

A newsletter by The Arc's Parent Coalition and Parent to Parent of Whatcom County

EMPOWER

The Arc of Whatcom County's mission is to improve the quality of life, increase the independence and assure the full inclusion in the community of all persons with developmental disabilities.

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The Arc of Whatcom County Annual Meeting and Pizza Party

Wednesday, May 28
6 - 7:30 pm
2602 McLeod Rd.
Bellingham, WA

Arc of Whatcom County Members are welcome to join us for our Annual Meeting, free pizza included!

Arc Staff and Board Members will be present to share updates from the programs as we look to the year to come.

Please RSVP to 360-715-0710 ext 200 or send an email to admin@arcwhatcom.org to let us know how many people in your family will be joining us.

If you are not a member,
but interested in learning more, please join us!
Membership is now FREE:
<https://arcwa.org/membership/>



What is the cause of autism? For our Eli, we have recently discovered the answer.

This topic has been taking over national headlines recently, but for our family, it has also been a deeply personal one. Our baby Eli was born prematurely in 2016. Soon after birth, we learned that Eli had two heart defects that would need surgeries. A few days later, we learned that Eli was also having trouble swallowing. A swallow study confirmed that each swallow was causing silent micro-aspirations and putting Eli at risk for pneumonia. We learned how to operate a feeding tube during our 92 day stay in the NICU, and then Eli came home to Bellingham. The following year, Eli was still aspirating, so we had a surgically placed G-Tube placed in the stomach. Eli received PT, OT, and feeding therapy locally, and was also seen in several clinics in Seattle. Eli had open heart surgery and thankfully, the heart defect was repaired. During preschool and Kindergarten, Eli had ongoing sensory sensitivity, motor delays, and periods of rapid growth. During this time Eli was also diagnosed with ADHD and Autism.

At Eli's autism diagnosis appointment, our Neurologist noticed that Eli had some unique facial features that didn't look like the rest of our family. This, along with Eli's long list of previous unrelated medical complexities, led her to ask us if we would be interested in looking into exome sequencing to find a possible over-arching genetic condition that might put Eli's complex puzzle pieces together. We did some research and decided that for us, it could be helpful to know if there was something else going on. We received a kit in the mail to swab saliva from Eli and both parents. We met with a genetic counselor and discovered that indeed, our

Eli was born with a very rare, genetic deletion on the DMNT3 gene, resulting in what we now know to be Tatton-Brown Rahman Disorder (TBRS). For Eli, this deletion was "de novo" or random, as it did not come from either parent.

This discovery has answered so many of our questions about our beautiful child and led to finding a community of people online who can relate (and even had the honor to have a play date with a couple!). These individuals and their families are all full of strength, joy and the resilience that only those of us who live this life can understand. It's a cause close to our hearts, providing much needed community and support.

We're now involved in TBRS's Patient Led research and fundraising efforts. TBRS was a mystery 11 years ago. Today, we have research, clinical experts, and a powerful community—all because families came together and shared their stories. We are really looking forward to meeting more of the TBRS community in person next year at the San Antonio convention at Morgan's Wonderland, a theme park for disabled children that was built by the family of a child with the same diagnosis!

Having the knowledge of TBRS has helped us plan for Eli's future, for school, and know which health screenings we should advocating for. These days, most of our hospital time is a distant memory. Eli can usually be found dancing to Taylor Swift, riding bikes, hiking through the forest, searching for crabs on the beach, singing, walking our dog Tundra, telling the most creative and hilarious stories, or playing with our cats Kiwi and Jasper. Eli is the most empathetic person I have ever met. We love watching Eli grow and thrive and develop into exactly the beautiful, joyful, energetic person that Eli was always meant to be. We are hopeful that any further research into the causes of Autism helps enhance the quality of life for autistic people and their families, builds support and understanding of neurodiverse populations, and lead to the development of a more inclusive policy.

For more information about TBRS, please visit: <https://tbrsyndrome.org/> For more information about exome sequencing and genetic testing, please visit: www.genedx.com

Parent to Parent

Coffee & Conversation

1st Monday of each month

May 5, 10am - 11am

June 2, 10am - 11am

The Arc of Whatcom County
2602 McLeod Rd., Bellingham

Parents and Caregivers of loved ones with developmental delays, disabilities, and on-going healthcare needs are welcome to join us for coffee (or tea) and a relaxed and friendly chat. Meet other caregivers in our community, find out new resources, and share your thoughts, insights, triumphs and experience. Adults only please! Light refreshments provided.

