

The Arc of Snohomish County Leadership Newsletter

2020 Issue 2

A Message from The Arc

Greetings to our Arc friends;

INSIDE

Page 1 - A Message from the Arc

Page 2 - Life in Quarantine

Page 3 - Life in Quarantine

Page 4 - Congratulations to all our graduates!

Page 5 - Arc News: New Programs and New Schedules

Page 6 - Tools & Resources

Page 7 - Boards & Commissions - Public Policy & Legal Advocacy

Page 8 - Get Involved - Did you Know - Federal Bills of Interest

The Arc of Snohomish County 2500 Hewitt Ave. Suite 300 Everett, WA 98201 425-258-2459

https://www.arcsno.org/

We certainly are going through some challenging times. We want you to know that although The Arc office is still closed, The Arc staff are working hard from home to provide the much needed services, support including informative speakers, and important resource navigation for individuals with intellectual and developmental disabilities and their families in Snohomish County. The Arc is still operating, just in a different way. You can connect with staff by leaving a phone message or sending an email. We are dedicated to answer your calls and messages as quickly as we can. If you are not sure which staff to email you can send a message to info@arcsno.org.

We have many virtual opportunities happening throughout the month so be sure to check out our Facebook page https://www.facebook.com/TheArcofSnohomishCounty/ or the calendar section of our website www.arcsno.org We miss you and can't wait to open our doors to in person events again.

I hope that you and your loved ones are happy and healthy,

Shayne Nagol

Shayne Nagel Executive Director 425-258-2459 Ext 102

Check out the Arc of Washington for up to date COVID-19 Resources

https://arcwa.org/covid-19/

Achieve with us.



"How wonderful it is that nobody need wait a single moment before starting to improve the world" -Anne Frank

Life in Quarantine

COVID-19 has been a serious problem for what seems like ages now. Sheltering in place is working, but it is difficult to say the least. We all know that this is a trying time for everyone, and more so for those with family members with I/DD. It is important to know that you are not alone in this. Many others are experiencing the same things as you right now, so we at The Arc wish to show you some of these stories.

Jessie lives with her son Stage, who is 13. He has multiple diagnoses, Mitochondrial Myopathy, Autism, Epilepsy, Visual Impairment, Non-Ambulatory (uses wheelchair/requires physical care/support), Brittle Bones, use a feeding tube, and more. Her daughter Chance is 6, and they also live with their stepfather Adam. Acashia, Jessie's oldest child, is 17 and lives full time with her dad.

In Jessie's own words: "There have been a lot of struggles throughout this process. Figuring out how to balance work, and having all of my children all at once. Losing the individual therapy and focus time I had for my son on Monday's because now his younger sister is home full time. She is a very busy 6 year old. It feels like we are in our usual frantic summer, but there was no time to plan and there are no camping trips, splashing in the lakes, visiting parks etc. so that makes it a challenge to keep two very different learners engaged. I'm also really concerned about my son's ability to continue to access quality healthcare. Not just for Covid-19, but also just his normal health risks. I don't currently have any caregiver support and the school was an essential support in my life. That instant loss of school support in addition to having no time to plan was a shock. He weighs almost 100 lbs. and requires lifting/transfers. I am physically drained each day. In addition to missing parenting time with my two step children due to safety concerns; as they live in another state and we did not feel that flying at this time was safe.



But like anything, there are bright spots as well.

"I often remind myself that everyone at the moment is in the same crisis. This gives space for calm and reassurance that everything will work out. I'm thankful to be home and quarantined in order to protect my son's health. I am thankful for the support of my husband Adam and my children's dad Jeff and their step mom Michelle. They are offering additional support with the kids. All four of us are an amazing co-parenting team. Though I am extremely tired; I am thankful to have my family healthy. I'm slowly finding a work and home life balance. I'm enjoying the quality time with my kids even though I may still be in my pajamas come dinner time and dinner might just end up being a peanut butter and jelly sandwich with some carrots and ranch on the side. I am giving myself the guilt free okay to just focus on surviving each day and that I don't have to be perfect. My kid's mental health and well-being is the priority so I have laundry piled up and I can't remember when I brushed my daughter's hair last."

One thing families of people with I/DD do better than most is prepare. We tend to understand that anything can happen, and you never know what can trigger an event or cause a problem. But no matter how hard you try, there is always something you aren't prepared for.

