succinct and age-appropriate way that doctors and nurses take good care of children with cancer and that good medicines exist to help cure these conditions.