



Informing Families ... Today and Tomorrow



A project of the Washington State DD Council

Person Centered: Creating a Life from the Inside Out

We talk a lot about person-centered practices—from service-planning to goal-setting across the life course—and there’s a good reason for that: individualized planning works.

It’s all about creating a life from the inside out; a life that’s built on the person’s interests, goals, abilities and needs, rather than one that’s defined by a service system.

A great example of how this works is through the Smart Living project featured in this issue (page 3).

Smart Living uses a person-centered approach to helping people connect with others and the world through technology.

It’s an effort that we hope will generate more use of technology to help people with I/DD have the same access to people and information available to everyone else.

A person-centered approach is also being used in a pilot project that creates Meaningful Activity Plans (page 3) for adults with challenging behaviors. It might stir some ideas for how to get your son/daughter involved in creating their own plans for the summer and beyond.



We’ve included a list of summer activity resources, and Rachel Nemhauser shares how she is researching camp options for her son whose behaviors make it especially difficult to find a program with the right supports.

Rachel does naturally what person-centered practices encourage everyone to do—plan from a place of strengths, interests, and assets.

We hope this issue sparks some ideas for planning this summer and beyond.

Executive Director
WA State DD Council



New: Employment Funding for High School Grads



The budget for the Developmental Disabilities Administration (DDA) includes new employment funding for high school transition graduates who:

- were born between September 1, 1993 and August 31, 1995;
- want to work;
- are not on a Home & Community Based Services Waiver (HCBS) but would like to be; and,
- are functionally and financially eligible for CFC personal care services.

Anyone who meets these criteria and requests the service will begin receiving long-term employment support through DDA after graduating and turning 21.

LONG-TERM EMPLOYMENT SUPPORTS

One to one support to help gain/maintain employment. The services are developed based on your interests & abilities and promote career advancement. For more information, visit: informingfamilies.org/topic/ses.

CALL TO REQUEST SERVICES

Visit informingfamilies.org/nps for a list of DDA’s Toll-Free Service Request & Information Lines in each region.



withinreachwa.org

WithinReach works to connect people across the state with the health care resources they need to be healthy, with a goal that all Washington families have access to quality health care.



The Right to Belong

by Rachel Nemhauser

Some people welcome summer with its lazy days, trips to the beach, suntans, fruity drinks, and a reprieve from nightly homework battles.

Me? I panic.

In my house, summer vacation is an oxymoron. There is no vacationing. Instead, there is a moderately tyrannical, but incredibly charming, 11 year-old named Nate to supervise, entertain and support (along with his older brother, Isaac).

In my quest to organize summer activities, I have to consider more than Nate's interests and abilities; I have to ensure that wherever he goes, he will be welcomed. All of him, including his sometimes not so endearing behaviors.

In other words, I don't want him to be kicked out like he was during mid-winter break earlier this year. That's right, Nate was kicked out of camp for children with disabilities because of behavioral problems.

Fortunately, no one was injured or harmed, but the staff were very frustrated and out of ideas. With no advance notice, no willingness to work on helping Nate improve his behavior, and no offer of increased support to enable him to continue to participate, we were notified that

Nate would no longer be welcomed to attend the camp he loves.

As Nate's mom, I can tell you that this hurt as much, or more than, his learning challenges, language limitations, and hyperactivity ever did.

I know that Nate's behavior can be very difficult. He's extraordinarily stubborn, vocal with his opposition, and persistent with his resistance. His behaviors can be tiring, and they might even make some people decide that having him involved is impossible.

But when individuals, organizations, and even specialized camps decide that people with difficult behavior are not entitled to participate, everyone loses.

Nate and children like him miss out on playing with other kids, exploring, building skills, and having fun. And the people who would have had the chance to meet him don't get to know the fabulous kid behind the behavior.

Despite my fears, I refuse to let Nate's winter break blow out define who he is or limit his experiences with other kids. Picking the right place for someone with Nate's challenges isn't easy, but finding a

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SUMMER RESOURCES

Special Needs Camp Directory
Center for Children with Special Needs has a statewide directory of camps, including tips for parents on what to expect and how to prepare. cshcn.org/resources-contacts/summer-camp-directory

Trips, Inc.

All inclusive vacation packages for individuals age 16 and older. tripsinc.com

Outdoors for All

(located in Seattle)

Adaptive and therapeutic recreation for children and adults with disabilities.

outdoorsforall.org

Local Parks and Recreation

City and county recreation programs provide inclusive opportunities for children and adults of all abilities, as well as specialized programs. Check your local paper or community notices for times and locations.

Service Organizations

Non-profit community groups, such as Elks Club, Lions Club, Kiwanis, Easter Seals, as well as many church and faith organizations have programs and activities to benefit children and adults with disabilities.

Exploration for All:

Autism Early Open

Explore Pacific Science Center during a special free morning visit before it opens to the public. No heavy crowds, softened general lighting and decreased noise level.

