

## **Care of the Adult with Down Syndrome**

### *Case Review Resources & Tools*

#### **Organizations:**

- Down Syndrome Association of Central New Jersey- <http://www.autism-society.org/>
  - Brochure included as resource
- National Down Syndrome Society (NDSS)- <https://www.ndss.org/>

#### **Resources:**

- Alzheimer's Association- Down syndrome and Alzheimer's disease: <https://www.alz.org/media/Documents/alzheimers-dementia-down-syndrome-ts.pdf>
- American Academy of Pediatrics- Health Care Information for Families of Children with Down Syndrome: [http://www.ndss.org/wp-content/uploads/2017/10/Health\\_Care\\_Information\\_for\\_Families\\_of\\_Children\\_with\\_Down\\_Syndrome-1.pdf](http://www.ndss.org/wp-content/uploads/2017/10/Health_Care_Information_for_Families_of_Children_with_Down_Syndrome-1.pdf)
- Cooley, W.C., & Hanks, C. (2019). Integrating young adult with intellectual and developmental disabilities into your practice: Tips for adult health care clinicians. Washington, DC: The National Alliance to Advance Adolescent Health. Retrieved from: <https://www.gottransition.org/resourceGet.cfm?id=367>
- Gray & Feldman- A Comparison Chart of 17-A Guardianship, Health Care Proxy and Power of Attorney: <http://gfrllp.com/Portals/gfrllp/Comparison%20Chart%20of%2017-A%20Guardianship.pdf>
- Heavey, E. & Peterson-Sweeney, K. (2010). Caring for an adult with Down syndrome. *Nursing2010*, 40(6), 53-56. Retrieved from: [https://journals.lww.com/nursing/FullText/2010/06000/Caring\\_for\\_an\\_adult\\_with\\_Down\\_syndrome.16.aspx](https://journals.lww.com/nursing/FullText/2010/06000/Caring_for_an_adult_with_Down_syndrome.16.aspx)
- McGuire, B. E., & Defrin, R. (2015). Pain perception in people with Down syndrome: a synthesis of clinical and experimental research. *Frontiers in behavioral neuroscience*, 9, 194. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4519755/>
- National Down Syndrome Society (2017). *Aging and Down Syndrome: A Health & Well-being Guidebook*. New York, NY: National Down Syndrome Society. Retrieved from: <http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>
- National Down Syndrome Society- NDSS Preferred Language Guide: <http://www.ndss.org/wp-content/uploads/2017/08/NDSS-Preferred-Language-Guide-2015.pdf>
- New Jersey Revised Statutes Title 26- HEALTH AND VITAL STATISTICS Section 26:2H-60- Determination of patient's capacity to make a health care decision (2014): <https://law.justia.com/codes/new-jersey/2014/title-26/section-26-2h-60/>
- Smith, D.S. (2001). Health care management of adults with Down syndrome. *American Family Physician*, 64(6), 1031-1039. Retrieved from: <https://www.aafp.org/afp/2001/0915/p1031.html>

- Wilson, L. (2010). American College of Preventative Medicine. Preventative Care for Adults with Down Syndrome. Retrieved from:  
<https://www.medscape.org/viewarticle/715382>

*\*Additional New Jersey and Pennsylvania Down Syndrome resources included courtesy of the Down Syndrome Association of Central New Jersey*

This work is supported with a grant funded by the New Jersey Council on Developmental Disabilities, in part by grant number 2001NJSCDD-02, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

# Who we are:

**Definition:** The Down Syndrome Association of Central New Jersey is a non-profit parent support group, established to assist families of children and adults with Down syndrome.

**Affiliations:** We are affiliated with the National Down Syndrome Congress and the National Down Syndrome Society.

**Activities:** We provide support, information and advocacy to parents, family members and professionals about Down syndrome.



call or email us

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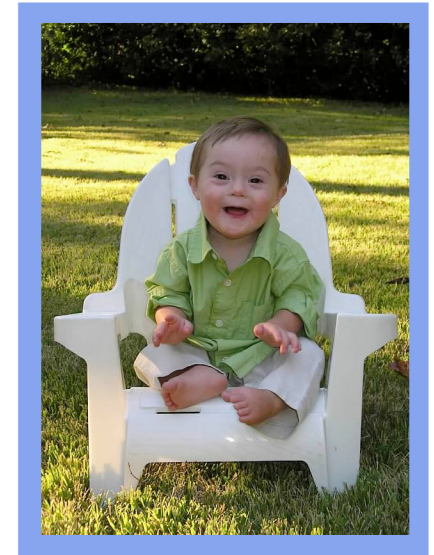


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## What we know:

### People with Down Syndrome:

- Have a chromosomal condition which results in some degree of developmental and cognitive delay.
- Thrive in loving homes and benefit from early intervention, medical care, and positive attitudes.
- Are more similar to others than they are different.
- Are attending neighborhood schools with their peers.
- Are holding competitive jobs and living in the community.
- Are dancers, skiers, hikers, office workers, child care providers and more.



