



# Informing Families...*Today and Tomorrow*

## Inside this issue...

- ⚙️ Cooking videos, technology, and exercise: How the DDC Community COVID grant is helping people with I/DD connect and engage.
- ⚙️ "What if we get sick?" How one family turned unthinkable questions into an action plan.
- ⚙️ Do you have a back up care plan?



Washington families have shown incredible resilience over the last nine months. Nothing looks quite like it did a year ago—from work, to school, to spending time with friends and family.

This season will be very different for most of us, and that can be a difficult adjustment, especially as the days grow darker and colder.

As we head into the winter months, it is important to be planning ways to stay active, healthy, and prepared—which is the theme of this edition.

We know there is a light on the other side of this crisis and we will get there together, just as we always do.

We are also excited to highlight stories from a few recipients of the COVID community grant that

was funded by the Developmental Disabilities Council. They are doing amazing work and showing how technology—combined with creativity and perseverance—is a game changer for many people, during the pandemic and beyond.

As always, we are proud to provide helpful information and resources through the Informing Families partnership. Feel free to call me at 360-586-3558 or send an email at [jeremy.norden-paul@ddc.wa.gov](mailto:jeremy.norden-paul@ddc.wa.gov) if you have questions, concerns, or ideas.

Stay well and keep in touch.

Jeremy Norden-Paul  
Executive Director  
Washington State DD Council



## Pathways to Respite

FOR THOSE WHO PROVIDE SUPPORT TO AN OLDER ADULT OR SOMEONE WITH A DISABILITY

PAUSE REST RESTORE RECHARGE

## Free Online Toolkit Pathways to Respite

Are you in need of a break, but the idea of taking some time to yourself feels like just another thing to do?

Pathways to Respite offers ideas and resources for restoring your energy in whatever way works for you right now.

For those who support a child or adult with disabilities, traumatic brain injury, and older adults living at home. Get started here: [informingfamilies.org/respite](https://informingfamilies.org/respite).





# Staying Healthy, Active and Connected with Help from DDC Grants

When our state went into lockdown last spring, the increased isolation and loss of everyday interactions hit everybody hard. For people with developmental disabilities, however, it brought social isolation into sharp relief.

In response, the Washington State DD Council invested \$25,000 to help increase social connection and the ability of people with Intellectual and Developmental Disabilities to adapt to the COVID-19 pandemic crisis.

Six grants were awarded to organizations across the state. The following highlights offer snapshots of the creativity and impact of the grants.

## HEALTHY LIVING

(The Arc of King County)

Getting Healthy with Eric feels like visiting with a friend. He takes viewers into his kitchen, or to the neighborhood park, where he models independent living by



cooking simple, healthy meals and ways to de-stress.

Eric Matthes and team have produced seven videos as of October, with plans to extend the series into spring.

The show, which models independent living skills, has been a big hit. The most popular has been a video on how to make a fruit parfait, followed by how (and why) to wear a face mask correctly.

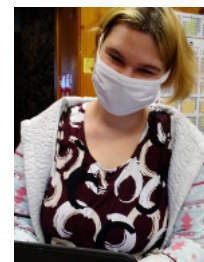
## TECHNOLOGY

(Community Colleges of Spokane Foundation— PACE Program)

When students were unable to attend online classes because they lacked the hardware, PACE leapt at the chance to apply for the DDC grant.

The community college-based program purchased seven laptops dedicated to students' use. They have been checked out on an as-needed basis and are allowing students from both the local (Spokane) community and rural areas to attend class.

Since PACE is no longer bound by geography, students from anywhere can now access classes. Having these laptops for student use helps to remove that boundary.



*PACE student Jamie S. found that having a laptop made it easy for her to access her classes. She signed up for Geography and Reading 1.*

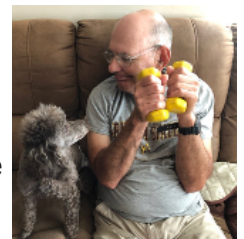
## EXERCISE

(Easterseals of Washington)

In response to COVID restrictions, Easterseals launched a telehealth program to provide access to nursing consultations, as well as an online fitness program for older adults with I/DD.

After kicking off the fitness program, however, they found that many participants lacked equipment. When Easterseals learned about the DDC grant, they immediately applied.

