

April is Autism Acceptance Month

AUTISM 101

WHAT IS AUTISM?

Autism is a complex, lifelong developmental disability that affects essential human behaviors such as social interaction, the ability to communicate ideas and feelings, imagination, self-regulation, and the ability to establish relationships with others.






RELATIONSHIPS SELF-REGULATION COMMUNICATION SOCIAL SKILLS

Autism is characterized in the DSM-V by:

- Persistent deficits in social communication and social interaction
- Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities

THE STATS

The symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe.

1 in 59 children are diagnosed with autism.
→ This is up from 1 in 88, five years ago, and 1 in 125, just ten years ago.

85% of autistic adults with a college education are unemployed.

3.5M+ individuals in the United States are on the autism spectrum; autism is the fastest-growing developmental disability in the U.S.

The diagnosis rate for autism is rising by 10-17% each year.

500,000 individuals with autism spectrum disorder are transitioning to adulthood in the United States.

Males are 4 times more likely than females to be diagnosed with autism.

88,000 individuals are on state waiting lists hoping to receive adult housing services; the rate continues to grow exponentially.

GETTING THE HELP YOU NEED

1 Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges.

2 Often times, there are no differences in how people with ASD look, that would set them apart from others, but people with ASD may communicate, interact, behave, learn, and experience the world in ways that are different from most.

3 The learning and cognitive abilities of people with ASD can range from gifted to significantly impacted.

4 A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. **These conditions are now all called autism spectrum disorder.**

While no single specific cause of autism is known, current research links autism to biological or neurological differences in the brain. The characteristic behaviors of ASD may or may not be apparent in infancy (18 to 24 months), but usually become obvious during early childhood (24 months to 6 years).

Currently, there is no cure for autism. However, continued research has provided a clearer understanding of the disorder and has led to better treatments and therapies that can positively change the associated behaviors.

The Autism Society is the largest and oldest grassroots autism organization in the nation, working hard every day to measurably improve the lives of all affected by autism throughout the lifespan. Our network provides advocacy, education, information and referrals, support, and the community at the local, state and national levels.

Our National Helpline offers our trained Information & Referral (I&R) Specialists to provide resources to services and supports across the country. To speak to an I&R Specialist directly, call 800-3-AUTISM (800-328-8476), or email info@autism-society.org. Visit www.Autism-Society.org to learn more.




Celebrate Differences

Supporting Individuals with Autism through Uncertain Times

The Frank Porter Graham Child Development Institute developed this guide full of user-friendly strategies, ready-made resources and examples, and links to additional supports to help families navigate this challenging time. Although designed for Autism, many of the tools in this toolkit would be applicable to other developmental disabilities as well. These resources focus on the following 7 support strategies designed to meet the unique needs of individuals with autism during this period of uncertainty.

7 Strategies to Support Individuals with ASD through Uncertain Times

1. Support understanding
2. Offer opportunities for expression
3. Prioritize coping and calming skills
4. Maintain routines
5. Build new routines
6. Foster connections (from a distance)
7. Be aware of changing behaviors

View the toolkit here:

<https://afirm.fpg.unc.edu/supporting-individuals-autism-through-uncertain-times>

Resources are available online and in PDF and Word versions so families can edit/print as needed.



The Arc Visits Olympia for Advocacy Day

On a crisp sunny morning in February, 21 of us from both Whatcom and Skagit counties boarded a charter bus and headed to Olympia for an opportunity to take part in an event sponsored by The Arc of Washington. This event, known as Advocacy Days, takes place every Wednesday during session on the capitol grounds and draws families and self-advocates from around the state to speak to their legislators. It offers an opportunity to learn more about policy and budget legislation that is currently active in both the House and Senate. The Advocacy Day we attended on February 19th was centered on caseload forecasting, a big concern in our state. Projections made through caseload forecasting are how funding for state services are determined. Caseload forecasting is not currently done for developmental disabilities services and that is a key reason why there are huge wait lists for people to receive services through the Developmental Disabilities Administration (DDA).