### Parents and Friends of Children with Down Syndrome:

- Share common concerns.
- Often benefit from the wisdom of each other's experiences.
- Can work together to be better advocates for our children.

## What we do:

### Together we:

- Provide support and information to parents of children with Down syndrome and others.
- Offer regular meetings, social activities and resources.



- Celebrate the lives of our children and encourage them to reach their full potential.
- Educate the community about the potential and needs of people with Down syndrome.
- Promote the inclusion of all people with Down syndrome.

## How to join:

To become a member of the Down Syndrome Association of Central New Jersey please send an e-mail to [dsacnj@arcmercer.org](mailto:dsacnj@arcmercer.org).

Please tell us about yourself and your family and include your contact information in the e-mail.

Please also tell us the age of your child with Down syndrome so we can plan age appropriate gatherings.

For more information about the Down Syndrome Association of Central New Jersey or for links to other resources please visit our website at [WWW.DSACNJ.ORG](http://WWW.DSACNJ.ORG)  
We are also available to talk at 1-866-369-6796

DOWN SYNDROME ASSOCIATION  
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# Down Syndrome Association of Central New Jersey

## DS Resources for New Jersey and Pennsylvania Residents

### New Jersey Support Groups

Down Syndrome Association of Central New Jersey (Mercer County and surrounding areas of Hunterdon, Somerset, Middlesex, Monmouth and Burlington Counties, NJ and Bucks County, PA)  
<http://dsacnj.org/>

Billy's Buddies (offered through the YMCA of Wyckoff, NY)  
<http://www.wyckoffymca.org/programs-services/special-needs/>

Bringing Up Down Syndrome (Burlington, Gloucester and Camden Counties)  
<http://bringingupdownsyndrome.org/>

Central NJ Down Syndrome Parent Advocacy Group (Union, Morris, Essex and Somerset Counties)  
<https://dsparentgroup.org/>

Jersey Shore Down Syndrome Association (Monmouth and Ocean County)  
<http://jsdsa.org/>

KIIDS: Knowledge and Information about Individuals with Down Syndrome (Southern NJ)  
<http://www.kiids.info/>

Network 21 (Middlesex and Monmouth Counties)  
<http://dsnetwork21.com/>

The Down Syndrome Group of Northwest New Jersey (Warren County)  
<http://www.dsgnwnj.org/default.htm>

21 Down (Atlantic, Cape May and Southern Ocean Counties)  
<http://www.21down.org/index.htm>



### Pennsylvania Support Groups - Bucks and Montgomery Counties

Bucks County Down Syndrome Interest Group (Bucks County, PA)  
<https://bcdsig.wordpress.com>

Montgomery County Down Syndrome Interest Group (Montgomery County, PA)  
<http://www.mcdsig.org>

## Medical Resources

Children's Hospital of Philadelphia's Trisomy 21 Program

<http://www.chop.edu/service/trisomy-21/home.html>

The JUDY Center for Down Syndrome in Hackensack, NJ

<http://www.hackensackumc.org/our-services/pediatrics-joseph-m-sanzari-childrens-hospital/judy-center-for-down-syndrome/the-judy-center-for-down-syndrome/>

## New Jersey Services and Resources

New Jersey Early Intervention System

<http://www.njeis.org/>

New Jersey Department of Children and Families (up to age 21)

<http://performcarenj.com/families/disability/index.aspx>

New Jersey Division of Developmental Disabilities (age 21 and up)

<http://nj.gov/humanservices/ddd/home/>

The ARC of New Jersey

<http://www.arcnj.org/>

Statewide Parent Advocacy Network

<http://www.spanadvocacy.org/index.php>

New Jersey Coalition for Inclusive Education

<http://necie.org/>

Special Olympics New Jersey

<http://www.sonj.org/>

