

ADULT AUTISM

A STORY BEHIND THE NUMBERS



CARSON & CHERYL

Many of you know the staggering statistics regarding autism, but let's talk about some little known facts that I have discovered. Did you know that the car door can be open and shut approximately **6 times** while driving down the freeway until the car can be pulled over to a complete stop? Life guards can make it to the top of the outdoor slide in approximately **2 minutes** from hearing screams and subsequently observing a kid hanging from the outside of the railing two stories above yelling, "to infinity and beyond!"? **Four out of five plumbers** will give a discount for retrieving Buzz Lightyear

out of the toilet for the **4th time** in a month? Approximately **3.2 people** will give free advice while waiting in line at the grocery store while your child is eating dog biscuits? It takes **2.5 adults** to lift a **90 lb.** kid who is laying flat in the aisle and does not want to be moved? Here is what I didn't know. I didn't know we would listen to our child's attempts at words as if he were giving the speech of a lifetime. How thrilling it would be to **hear numbers 1-10 counted** over and over again all day long. The excitement of passing by the adolescent diaper section and not purchasing any, **hearing the word "mom"** would bring tears to my eyes, or a **reciprocal hug** would be so priceless. I could feel so much stress and pressure, financially, emotionally, spiritually, and physically; and yet so much **love and hope.**

- Cheryl, Carson's mom

THE NUMBERS SPEAK FOR THEMSELVES

HOW OLD HE WAS WHEN HE FIRST SAID "MOM"	9
HOW MANY BROKEN IPADS HAVE BEEN REPLACED	7
HOW MANY DIFFERENT FOODS HE WILL EAT	4
HOW MANY TIMES THE PLUMBER HAD TO COME TO RETRIEVE BUZZ	6
HOW MANY TRAIN TRACKS HE HAS	MORE THAN HE CAN COUNT
HOW MANY TIMES A WEEK HE BUYS VHS VIDEOS AT SAVERS	2
HOW MANY VISITS TO THE HOSPITAL FOR SERIOUS SELF-INJURIES	4
HOW MANY NON-PAID "FRIENDS" HE HAS	0
HOW MANY PARTIES HE HAS BEEN INVITED TO	0
HOW MANY NIGHTS HIS PARENTS WAKE UP WORRIED ABOUT HIM	ALMOST EVERY NIGHT
HOW MANY DAYS HE NEEDS HELP TAKING CARE OF HIS NEEDS	365 DAYS A YEAR



ADULT AUTISM

THE POWER OF NUMBERS



Adult Autism Center
of Lifetime Learning
A SERVICE OF PINGREE

THE NEED 🙌🙌

AUTISM IN UTAH

1/58

individuals are diagnosed with autism in Utah

INTELLECTUAL ABILITY

31%

of individuals with autism spectrum disorder (ASD) who also have an intellectual disability

WAITING FOR SERVICES

3,127

is the number of people on the Division of Services for People with Disabilities (DSPD) waiting list

THE CLIFF

22

YEARS OLD

is the age when individuals with autism no longer qualify for federally mandated educational services

ADULTS WITH AUTISM

3,500

adults in Utah who have autism and an intellectual disability

THE COST 💰

\$175-196

BILLION

the annual U.S. costs of adult autism services

\$461

BILLION

the cost of caring for Americans with autism by 2025 in the absence of more effective interventions and support across the life span

\$100,000

the annual cost of providing quality day programs for the severely affected

THE SOLUTION 📈

\$1.4

MILLION

Valley Behavioral Health has paid for the cost of the land for the Adult Autism Center

\$120,000

Valley Behavioral Health has paid for the cost of architect fees for the Adult Autism Center

\$5.5

MILLION

raising the funds to pay for the cost to build the Adult Autism Center



Adult Autism Center

The Pingree Center was the first program of its kind created to serve preschool children with Autism Spectrum Disorders back in 1977. It is considered the gold standard of treatment for individuals with autism. The program has expanded over the years and now serves individuals as old as 21. As these children age into adulthood, many of them still need the level of support provided by the services at the Pingree Center, but they need a program focused on vocational skills, community integration, increased independence, and daily living skills. Valley Behavioral Health, who owns and operates the Pingree Center, has started construction for the Adult Autism Center just west of Wheeler Farm.

The Need

1

Adults with autism who have significant needs require a robust day program.

A. There are a number of services in the community for adults with disabilities, including autism, but there is a gap in services for adults with autism who have significant needs. The adults who will be served at this program require 24/7 care and supervision, they have lower cognitive and adaptive abilities, very limited communication skills, and many have severe aggressive and self-injurious behaviors, but continue to learn and progress with a quality program.

B. Adults with this level of need age out of educational services at 22 years old and typically at least one parent has to quit their job to be their full-time caretaker because there are not programs for them to go to during the day.

2

Programs for adults with autism should enhance learning and daily living skills, as well as community integration and vocational skills development.

