Pediatric Healthcare Guidelines from 12-21 years

Laura Cifra-Bean MD
Medical Outreach Director, DSANEO
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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.

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
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

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
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.”

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


Dry skin

Pimples and Boils

Hidradenitis suppurativa
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://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.dsrf.org/resources/the-lowdown-podcast/reversing-course-down-syndrome-and-regression/
Encourage increasing independence for activities of daily living including hygiene, and dental care

DSANEKO program on Self Care, Dec 7, 6:30-8:00
RSVP to Debbie@dsaneo.org

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


https://adscresources.advocatehealth.com/toilet-hygiene/
Puberty

Timing of puberty is not delayed

Period management


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

https://www.nytimes.com/wirecutter/reviews/thinx-period-panties/
Story About How to Change My Pad

1. This is how I will change my sanitary pad.
2. I will go to the bathroom for privacy.
3. I can keep clean pads and underwear in a bag so I can bring the supplies to the bathroom with me.
4. When I go to the bathroom, I will pull down my pants and my underwear.

5. I will sit on the toilet.
6. I will put the dirty pad out of my underwear.
7. I will fold it in half so I don’t see the blood. Then I will wrap it in the toilet paper.
8. I will throw the pad and toilet paper in the garbage can.

9. I will NOT throw it into the toilet.
10. I will make sure there is no blood on my underwear. If there is, I will need to put on clean underwear.

11. I will get a new, clean sanitary pad out of my bag.
12. I will open the wrapper and take the pad out.
13. I will remove the paper so I can see the sticky tape.
14. I will put the clean pad in my underwear with the sticky side touching my underwear.

15. I will make sure the pad sticks to my underwear.
16. I can throw the paper away in the garbage can.
17. I will pull up my underwear and pants.
18. I will take my bag of supplies with me when I leave the bathroom.
19. I will wash my hands.
20. If I have questions, I can ask my mom.
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://adscresources.advocatehealth.com/dating-faqs/

Safety including Social media and internet use

Boundaries
https://adscresources.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
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/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.frnohio.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 or Debbie@dsaneo.org
Thank You
