

# Pediatric Healthcare Guidelines from 12-21 years

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# American Academy of Pediatrics Health Supervision for Children and Adolescents with Down Syndrome

Guidelines were first created in 1994. They were revised in 2011, and most recently in 2022.

<https://publications.aap.org/pediatrics/article/doi/10.1542/peds.2022-057010/186778/Health-Supervision-for-Children-and-Adolescents>



# Concerns throughout Childhood

From ages 12 to 21 years there are common issues that your child's provider will evaluate each year through a history, and physical exam.

Testing includes assessment of hearing hearing and vision.

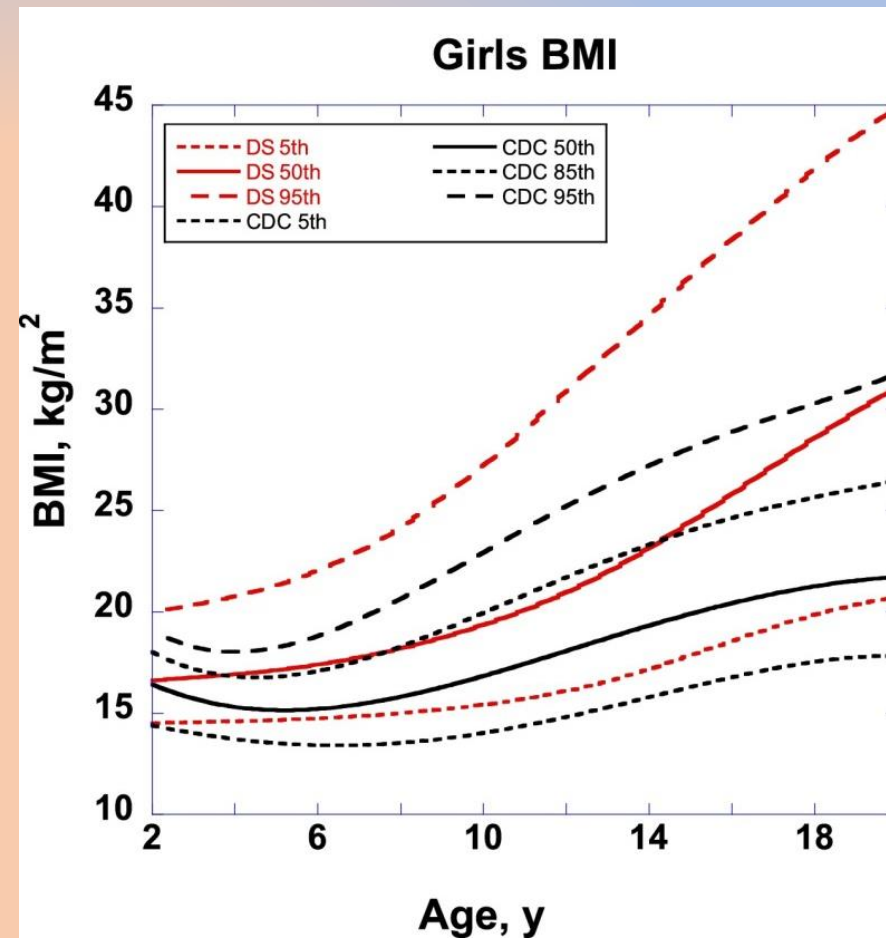
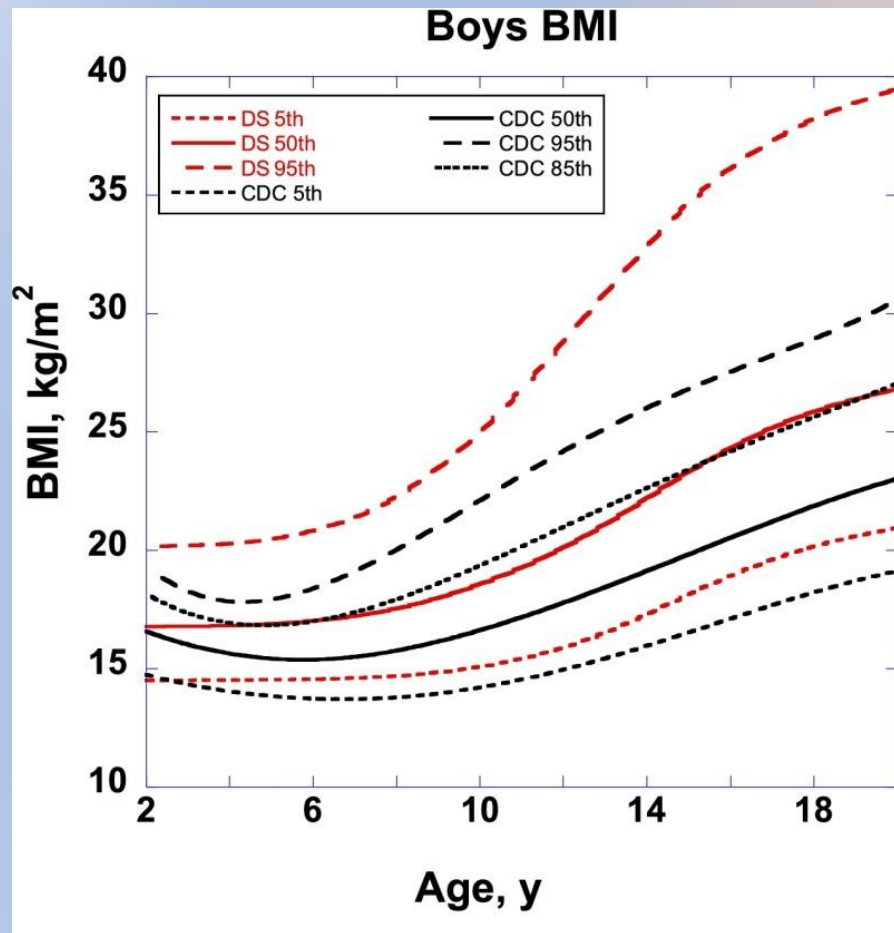
Vaccines are per the usual schedule – people with Ds are at high risk from respiratory infections so it important to discuss COVID, flu, and pneumonia vaccines with the provider



