

Down Syndrome

TIPS AND RESOURCES FOR FAMILIES



What causes Down syndrome?

Individuals with Down syndrome usually have an extra copy of chromosome 21. Although some cases may have a slightly different cause, all cases involve chromosome 21. Down syndrome occurs in about 1 in every 700 to 1,000 births. The chance of giving birth to a baby with Down syndrome increases if the mother is over 35 years old. Down syndrome affects both males and females of all ethnic and socioeconomic backgrounds. It is the most prevalent chromosomal cause of intellectual disability, and most cases are not familial (heritable).

What are the effects of Down syndrome?

Down syndrome results in higher-than-normal risks for many medical conditions, most notably congenital heart disease (most correctable by surgery), hearing and vision impairments, gastrointestinal problems, leukemia, and Alzheimer's disease. It is characterized by an expected life span (55 to 60 years on average) that, although shorter than the general population, has quintupled over the last century. Persons with Down syndrome should see a physician to monitor these medical conditions.

Individuals with Down syndrome have distinctive cognitive, language, and behavioral profiles. In general, they have higher levels of adaptive behavior (e.g., self-care, getting along with others) than of intelligence. For most persons with the syndrome, expressive language, grammar, and speech articulation are particularly challenging. Most individuals are able to function successfully in integrated school, living, and work environments.

Can Down syndrome be treated?

Early intervention is the best treatment for young children with Down syndrome. Children should begin physical therapy and developmental education as soon as possible. With appropriate supports, students with Down syndrome can be educated in general education classrooms with typically developing peers. High-quality early intervention, education, and supports for work and community living enable most individuals with Down syndrome to live long, productive lives.

What are the special needs of my family?

Family supports are helpful. Membership in organizations such as a local Down Syndrome Association chapter or The Arc helps families connect with others facing similar issues across the life span. Training programs are available to help parents understand special education law and to become effective advocates for their children. Support groups may be helpful to siblings or other family members. A broad range of adult community services are available, including centers for independent living and self-advocacy programs.

Please see reverse for resources.



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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center** (VKC) works with and for people with disabilities and their family members, educators and service providers, researchers, students, and policy makers. Faculty and staff engage in interdisciplinary research, training, service, and information dissemination and work in collaboration with local, state and national networks and partners. (615) 322-8240, toll-free (866) 936-8852, vkc.vumc.org

Down Syndrome Clinic

The Monroe Carell Jr. Children's Hospital at Vanderbilt offers a clinic for children referred by their primary care provider. The Clinic provides comprehensive medical care that includes a variety of specialty services. A Vanderbilt Kennedy Center social worker meets with families to provide information about related therapeutic and educational services. Contact (615) 343-3696 or toll-free (866) 900-3696.

Next Steps at Vanderbilt University

Inclusive 4-year certificate program for persons ages 18-26 with intellectual disability on the Vanderbilt campus. Contact NextSteps@vanderbilt.edu or (615) 322-3978.

Sibling Programs

Support for siblings who have a brother or sister with a disability, chronic health care issue, or mental health concern. SibSaturdays, ages 5 to 12 and Tennessee Adult Brothers and Sisters (TABS), ages 18+. Contact info.tabs@vumc.org.

Tennessee Disability Path inder

Tennessee Disability Pathfinder provides free information, referral sources, and help with navigating services via phone, email, and website. Assistance is available to individuals of all ages, all types of disabilities, and all languages spoken. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and is partially funded by Tennessee Council on Developmental Disabilities and other state agencies. (615) 322-8529, toll-free (800) 640-4636, TNPathfinder.org

Take Part in Research

StudyFinder is a searchable database that lists current VKC studies. Studies seek people of all ages with and without developmental disabilities. See vkc.vumc.org/studyfinder. Research Match is a secure place for volunteers and researchers to connect. See researchmatch.org

Best Buddies

Best Buddies Colleges, an international organization, pairs people with intellectual disabilities in one-to-one friendships with college students. For chapter, see <https://anchorlink.vanderbilt.edu/organization/bestbuddiesvandymed>

Other Resources

- Down Syndrome Association of Middle Tennessee www.somethingextra.org, (615) 386-9002.
- Health Library, Jr. League Family Resource Center, Monroe Carell Jr. Children's Hospital at Vanderbilt www.childrenshospitalvanderbilt.org/information/family-resource-center
- International Mosaic Down Syndrome Association www.imdsa.org, 1-888-IMDSA-21
- KidsHealth information for kids, teens, and parents www.kidshealth.org
- National Down Syndrome Congress www.ndsccenter.org, (800) 323-6372
- National Down Syndrome Society
Tennessee chapters: Chattanooga, East Tennessee, Memphis and Mid-South, Middle Tennessee, plus other affiliated organizations. www.ndss.org, (800) 221-4602
- The Arc US www.thearc.org, (800) 433-5255
- The Arc Tennessee www.thearctn.org, (800) 835-7077 or (615) 248-5878. See also Tennessee chapters.
- STEP (Support & Training for Exceptional Parents) tnstep.info, (800) 280-STEP
- Tennessee Developmental Disabilities Network TNDDNetwork.org