We started our day in Olympia with a briefing from The Arc of Washington and other advocacy groups on the latest legislative issues. Then we set off to meet with our legislators. The sun warmed us as we walked across the Capitol campus and to the legislator's buildings for our meetings with district 40 and 42 representatives. Our group split into two, based on the district we live in, and went off to our respective meetings in conference rooms which allowed space for all of us to sit as a group. Each person had the opportunity to speak for 2-3 minutes, sharing their personal story and concerns that affect them or their family member.

Self-advocates and family members talked to legislators and their staff from District 40 - Representative Lekanoff, Rep. Ramel, and Senator Lovelett and District 42 - legislative assistants for



Attendees from the 40th district with their state senator, Liz Lovelett.

Representative Shewmake, Rep. Van Werven, and Senator Ericksen. People voiced concerns centered around various issues including: social security reporting, bus restraints, funding for DDA caseload forecasting, and how some particular bills would benefit or affect them or their family member.

At mid-afternoon, we embarked on our journey towards home and reflected on the highlights of the day. Here are some comments that were expressed:

- *I liked having time to meet the representatives and Senator for my district. They listened to me.*
- *I didn't expect such a relaxed opportunity to share what matters to me as a parent (for my family member).*
- *I liked the whole thing....the whole day was amazing!*
- *I was happy to tell my friend's story (because she couldn't come). As an advocate, that is important to me.*
- *I didn't expect to have access to talk and really be listened to by my representatives! Now I know that I can contact them and share concerns.*
- *Democracy in action- what a fun day at the capitol!*

You are not alone. We are here to help.



- Call: 360-715-0170 ext 302
- Email: p2p@arcwhatcom.org
- Facebook Messenger (Search Parent to Parent of Whatcom County)

Sibshops - Now Virtual through "ZOOM" Group Chat

A popular fun filled event for brothers and sisters of kids with developmental differences, delays, and on going health care needs.

National Sibling Day - Friday, April 10th
12:30 - 1:30 pm
Ages: 6 - 12 yrs

Register: p2p@arcwhatcom.org

Parents, after registering you will receive an email containing the link for your child to join Sibshops via Zoom. Pre-registration is REQUIRED so you can get the link. Must be able to connect through a cell phone, tablet or computer. Karlene Umbaugh and Melissa Abraham will be the group facilitators, and we can't wait to see you!

Parent Support meeting is now Virtual!

We may not be therapy, but we sure are therapeutic! We understand how isolating it can be right now, so we are hosting our monthly Parent Support Meeting through ZOOM. We will share knowledge, resources, provide support and guidance.

Monday, April 13th
7 - 8:00 pm

Register: p2p@arcwhatcom.org

After registering you will receive an email containing the link for you to join the Parent Support Meeting. Pre-registration is REQUIRED to get the link. Must be able to connect through a cell phone, tablet or computer.

Washington Autism Alliance & Advocacy (WAAA) helps to expand access to resources, healthcare, education, and services for people with autism and other intellectual and developmental disabilities in Washington State. WAAA offers family navigation, advocacy and legal services, training workshops, online support groups, and a vast online resource library. In addition to the organization's new logo, WAAA recently welcomed Northwest Washington Regional Outreach and Advocacy Coordinator, Krystal Trull, to the team to locally serve residents of the northwest region of the state. Having a child with autism herself, Krystal brings both personal and professional experience to this position and is eager to help families needing support in Whatcom County. For more information, visit WAAA's website or contact Krystal directly.

<https://washingtonautismadvocacy.org/>
 Krystal Trull, CFLE-P
 Regional Outreach and Advocacy Coordinator,
 Northwest WA
 krystal@washingtonautismadvocacy.org
 360-474-7368



Community Resources

Important updates on emergency changes to in-home care providers due to COVID-19

- Provider regulations for hiring and providing services are currently relaxed.
- Providers can continue providing services and are exempt from work-stoppages due to any trainings (CE, Basic and DOH certifications) that have not been completed.
- For those just now coming through the contracting process, the background screening is just the Name and Date of Birth background check.
- Those providers who have completed fingerprinting but do not have completed screenings may continue to provide services.
- 20 hour per month restrictions for Limited Service Providers and Respite-only providers is suspended.
- These provider qualifications remain in place: To continue providing personal care or direct support services to DSHS clients Long-Term Care Workers must: be 18 years of age, complete and be found eligible under the State Name and Date of Birth Background check, and complete the Orientation and Safety training: found online at: https://www.myseiubenefits.org/training/learn-about-classes/orientation-safety/?fbclid=IwAR06uPSGLM37IAGQqTfla0x7dazcWS_qLVYRvNPK6GgbZnkjECbx5DO-w70