Monthly Parent Connect

2nd Monday of each month

May 12, 7 - 8pm

June 9, 7 - 8pm

Virtual Meeting via Zoom

This is a meeting for parents and caregivers of children with developmental delays, disabilities, and ongoing health care needs. After registering you will receive an email containing the link for you to join the Parent Support Meeting via Zoom. Please register early so you can get the link. Register by sending an email to p2p@arcwhatcom.org

Dads Social & Pizza

6pm, Thursday, May 8

Coconut Kenny's, 1740 La Bounty Dr, Ferndale

Our Dads Social & Pizza is for fathers raising loved ones with delays, developmental disabilities, and special healthcare needs. A chance to be able to meet and talk with other dads that are dealing with similar issues and enjoy wonderful pizza. Parent to Parent will supply the pizza and soda. Beer available for individuals to purchase on their own. Dads will be meeting in the side room to the right when you enter the restaurant. Please RSVP so we can get a heads up on how many people will be there. For questions or to register contact P2P at (360) 715-0170 ext 302 cwhatcom.org

Sibshops are free fun filled event for brothers and sisters of kids with developmental differences, delays, and on-going health care needs.



Cupcake Decorating Sibshop

Thursday, June 19 from 1 – 2:30 pm

The Arc of Whatcom County

2602 McLeod Rd.

Ages 6 - 12

We will play AWESOME games and eat cupcakes while connecting! Limited spots available! Please RSVP by Monday, June 16th to guarantee your child's spot. If this is your child's first time, please arrive 10 minutes early to fill out our Sibshop Form. To register your child for these events, please us a call at 360-715-0170 ext 302 or email at p2p@arcwhatcom.org.

Super Sitter Training



Tues & Wed, June 17
& 18

9:30 am - 2:30 pm

Thurs, June 19,

12:45 pm – 2:45 pm
(Sibshop day)

This popular class is available for youth ages 13 and older and teaches basic baby-sitting skills along with skills caring for children with disabilities. Participants will gain confidence in caring for children, particularly for children with special needs, and they will also enjoy the learning environment of the camp as they meet new friends.

This training also includes a day of infant/child CPR and First Aid certification.

<https://arcwhatcom.org/2025-super-sitter-training/>

Workshops



Special Needs Master Plan

A virtual session for families with loved ones with intellectual and developmental disabilities

May 27, 2025

6PM PST



Objectives and goals of this workshop:

- Address Immediate Needs
- Understand Planning Process
 - Funding Strategy
 - Costs of Care
 - Legal Strategy
 - Support Strategy
- Coordination of Public Benefit
 - Care Planning
- Planning for the Whole Family

Mary is both personally and professionally passionate about the special needs community. When Mary isn't helping families navigate the world of special needs planning, she is with her amazing husband, Jay, and two incredible children, Charlie and Ruth.

This webinar is offered as educational information only and not designed to be taken as advice or a recommendation for any specific product, strategy, or service. The information provided is not written or intended as specific tax or legal advice. We are not authorized to give tax or legal advice. Individuals are encouraged to seek advice from their own tax or legal counsel.

[Register Here](#)



**Wednesday, June 11
11am - 1pm**

**Arc of Whatcom County
Dan Godwin
Community Center
2602 Mcleod Rd,
Bellingham**

Home & Beyond: Staying Safe Together

Caring for someone with a disability comes with unique challenges and responsibilities — and your role as a caregiver is invaluable. We invite you to join us for an informative and supportive workshop.

We will discuss:

- Emergency Preparedness (e.g. fire, flood, power outage)
- Building Safety Supports into a IEP/504 Plan
- Home Security (smart devices, alert systems)
- Emergency Contact Planning & Communication Tools
- De-escalation and Self-Advocacy in Public Settings
- Building a Safety Circle (trusted allies, family, support workers)

Whether you're a parent, sibling, spouse, or other caregiver, your presence and perspective matter. Let's come together to learn, support one another, and build a stronger safety net for those we care for. If you are unable to attend the presentation, free Safety Packets will be available at our office Monday-Thursday from 10am - 1pm. Please email admin@arcwhatcom to set up a time if those hours do not work for you..