Pilot Program Promotes Benefits of Person Centered Planning

This past March, our state began implementing a pilot program for individuals living in Adult Family Homes who experience challenging behaviors.

The Meaningful Home Based Activities Pilot Program (MHBA), a partnership between Developmental Disabilities Administration (DDA) and Home and Community Services (HCS) helps individuals create a Meaningful Activity Plan (MAP) that builds on the person's strengths, preferences, choices, and abilities. The pilot comes with an increase in the daily rate to help ensure that people have the support they need to bring their activity plans to life.

The purpose is simple; people who engage in activities that are meaningful to them have a better quality of life and fewer crises.

Kate Gallagher, MHBA program manager for DDA, is excited about the possibilities that MAP holds. "People are happier and healthier when they have a say in planning their goals and dreams. And we do ask people to dream big."



"People are happier and healthier when they have a say in planning their goals and dreams."

The program prompts an exploration of ideas and goals to build into an individual's MAP.

"We ask people what makes them laugh, what's fun, and what they'd like to try," Gallagher says, giving examples of the types of questions they ask. "We want individuals to own their MAPs. Getting their input and respecting their personal interests and needs is key."

For those who are not in the pilot program, there are free online discovery tools, such as My Life Plan (mylifeplan.guide) or the Star Form (informingfamilies.org/star), that can help identify strengths, interests, and supports to help make any goal—big or small—a reality.



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camp that celebrates him for all his strengths and challenges is my top priority.

I started researching options by referencing the Summer Camp Directory distributed by the Center for Children with Special Needs.

In calling around, I was touched by the open-mindedness of places like

the Highland Center and Helpful Hands in Bellevue, and Community Care Summer Camp in West Seattle. Their primary focus is what they can do to help support my son so that he can fully participate, and that feels good to know.

My hope as the mom of a very complex, utterly unique, completely adorable and often exasperating little

Smart Living: Expanding Life Through Technology

When the DD Council received funding from the Developmental Disabilities Administration to explore ways that technology could be used to create greater independence for people with I/DD, things did not go exactly as planned.



"We thought we would get all these homes outfitted with some really great technology," says Sue Elliott of The Arc of Washington, the contractor for the project. "But instead of connecting devices to people's homes, we found that people needed devices to connect to other people."

According to Marsha Threlkeld, the assistive technology expert brought in to run the project, "Every person was dealing with isolation across the board. They weren't getting out and didn't have the ability to be in touch with others and the world. People need to communicate and make choices. That's how our lives get bigger."

Threlkeld used a person-centered approach to learn about the individual before looking at technology options.

"I asked what they like to do, where they like to go, who they spend time with, and relationships that are important to them. It's completely person-centered. I'm trying to understand what they want for personal growth and change. After that, we could start to see gaps."

The gaps pointed to problems the person wanted
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guy is that the world keeps taking the extra time to make sure he's included, even when (or especially when) he makes it hard.

Ask for help. Ask for ideas. Ask me for a few of my hard-earned tips and tricks. It is not always easy, but I promise you that if Nate is involved and included, it will definitely be worth it.

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to solve and what needs technology could help with.

Because none of the participants had any experience with technology, Threlkeld had to ensure that everyone involved in the person's daily life was on board.

"Getting everyone keen on using technology is really the key to making it work. You have to find out how the staff learn and what their abilities are."

For staff with little or no interest in technology, it took a little more time to introduce the concepts without overwhelming anyone. "I didn't want them to shut down if I gave them too much at once."

After discovering what one of the participants, "Dan," liked to do, Threlkeld set him up with an iPad. His supported living provider arranged for WiFi after ensuring that Dan could afford the monthly cost.

Dan and his supported living staff worked with Threlkeld to create a plan on how to use the iPad. The plan included pictures of things Dan liked to do and

"People need to communicate and make choices. That's how our lives get bigger."

people with whom he wanted to stay in touch.

When Threlkeld called to check in and see how it was going, she received an enthusiastic report. "[The staff person] said that they had been on the internet, looking at food sites, and Dan said he wanted Indian food. The staff couldn't believe it. He said, *Who knew Dan liked Indian Food! I had no idea, all these years!*"

Another big discovery came through basic cable. "The staff always thought Dan didn't like to watch TV, but once he had basic cable and WiFi, and could watch shows on his iPad, they realized that it wasn't that he didn't like television—it was that he couldn't see it! Now, Dan goes online to pick movies he wants to see and a whole world is opening up to him."

It didn't stop there. They added FaceTime to the mix so that Dan could stay in touch with a friend from church whose visits had dropped due to health issues. Dan can now log on and visit with his friend on a regular basis. Threlkeld points to access to technology as a civil rights issue. "When you have people whose ability to be with others is limited in life, shouldn't they have the same opportunities as the rest of us?"

MAILING LABEL