# Nutritional Status

Monitor weight

Look at BMI on the chart not specifically for people with Ds to gauge weight status



[Pediatrics. 2016 Oct; 138\(4\): e20160541.](#)  
 doi: [10.1542/peds.2016-0541](https://doi.org/10.1542/peds.2016-0541)

Many teens and adults with Ds are overweight or obese and that puts them at risk for medical problems such as sleep apnea, type 2 diabetes, and joint problems

A healthy diet and regular exercise are important to prevent weight gain

A complete blood count and iron studies are recommended yearly





# Obstructive Sleep Apnea

Symptoms can include:

Snoring

Restless sleep

Daytime sleepiness

Nighttime awakening

Behavior problems

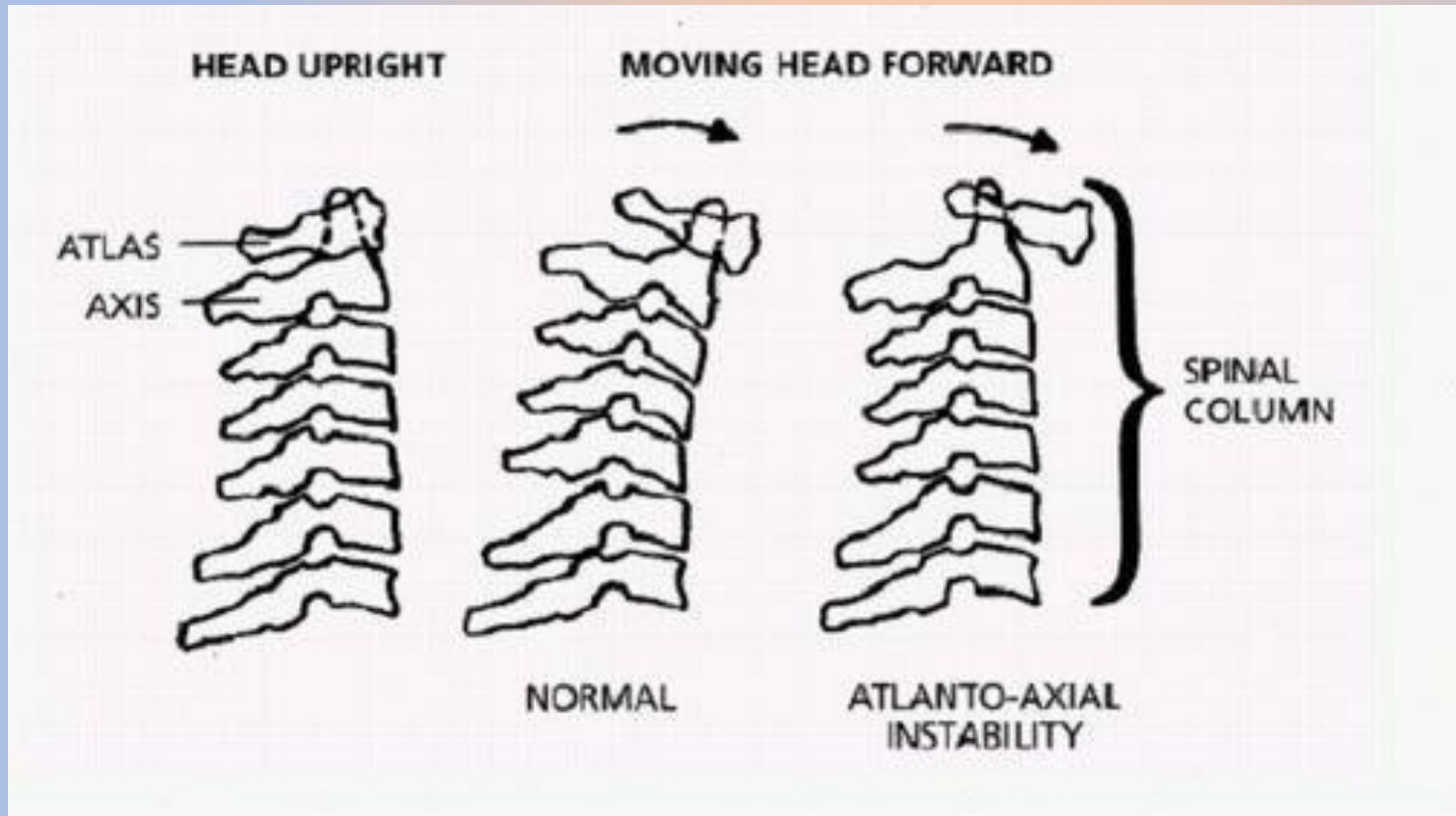
Abnormal sleep position

Diagnosed by a sleep study

Usually managed by an ENT specialist



# Atlantoaxial instability



<http://medcarepediatrics.blogspot.com/2013/04/atlanto-axial-instability-and-children.html>

# AAI Precautions for All People with Down syndrome

Avoid excessive flexion or extension of the neck during any, anesthetic, surgical or radiologic procedure to minimize risk of spinal cord injury

Avoid trampoline use unless it is part of a training program with appropriate supervision and safety measures

Participation in contact sports such as football, soccer, and gymnastics, places children at risk for spinal cord injury



# Atlantoaxial Instability (AAI)

From the American Academy of Pediatrics

“Contact physician immediately for an x-ray of the neck in neutral position if your child has:

- Change in how he or she walks
- Change in how he or she uses arms/hands
- Change in bowel or bladder control
- Head stays tilted
- Neck Pain
- New onset weakness
- Decreased activity level or function

If the x-ray is abnormal or symptoms persist, the child should be referred as soon as possible to a pediatric neurosurgeon or pediatric orthopedic surgeon experienced in managing atlantoaxial instability.”

