



INCLUSIVE 4-H: DOWN SYNDROME

WHAT IS DOWN SYNDROME?

Down syndrome is a condition in which a person is born with one extra copy of chromosome 21. Typically, a baby is born with 46 chromosomes and someone with Down syndrome has 47. This extra copy changes how the baby's body and brain develop. Down syndrome is usually caused by an error in cell division called nondisjunction. It is not clear to medical professionals why this happens.

Usually, people with Down syndrome will have an IQ in the mildly to moderately low range and may be slower to speak than other children.

Down syndrome typically causes unique physical changes due to the abnormal pre-natal development. Some of these physical differences that may cause challenges in day-to-day life include:

- Underdeveloped ears, leading to hearing challenges and ear infections
- A tongue that tends to stick out of the mouth
- Small hands and feet which can affect motor skills
- Poor muscle tone or loose joints

People with Down syndrome also frequently experience other medical challenges such as sleep apnea, eye diseases, and heart defects at birth. Down syndrome can cause delays in physical and intellectual milestones compared to their neurotypical peers. A child with Down syndrome may learn to walk and talk later in life than a child without Down syndrome. The developmental challenges can create barriers to communication and education. A child with Down syndrome may or may not be able to complete the same school courses as their peers without Down syndrome.

Many children with Down Syndrome benefit from special services to improve their physical and intellectual abilities, helping them develop to their full potential. These services include speech, occupational, and physical therapy.

People with Down syndrome may look and act similar, but each person has different abilities. It is important to remember that children with Down syndrome are more similar to their peers than they are different. They should be given the same opportunities for growth as anybody else. After graduation, many people with Down syndrome are able to enter the workforce or post-secondary education. Each person's needs, skills, and desires are unique and the person should be encouraged to explore and develop them.

IMPORTANT CONSIDERATIONS

- Have contact information for parents or guardians and the member's doctor in an accessible place. An example of this would be behind the child's nametag and in the medical forms box at the location of 4-H events. This form should include information such as what kinds of medications the child is taking, allergies, if any adaptive devices are used, and other health conditions.
- Visit with the member and his or her family to discuss accommodation needs in the 4-H setting. If the family is unfamiliar with the 4-H program, describe how it works and develop an accommodation plan for the 4-H member. Examples of questions to ask could include: "What projects are you interested in and how can we modify them to meet your needs?" and "What would you like to accomplish through 4-H (new skills, new friendships, learn new things, etc.)?"
- Learn what the member enjoys and try to weave that into the 4-H experience (e.g., including their favorite food as a snack, having their favorite color marker for craft projects, etc.)
- Avoid stereotyping someone with Down syndrome. Always make an effort to learn what makes them unique just as you would any other 4-H member. People with Down syndrome are capable of many things, but may not always be able to show or communicate their skills in new settings.
- Some accommodations for a member with Down syndrome may include:
 - a. Break down tasks and activities into small pieces and allow extra time to complete a task.
 - b. Avoid long periods of time where the member will be required to sit quietly, and keep activities short and interesting.
 - c. Allow the member to have an assistant during certain tasks to help with communication and understanding (e.g. another 4-H member or a family member). Someone with Down syndrome may process information at slower rate of speed and in certain situations (such as during a livestock show), this can cause problems. Having a helper show them what they need to do can help with participation.
 - d. Create a safe and welcoming environment by ensuring the other 4-H members are including the member with Down syndrome in activities.
 - e. Some members with Down syndrome may need more accommodations than others; a lot of this will depend on the activities to be completed and the member's level of comprehension.
- Consider offering training to 4-H volunteers about interacting with 4-H members who have disabilities.

ADDITIONAL RESOURCES

There are multiple types of Down Syndrome. For more information about Down Syndrome types and symptoms, you can visit www.CDC.gov or www.globaldownsyndrome.org

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