"I never planned on not being able to access his medical appointments, therapies, and routine care. Though I understand that we will all experience an impact from this medical crisis. So I am thankful for having my own medical experience with him and have confidence in myself and my ability to manage his medical needs. I am fortunate that my children have been behaving well and are happy. They are enjoying their time at home and are emotionally coping well. Though I am exhausted trying to ensure each day is full of purposeful activity when I am able to, knowing that they are happy helps get me through it."

Achieve with us.



"We don't develop courage by being happy every day. We develop it by surviving difficult times and challenging adversity."

-Barbara De Angelis

Life in Quarantine

Continuing in our quarantine stories, we have Sopars Tauch, another employee here at The Arc

Sopars lives with her husband Anthony, and their two children Summer (14) and Kai (12). Kai is diagnosed with severe autism, sensory/auditory processing disorder, PTSD, and is nonverbal. They have been staying at home since Everett schools closed on March 12.

"The cancellation of everything has been really hard," Sopars said. "There are so many [services] I worked so hard for. ABA in his center, Special Olympics practices, my daughter's freshman year of high school. Both kids have been extremely emotional during this time. Kai has been all over the place emotionally, and he has been crying out of the blue and breaking things again. I've been watching closely for any signs of sadness [with my kids] and tend to them."

Trial by fire is something all families with I/DD diagnoses go through, and in many ways this ordeal is more of the same.



"Ever since our son was diagnosed, we fought so hard to get out of the isolating life of a special needs family, only to feel like we are right back where we started. Cancellations of social and physical activities in which we as a family count on to keep our children mentally and physically healthy have been especially hard."

Fortunately for Sopars and her family, there is always something positive to find as well.

"We've moved ABA to in home, which has given Kai some much needed structure and me some time off to focus on work. We also have his school electronics to give him an opportunity for engagement. Summer has begun reconnecting with her teachers and Cheer squad over Zoom and doing some distance workouts with her squad."

There have also been some surprising positive developments as well.

"We are actually getting a lot more connections for home care and respite opportunities through this time."

"I think it is very important to make sure we still do go for a walk even in our own backyard and breathe that fresh air, take the family for a scenic drive just to know that life still exists and the world did not end. I worry so much about the kids and the family's mental health. It's like our lives have just stopped. We as a family ran a robust schedule prior to this. Now just making through the long days has its challenges of making sure everyone is happy and engaged and content...all the while trying to put in some work on top of it."

Thank you to Sopars and Jessie for opening up their lives and their stories to us. Knowing that we all have struggles during this difficult time will help us all to know that we are not alone, and we can always find strength in each other.

We will continue to post other stories throughout this crisis that will tell you all that you are not alone, and we can get through this together.

If you would like to share your quarantine story, please contact <u>lake@arcsno.org</u> to have your story featured in the next newsletter.

Achieve with us.



"You have power over your mind—not outside events. Realize this, and you will find strength."

- Marcus Aurelius

Achieve with us.

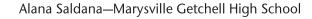
Congratulations to our Class of 2020 Graduates!

We at The Arc are excited to recognize our siblings and transition graduates for the 2019-2020 school year! We know you are unable to experience the usual graduation ceremony, so we would like to acknowledge your accomplishments, which are all the more impressive given this difficult time. Congratulations to you all!



Acashia Atkins—Legacy High School

Ahmed Maher Shebl—Snohomish School District Transition Center



Alexandra Kube—Everett Community College

Cassidy Williams—Arlington High School & Everett CC

Ethan Wood—Mariner High School

Hercis Hernandez—Mariner High School

Jennifer Pickrell—Marysville Transition Program

Michelle A Mendoza Cortes—Edmonds Woodway High School

Michou Mayer—Everett School District Transition Program

Neil Riker—GOAL, Everett School District

Nolan Schaffer—Washington State School for the Blind

Rachel Lee Powell—Mukilteo Community Based Transition Center

Raymond Johnson—Kamiak High School

Seth Perera—Snohomish Transition

Sophia Benjamin—Archbishop Murphy High School

Stephen Nguyen—Cascadia College

Taryn Solie—Jackson High School

Trevor Solie—Project Search, Everett School District













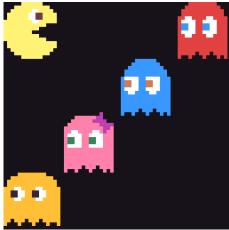


"Think like a queen. A queen is not afraid to fail."

- Oprah Winfrey

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Arc News: New Programs and New Schedules



Pixel art from a participant of the Art and Self Expression Program

While this new world of COVID-19 has been an extraordinarily trying time, the forced adjustments everyone is making has a silver lining. New and exciting opportunities are being presented, and thanks to some creative thinking The Arc has been able to take advantage of this situation and introduce some new programs. These programs are being done entirely remotely, not only making them compliant with all distancing efforts, but also increasing the accessibility in the process. One of these programs is the Art and Self Expression program.

