Creating a Virtual Ramp to the World

Smart technology makes life easier by performing tasks that save time and create new connections to people, places and ideas; but for people with disabilities, it does more than make life easier—it makes life more equal.

Imagine living a little more independently, doing things for yourself such as leaving a computer and going to another room without needing to wait for someone else to unplug your headset or to open the door.

As our Smart Living pilot project is demonstrating (see feature article), technology is making life more self-directed and choice-driven for four Olympia women who share a home through a Supported Living program.

When I shared some of the ways technology is being used, the reaction I get most often from people is, “I want one of those!”

Technology can make a big impact. It opens doors and creates connections to other people, places and ideas that expand an individual’s life.

Although our Smart Living project in Olympia is focused on technology for the home, it clearly has benefits in every area of life.

From person-centered life plans to educational goals in IEPs (see Nate’s Story inside this issue), technology can be an integral part of a person’s support system to reach most any goal.

Technology is moving ahead by leaps and bounds, creating community and connections through social media and apps. The disability movement needs to ensure that technology, which provides access to today’s communities and opportunities, is made available to everyone. One way we can do this is by sharing with each other the many ways that technology is improving the lives of children and adults with I/DD.

If your family member is using technology at home, school or out in the community, I would really love to hear how it connects them to the world, or to resources that allow them to live more independently. Please email your story to me directly at: ed.holen.wa.gov/ddc.

Sincerely,

Ed Holen, Director
Washington State Developmental Disabilities Council

Last year, the DD Council and The Arc Washington State launched Smart Living, a pilot project to explore ways that technology can assist people with I/DD in their homes. Funded by a grant through DDA’s Roads to Community Living, the project sought to identify:

- Resources and processes needed to incorporate technology as part of an individual’s support system.
- The ability of technology to create greater independence and choice.

Marsha Threlkeld, the assistive technology expert hired to run the project, used a person-centered approach to assess each individual’s needs and preferences, find the best technology to meet their needs, and assist with arranging for installation and training for everyone who uses the devices.

(Cont’d inside)
Get Organized
Documents, medical reports, IEPs, and other papers will grow over the years, so be sure to keep them filed and organized so that you know right where to look for what you need, when you need it.

Document Changes
Keep a written record of the specific things you notice with your child that cause you concern—such as new behaviors—and any solutions you might have that relate to your child’s IEP.

Communicate in Writing
Poor communication and unclear expectations can create issues down the road. Sending your ideas to the IEP team ahead of the meeting can help shape the discussion and draft the plan. And sending a letter of understanding after a meeting is a way to avoid misunderstandings.

For day-to-day information sharing, some parents send a notebook to school, with information that’s helpful to school staff, such as something new that’s happened at home. School staff can then send notes back as needed.

Keep it Positive
Use positive language, and focus on what will help your child work toward their long term goals. Focusing on a positive vision for your child’s future helps to weather bumps in the road. And there will be bumps.

Invite IEP Participation
Make sure your child is a meaningful participant in their IEP, life goal setting, career planning and decision-making. It’s also a good idea to invite their para-educator/aide, as well as anyone who knows your child well.

Include Technology
Consider technology (devices, apps and adaptive equipment) as part of your child’s educational support. Think about ways that devices and apps can be used to reach IEP goals, improve communication, learn job skills, and have greater Independence.

Get Help
If you’ve agreed to a program that’s not having the results you’d hoped for, and the school district doesn’t want to change its approach, it’s a good idea to ask for outside help.

Parent-to-Parent and PAVE can connect you with parents and advocates in your area who can help: Parent to Parent: 800-821-5927; PAVE: 800-5-PARENT.
The Office of Education Ombudsman provides conflict resolution and information: 866-297-2597.

Nate’s Story
Nate has struggled with communication his entire life. He didn’t have any words until he was three, wasn’t putting words together into sentences until he was 10, and even at almost 13 has a very difficult time being understood by the people around him.

From as early on as Kindergarten, his speech therapists have been slowly introducing him to using an iPad to communicate. In every IEP, he has speech and articulation goals, but also goals specifically related to increasing his proficiency, ability, and willingness to use his iPad to communicate.

