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Voice given to hundreds of Albertans

CALGARY – Alberta Health Services is using modern technology and old-fashioned ingenuity to give voice to people who are otherwise unable to communicate effectively.

The Augmentative Communication and Educational Technology Service (ACETS – pronounced 'assets') team is currently working with more than 150 children and adults with severe communication difficulties that prevent them from speaking, handwriting or signing. These difficulties are often caused by cerebral palsy, Down syndrome, autism, muscular dystrophy, multiple sclerosis, ALS (Lou Gehrig's disease), Parkinson's disease, stroke or brain injury.

"Our patients have the same need and desire to communicate as anybody else," says ACETS co-ordinator Kim Beckers. "They have simply lost, or never had, the verbal or motor skills necessary to effectively convey their thoughts. Imagine not being able to tell a loved one: 'I'm in discomfort,' or 'I'm hungry,' or 'I want this.'"

"ACETS helps patients, their families, friends, teachers and colleagues to overcome communication barriers, and give people who cannot speak the chance to be heard and understood. I cannot overstate the impact this has on people's lives and relationships."

The service has allowed Tobynn Geurts to effectively communicate complex thoughts with family and friends for the first time in her life. The 12-year-old has a severe form of cerebral palsy and, until recently, could only communicate with head nods for 'yes' or 'no'. ACETS helped Tobynn access a speech generating communication device in January.

"Until I got my computer, it was very frustrating because people didn't either understand or take the time to figure out what I needed," says Tobynn, who uses a switch at her left elbow to scroll through words and phrases to craft sentences spoken by a computer-generated voice.

Speech language pathologists, occupational therapists and a technician at ACETS work with Tobynn, her family and staff at Emily Follensbee school in southwest Calgary to ensure the youngster can talk and act like any other pre-teen.

"We started the Speech Generating Communication Device pilot to help Albertans purchase these devices," says Mary Anne Jablonski, Minister of Seniors and Community Supports. "I am pleased that the partnership between Alberta Health Services and my Ministry's Alberta Aids to Daily Living program has made such a difference in the lives of our clients and especially in enhancing their relationships with their families, caregivers and teachers."

Tobynn's dad Andre says the device has made Tobynn's life a lot better.

"For her to have a voice now, that's pretty cool. She surprises us all the time with what she asks us about and what she knows."

Adds Tobynn's teacher Algis Grajauskas: "We always knew Tobynn was a very intelligent girl. Now with her voice, she proves every day she's even smarter than we thought."

Speech generating communication devices can cost as much as \$10,000 with funding mostly covered by Alberta Aids to Daily Living. Families pay a 25 per cent cost-share portion up to a maximum of \$500. Families that are lower income do not share in the cost of the devices.

The ACETS team assesses patients' communication needs and makes recommendations for equipment and therapy techniques. But Cherie Dalton, an occupational therapist with ACETS, says the team also teaches patients how to communicate without using the high-tech devices.

"We also encourage them to vocalize or gesture when they can and, when that isn't enough, they can use a device," says Dalton. "We provide a whole toolbox of strategies."

ACETS does not assume a primary therapy role but relies on collaboration and partnerships with therapists, family members and educators. These partnerships earned ACETS the Canadian Association of Speech Language Pathologists and Audiologists (CASLPA) Award of Excellence for Interprofessional Collaboration last month.

ACETS, based at the Alberta Children's Hospital, celebrates its 10th anniversary this year. The service was established with community support from the Alberta Children's Hospital Foundation.

Alberta Health Services is the provincial health authority responsible for planning and delivering health supports and services for more than 3.7 million adults and children living in Alberta. Its mission is to provide a patient-focused, quality health system that is accessible and sustainable for all Albertans.

- 30 -

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