

What families can do while waiting to access services

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Disclosures

Today's speaker has no financial relationships with an ineligible company relevant to this presentation to disclose.

None of the planners have relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients

All relevant financial relationships have been mitigated



Objectives

What individuals and families can do while waiting to access services

Connect you with specific programs, services, and supports

Identify barriers that current exist

Navigation ideas and strategies



Rey Daoed, Artist

Autism and Apraxia

Typing, handwriting, speech apps

<https://reydaoed.wixsite.com/artwork/bio>

What to do while waiting to access services

<https://www.seattlechildrens.org/clinics/autism-center/patient-family-resources/>

What to Do While Waiting for an Autism Evaluation

- [What to Do While Waiting for a Seattle Children's Autism Center Appointment](#) (PDF) ([Spanish](#)) ([Somali](#)) ([Vietnamese](#))
- [First Concerns Toolkit](#), Autism Speaks
If you have concerns about how your child is communicating, interacting or behaving, this toolkit will help you.
- [Five Things to Do While Waiting for an Autism Evaluation](#) ([Spanish](#)), Autism Speaks
- For a list of agencies and providers who do autism evaluations, email autismresources@seattlechildrens.org.

What to Do While Waiting for an Autism Center Appointment

This handout includes resources that may help you while waiting for your child's appointment at the Seattle Children's Autism Center.

Early intervention and educational services in Washington

For children birth to 3

Children with developmental delays may qualify for early intervention services even before they have a formal evaluation or get a diagnosis. For children under the age of 3, services are most often provided by local centers known as Birth to Three Centers or Neurodevelopmental Centers.

To find out more about early intervention services in Washington, contact:

- Family Health Hotline at 1-800-322-2588
- WA State Department of Children, Youth and Families website at dcyf.wa.gov/services/child-development-supports/esit

For children over 3

IDEA, the Individuals with Disabilities Education Act, is a law that ensures that all children with special needs have access to free and appropriate public education. Children who qualify for IDEA services continue to receive educational services when they turn 3, through a family's local school district. These services are often provided through developmental preschools. A diagnosis of autism is not required to get services.

To find out more, contact your local school district by visiting the Washington State Office of Superintendent of Public Instruction website at K12.wa.us/maps/SDmainmap.aspx or call 360-725-6000.

Speech and occupational therapy services

Your health insurance may cover speech and occupational therapies for communication, social, motor and sensory delays and deficits. Contact your insurance provider to find out which services and providers are covered.

Other options for getting your child evaluated

Centers of excellence list

Other options for getting your child evaluated can be found through the Washington State Health Care Authority Centers of Excellence list at hca.wa.gov/assets/billers-and-providers/index-coe-applied-behavioral-analysis.pdf. You can also contact your insurance company and ask them for a list of providers who can evaluate your child.

1 of 2

To Learn More

- Autism Center
206-987-8080, or 1-877-987-2000
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.



What to Do While Waiting for an Autism Center Appointment

Autism research

Taking part in research is a possible way to have your child evaluated for autism. Seattle Children's Research Institute and The University of Washington Autism Center (UWAC) both offer research opportunities that might include an evaluation for autism. This option may or may not provide family support, guidance, or follow up care. We recommend you consider keeping your referral at Seattle Children's Autism Center to establish care and receive ongoing support.

To learn more about autism research opportunities:

- Seattle Children's Research Division
206-884-8266
seattlechildrens.org/research
- University of Washington Research
877-408-8922
depts.washington.edu/uwautism/research/index.html

Suggested reading and websites

Seattle Children's Autism Center

seattlechildrens.org/clinics-programs/autism-center/resources/

Provides autism education, support groups, Autism 101 and Autism 200 series information and The Autism Blog at theautismblog.org.

Autism Speaks: First Concerns Toolkit

autismspeaks.org/early-access-care/first-concern-action

If you have a concern about how your child is communicating, interacting or behaving, you are probably wondering what to do next. This tool kit provides you with specific resources and tools to help guide you on the journey from your first concern to action. The kit is also available in Spanish.

Autism Navigator-Family Resources

autismnavigator.com/a-seamless-path

Resources to improve early detection of autism as well as information related to intervention and strategies to support your child's learning and development.

Books

A Parent's Guide to High-Functioning Autism Spectrum Disorder: How to Meet the Challenges and Help Your Child Thrive

Sally Ozonoff, Geraldine Dawson and James McPartland, 2014

Does My Child Have Autism: A Parent's Guide to Early Detection and Intervention in Autism Spectrum Disorders

Wendy Stone and Theresa DiGeronimo, 2006

More Than Words

Fern Sussman, 2012

Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201. This handout has been reviewed by clinical staff at Seattle Children's. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's healthcare provider.
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Good place to start

[Seattle Children's Autism Center Patient and Family Resources Website](#)

The Autism Blog

Autism 101 video series: Spanish

Conversations about Autism Past lectures viewable on-line

First Concerns Toolkit

Autism: Frequently Asked Questions for parents new to the diagnosis

Local Autism and/or IDD Organizations

5 Things You Can Do While Waiting for Autism Evaluation

1. Learn more about autism.

Make a list of questions for the visit and prepare to take action if your child is diagnosed with ASD.