The Art and Self Expression program is a safe space for all-abilities peers to connect with one another through art. All mediums are allowed, grab any art supplies you wish to use and create whatever you like with the

group. The goal is to foster self-expression, develop creativity, encourage sharing, and to engage with others. Meetings are every Wednesday at 4 PM, feel free to show up and create!

Another new program that has emerged from this time is the <u>Parent to Parent Happy Hour</u>, occurring every Sunday from 7-8pm. This is exactly what it sounds like, an opportunity for parents to get together and talk about the highs and lows of parenting accompanied with their favorite beverage of choice. A highly social and informal affair, feel free to meet up at anytime and exchange war stories and amusing anecdotes with other like minded parents.

Finally, we've also seen the creation of the <u>Zoom at Noon</u> meeting for self advocates that occurs every Tuesday at, well, noon! This is an opportunity for self advocates to get together safely and remotely to hang out in a fun, social setting. Each week has it's own unique thing that allow for everyone to have fun together during this trying time.

Other opportunities have also presented themselves for other established programs. The Snohomish County Father's Network is now meeting twice a month remotely, rather than once a month in person. Using video meeting technologies like Zoom allows fathers who can not leave their home responsibilities to attend meetings they would otherwise be unable to participate in. Participants are even able to listen in while commuting, allowing for a far wider participant pool than we have seen in the past.

We at The Arc will continue to try to improve upon our existing programs, and introduce more new and exciting ones in this difficult time. Until we can safely meet again, we look forward to seeing you online!

Interested in participating in any of these fun new programs? Check out The Arc of Snohomish County's website calendar for a full list of events.

For more information on these specific programs, contact:

<u>Moranne@arcsno.orq</u> for Art and Self Expression and Parent to Parent Happy Hour

Kylie@arcsno.org for Zoom at Noon

<u>Jake@arcsno.org</u> for Father's Network



We're here to help you have a voice

You are the expert in telling your story and how it relates to decisions being made by lawmakers.

Although impacting government may feel overwhelming, we're here to help you have a voice.

It only takes a few steps:

Be informed

• Sign up for Action Alerts

Get Connected

- Join The Arc
- Join a parent coalition
- Join a self-advocacy group

Take Action

- Visit The Arc of Washington State's Online Action Center
- Send emails
- Make phone calls
- Attend town hall meetings
- Participate in Advocacy Days
- Visit your legislators in person.

For tips on Legislative
Advocacy visit Hot Tips
https://arcwa.org/content/uploads/sites/35/2019/11/Hot
-Tips-2020.pdf

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Tools & Resources

Sign up

Legislative Alerts & Updates

The Arc of Washington State | http://capwiz.com/arcwa/mlm/signup/ Sign up for legislative action alerts related to developmental disability. Receive the information you need, to voice your opinions on bills during the legislative session. Alerts provide you with messages for your legislators that you can use as is, or edit using your own words. Enter your name and address and click! Your message will automatically be sent to all of your legislators. Toll free Legislative Hotline 1-800-562-6000. Email or call, action takes less than 5 minutes!

Find Your

Legislative District and Elected Officials

Washington Legislature | http://app.leg.wa.gov/DistrictFinder/
Find your legislative district and elected officials.

Hot Tips

Legislative Advocates on Developmental Disabilities

The Arc of Washington State |

https://arcwa.org/content/uploads/sites/35/2019/11/Hot-Tips-2020.pdf Some of the topics included:

- Tips for meeting with elected officials.
- How to create a short, clear message.
- The bill process—how a bill becomes a law.
- The state budget process.

Resource Library

The Arc of Washington State | http://arcwa.org/library/all

A comprehensive list of documents and websites that support developmental disability issues.

The Arc of United States | https://thearc.org/policy-advocacy/

For nearly 70 years, The Arc has been at the forefront of the fight for the civil rights and inclusion of people with intellectual and developmental disabilities (I/DD) and their families, playing a lead role in major victories in civil rights, community living, education, income security, and other important issues.



Find an open board or commission, get involved and have your voice heard!

The Arc can provide support, resources and tools to help you be an effective and successful disability advocate on local Boards and Commissions.

For information contact: Autumn Chancellor at Autumn@arcsno.org 425-258-2459 x107

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Boards & Commissions

Advocate for Disabilities on Boards and Commissions

Boards and Commissions serve as a bridge between the community and government, ensuring oversight and raising awareness on important community issues. They provide a setting for citizens to volunteer their time and energy in government and on behalf of the community to advocate for issues.

