



Down Syndrome Association
of Central New Jersey



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Talking to Your Child About “What is Down Syndrome?”

Does your child have a peer, classmate, friend or family member with Down Syndrome (or another disability)?

Chances are when the person they know is a baby, infant or even a toddler your child may not notice that a disability or difference is present. However, at some point, your child will notice and may have questions. Having an open conversation can be helpful to ensure your child will have less bias and clear perceptions, be more comfortable and free of misconceptions about the person they know.

If you are not sure if you clearly understand what Down Syndrome is then please first read up on the condition yourself before discussing with your child, as you would not want to be the source of false information. Hopefully you can help dispel myths about Down Syndrome rather than propagate them. See our attached Document About Down Syndrome for some basic information.

You may decide it is time to discuss things with your child for a number of reasons. Your child may ask, what is “wrong” with the person they know with Down Syndrome or why they behave or look a certain way. You may also decide to discuss things with your child before they ask or if you sense they have some uncertainties or discomforts with regards to the person they know.

Here are some key points for discussing Down Syndrome with your child.

- ❖ Explain – the person they know has Down Syndrome (this is not a disease, ailment, or illness). This is a condition which developed before they were born. The cells in the body of people with Down Syndrome have 47 chromosomes (the things that carry our genes) instead of 46 which most people have. This extra chromosome may give them some special physical characteristics (appearance traits) and may cause them to learn a bit differently. They are not sick. They have unique strengths and talents just like your child.
- ❖ Explain – NOTHING is *wrong* with the person they know. Rather the person may have certain special challenges with learning and/or coordination and strength which means it may take them a bit more time and effort to learn certain things or perform certain tasks.

❖ Explain and stress - **Someone with Down Syndrome is MORE ALIKE THEN DIFFERENT**

- Focus on the similarities. It is human nature for people to feel uncomfortable around people perceived to be “different” from them. By pointing out the similarities shared, your child will feel more comfortable with the differences they may have noticed and rather will focus on the similarities. Normalize it! Just like we teach our children about how people are different with regards to hair color, skin color, talents and personalities, people are also different with regards to how quickly they learn and how strong or coordinated they are – this does not make them better or worse or normal or not normal. Children with Down Syndrome are just as likely to enjoy art, music, dance, swimming, reading, playing on the playground or sports. Another similarity you may want to point out to your child is that children with Down Syndrome also like to make friends, have friends, and be accepted!
 - Explain that a child with Down Syndrome will be able to do nearly everything a child without Down Syndrome can do – such as walk, run, swim, play sports, read, write, go to college, work and live a meaningful, productive life – they just may need a little additional support and help to achieve these skills and endeavors.
 - If upon conversation you and your child discover that indeed they do share a lot in common, then encourage your child to seek friendship with the person they know as they will likely be surprised what a great friend they may receive in return.
- ❖ Explain and encourage “*People First Language*” (for older children and teens).
- People with Down Syndrome should always be referred to as a person first such as “a person with Down Syndrome” rather than a “Down Syndrome kid” or “Down’s Kid”
 - People “have” Down syndrome, they do not “suffer from” it and it is not a disease.
 - **Terms such as retarded should be avoided** and replaced with “intellectual or cognitive disability” when referring to a persons challenges. The word retarded should also never be used casually or in a derogatory manor such as referring to something or someone unpleasant or considered inappropriate as “that is so retarded.” Using this word is hurtful and suggests that people with disabilities are not competent.

Written for the Down Syndrome Association of Central New Jersey by Melissa Burgos, MD

- See more at: <http://www.ndss.org/Down-Syndrome/Preferred-Language-Guide/#sthash.zjUAh5II.dpuf>