<https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Atlantoaxial-Instability-in-Children-with-Down-Syndrome.aspx>





# Cardiac Issues

Follow up on congenital heart issues

Be aware that **new** conditions with heart valves can occur

Symptoms can include:

tiring more easily

shortness of breath with exercise

a new murmur or sound found when listening to the heart

may need evaluation with an echocardiogram



## Autoimmune diseases

Celiac disease – screen by history

lab work for TTG IgA and quantitative IgA if symptoms

Thyroid disease – lab work for TSH every year

Type 1 diabetes

Alopecia

Juvenile Idiopathic Arthritis



# Skin Conditions

<https://downsyndromecenter.libsyn.com/94-skin-conditions-in-down-syndrome-with-dr-jillian-rork>

<https://downsyndromecenter.libsyn.com/95-skin-conditions-in-down-syndrome-part-2-with-dr-jillian-rork>

Dry skin

Pimples and Boils

<https://adscresources.advocatehealth.com/folliculitis-and-boils-in-people-with-down-syndrome/>

Hidradenitis suppurativa

[https://pedsderm.net/site/assets/files/1028/spd\\_edited\\_hs-downsyndrome\\_color\\_web.pdf](https://pedsderm.net/site/assets/files/1028/spd_edited_hs-downsyndrome_color_web.pdf)



# Neurologic Issues

Monitor development and behavior

Seizures

Moya Moya



# Common Mental Health Concerns

Behavior concerns - important to rule out a medical cause

<https://adscresources.advocatehealth.com/resources/the-groove>

Attention Deficit Disorder

Anxiety

Depression

The guidelines recommend that with psychotropic medications start at the lowest dose and change the dose according to the patient's response. Start low and go slow. People with Ds can be more sensitive to medications.



# Regression

[https://dsmig-usa.org/resources/Documents/21DSMIG\\_Regression%20in%20Persons%20with%20Down%20Syndrome\\_0928.pdf](https://dsmig-usa.org/resources/Documents/21DSMIG_Regression%20in%20Persons%20with%20Down%20Syndrome_0928.pdf)

[https://www.frontiersin.org/articles/10.3389/fneur.2022.940175/full?&utm\\_source=Email\\_to\\_authors&utm\\_medium=Email&utm\\_content=T1\\_11.5e1\\_author&utm\\_campaign=Email\\_publication&field=&journalName=Frontiers in Neurology&id=940175](https://www.frontiersin.org/articles/10.3389/fneur.2022.940175/full?&utm_source=Email_to_authors&utm_medium=Email&utm_content=T1_11.5e1_author&utm_campaign=Email_publication&field=&journalName=Frontiers%20in%20Neurology&id=940175)

<https://jneurodevdisorders.biomedcentral.com/counter/pdf/10.1186/s11689-022-09446-w.pdf>

<https://www.dsrf.org/resources/the-lowdown-podcast/reversing-course-down-syndrome-and-regression/>



# Transition to Adolescence and Adulthood

Encourage increasing independence for activities of daily living including hygiene, and dental care

DSANEO program on Self Care, Dec 7, 6:30-8:00

RSVP to [Debbie@dsaneo.org](mailto:Debbie@dsaneo.org)

<https://www.ohiof2f.org/cleveland-transition-bootcamp-booster-sessions/>

<https://adsresources.advocatehealth.com/bathing-and-showering-tips/>

<https://adsresources.advocatehealth.com/toilet-hygiene/>



# Puberty

Timing of puberty is not delayed

Period management

<https://adscresources.advocatehealth.com/use-of-birth-control-in-women-with-down-syndrome/>