If a family needs to have a provider work over their 40 hour Work Week Limit due to a COVID-19 related reason, they can reach out to the Case Resource Manager and request a temporary overtime approval. All the above is effective immediately. All of the above will revert to in-place requirements once the COVID-19 impact is released by the governor.

WTA is temporarily reducing fixed route and paratransit bus service*

On Mondays through Fridays, all buses will run on Saturday schedules.

On Saturdays and Sundays, all buses will run on Sunday schedules.

Ride the bus for essential trips only. Fares are free. Board from the rear door unless you require the ramp.

For more information, call (360) 676-7433 or visit ridewta.com



WTA
*Starting March 30, 2020

Get an Emergency Supply of Meds

Commissioner Mike Kreidler issued Emergency Order No. 20-01. This order directs insurance carriers to permit a one time early refill of necessary medications for patients. This will help facilitate continuance of therapy in the case of home isolation. The Order also directs insurance carriers to waive co-pays and co-insurance related to COVID-19 testings.

Read the full Emergency Order: <https://www.insurance.wa.gov/sites/default/files/documents/emergency-order-number-20-01.pdf>



Parent Coalition Online Workshop: Establishing a Guardianship for family members, caregivers and community members

12:00 - 2:00 pm, Friday, April 17
Online ZOOM Meeting

Thinking about Guardianship? Navigating the legal system on your own can be intimidating. We're not attorneys or facilitators, we are families who have navigated the court system and want to be a resource to others. Pre-made packets are available for purchase from the Whatcom Superior Court Clerk's Office. These packets are tailored to meet Whatcom County's requirements and contain all basic documents that you will need.

Participants must:

- Purchase the guardianship packet (\$40.00 cash) in person between 9 a.m. and 11 a.m. at the Clerk's office, or may pay by phone and have the packet mailed to them. Whatcom Superior Court, 311 Grand Avenue, 3rd Floor, Suite 301, Bellingham, WA 98225 Phone: 360-778-5560
- RSVP to parentcoalition@arcwhatcom.org or 360-715-0170 ext. 306 to register and receive the zoom link

Whatcom Superior Court Updates for all Guardians: The Superior Court has reviewed and signed orders on guardianship cases that were already scheduled or noted. Presently, hearings are being delayed until after the first part of May. No in person appointments are happening or being scheduled at this time including meetings with the Guardianship Facilitator for review of documents. Guardians may turn in their reporting paperwork or any other paperwork by mail or between 9 a.m. and 11 a.m. at the Clerk's office.

Do you need low-cost internet?

If you are eligible for public assistance programs such as the National School Lunch Program, Housing Assistance, Medicaid, SNAP, or SSI, you may be eligible for free internet for 60 days. This will help kids and parents have access to educational materials from home. Visit <https://internetessentials.com/apply> for more information.



Washington Office of Superintendent of
PUBLIC INSTRUCTION

Looking for guidance during this time regarding K-12 Special education? Visit <https://www.k12.wa.us/about-ospi/press-releases/novel-coronavirus-covid-19-guidance-resources/special-education-guidance-covid-19>

DID YOU KNOW?

For anyone using personal care hours through DDA, you can call or email your case manager and request additional hours because of the the loss of natural supports due to school closures. It's known as "exception to rule" and they're going to try to process as many requests as possible as quickly as possible.

<https://www.dshs.wa.gov/dda/consumers-and-families/dda-coronavirus-information>



During this time of national crisis there is much misinformation about COVID-19, perhaps even more so for people wanting to know how it may affect individuals with Down syndrome. The NDSC has gathered and vetted many sources and resources to help our families, and the professionals who serve them, as we all work to flatten the curve. Visit their new Resource Library to find practical information about the virus, resources to help families adapt to online or distance learning and at home therapies, and ideas for family fun activities during quarantine.

