



## **Birth through Age Five: Checklist of Considerations and Resources!**

### **Week 1: Parent Mentor(s) if applicable & Reminder to join FB group**

Would you like to be connected with a parent mentor? Our [“First Call”](#) program is a recognized, trained partner of the National First Call Center. We have trained parent mentors in almost every county that we aim to serve.

Reach out today to get matched: [firstcall@DSAmD.org](mailto:firstcall@DSAmD.org) / 443-300-6972

AND don't forget to join the DSAmd private Facebook group if you “do” social media:  
<https://Facebook.com/groups/chesapeakeDownSyndrome>

### **Week 2: Upcoming DSAmd events**

Check out all of our upcoming events, and sign up to learn more at:  
<https://DSAmD.org/events>

### **Week 3: Healthcare**

Did you know - there's a checklist of what to do, and when - for many children with Down syndrome?

Here's the checklist from the American Academy of Pediatrics for children with Down syndrome:  
[https://www.ndss.org/wp-content/uploads/2017/10/Health\\_Care\\_Information\\_for\\_Families\\_of\\_Children\\_with\\_Down\\_Syndrome-1.pdf](https://www.ndss.org/wp-content/uploads/2017/10/Health_Care_Information_for_Families_of_Children_with_Down_Syndrome-1.pdf)

We recommend printing them: one for you, and one to take to your next pediatrician appointment!

### **Week 4: Healthcare part two - Down Syndrome Clinics.**

You do not have to go to a DS Clinic, but many families find it helpful to have one place that helps coordinate care, and really understands people with Down syndrome and any unique-to-Down-Syndrome health considerations they might have.



**DSAmd** |

**DOWN SYNDROME  
ASSOCIATION  
OF MARYLAND**

1. [Kennedy Krieger Institute - KKI](#). Here's information about the Kennedy Krieger Down syndrome clinic. There are mixed reviews in our Facebook group, but for the most part: people appreciate having a clinic that understands Down syndrome that's in our backyard. Everyone seems to love Dr. Capone, who's a world-renowned Down syndrome expert in adult care. Kennedy Krieger Institute is also a common source of therapy providers (physical therapy, speech, occupational.) It is located in Baltimore City.

<https://www.kennedykrieger.org/patient-care/centers-and-programs/downsyndrome-clinic-and-research-center>

2. [Childrens' National Hospital](#). Here's information about the Washington, DC Down Syndrome Clinic at Childrens' National Hospital. Many of our families love Dr. Rosenbaum. <https://childrensnational.org/departments/down-syndrome-clinic/locations>

### **Week 5: Healthcare Part Three - Therapies.**

Infants & Toddlers Early Intervention Services can help with therapies, and often in your home. They can also make recommendations about head start programs, MyGym, or other social groups and activities happening near you! "Infants and Toddlers" is a division of your local school district.

If not already done, Here's how to make a referral for yourself: <https://online.mditp.org/login> or you can call the office line: **410.396.1666**

### **Week 6: Oral health.**

Here's a 30-minute recording where we had two dentists from Smiles4Children in Catonsville talk with DSAmd families about oral health for kiddos with Down syndrome:

<https://www.facebook.com/cdspg/videos/544763110230060>



### **Week 7: Speech Therapy.**

With express permission from Dr. Libby Kumin, CCC-SLP to DSAmd, we developed a one-page advocacy form to help parents with the language they need to advocate for early communication and feeding evaluation and intervention. See the one-pager here on our website:

<https://static1.squarespace.com/static/61b6763e7a524833b4a6956a/t/647f58bc7be4a24c773f2839/1686067388233/Early+Speech+Advocacy+One-Pager.pdf>

Additionally, we are able to share two attachments with permission from Dr. Kumin: the Pre-speech Recording Form, and the Early Social Interactions form – see them both at:

<https://www.DSAmd.org/resources>

We encourage all families to advocate for an early feeding and speech-language evaluation, and work on the assessment forms together with your practitioner. We hope you can use the findings from these forms to advocate for your loved one with Down syndrome to receive consistent and early intervention if recommended.