[Autism Speaks 100 Day Kit for Young Children](#)

2. Gather your child's information.

Create a binder/folder with your child's medical records and any previous developmental or behavioral evaluations your child has received. Bring to appointments.

Bring your own notes on your child's behavior, as you observe it in different places and with different people.

Jot down some thoughts on what you consider to be your child's strengths and weaknesses.

3. Learn what to expect at the evaluation.

Some evaluations are done by a team of specialists, others by a single provider. It should involve direct interaction between the provider and your child.

This should include a structured, play-based assessment called the Autism Diagnostic Observation Schedule ([ADOS](#)).

Your child may also complete one or more cognitive, or "thinking skill" tests.

As a parent, you'll be asked questions about your child's behavior and development. In addition, you'll probably fill out one or more "checklists."

It can feel like a lot of questions, to be sure! Just remember that this information helps the professional make the most accurate and helpful diagnosis.

You should have a chance to meet with your child's evaluation team to discuss the assessment and diagnosis.

You should also receive their written report. (Also see the "[Diagnosis](#)" page of the [Autism Speaks website](#).)

4. Arrange support.

Many parents find the diagnosis process emotional and even a little overwhelming.

Rather than go it alone, consider inviting someone you trust to accompany you and help take notes and help you remember your questions.

5. Get the ball rolling on intervention services.

Let the recommendations from the provider be your guide but also consider prioritizing based on what is realistic for your child and family

Parent 2 Parent Washington State <https://arcwa.org/parent-to-parent/>

Autism Speaks Autism Response Team at 888-288-4762 (*Español* 888-772-9050) or email us at familyservices@autismspeaks.org

You do not need an autism diagnosis to access:

Public School Special Education

- 504 plan
- Individual Education plan (IEP)
- Speech
- Occupational
- Behavior Supports: Behavior Intervention Assessment and Plan
- Social Skills or Buddy Groups
- Accommodations as identified

Community Based and Therapeutic Services:

- Birth to 3 | Early Intervention
- Speech
- Occupational
- Behavioral Health Therapy
- ABA: Medicaid, maybe. Private insurance, no.
- Social Skills groups
- Adaptive/Specialized Recreation and Camps
- Support Groups for Parents and Caregivers

Difficult to obtain without a diagnosis

ABA from private or commercial insurance: Refer to WA Autism Alliance for advocacy

ABA services: offered at 0-3 or Early Intervention programs

DDA services: unless there is significant intellectual impairment, IQ under 70

Recreation or camps: specifically designed for individuals with autism

Social Security Assistance: unless there is significant intellectual or adaptive impairment

Peeking behind the door?

A Parent's Guide to High-Functioning Autism Spectrum Disorder:
How to Meet the Challenges and Help Your Child Thrive Sally Ozonoff,
Geraldine Dawson and James McPartland, 2014

**Does My Child Have Autism: A Parent's Guide to Early Detection and
Intervention in Autism Spectrum Disorders** Wendy Stone and Theresa
DiGeronimo, 2006

More Than Words Fern Sussman, 2012

Autism books, videos, and Links coming soon. Katrina will share on Google Drive

AS 360 comprehensive autism on-line resource coming in 2023

Barriers to services

- Prefer care in a language other than English
 - Cultural differences
 - Socio-economic status
 - Housing
 - Transportation
 - Mental Health
 - Substance use
 - Intellectual Development Disorder
 - Literacy
 - Safety
 - Job stability
 - Incarceration
 - Educational support from school
 - Access to healthcare
 - Other
- Lack of services
 - Wait times
 - Confusing
 - Location
 - Insurance type
 - Family circumstance
 - Parent / caregiver readiness
 - [Significant challenging behaviors](#)

Effective Navigation

Advocate/Case Manager:

- WISE
- DDA
- Medicaid Case Manager
- Arc of your county
- Open Doors for Multicultural Families
- WA Multicultural Link
- VFAB: Hope Central
- Sea-Mar
- Provider: social worker
- School case manager
- Faith-based groups
- Natural supports

These steps are a privilege:

- Pleasantly persistent and tenacity
- Escalate Escalate Escalate
- If the light is not shining where you need it to shine, move the light. Contact elected officials.

Connect with non-profit legal support:

The power of you

- NW Justice project
- Office of Education Ombuds
- WA Developmental Disability Ombuds
- Disability Rights WA
- Developmental Disabilities Council of WA

It's not just you

These services are difficult to access—and in some cases impossible



The proposal for [Enhanced Behavior Support Homes \(EBSH\)](#) in Washington state is an attempt to provide appropriate housing options to meet the needs of DDA-eligible individuals with high-needs autism and / or IDD who experience **significant challenging behaviors**.

<https://washingtonautismalliance.org/why-do-we-need-enhanced-behavior-support-homes/>



Questions?

THANK YOU!

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Shameless plug: IDD Autism Resource Navigation ECHO starts Wed Feb 16, 8:30-10. Every 3rd Wed.

To Register: <https://uw-ctu.org/echo/echo-idd-wraparound-impact/>