To see the NEW library of resources visit https://www.ndscenter.org/programs-resources/covid-19-resources/?fbclid=IwAR0zRhPxzY7QNQRTgI97_Fw_yHnovLX8JyIxl4bKK6ewNuWefvftkLGcZC4

2020 Smiles of Life Calendar Spotlight: ANNA & KAI



Kai and Anna are fun-loving best friends. Both were born with Down syndrome, the most commonly occurring chromosomal condition. Although Down syndrome is what brought their families together, Kai & Anna's friendship is based on their laughter and humor. When they are together, they love to swim. They enjoy playing with friends, going to the beach, and having sleep overs. Anna is involved in Special Olympics and Unified sports, including basketball, bowling, and volleyball. Kai has a puppy, 'Olive', and a dog 'Shadow'. You may have seen Kai with his stuffed dog 'Brutus' who accompanies him almost everywhere. Although Kai loves 'Brutus' his stuffed dog, he'll let you know that Anna is his best friend! They both have a great sense of humor and enjoy being silly. These two are inseparable and are determined to live each moment to the fullest.

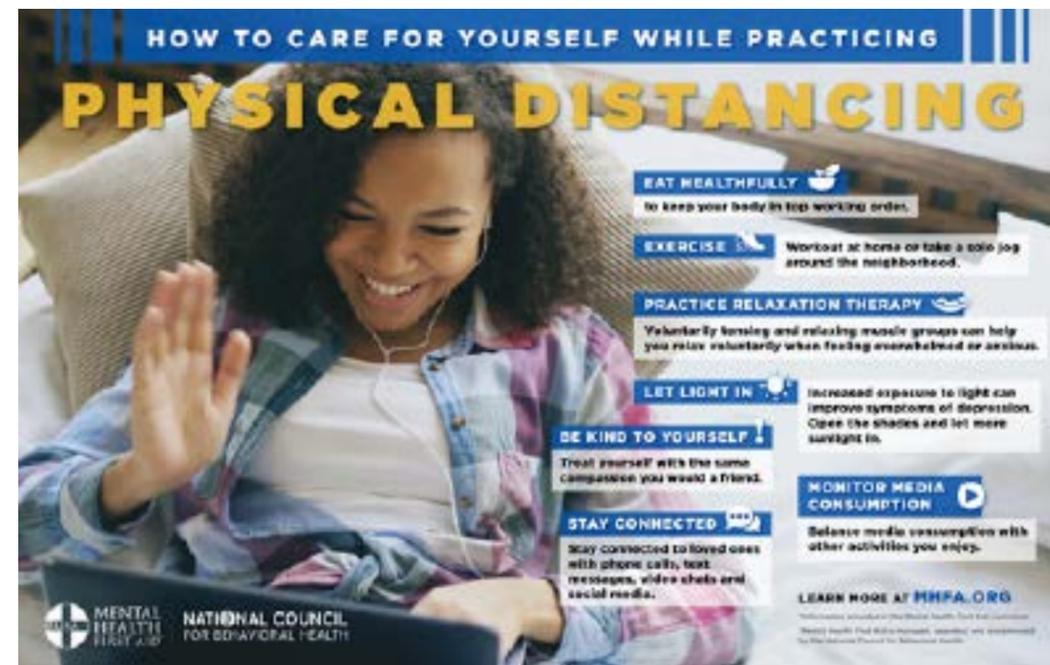


Membership in the National Network of Gifted Self-Advocates

The National Network of Gifted Self-Advocates is currently under establishment! The organization is seeking at least three additional members, preferably gifted and talented members. The organization's mission is to be the voice of the gifted, by the gifted, for the gifted, before corporations and legislatures within the United States for the purpose of enabling the gifted and talented to live richer lives where they are fully welcome and supported. For further information and if you are interested in becoming a member, please email Ryan at happytobe2e@gmail.com.

