

To get connected to The Arc's Down syndrome Outreach:  
(360)715-0170 ext. 304 or [jessikah@arcwhatcom.org](mailto:jessikah@arcwhatcom.org).  
Providers can refer a family by using The Arc's referral form and checking the DsO box.

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## WHATCOM COUNTY CHILD HEALTH NOTES

Promoting early identification and partnerships between families, primary health care providers & the community.

Distributed by: Down syndrome Outreach, The Arc of Whatcom County

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### AAP Health Supervision Guidelines

#### A few highlights:

- **Hearing screening:** The AAP recommends hearing screening between birth to 1 month, an audiology evaluation at 6 months old, and hearing testing annually from 1 to 21 years old.
- **Vision screening:** The AAP recommends eye exams once between birth and 1 month, and once between 1 month and 1 year. After that, ophthalmologic exams are recommended annually from 1 to 5 years old, every 2 years from 5 to 13 years old, and every 3 years from 13 to 21 years old, looking for cataracts, strabismus, and nystagmus in particular.
- **Thyroid screening:** The AAP recommends thyroid screening as part of the newborn screen during the newborn period to 1 month, then at 6 months, and annually from 1-21 years old.



### **What's new in Down syndrome? Information for counseling parents**

*"My doctor was so helpful when he told me my baby would be able to do pretty much everything I hoped he would be able to do in life, even though he had Down syndrome. That was an extreme relief."-----A physician parent of a child with Down syndrome.*

Down syndrome (DS), also called Trisomy 21, is the most common cause of intellectual disability and the most common chromosomal condition diagnosed in the United States. It is caused by an extra copy of chromosome 21. Each year, about 1 out of every 700 babies born in the United States have DS. Approximately 83,000 children and adolescents with DS are living in the United States.<sup>1</sup>

Each child with DS is different with unique strengths, challenges and abilities. Generally, individuals with DS have borderline to moderate intellectual disability and hypotonia. Additionally, individuals with DS are at greater risk than the general population for a number of health concerns including heart defects, hearing, vision and thyroid abnormalities, and obstructive sleep apnea. Between 10 and 20% of those with DS also qualify for the diagnosis of autism.

The prognosis, treatments, and perception of DS have improved in recent years and so has the need for up-to-date information for health care providers and families. The average life expectancy of individuals with DS is now 60 years, with many living into their sixties and seventies.<sup>2</sup> People with DS are attending college, obtaining employment, living independently, and getting married.

### **DOWN SYNDROME INFORMATION ACT (2016): WASHINGTON HB 2403 – WHAT YOU SHOULD KNOW**

- This law was enacted out of patients' and families' need for consistent, up-to-date, accurate, and evidence-based written information about Down syndrome. Expectant parents with a prenatal diagnosis of DS and parents of a child with a postnatal diagnosis of DS were receiving inconsistent and, at times, erroneous information. The law directs the WA Dept. of Health (WA DOH) to develop free high quality [resources](#) on DS which must:
  - Have been reviewed by medical experts and national Down syndrome associations.
  - Address accurate, non-biased views on physical, developmental, educational, and psychosocial outcomes; life expectancy; clinical course; and intellectual and functional development and therapy options.
  - Be culturally and linguistically appropriate.
  - Provide contact information for support services, including information hotlines, clearinghouses, and national and local organizations.
- The WA DOH provides free materials for health care providers and facilities for distribution to expectant parents with a prenatal diagnosis of DS and to parents of a child with a postnatal diagnosis of DS.

Developmental & Educational Outcomes	Therapy Options
<ul style="list-style-type: none"> <li>• 39.4% of individuals with DS have an IQ in the mild intellectual disability range, and 1% have an IQ in the borderline intellectual function range.<sup>3</sup></li> <li>• Attention problems, hyperactivity, oppositional behavior, defiance, and wandering off are some of the common behavior concerns reported in young children.</li> <li>• In older children, internalizing conditions such as anxiety and depression can occur.</li> </ul>	<ul style="list-style-type: none"> <li>• The most common types of therapies for children with DS: <ul style="list-style-type: none"> <li>○ Speech therapy</li> <li>○ Physical therapy</li> <li>○ Occupational therapy</li> </ul> </li> <li>• Therapies can be obtained through: <ul style="list-style-type: none"> <li>○ Early intervention services (birth up to age 3)</li> <li>○ Public school district</li> <li>○ Private therapy offices</li> </ul> </li> </ul>

### References

<sup>1</sup> CDC Website: Down syndrome Data and Statistics. <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>

<sup>2</sup> National Association for Down syndrome Website: facts about Down syndrome. <http://www.nads.org/resources/facts-about-down-syndrome/>

<sup>3</sup> Global Down syndrome Foundation Website: facts about Down syndrome. <http://www.globaldownsyndrome.org/about-down-syndrome/facts-about-down-syndrome/>

### Resources

#### Regional:

- [Down syndrome Specialty Clinic](#) at the University of Washington Center on Human Developmental and Disability (CHDD) directed by Dr. Lisa Herzig, Developmental Pediatrician, and served by an interdisciplinary team of specialists. Call 206-598-3327 for an appointment.
- [Virginia Mason Down syndrome Clinic](#) with Dr. Rebecca Partridge. Dr. Partridge is the mother of a child with Down syndrome. She is also board certified in Pediatric Emergency Medicine and a primary care provider. Call (425) 557-8000 for an appointment or to arrange a phone consultation.
- Your local children's hospital's Neurodevelopmental Department.

#### National Resources:

- The American Academy of Pediatrics [Clinical Report—Health Supervision for Children with Down Syndrome](#) by Marilyn Bull and the Committee on Genetics. *Pediatrics* 2011; 128: 393-406. ([Checklist format](#) for the AAP Guidelines)
- Hickey F, Hickey E, Summar KL. "Medical update for children with Down syndrome for the pediatrician and family practitioner." *Advances in Pediatrics* 2012 59 (1): 137-57. [doi:10.1016/j.yapd.2012.04.006](https://doi.org/10.1016/j.yapd.2012.04.006). [PMID 22789577](https://pubmed.ncbi.nlm.nih.gov/22789577/).
- [The Intellectual and Developmental Disabilities Toolkit](#) by the Vanderbilt Kennedy Center for Research on Human Development. The IDD Toolkit offers health care providers best-practice tools and a wealth of information regarding specific medical and behavioral concerns of adults with IDD including resources for patients and families.
- [Understanding a Down syndrome Diagnosis](#), a booklet from The Joseph P. Kennedy, Jr. Foundation found at [lettercase.org](http://lettercase.org). Available in both print and digital formats and in multiple languages.
- [Brighter Tomorrows](#), includes a section on Down syndrome Pregnancy. Administered by the National Center for Prenatal and Postnatal Resources at the University of Kentucky's Interdisciplinary Human Development Institute

#### Professional and Parent Groups:

- National Down syndrome Society: <http://www.ndss.org>
- National Down syndrome Congress: <http://www.ndscenter.org/>
- Down syndrome Connect, a NIH-sponsored national registry for those with Down syndrome to keep families informed of opportunities to participate in studies as they become available: <https://dsconnect.nih.gov>
- Regional Support Networks: <http://www.doh.wa.gov/Portals/1/Documents/Pubs/344-066-DownSyndromeResources.pdf>

### WHATCOM COUNTY SPECIAL NEEDS INFORMATION AND RESOURCES:

- For children birth through age 18
- For children under age three:
- For children age three and older:

