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CIDSO NEWS

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Social Security and Down Syndrome

By Molly Clarke, SSDI Help Blog Writer

Although children with Down syndrome can become self-sufficient, hold a job, and even live independently, some individuals with Down syndrome may need increased levels of support throughout their entire lives. This can put a significant financial strain on a family or caregiver.

If you or a loved one has Down syndrome, you may be eligible to receive Social Security Disability benefits. These benefits can be used to offset the cost of day-to-day expenses and supportive care. This article will walk you through the basics of SSD benefits and will provide you with the information needed to begin the application process.

Disability Benefit Programs

The Social Security Administration provides two separate disability programs for which individuals with Down syndrome may qualify: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Both programs have distinct requirements, so choosing the right SSD benefit program depends on your specific circumstances. Let's take a look at each program:

SSDI is intended for disabled workers and their families. It is funded through payroll taxes, meaning applicants must have significant work history and must have paid Social Security taxes over the course of their employment. If you or your loved one have not held a job consistently for some time, it is not likely that you will qualify for SSDI. Learn more about qualifying for this program, <http://www.disability-benefits-help.org/ssdi/qualify-for-ssdi>. Individuals who qualify for SSDI will become eligible to receive Medicare after a two year waiting period.

SSI is a needs-based benefit program that pays benefits to disabled individuals of all ages. Instead of employment history or tax credits, SSI is awarded based on strict income and resource limits. For children under 18, eligibility will be based on the parent's income. Learn more about qualifying for SSI <http://www.socialsecurity.gov/ssi/text-eligibility-ussi.htm>. Individuals who qualify for SSI will automatically be eligible to receive Medicaid.

Medical Eligibility Requirements

In addition to the requirements listed above, the Social Security Administration also maintains a guidebook of disabling conditions called the "blue book". Applicants must meet specific medical criteria contained in the blue book to receive benefits. Part A of the guidebook contains listings for adults and Part B contains listings for children.

Non-mosaic Down syndrome is listed under section 10.06 for adults or 110.06 for children (Congenital Disorders that Affect Multiple Body Systems). These listings require that applicants provide the SSA with the following medical evidence:

A laboratory report of karyotype analysis signed by a physician, or an unsigned karyotype analysis *and* a physician's statement that the applicant has Down syndrome; or

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A physician's report stating that you have chromosome 21 trisomy or chromosome 21 translocation consistent with prior lab analysis, as well as the distinctive physical features of Down syndrome; or

A physician's report stating that you have Down syndrome with the distinctive physical features *and* evidence demonstrating that you function at a level consistent with non-mosaic Down syndrome.

Unfortunately, there is no blue book listing for mosaic Down syndrome. But an individual with mosaic Down syndrome may still qualify for SSD benefits by matching the symptoms for another listed condition. These might include:

- Congenital heart disease – Section 4.06 (adult) or Section 104.06 (child)
- Musculoskeletal Conditions – Section 1.00 (adult) or Section 101.00 (child)
- Hearing loss – Sections 2.10 and 2.11 (adult) or Sections 102.10 and 102.11 (child)
- Organic Mental Disorders – Section 12.02 (adult) or Section 112.02 (child)

The Application Process

To apply for disability benefits as an adult over the age of 18, you can fill out the necessary forms online or in person at your local Social Security office. Be sure to have all copies of relevant medical records, employment documentation, and proof of income.

Applying for benefits on behalf of a child is slightly different. The application process for a child requires that the applicant attend a mandatory interview with an SSA representative. If you are applying on behalf of a child, you should call the SSA immediately to schedule your interview appointment. It can take several months before the next interview appointment becomes available. While you wait, you should use the time to collect all necessary documents and records. It's also important to obtain written statements from instructors or therapists who can attest to the applicant's specific limitations.

Since the approval process can take up to two years, it's important to begin right away. Even if your claim is denied, you have the right to appeal this decision within 60 days. The appeals process will give you the chance to gather more medical evidence and present a stronger claim. In fact, many more applicants are approved during the appeals process than during the initial application process.

If you remain persistent in your efforts, you or your loved one will be awarded the benefits you need. For more information about applying for Social Security Disability benefits with Down syndrome, visit <http://www.disability-benefits-help.org/disabling-conditions/down-syndrome-and-social-security-disability>

Sensory Friendly Movie

Join us for "Frozen" on Saturday, December 14, 2013 at 10:00 AM. This "sound down/lights up" movie is hosted by the Starplex Theater in Normal. The Starplex offers free child admission with one \$6 adult ticket purchase.



Kirsten Boswell: An Inspiration

Friend "MarcFirst" on FaceBook and watch the inspiring video featuring Kristen Boswell and her Mom, Wendy.



2013 CIDSO Grant Recipients

The purpose of the CIDSO Grant is to promote independence and inclusive opportunities for all people in our area with Down syndrome that they may become productive citizens with the maximum opportunity to reach their full potential as human beings. Congratulations to the following CIDSO Grant Winners:

Seedling Theatre: Funds will be put toward the 2013 Christmas Production

Parkside Junior High School: Funds will be used to purchase lower level reading books and various sensory items for the school IMC (library)

Gymnastics Etc: Funds will be used to support Lion's Spirit Cheer Team, the special needs cheer team

Coming Soon!

Christmas Party
December 1st

Sensory Friendly Movie
December 14th

CIDSO Board Meeting
January 6th

We're on the Web!

See us at:

www.cidso.org

Facebook Fan? Like Us!
Central Illinois Down
Syndrome Organization

About Our Organization

The Central Illinois Down Syndrome Organization (CIDSO) is a not-for-profit organization of families and interested persons working to increase public awareness, support families, and improve opportunities for those touched by Down syndrome. Established in 1974 to act as a support service, we serve Bloomington, Normal, and the McLean County area. Our organization is the oldest Down syndrome parent group in Illinois and the second oldest in the nation.

New Parent Outreach

The process of acceptance begins as soon as Down syndrome is suspected. To support parents and extended family during this time, a parent outreach member will gladly make hospital or home visits. Informational packets are also available to new parents. Parent Outreach Members, *Brenda & Kevin Harms*, (309) 378-2388 and *Rick & Jennifer Bauersfeld*, (309) 874-2038, can be contacted any time.

Enrichment/Participation Fund

This fund is designed to enrich the lives of those born with Down syndrome and promote community involvement/participation. It is available to any person with Down syndrome regardless of involvement/participation in CIDSO. Applications are reviewed at the quarterly board meetings and must be received by CIDSO at least 10 days prior to the board meeting. Additional details and applications can be found in the "Resource" section of the CIDOS website. <http://cidso.org/resources.asp>

Disclaimer Policy

The editor of this newsletter concerns with a professional writes as a non-professional. CIDSO does not promote or recommend any therapy, treatment, institution, political affiliation or professional system and any information contained herein shall not imply such. Please discuss specific concerns with a professional.