You can be a voice and a leader for developmental disabilities as decisions are made in your community. The Arc of Snohomish County encourages individuals and family members to participate on boards and committees.

Vacancies on Boards and Commissions in Snohomish County

Please click on the following Arc of Snohomish County link:

https://tinyurl.com/boardvacancies for current openings on Boards and Commission at the city/town level in Snohomish County. This list is current as of March, 2020.

When navigating city websites searching for boards and commissions vacancies, please note that this information may be found either: on one webpage; and/or require additional enquiry from individual Boards and Commission.

If all else fails, one can always call or visit the relevant city office for guidance. A general application may be required for consideration. Vacancies may be open until filled or open until a deadline.

Public Policy & Legal Advocacy

Public Policy and Legal Advocacy at The Arc https://www.thearc.org/what-we-do/public-policy

Take a look at the National Arc and sign up for their Action Alerts.



Sign up for Action Alerts

The Arc keeps up on many issues that are important to individuals with Intellectual/ Developmental Disabilities (I/DD) and their families.

Medicaid, the Affordable Care Act (ACA), Supplemental Security Income (SSI), Social Security, Medicare and civil rights laws like the Americans with Disabilities Act (ADA) are critical for people with I/DD and their families, providing benefits, supports, and civil rights protections that help make community living possible.

In 2017, The Arc called on all advocates to join us in reaching out to the President, Congress, Governors, and state legislators to educate them and to urge them to preserve - not cut - these essential programs and civil rights laws.

These federal programs provide the key to community living and inclusion for people with I/DD across the nation. We are stronger together when we join together as a collective movement to ensure that these programs and civil rights are protected.



The Arc of Snohomish County

2500 Hewitt Ave, Suite 300 Everett, WA 98201 425-258-2459

www.arcsno.org info@arcsno.org

Shayne Nagel Executive Director Shayne@arcsno.org

Jamie Coonts
Program Director
Jamie@arcsno.org

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Get Involved

Note that all events are currently conducted remotely. We will be conducting in person events again once it is safe for all interested parties. Thank you for your understanding at this time.

I.CAN Women's Self-Advocacy Group

2nd Tuesday of each month | 10:30am-12pm

We are a group of self-advocates open to all women ages 16 and up. A casual environment that combines learning with fun experiences. We share resources and skills, and hold the belief that everyone has something to contribute to our group. Please contact Kylie Walsh at Kylie@arcsno.org or 425-258-2459 x121 or Corinna Fale at Corinna@arcsno.org or 425-258-2459 x103.

Self-Advocates in Leadership (SAIL)

2nd Tuesday of each month | 1pm-4pm

Group of self-advocates focused on legislative change. Open to all. SAIL is a statewide coalition of people with developmental disabilities that strives to shape public policies that affect people with developmental disabilities.

Please contact Corinna Fale at Corinna@arcsno.org or 425-258-2459 x103.

People First of Snohomish County

4th Tuesday of each month | 11am-12:30pm

A self-Advocacy organization by and for people with intellectual and developmental disabilities. We are focused on educating ourselves and others, advocating for our rights, having fun! We believe we are PEOPLE FIRST and our disabilities are secondary. Please contact Kylie Walsh at Kylie@arcsno.org or 425-258-2459 x121.

Due to coronavirus cancellations, please check our website calendar at www.arcsno.org/calendar for updates

Did you know?

Families that qualify for free or reduced meals are eligible for additional EBT funds between June 30th and August 31st. School districts will be sending information home to families, but if you know of some families in need who have not yet applied for meal benefits they will ONLY be eligible for this extra money if they are on Free and reduced meal benefits before June 30th. Families who already have EBT benefits will have the money automatically added to their EBT card.

The below link to OSPI's web page that provides information for the P-EBT program, scroll down to the bottom of the page for FAQs. https://medium.com/@waOSPI/what-is-pandemic-ebt-a7a086fcaf94

Federal Bills of Interest

H.R. 6800 The Heroes Act

This bill is a further stimulus plan in response to the COVID-19 epidemic. It contains very specific language in regards to caretakers and the disabled, covering many financial burdens that come about because of live in care. Among the considerations for funding in this bill are respite care, childcare, expanding availability of PPE to group living settings, stabilization of live in provider wages, stability of benefits in response to instability of employment, and many others. Many, if not all, of these services have yet to be addressed in other COVID-19 stimulus legislation. This bill is currently in the Senate. The Arc of the United States strongly supports this bill.