National Association for Down Syndrome (1960–) [1]

By: Rauch, Grace


Editor's Note: The following article contains discussion of terms that, as of 2022, are no longer acceptable for describing people with disabilities. Terms such as "Mongolism," "Mongoloid," and "retarded" belong to the people who originally used them and do not reflect the views of the Embryo Project authors and editors.

The National Association for Down Syndrome, or NADS, is an organization [6] that was founded in 1960 by Kathryn McGee in Chicago, Illinois, to support people with Down syndrome [7] and their families in improving their quality of life. Originally named the Mongoloid Developmental Council, NADS is one of the oldest organizations serving people with Down syndrome [8] and their families in the United States. According to NADS, Down syndrome [8] is a genetic condition that occurs in one in every seven hundred ninety-two people and that causes delays in physical and intellectual development. Members of NADS work to provide information, resources, and access to services and programs for families with Down syndrome [8], educate the public, address social policy issues and challenges, and facilitate advocacy efforts within the Down syndrome [8] community. For over sixty years, NADS has helped support individuals born with Down syndrome [8], one of the most common genetic disorders, in the US to find acceptance, develop their capabilities, and work toward independence.

Down syndrome [8], also called Trisomy 21, is a developmental disorder that occurs when an individual has an extra copy of the twenty-first chromosome, giving them extra genetic material. Down syndrome [8] is characterized by distinct facial features and intellectual disabilities. People with Down syndrome [8] were historically institutionalized and were often isolated. Down syndrome [8] was first described as "Mongolism" in 1866 by John Langdon Down, a physician and medical researcher who worked during the nineteenth century. Down used the term "Mongolism" because he associated the characteristic facial features of Down syndrome [8] with people of Mongolian origin. The condition was called "Mongolism" until the early 1970s, when Gordon Allen, a researcher studying genetics in the mid-twentieth century, and his colleagues urged others to no longer use the term due to its racist origins. Thus, the condition was renamed Down syndrome [8], after Down. In this Embryo Project Encyclopedia article, we will refer to the condition as Down syndrome [8] throughout, though most researchers and physicians did not adopt the term Down syndrome [8] until the late 1960s and early 1970s.

According to NADS, the original purpose of the organization [6] was to serve as a support group for families of children with Down syndrome [8]. In 1960, McGee and her husband Martin McGee gave birth to their daughter, Tricia, in Chicago. The family pediatrician told the couple that their daughter had Down syndrome [8]. Their pediatrician recommended placing her in an institution, as was common at the time, because Tricia would never walk or talk, but the McGees decided to take her home. At the time, parents of newborns with Down syndrome [8] did not have access to advice, direction, encouragement, or any other type of support because there were no organizations or support groups available. After giving birth to Tricia, McGee began reaching out to parents of children with Down Syndrome and health professionals to find resources and support. In 1960, McGee used the support tools and community she had found on her own to create the Mongoloid Development Council, or MDC, to provide resources to other people with Down Syndrome and their families.

As a mainly parent-driven organization [6] when the group started in 1960, their activities primarily focused on setting up meetings, arranging speakers, sharing the latest information on Down syndrome [8], and providing support to new parents of children with Down syndrome [8]. In the 1960s, the group began to actively involve professionals to speak on Down syndrome [8] at their meetings held in McGee's home and in downtown Chicago for many years. Though McGee founded the organization [6] and fulfilled the role of president, her official title was Executive Secretary because, according to NADS, it was socially unacceptable for women to serve as presidents of organizations during the 1960s and that even being secretary was considered radical. McGee sustained the organization's success through secretarial work, meeting planning, writing newsletters, bringing in speakers, answering phone calls, and many other tasks.

In the early 1960s, Marjorie Lee, a knowledgeable parent advocate, and her husband became involved as leaders in the organization [6]. In 1961, the MDC elected Lee's husband John as president of the organization [6], and he arranged nonprofit status for the organization [6]. Lee visited hospitals in the area with McGee to convince the hospital staff to call them when a child was born with Down syndrome [8] so that they could immediately connect with the children's families and provide them support. The pair of women also put effort toward educating doctors, arranging education for preschool aged children with Down syndrome [8], overcoming intellectual disabilities that cause individuals with Down syndrome [8] to have lower traditional measures of intelligence, and providing opportunities for the children to become involved in the community. On 10 September 1963, MDC gained official status when McGee filed a certificate of incorporation with the Illinois Secretary of State. That made the MDC the first known officially organized support group for families of children with Down syndrome [8], which allowed the organization [6] to reach more people. Lee's husband remained an active president until he resigned in 1984 and various other people led MDC.
Throughout the 1960s, MDC also began holding conferences where they invited professionals who studied Down syndrome to meet and share their research regarding the condition. In 1965, Helmut Haubold, a physician working in Munich, Germany, spoke at an MDC conference about his method of treatment for Down syndrome called the Haubold treatment and the importance for children with Down syndrome to maintain good health, along with getting social, intellectual, and educational stimuli. Additionally, Jérôme Lejeune, the researcher who had discovered that Down syndrome was caused by a chromosomal abnormality in 1958, spoke at several conferences that MDC held throughout the decade.