### **Week 8: LISS Funding.**

Did you know, Maryland has a twice-a-year lottery-system grant for \$2,000 per family? Click here to see an “FAQ” about the Low-Intensity Support Services grant process, with tips and tricks to consider from experienced DSAmd families:

<https://static1.squarespace.com/static/61b6763e7a524833b4a6956a/t/636926fbbff98b2ccfacbafd/1667835643133/LISS+FAQs.pdf>

### **Week 9: Infants & Toddlers.**

Have you had your intake appointment with Infants & Toddlers, yet? Feel free to follow up, and get in the system if not already done.

Here's how to make a referral for yourself: <https://online.mditp.org/login> or you can call the office line: **410.396.1666**



### **Week 10: Parent Mentor & Private Facebook Group reminder**

Would you like to be connected with a parent mentor? Our [“First Call”](#) program is a recognized, trained partner of the National First Call Center. We have trained parent mentors in almost every county that we aim to serve.

Reach out today to get matched: [firstcall@DSAmid.org](mailto:firstcall@DSAmid.org) / 443-300-6972

AND don't forget to join the DSAmd private Facebook group if you “do” social media:  
<https://Facebook.com/groups/chesapeake Downs Syndrome>

### **Week 11: Looking for a doctor recommendation?**

Check out this DSAmd-curated and crowd-sourced list of physicians recognized as awesome for Doctors' Day 2022 and 2023. The list is organized/sorted by location, name and type - check out the tabs on the spreadsheet when you **click here:** <https://bit.ly/dsamdtopdocs>

### **Week 12: Siblings Support info FYI**

We try to host sibling workshop events and meetups every quarter. Check out all of our upcoming events, and sign up to learn more at: <https://DSAmid.org/events>

### **Week 13: Inclusion research!**

Research findings from studies comparing children who have been educated in special schools and classrooms indicate that it is difficult to provide optimal learning environments in such schools or classrooms.

One particular study done in 2000 compared the achievements of teenagers of similar ability and family background educated in special schools and mainstream settings. The study showed significant educational benefits for teenagers who had been through mainstream education with 25-30 hours of additional learning support assistance.

Read more at:

[https://library.down-syndrome.org/en-us/news-update/06/1/inclusive-education-individual s-down-syndrome/](https://library.down-syndrome.org/en-us/news-update/06/1/inclusive-education-individual-s-down-syndrome/)



One inclusion resource we trust and partner with is the Maryland Coalition for Inclusive Education - MCIE. Here's a blog and podcast they manage which might be interesting to your family: <https://www.mcie.org/think-inclusive>

### **Week 14: Down Syndrome Research**

DS-Connect® is a powerful resource where people with Down syndrome and their families can:

- Connect with researchers and health care providers.
- Express interest in participating in certain clinical studies on Down syndrome, including studies of new medications and other treatments.
- Take confidential health-related surveys. These surveys are aimed at better understanding of the health of people with Down syndrome across their lifespans.

Recently, a lot of funding was distributed to researchers to study Down syndrome-specific conditions or challenges - but they will only be successful if members of the Down syndrome community sign up to get involved. If you're interested and willing - here are details about getting connected with DS-Connect through the National Institutes of Health:

<https://dsconnect.nih.gov/>

### **Week 15: Apply for DDA**

Reach out to the Developmental Disabilities Association - DDA by phone, email, or in-person. Get your loved one connected early to help ease the process of getting support later, when you might really need it.

**[https://health.maryland.gov/dda/Pages/DDA\\_Eligibility\\_Application\\_Process.aspx](https://health.maryland.gov/dda/Pages/DDA_Eligibility_Application_Process.aspx)**

### **Week 16: Apply for FMLA at work**

We encourage any parents or guardians who are eligible or working outside of the home to consider applying for FMLA because they have a child with a disability. If you never have to use



this protection, that's OK. And if you do need the documented protections, applying now will ensure your job is more safe in case of upcoming medical leave needs, appointments, etc.

Details about FMLA: <https://www.dol.gov/agencies/whd/fmla/faq#9>

### **Week 17: Childcare.**

Got childcare questions or needs? There are free resources for that!

- **Help with finding childcare:**  
<https://www.marylandfamilynetwork.org/for-parents/locate-child-care>
- **Help with making sure your childcare provider understands your kiddo and is including them to the best of their ability:**  
<https://abilitiesnetwork.org/programs/project-act/program-overview/behavioral-consultation-services/>