<https://adscresources.advocatehealth.com/menstrual-hygiene/>

<https://www.nytimes.com/wirecutter/reviews/thinx-period-panties/>



## Story About How to Change My Pad



## Terri Couwenhoven resources

### Books:

**A Girls' Guide to Growing Up  
Choices & Changes  
in the Tween Years**

**The Boys' Guide to Growing Up  
Choices & Changes  
During Puberty**

### Podcasts:

[Puberty and Sexuality Issues, Part 1](#)

[Puberty and Sexuality Issues, Part 2](#)



# Relationships

<https://adsresources.advocatehealth.com/dating-faqs/>

<https://adsresources.advocatehealth.com/search/people-with-down-syndrome/?sort=titleasc&category=Puberty%25c%25+Sexual+Health%25c%25+and+Relationships>

# Safety including Social media and internet use

## Boundaries

[https://adsresources.advocatehealth.com/assets/1/13/Boundaries\\_Handout.pdf?2599](https://adsresources.advocatehealth.com/assets/1/13/Boundaries_Handout.pdf?2599)

DSANEO virtual programs Jan. 11 at 7 pm  
Feb. 8 at 7 pm

## Monitor content and communication

[https://adsresources.advocatehealth.com/assets/1/13/Rules for Social Media Safety.pdf?1645](https://adsresources.advocatehealth.com/assets/1/13/Rules_for_Social_Media_Safety.pdf?1645)





# Transition to middle school, high school, and beyond

Important to include transition planning in the IEP

<https://dodd.ohio.gov/your-family>

<https://dodd.ohio.gov/your-family/all-family-resources/4-find-your-county-board>

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

<https://www.dsaneo.org/families/adults-ages-18/> - Laurie Kowalski

<https://www.ohiof2f.org/cleveland-transition-bootcamp-booster-sessions/>

<https://thinkcollege.net/>



# Important Concepts to Consider for People Approaching age 18

Guardianship vs power of attorney

<https://www.disabilityrightsohio.org/guardianship-frequently-asked-questions>

<https://www.ohiolegalhelp.org/>



# Financial Considerations

## Ohio SSI/Medicaid

<https://www.ssa.gov/benefits/ssi/>

<https://www.ssa.gov/pubs/EN-05-11000.pdf>

<https://www.ssa.gov/ssi/text-understanding-ssi.htm>

<https://www.ssa.gov/disabilityresearch/wi/medicaid.htm>

<https://codes.ohio.gov/ohio-revised-code/section-1751.14>

## Stable accounts

<https://www.redtreehouse.org/resources#search/view-resource-details/59cfdbfed07b9f093ae41380/>

## Waivers

<https://dodd.ohio.gov/waivers-and-services/waivers>

## Estate Planning

<https://www.frn ohio.org/resources/listing/special-needs-trusts-and-able-accounts>



DSANEO Parent webinar about SSI, Medicaid, Waivers and Trusts.

Melissa Yasinow from Hickman and Lowder

January 23, 2023

6:30-8:00pm on Zoom

RSVP to [Laurie@dsaneo.org](mailto:Laurie@dsaneo.org) or [Debbie@dsaneo.org](mailto:Debbie@dsaneo.org)



[https://aap2.silverchair-cdn.com/aap2/content\\_public/journal/pediatrics/149/5/10.1542\\_peds.2022-057010/3/peds\\_2022057010supplementarydata.pdf](https://aap2.silverchair-cdn.com/aap2/content_public/journal/pediatrics/149/5/10.1542_peds.2022-057010/3/peds_2022057010supplementarydata.pdf)

Thank You





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<https://adscresources.advocatehealth.com/>

[https://adscresources.advocatehealth.com/assets/1/13/Boundaries\\_Handout.pdf?2599](https://adscresources.advocatehealth.com/assets/1/13/Boundaries_Handout.pdf?2599)

<https://adscresources.advocatehealth.com/dating-faqs/>