During the 1960s, several changes occurred regarding how people with Down syndrome were labelled that influenced how MDC discussed the condition and their own work. In 1965, the World Health Organization recommended changing the name "Mongolism" to Down syndrome after John Langdon Down because of the misleading racial connotation. On 10 April 1972, MDC officially changed its name to National Association for Down Syndrome, or NADS, to reflect the global name change for the condition that occurred in 1965. NADS also made the decision to change their materials to reflect the change and exclude the word "Mongolism."

Throughout the 1970s, McGee worked with several other groups that had missions complementary to NADS to create larger support networks for people with Down syndrome. In 1972, McGee worked with two doctors to start a Down syndrome group to work with the National Association for Retarded Citizens, or NARC. She co-founded the National Down Syndrome Congress, or NDSC, in 1973 as the second nationally known support group for Down syndrome. As of 2022, the NDSC continues to dedicate its efforts as a nonprofit organization toward an improved world for individuals with Down syndrome through advocacy, public awareness, and information.

McGee resigned as the leader of the organization in 1975. At that time, she became dedicated more time to long-term concerns for individuals with Down syndrome, including becoming active with the Misericordia Heart of Mercy, a facility in Chicago that houses individuals with developmental disabilities where her daughter Tricia lived.

In 1974, Sheila Hebein, another mother of a child with Down syndrome, was elected to the board of directors of NADS, where she served until she took on the role of Executive Director in 1979. During her time in NADS, she worked closely with other professional and Down syndrome organizations such as the National Down Syndrome Congress, National Down Syndrome Society, and the Down Syndrome Affiliates in Action. Hebein helped develop local support groups for people with Down syndrome and their families, as well as a temporary foster care program that helped find homes for children with Down syndrome. Hebein also helped create the Parent Support Program, which trained parents to offer support and counseling to new families that received a Down syndrome diagnosis or had a child with Down syndrome, and a Hospital Education Program that educated medical professionals on current Down syndrome information and encouraged them to refer new parents to NADS. In 1975, Hebein formed the first local support group for families of people with Down syndrome.

In the second half of the 1970s, NADS launched new programs to help train parents to support their children with Down syndrome and ensure that people with Down syndrome had adequate access to education. In 1975, US President Gerald Ford signed into law the Education for All Handicapped Children Act, called the Individuals with Disabilities Education Act, or IDEA, as of 2022, which made it federal law that children with disabilities had access to education. Despite the passage of IDEA, many families whose child had Down syndrome still lacked access to appropriate education. NADS developed programs to assist those families in fighting for their child’s newly legalized rights. In 1979, NADS developed the Parent Support Program to train volunteer parents of children with Down syndrome to mentor, support, and share resources with new parents of a child with Down syndrome and to help parents face the challenges that sometimes arise in raising a child with Down syndrome.

In the 1980s, NADS expanded their efforts to provide better support and education to people with Down syndrome and their families. In 1980, NADS began to consistently hold their research conferences for families and professionals every other year. Also in 1980, NADS launched their first Hospital Education Program to educate doctors in the Chicago area about referring new parents of a child with Down syndrome to their organization. The Hospital Education Programs educate medical professionals on current information on Down syndrome, prepare the professionals to give sensitive care and support, and increase referrals to NADS’s Parent Support Program. In 1982, NADS created a foster care program in collaboration with the Illinois Department of Children and Family Services and a private adoption agency. The program allowed several NADS families to become licensed foster families and facilitated adoption for children with Down syndrome during a time when it was more common for parents to relinquish their rights to their child with Down syndrome. In 1984, NADS trained its first group of Public Speakers to deliver educational presentations about Down syndrome because the need for their education programs in Chicago hospitals was growing.