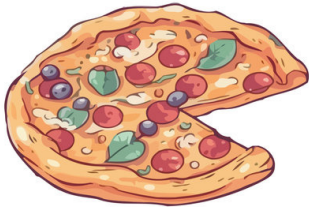


Let us know you're attending by scanning the QR Code or clicking [HERE](#)

Self Advocacy

Build your Self-Advocacy & Leadership Skills. These meetings empower individuals to develop advocacy and leadership skills and set lifetime goals for employment, independence and community involvement.

Self-Advocacy Group Meetings



Wednesday, May 28, 6:00-7:30pm

The Arc Membership Pizza Party

Join us for The Arc Membership Pizza Party at
2602 McLeod Rd, Bellingham WA 98225.
No Self-Advocacy Meeting on May 1st.

Thursday, June 5, 4:30-6:30pm

Healthy Relationships

We will have a conversation on Friendships, Peer Relationships, Boundaries, and Consent. Please join us for a fun and friendly discussion on zoom.



Self-Advocacy Group Connecting to our Community

Monday, July 21, 6 - 8pm

Spin Dance

Meet in-person at the Spin Dance at Depot Market Square.

Friday, August 1, 6 - 8pm

Silent Disco

Meet in-person at the Silent Disco at Max Higbee Center, 1400 N. State Street, Bellingham

The virtual meetings are on zoom. After registering you will receive an e-mail containing the link for you to join the Self-Advocacy Meeting. For more questions or information call (360) 715-0170. Pre-registration is REQUIRED to get the link. Must be able to connect through a cell phone, tablet or computer.

Register at: SelfAdvocacy@arcwhatcom.org



SELF-ADVOCACY

A program of The Arc of Whatcom County

"Be Strong. Be Proud. Be Heard."



Sponsored by The Arc of Whatcom County with funding from the Whatcom County Developmental Disabilities Program

Recreational Opportunities

Summer Resources for Families 2025

The warm weather and longer days are great opportunities to spend time with friends and family. Washington state offers many great programs and activities for all communities and individuals.

Community Centers and YMCA

Craft classes, yoga, cooking, music, swimming, arts, and special events are often low-cost and easy to join.

Libraries

Libraries host free events and story times and are great resources for finding out what else is going on in the community.

Museums for All

Those receiving food assistance (SNAP benefits) can get free or reduced admission to more than 900 museums throughout the United States by presenting their SNAP EBT card. To learn more and find participating museums near you visit <https://museums4all.org/>

Orca Cards

The Orca Card pass offers a convenient, more affordable way to ride public transit in the Puget Sound area. To learn more about the Orca pass visit <https://www.myorca.com/>

State Parks Discover

Washington State Parks and Recreation Commission offers the Disability Pass to all Washington State residents who meet the Social Security Administration's definition of disability. To learn more visit <https://www.parks.wa.gov/1207/Disability-Pass>.

Disabled Hikers

Disabled Hikers founded in 2018 aims to advocate for inclusion and accessibility in the outdoors. The site offers trail guides, resources, and stories from other individuals accessing the outdoors. To learn more visit www.disabledhikers.com

Learn more at: <https://informingfamilies.org>



Adaptive and Inclusive Summer Camp

July 7th - August 21st

10am-2pm

Monday - Thursday

AIROW Project's 2025 Summer Camp Programs include but are not limited to varied levels of hiking, swimming, boating, biking, group games, team building, community engagement, arts & crafts, and more. Adaptive equipment can be provided, and all activities are adapted based on the specific needs of our campers. DDA Funds accepted.