Easterseals reports that participants are staying happy, healthy and active thanks to this grant—something that is more important than ever!



For more information about DDC COVID Community Grant recipients and their programs, visit: [ddc.wa.gov/com-grant](https://ddc.wa.gov/com-grant).



My family spent the beginning of the COVID-19 pandemic isolated in a small, high-rise apartment in downtown Auburn. We sat with eyes glued to the news, our browsers permanently open on our computer screens. Every morning, we would check infection and fatality rates.



## Emergency Planning in a Pandemic

by Whitney Stohr

As a “Medical Family,” our two-year-old son Malachi is medically complex and falls into the high-risk category of those most vulnerable to the health impacts of COVID-19.

Every few days, I would look at my husband and begin to vocalize the question on both our minds.

“But, what if —”

“Don’t. We can’t think about that.”

We both knew the question: What if we both get sick?

We also knew the answer. Or rather, the fact that neither of us had an answer.

We acted early to protect ourselves. We began working from home. We canceled meetings, appointments and family outings. We had groceries delivered. Non-urgent mail was “quarantined” just inside our doorway for no less than a week prior to opening.

Even though our son requires 24-hour care, we made the decision to suspend home nursing. This meant that, in addition to working full-time jobs, we also became full-time caregivers.

We began working, sleeping and caring for Malachi in shifts so that someone was always awake with him, day and night.

We did everything “right,” but still that question lingered in our minds.

“What if we both get sick?”

Soon, Malachi’s service providers also began reaching out, reminding families to create plans for alternative care. For families like mine, that is easier said than done.

The hard truth is that there are few people who can provide the care my son requires. There are few places he can go.

Malachi requires specialized, skilled nursing by someone with a high-level understanding of his medical equipment. And yet, we still needed a plan. Just in case.

We discussed emergency preparedness on three levels:

### 1. Medical Supplies

We assumed the national stockpile of some items would reach critical lows. We took steps to extend

the life of single-use supplies, sanitizing and reusing items when possible. We found alternatives online. We inventoried every item so nothing would be overlooked.

### 2. Medical Care

We made a list of all the people who could care for our son, and we discussed what to do in different situations. What if one of us tests positive? What if one (or both) of us is exposed? Where will we isolate? How will we ensure 24-hour care for Malachi if only one of us can provide care? Who are we willing to bring into our home to help? What if Malachi gets sick?

### 3. Medical Contingency Plan

We discussed worst-case scenarios. What if we both get sick and are hospitalized? What if one, or both of us, dies? Who do we charge with the care of our son?

Is our family’s emergency preparedness perfect? Absolutely not. We have plans, but we made them knowing that even our best plans are still imperfect ones.

It is impossible to foresee every outcome that may arise in an emergency.

What we *must* do is take time to consider the important questions and create the best possible plan with the information we have in front of us.



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## Do You Have a Back Up Care Plan?

Being prepared, having a plan, and staying informed is not an extra thing to do. It's essential.

Many people with developmental disabilities rely on caregivers to assist with personal-care tasks, meal preparation, mobility, medication management and more.

When the primary caregiver is unable to provide care, it is crucial that a back-up plan be implemented.

The written plan identifies the emergency contact person and back-up caregivers.

The plan should be developed and stored somewhere easily accessible.

The client, family, and case



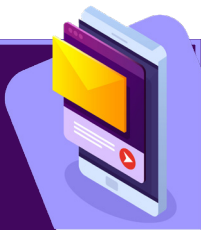
resource manager should be included in the plan development.

During the DDA assessment, this should be documented in the Emergency Planning section and reviewed annually.

### LEARN MORE

The Developmental Disabilities Administration (DDA) [Life Sustaining Equipment](#) and [Emergency Preparedness](#) care provider bulletins offer information and resources to help your family prepare for emergencies.

### *DDA News and Information*



**Get instant updates from the Developmental Disabilities Administration.**

- News & announcements
- Provider information
- Resources
- Trainings & events

### **How to Sign up**

- Text "DDA" to 468311
- Visit [dshs.wa.gov/dda](https://dshs.wa.gov/dda)
- Scroll down the home page and click on the GovDelivery envelope and sign up link for news and information.