He continues to prefer to use his voice to talk, but he speech team has made it a priority that he also is able to supplement his voice with technology when he needs it.

It’s a work in progress, and he’s still a reluctant user, but the world will be wider for him if he’s able to express himself, so we keep working on it. He has a lot to say and ultimately I think this technology can help him say it.

—Rachel Nemhauser
As we reported last year, Threlkeld’s initial assessments showed that the technology gap was pointing to an even larger issue: social isolation.

“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.”

The project eventually focused its efforts on the home of four women supported by Kokua Residential Services in Olympia. Over the past several months, the house has been outfitted with devices, apps and equipment to assist with:

**Safety** (Ring video doorbell and Nest Protect Smoke and Carbon Monoxide Alarm)

**Communication** (Go Talk 20, iPad, large button phone)

**Comfort/Stress Reduction** (Gameyly Supersoft Chicken, Speck iPad holder)

**Accessibility** (remote control door opener, wireless headset, touch free faucet, Echo Dot)

One standout device is the Echo Dot, a voice-operated unit the size of a hockey puck that communicates with household equipment, like the lamp in one of the bedrooms. A simple voice command is all it takes to turn on the light.

Echo also answers questions posed to her about random topics, even when she’s not asked. Erin Manemann, lead staff for Kokua, jokes about Echo’s tendency to insert herself into conversations that have nothing to do with her.

“I was asking someone a question one day and Echo started answering. We were all like, wait…who’s that?”

**Independence and Choice**

“Julie’s” bluetooth headset, another voice command device, gives her control over her computer without keeping her tethered to one spot.

Prior to getting the wireless unit, if she wanted to stop and do something else, she would have to call out for staff and wait for them to unplug her.

Soon, she will have a voice operated door opener (Private-Door Solo) that will connect to Echo, giving her privacy and control of when she comes and goes from her room.

Julie also received an iPad, which she uses to connect with friends and family through Skype and Facebook.

Although there are some issues with the voice software used with the headset that need to be ironed out, these four devices—Echo, iPad, door opener and headset—promise Julie greater autonomy, choice, and connection to other people.

**Lessons Learned**

As Threlkeld writes in her preliminary report, “Equipment must be introduced a little at a time or it is overwhelming for the staff and program who are very busy with day to day needs and routines.” Having an in-house go-to person, she points out, is essential.

Threlkeld set up some of the equipment herself, as well as working jointly with Manemann. But other equipment, such as modifying the door opener to function with voice command, requires outside help from a technician.

Threlkeld also met with a member of the Amazon Smart Home Consultants team, which offers in-home consultation and follow along in the extended Seattle area.

It’s too early yet to know the full impact. “Some of the work is trial and error,” Threlkeld observes, “as some equipment works much better for people than ever anticipated and some equipment does not hold all the possibilities originally envisioned. People’s involvement with it is evolving.”

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(Smart Living con’t from front page)
**Summer Health Tips**

**Stay HYDRATED**

The body’s initial responses to dehydration are thirst to increase water intake, along with decreased urine output to try to conserve water. The urine will become concentrated and more yellow in color. As the level of water loss continues, more symptoms can become apparent.

**Signs of dehydration include:**
- Heat exhaustion
- Headaches
- Nausea and/or vomiting
- Fainting
- Confusion
- Urine output decreases & becomes concentrated and appears dark
- Sunken eyes
- Blurred vision
- Wrinkled or saggy skin
- Extreme dryness in the mouth
- Fever or temperature over 102 degrees
- Severe pain or blistering of skin

*If you suspect dehydration, prevent further complications by drinking lots of fluids—water, fruit juice ice cubes (see right), Popsicles, Gatorade, Pedialyte, Powerade, etc.*

**Keep COOL**
- Make sure there is good ventilation in the house.
- Find or create shade when outside.
- Use cool water compresses.

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**Fruit Juice Ice Cubes**

**Ingredients:**
- 3/4 cup (each) of apple, cranberry and orange juice. The amount may vary depending on the size of your ice cube tray.

**Directions:**
- Pour the apple juice into the ice cube tray, dividing evenly throughout the tray to create the first layer.
- Freeze.
- Repeat with cranberry juice.
- Repeat with orange juice.