Learn more at: www.theairowproject.org



SENSORY SPACE AT THE NORTHWEST WASHINGTON FAIR

Date: August 7 - 16, 2025

Hours: 12 - 5pm

Location: Located in BP Place, next to the Young Life BBQ and adjacent to Dairy Women Moo'wiches

Sponsored by Becoming Complete
becomingcomplete.org

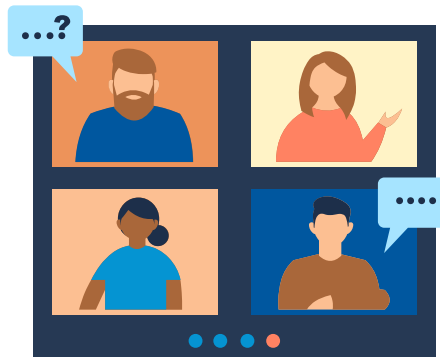
If you would like more information please contact
rhonda@becomingcomplete.org
for more details!

Does your loved one need a break at the fair? This space will offer a quiet place to take a break from the large crowds, overwhelming noises and provide families with sensory-friendly activities. All ages welcome!



Virtual Office Hours

Information and resources for individuals with intellectual and developmental disabilities and their families



Staff are available every Thursday (unless it is a holiday)

11am - 12pm, No RSVP needed

<https://us02web.zoom.us/j/86909304702>

Meeting ID: 869 0930 4702

Do you have questions about:

- Special Education
- Disability Systems & Resource Navigation
- Future Planning & Transition to Adulthood
- Disability Family Support

There is no password to join but participants will be in a waiting room, until we admit you. We can utilize breakout rooms to enhance privacy, if multiple participants have joined.



Scan here to enter Zoom



admin@arcwhatcom.org
360-715-0170
www.arcwhatcom.org

Transition to Adulthood Timeline

What to do and when to do it, here are some activities to do by age.

15-16	<p>Apply for a Washington State I.D. card. (before 18 is easier) Located at 4180 Cor-date Pkwy Ste. A, Bellingham, WA (360) 676-2096</p> <p>WHY: A photo ID will be needed to apply for many adult services.</p>	
16	<p>Apply with Developmental Disabilities Administration (DDA) WHY: Case management, family support and other services to help your son or daughter maximize their independence. Long term supports for employment after age 21. Applying early helps ensure funding availability. 360-714-5000</p>	
17-17 ½	<p>Consider if guardianship is necessary and determine type of guardianship.</p> <p>WHY: At age 18 your son/daughter becomes a legal adult and may need support making legal, medical and vocational decisions. Consider alternatives to full guardianship. Contact the Arc, 715-0170 for resources and planning guides.</p>	<p>GUARDIANSHIP and alternatives</p>
17-19	<p>Apply for low income Housing at the Housing Authority</p> <p>WHY: The wait list for housing can be long, so it's important to apply early. (360) 676-6887. Learn about housing choice vouchers and project based housing.</p>	
18	<p>If your child does not receive Social Security Benefits—apply now!</p> <p>WHY: He or she is now an adult and parent's income is not counted. He/she may be eligible for cash and medical benefits. There are many provisions available, called WORK INCENTIVES, that allow people with disabilities to keep benefits, including Medicare/Medicaid, while working.. He or she needs to pay rent to the family in order to maximize SS benefits.</p>	
18	<p>Ask your DDA case manager about Personal Care funding.</p> <p>If your son or daughter needs help with bathing, grooming, dressing, laundry, etc. funding may be available for Personal Care. Support can be provided by either family members or a contracted provider. Contact your DDA case manager and ask about the "Community First Choice" (CFC) Program 360-714-5000. Apply now to see how this and other services may benefit your family.</p>	<p>Personal Care</p>
Senior year	<p>Fill out the Free Application for the Federal Student Aid (FAFSA)</p> <p>WHY: If seeking aid to attend college, this form must be filled out by March 1 of Senior year for best consideration. www.fafsa.ed.gov</p>	
18-21	<p>Apply for services with the Division of Vocational Rehabilitation (DVR)</p> <p>WHY: This agency helps people with disabilities get and keep a job, and understand how working affects benefits. 360-812-6610</p>	
19-20	<p>Apply to the Job Foundations Program</p> <p>WHY: Connects students their second to last year of school with adult vocational agencies to ensure an effective transition to work and adult life. Must be DDA eligible. Talk with your teacher or DDA case manager.</p>	
Anytime	<p>Apply for job search assistance with WorkSource Youth Services</p> <p>WHY: This is a local program that can help self-directed job seekers find part time and/or summer employment to help develop work skills.</p>	
Anytime	<p>Whatcom Transportation Authority and Paratransit services</p> <p>WHY: Learning to ride the bus helps your son or daughter to be more independent. They offer flexible alternative public transportation for people with disabilities. Ask about travel training and reduced fares. 360-676-7433</p>	
Anytime	<p>Connect with the Arc of Whatcom County</p> <p>WHY: Assistance in helping navigate system, connects with resources, and provides support to parents by other parents of individuals with disabilities. 360-715-0170.</p>	



Need Paperwork & Application Support from Arc Staff Members?