Into the 1980s, according to NADS, many parents of people with Down syndrome perceived that medical professionals were not adequately treating those diagnosed with Down syndrome and that individuals with the condition needed greater legal protection. According to the Global Down Syndrome Foundation, some medical professionals at the time were withholding lifesaving medical treatment from infants and children with Down syndrome and even starving some newborns to death. NADS fought against those medical practices. According to NADS, Hebein, who continued to serve as the organization’s Executive Director, participated in national conversations to push for more protections for infants with Down syndrome. One such...
conversation that was happening at the time had to do with adding an amendment to the US Child Abuse Law, a law that considers physical and mental harm, neglect, and sexual abuse of a minor a crime. Advocates specifically pushed for such protections after a controversial case in Indiana in 1982, when the parents and doctors of a newborn with Down syndrome [8] born with several feeding defects decided to starve the newborn rather than conducting the life-saving surgery the newborn needed to survive, as they did not see the newborn as worth saving. That case catalyzed a push for an amendment called the Baby Doe Amendment [11] to the Child Abuse Law to require hospitals and physicians to provide impaired infants maximal care to be eligible for federal funding. The Baby Doe Amendment was added to the Child Abuse Law in 1984. That was the first law to mandate the protections that Hebein and other advocates had been pushing for over the course of many years.

In 1987, NADS trained a group of parent volunteers called Education Facilitators to assist and advocate for parents experiencing problems with their school districts and dealing with education challenges. NADS states that parents often experienced problems when their child with Down syndrome [9] transitioned between grades and with their child feeling excluded in a traditional classroom setting. Another NADS program, called the Parent-to-Parent program, gave parents in the Chicago metropolitan area the opportunity to get advice and share their experiences with other NADS parents. NADS also provided education programs to make other children in schools aware of children with Down syndrome [8] and how they have gifts and challenges.

In the late 1980s, NADS also launched new programs specifically aimed at meeting the needs of adults with Down syndrome [8]. According to NADS, adults with Down syndrome [8] often were shunned and neglected throughout their lives, and many were institutionalized, put into group homes, or separated from their families at some point in their lives. NADS helped connect adults with Down syndrome [8] with counselors and other individuals with Down syndrome [8] to help them build community and receive psychological support. In 1989, NADS created the Family Study and Service Program at the University Affiliated Program for Developmental Disabilities, at the University of Illinois [12] in Chicago, Illinois. The University Affiliated Program allowed Dennis McGuire, who had an extensive background in family counseling, to work with NADS families in the Chicago metropolitan area by providing home visits, counseling and referral services, and address some of the psychosocial problems in adults with Down syndrome [8].

In the 1990s, NADS published materials to help correct inaccuracies and myths in some earlier publications on Down syndrome [8], opened the Adult Down Syndrome Center, and created programs to increase support for adults with Down syndrome [8]. In 1990, NADS published a twelve-page booklet for new parents titled “A Baby First” for new parents. NADS also provided new parents a Special Delivery Folder they developed as a part of the new parent packet. In 1991, NADS collaborated with Lutheran General Hospital in Park Ridge, Illinois, to open the Adult Down Syndrome Center, or ADSC, in January 1992. The ADSC provides medical care to teens and adults with Down syndrome [9]. The work of the Adult Down Syndrome Center allowed NADS to become aware of the needs of families in crisis and developed a Specialized Respite Care Program to assist the families in need of immediate intervention. In 1997, NADS developed the Adult Mentoring Program because the organization [8] found that many individuals with Down syndrome [8] were lonely. That program provides support to young adults who were experiencing isolation and needed opportunities to get involved, which created an environment for adults with Down syndrome [8] to make new friends.

In 1998, NADS held their first Family Behavior Retreat, which is a weekend retreat offered to families of children with Down syndrome [8]. The retreats benefitted the children through engaging activities, while the parents were able to learn new ways to help their child and get connected with other families that could share their experiences and support and encourage each other. Also in 1998, NADS began providing special services through a group called Down Syndrome and More. The group serves families whose child with Down syndrome [8] has an additional diagnosis, such as autism or ADHD. Autism, or autism spectrum disorder, is a developmental disability that impacts the nervous system and impacts communication and social interaction. ADHD, or attention deficit hyperactivity disorder affects a person’s ability to pay attention and may cause hyperactivity. Like Family Behavior Retreats, NADS offers a More Than Down Syndrome Retreat for families with a child who has a dual diagnosis.

During the 1990s and early 2000s, NADS implemented a work experience program, which was a program at the Adult Down Syndrome Center to help individuals with Down syndrome [9] who graduated from high school or a special education program, but lacked the skills and options for a career. The program provided teens and adults with Down syndrome [8] the opportunity to develop office experience and skills needed to enter the job market. According to NADS, the work experience program no longer exists as of 2022 due to the lack of space in the Adult Down Syndrome Center as a result of increased demand for medical services.