No Self Advocacy Meeting in April

To ensure the health of our staff and Self Advocates, our April 2nd Meeting is cancelled. We will be updating our families and self advocates in regards to the May meeting, as soon as we have more information. Please call 360-715-0170 or email SelfAdvocacy@arcwhatcom.org for more information or to connect with Art, our Self Advocacy coordinator.



The Parent Coalition

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.

The Parent Coalition newsletter is published monthly by:

The Arc of Whatcom County
Dan Godwin Community Center
2602 McLeod Road
Bellingham, WA 98225
(360) 715-0170
www.arcwhatcom.org

Office is currently closed due to COVID-19

Newsletter Production Staff:
Melissa Abraham, Karlene Umbaugh, Monica Burke

Executive Director: Beverly Porter
Program Director: Monica Burke
Care & Resource Coordinator: Mary Jo Durborow
Parent Coalition Co-Coordinator: Barbara Roxas

Self Advocacy Coordinator: Art Maas
Asst Inclusion Advocate: Terri Hansen
P2P Coordinator: Karlene Umbaugh
P2P Parent Assistant: Melissa Abraham
Padres a Padres: Marta Mejia

Board of Directors
Michelle Karaffa, President
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Dale Whipple, Director
Detrick Grimes, Director
Susan Radke, Director
Bahar Yolac, Director

Stay Connected

Online Community Calendar:
Visit The Arc's website at www.arcwhatcom.org and click on **Events**.

Facebook: Visit our FB page: www.facebook.com/ArcWhatcom for the latest information and events.

E-alerts: The Parent Coalition emails updates on legislation, workshops, and upcoming activities. To sign up, visit www.arcwhatcom.org or email parentcoalition@arcwhatcom.org.



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

A Note from The Arc Regarding COVID-19

The Arc of Whatcom County is committed to reducing the threat of COVID-19 and caring for the health and well-being of our members, volunteers, employees, and our communities. In response to the public health concerns regarding the spread of COVID-19, our offices at the Dan Godwin Community Center are temporarily closed to the public until further notice. We are cancelling in-person events and gatherings for the immediate future. This includes Sibshops (see pg. 2 for a virtual option), Down syndrome Outreach's Spring Fling, and the Latino Family Egg Hunt. However, we are continuing to provide support, information and advocacy services.

Staff will be accessing email and voicemail and we are working to develop alternative methods for connecting and learning. You are always welcome to contact us via Facebook, by phone at 360-715-0170, or by email at parentcoalition@arcwhatcom.org. We recognize this is a challenging time for all, and we remain deeply committed to supporting one another. We will continue to monitor developments, adjust where necessary, and do our part to reduce the spread of COVID-19.

Whatcom Social Media Resources

For Families of Individuals with Developmental Disabilities and other Special Health Care Needs

Websites

Whatcom Taking Action for Children with Special Healthcare Needs

www.WhatcomTakingAction.org

The Arc of Whatcom County

www.ArcWhatcom.org

Parent to Parent of Whatcom County

www.P2PWhatcom.org

Whatcom County Infants and Children's Council (WICC)

www.whatcomicc.wordpress.com

Facebook Pages

Whatcom Taking Action for Children with Special Healthcare Needs

www.facebook.com/WhatcomTakingAction

The Arc of Whatcom County

www.ArcWhatcom.org

Parent to Parent of Whatcom County

www.P2PWhatcom.org

Whatcom County Infants and Children's Council (WICC)

www.facebook.com/WhatcomICC

Autism Bellingham Whatcom

<https://www.facebook.com/AutismBellinghamWhatcom/>

Facebook Groups

P2P: Whatcom County

www.facebook.com/groups/1289791781074855

Bellingham Moms of Children with Special Needs

www.facebook.com/groups/bellinghammothersofspecialneedschildren

Whatcom "Sensational" Parents

www.facebook.com/groups/whatcomsensationalparents

Bellingham Autism Moms & Dads

www.facebook.com/groups/1030189507069519

Special Education Parent Advisory Committee (for Bellingham Schools)

www.facebook.com/groups/spedpac/?ref=group_browse_new

Whatcom Area Families Exploring Down syndrome

www.facebook.com/groups/382131828513542/

Autism Support Group

www.facebook.com/groups/1809136672498381/