**2nd & 4th Wednesday
of every month**

May 14, May 28

~~June 11*~~, June 25

11am - 1pm

**Dan Godwin Community Center
2602 McLeod Rd., Bellingham**

Join Arc Staff in-person at the Dan Godwin Community Center. We will be supporting families with filling out paperwork for their loved ones. Bring a laptop or tablet if you have one, some laptops will be available for use at the Arc.

- Partners4Housing Residential Assessment
- Developmental Disabilities Administration (DDA) Eligibility
- Supplemental Security Income (SSI)
- Guardianship
- Use of our printer, scanner, and paper shredder free of charge

We may not have time to complete all your paperwork, but this is a great opportunity to have support looking over where to start.

If you need private one-on-one support, please email admin@arcwhatcom.org to set up an appointment at a different time. At our Paperwork Support Workshops, staff may be helping multiple people, and we cannot guarantee privacy.

*Cancelled, we will be holding our Home & Beyond: Staying Safe Together workshop

(360) 715-0170



admin@arcwhatcom.org



The Washington State Developmental Disabilities Council, The Arc of Washington State and Self Advocates in Leadership (SAIL) have created a campaign to help people understand and participate in potential changes coming to their Medicaid services. We have a new webpage and series of videos dedicated to sharing information. These resources provide essential details on what Medicaid is, who uses it, and how it impacts lives across our community.

Share Your Story:

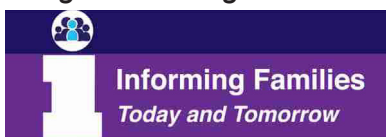
Your story can make a difference. Create a story with help of our team to explain why Medicaid Matters to you. The story will be available for you to send to anyone you want, as well as be shared on our website with the rest of the community. Help us show why Medicaid is essential by sharing your experience in one of these ways: Record a video using your cell phone, schedule a Zoom session with The Arc of Washington State and record through Zoom, or submit a picture of you or your loved ones and a written piece on why Medicaid matters to you. If you are interested in sharing your story, please fill out the Medicaid Matters Story Form Do you have questions or need help submitting your story? Please reach out to reply@arcwa.org.

Ways to Take Action:

Your elected officials in Congress are considering some very difficult decisions about Medicaid and need to hear from you, their constituent, about how those decisions will impact your life.

To submit find videos, share your story or find out more about your Congressional District, visit:

<https://informingfamilies.org/medicaid-information/>



NAVIGATING SSI APPLICATIONS

ONLINE CLASSES

7

MAY

12:00 PM

CHILDREN
UNDER 18

14

MAY

12:00 PM

YOUTH AGES
18 +

Join NW Access Navigating SSI Applications classes! These classes are online, free, and are created and led by a certified benefits planner. These classes are intended for parents and service providers of youths with disabilities in Washington, Oregon, and Idaho. Get a better understanding of the SSI application process, learn tips and strategies to navigate it, and get a chance to ask questions.

Register here:

www.nwaccessfund.org/youth/navigating-ssi/

Have a disability benefits question? Check out the Make It Make Sense Series on YouTube, where we explain complicated benefits questions, like - What's an ABLE account? How does work impact SSI benefits? What's a DAC? What's the difference between SSI and SSDI? and more!

Check out the YouTube channel here:

youtube.com/@northwestaccessfund2564

Staff & Board of Directors

The Arc of Whatcom County provides leadership support for individuals with developmental disabilities and their parents/guardians. The goal of the Parent Coalition is to enable persons with developmental disabilities and their parents/guardians to become effective and involved in accessing services.