During the beginning of the twenty-first century, NADS increased access for the Hispanic community as well as addressed social concerns such as genetic counseling and education. In 2005, NADS expanded their efforts to serve the Hispanic community by formalizing a program for Hispanic families, making materials more accessible, hiring a bilingual coordinator, providing access to bilingual volunteers, and collaborating with other organizations in the Chicago area that are already serving the Hispanic population. NADS’ executive director spoke at a conference in 2007 for genetic counselors. Another concern NADS had about the medical community was early detection of Down syndrome [8] and biases that could influence life and death decisions, as well as physician care. NADS has continued to fight for children with Down syndrome [8] to have a level playing field not only after they are born, but before. In the 2010s, more students with disabilities were included in general education classes and received more care from the Adult Down Syndrome Center as the demand increased. McGee, who founded the organization [8],
As of 2022, NADS continues to fulfill their mission by providing their services to people and members in the US. Linda Smarto, the mother of three daughters, one of whom was born with Down syndrome, serves as the Executive Director for NADS where she supports and enhances NADS' programming to better serve people with Down syndrome and their families. Smarto has been volunteering with NADS for over twenty-five years as of 2022 and joined the staff of NADS in 2010. She has been volunteering with NADS since 2010 and joined the staff of NADS in 2010. NADS continues to work for over twenty-five years as of 2022 and joined the staff of NADS in 2010. He has remained involved with NADS through special projects, attending meetings, and serving on the team of the Adult Down Syndrome Center. NADS continues to hold their conference for parents and professionals every other year, with a concurrent conference to educate teens and adults with Down syndrome about social relationships, issues, resources, community development, work skills, and other inclusive drama and dancing. As of 2022, NADS has existed for over sixty years to support all persons with Down syndrome in achieving their full potential. Since their inception, NADS has supported Down syndrome research, released accurate medical information about the condition. They have also created dozens of programs to support individuals with Down syndrome and their families, educate doctors, and increase awareness. NADS started at a time when people with Down syndrome were commonly shunned or institutionalized and has worked over the duration of its existence to fight for acceptance and care for people with Down syndrome. Social misconceptions about children with Down syndrome continue to affect many people, but NADS continuously works to educate communities about what Down syndrome is, helping to allow people with Down syndrome to be more included throughout society and have access to education and resources they need. As of 2022, NADS continues to raise awareness for Down syndrome and helps to improve the lives of people with Down syndrome and their families.

Sources

The National Association for Down Syndrome, or NADS, is an organization that was founded in 1960 by Kathryn McGee in Chicago, Illinois, to support people with Down syndrome and their families in improving their quality of life. Originally named the Mongoloid Developmental Council, NADS is one of the oldest organizations serving people with Down syndrome and their families in the United States. According to NADS, Down syndrome is a genetic condition that occurs in one in every seven hundred ninety-two people and that causes delays in physical and intellectual development. Members of NADS work to provide information, resources, and access to services and programs for families with Down syndrome, educate the public, address social policy issues and challenges, and facilitate advocacy efforts within the Down syndrome community. For over sixty years, NADS has helped support individuals born with Down syndrome, one of the most common genetic disorders, in the US to find acceptance, develop their capabilities, and work toward independence.

**Subject**
- 21 trisomy
- Children with Down syndrome
- Mothers of children with Down syndrome
- Down syndrome--Patients--Biography
- Chromosome abnormalities
- Chromosomal mosaicism
- Down Syndrome
- Down's Syndrome
- Amniocentesis
- Trisomy
- Learning Disabilities
- Developmental Disabilities
- Disabled Children
- Disabled Persons
- Persons with Mental Disabilities

**Topic**
- Disorders
- Organizations
- People
- Ethics

**Publisher**
Arizona State University. School of Life Sciences. Center for Biology and Society. Embryo Project Encyclopedia.

**Rights**
Copyright Arizona Board of Regents Licensed as Creative Commons Attribution-NonCommercial-Share Alike 3.0 Unported (CC BY-NC-SA 3.0) http://creativecommons.org/licenses/by-nc-sa/3.0/

**Format**
Articles

**Last Modified**
Thursday, December 22, 2022 - 21:09

**DC Date Accessioned**
Thursday, December 22, 2022 - 20:55

**DC Date Available**
Thursday, December 22, 2022 - 20:55

**DC Date Created**
2022-12-22

- Contact Us

© 2021 Arizona Board of Regents

- The Embryo Project at Arizona State University, 1711 South Rural Road, Tempe Arizona 85287, United States

**Source URL:** https://embryo.asu.edu/pages/national-association-down-syndrome-1960

**Links**