Arc of Whatcom County Staff:

Executive Director: Beverly Porter

Assistant Director: Rhonda Rische

GIDES Family Advocate: Barbara Roxas

Asst Inclusion Advocate: Terri Hansen

Family Advocate: Laura Kaptinski

Parent to Parent & Self Advocate Coordinator:
Karlene Umbaugh

P2P Parent Assistant & Parent Coalition

Co-Coordinator: Melissa Abraham

Padres a Padres: Marta Mejia, Alina Zollfrank

Office Manager: Hilary Scheibner

Board of Directors:

Missy Bartell – President

Ken Larson -Vice President

Susan Jewell – Treasurer

Sam Hogan – Secretary

Dale Whipple – Director

Ellie Posel – Director

Margaret Jahn – Director

Melanie Hartley – Director

Frances Chalmers – Director

The Parent Coalition is funded by grants from the Developmental Disabilities Program of Whatcom County, the United Way and your generous donations.



We are affiliated with The Arc of United States with more than 140,000 members and nearly 700 state and local chapters nationwide, we are on the front lines to ensure that people with intellectual and developmental disabilities and their families have the support they need to be members of the community.

Our office is open to the public Monday through Thursday, 10am - 1pm if you would like to browse our Lending Library or are in need of resources. Staff are also available by appointment outside of those times. Please call 360-715-0170 if you are needing any assistance and would like to connect with a staff member.

The Arc of Whatcom County
Dan Godwin Community Center
2602 McLeod Rd
Bellingham, WA 98225-1368

Phone: (360) 715-0170 Fax: (360) 715-8522

Email: admin@arcwhatcom.org To see a list of staff positions and extensions, visit:
<http://arcwhatcom.org/about-the-arc/staff/>

MAY

**No Self-Advocacy Meeting on May 1st.*

1 Thursday, 11am -12pm
Open Office Hours

5 Monday 10 - 11am
Coffee and Conversation

8 Thursday, 11am -12pm
Open Office Hours

8 Thursday, 6pm
Dads Social

12 Monday, 7 - 8pm
Virtual Parent Connect

14 Wednesday, 11am - 1pm
Paperwork Application
Support

15 Thursday, 11am - 12pm
Open Office Hours

22 Thursday, 11am - 12pm
Open Office Hours

27 Tuesday, 6 - 8pm
Building your Special Needs
Plan Workshop

28 Wednesday, 11am - 1pm
Paperwork Application
Support

28 Wednesday, 6 - 7:30pm
Arc Annual Meeting & Pizza
Party 2602 McLeod Rd,
Bellingham

29 Thursday, 11am - 12pm
Open Office Hours

JUNE

2 Monday 10 - 11am
Coffee and Conversation

5 Thursday, 11am -12pm
Open Office Hours

5 Thursday, 4:30 - 6:30pm
Self Advocacy Meeting

9 Monday, 7 - 8pm
Virtual Parent Connect

11 Wednesday, 11am - 1pm
Home & Beyond: Staying
Safe Together Workshop

12 Thursday, 11am - 12pm
Open Office Hours

17 Tues, 9:30 am - 2:30 pm
Super Sitter Training

18 Wed, 9:30 am - 2:30 pm
Super Sitter Training

19 Thursday, 11am - 12pm
Open Office Hours

19 Thursday, 1 - 2:30pm
Cupcake Decorating Sibshop

25 Wednesday, 11am - 1pm
Paperwork Application
Support

25 Wednesday, 6 - 7:30pm
Board of Directors Meeting
[https://arcwhatcom.org/
about-the-arc/board-of-
directors/](https://arcwhatcom.org/about-the-arc/board-of-directors/)

26 Thursday, 11am - 12pm
Open Office Hours



OUR LENDING LIBRARY IS AVAILABLE!

*Please
click on
the link
and click
on books.*

Search our collection on our website at
[the Resources tab under books.](#)

The Arc
Whatcom County

PARENT TO PARENT



STAY CONNECTED



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ParenttoParentWhatcom](http://www.facebook.com/ParenttoParentWhatcom)

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WhatcomCountySelfAdvocacy](http://www.facebook.com/WhatcomCountySelfAdvocacy)

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DownsyndromeOutreach](http://www.facebook.com/DownsyndromeOutreach)

Follow our Instagram @arc_whatcom

Find resources, information and more at:
www.arcwhatcom.org