A. There is a critical need for quality programs for adults. The Adult Autism Center will include fitness education, vocational training, home living and life skills, academics, arts and crafts, agriculture, social and leisure skills, culinary training, a library, and a medical/dental station.

B. Valley Behavioral Health has invested just under \$2 million for the Adult Autism Center, and construction has begun, with a projected end date of July 2020. This 16,000 sq. ft. center can accommodate up to 100 adults.

How You Can Help

Legislative action will ensure these vulnerable adults in Utah get the supports they need, and will cost less in the long run, as the more independence they continue to learn, the more opportunities they will have.

1

We are asking for \$2 million to go toward the building of the Adult Autism Center. We have funding for the remainder of the costs.

2

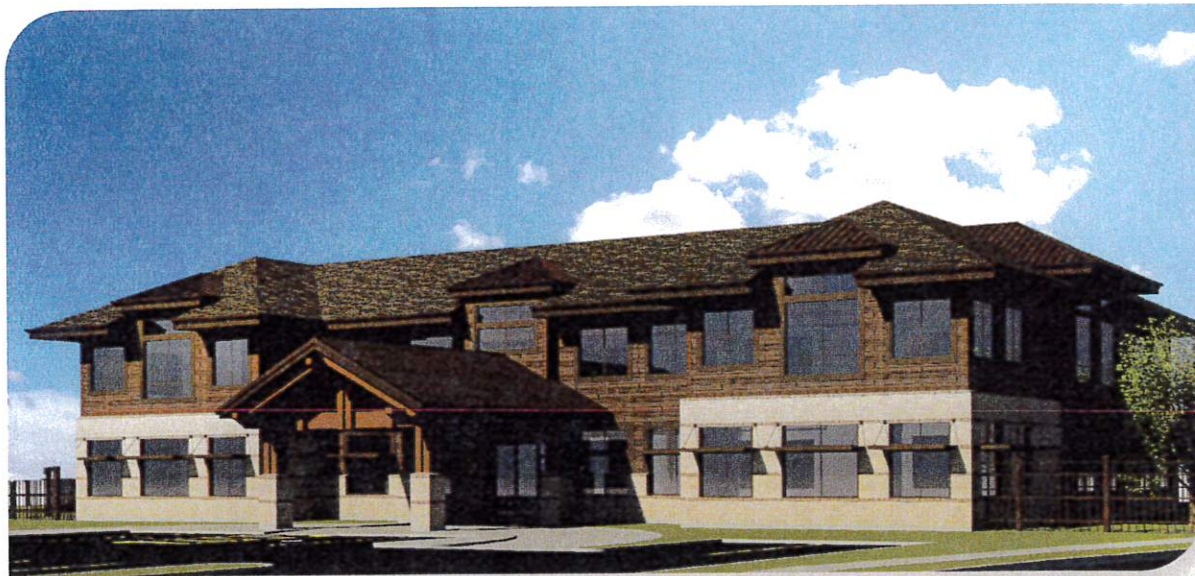
We are asking for support for legislation sponsored by Rep. Craig Hall that would create an adult autism treatment account, to be funded in the future, to support quality programs that will help these individuals continue to learn and gain independence.

The Adult Autism Center location

6230 S 900 E Murray, Utah.



Adult Autism Center
of Lifetime Learning
A SERVICE OF PINGREE



Carson

“I once heard a man say his biggest wish was to live one day longer than his disabled son. The ultimate dread for us, and for every parent of a special needs adult, is that no one will love and take care of him like we do. What will he do after he turns 22? Who will care for him when we’re gone? Where will his safe shelter be?”

The Adult Autism Center will be that place for Carson to spend his days. The Pingree Center knows autism. They know how to handle the hard days with behaviors and meltdowns. They also know how to celebrate the good days, the continued learning and growing. I’m excited for Carson to continue to get the individualized, intensive program as an adult that he has had as a child at Pingree, adding vocational and life skills. Independence equals opportunity – and the more independence he learns, the better quality of life he will have. Pingree gives Carson his best chance at the quality of life he deserves.”

- Cheryl, Carson’s mom



State of Utah

GARY R HERBERT
Governor

SPENCER J. COX
Lieutenant Governor

Utah Department of Health
Executive Director's Office

Joseph K. Miner, M.D., M.S.P.H., F.A.C.P.M.
Executive Director

Division of Family Health and Preparedness

Paul R. Patrick
Division Director

Children with Special Health Care Needs
Bureau

Noël Taxin, M.S.
Bureau Director

Gary Larcenaire
Valley Behavioral Health
4460 South Highland Drive, Suite 310
Salt Lake City, Utah 84124

Dear Mr. Larcenaire,

As you are aware, Autism Spectrum Disorder is estimated to affect over 62,000 individuals in Utah. Approximately 32,323 individuals with Autism in Utah are transition-aged youth (14-years-old) or adults, a majority of whom become unemployed or underemployed. This requires parents or other family members to provide additional support which increases household expenses and limits potential caregiver earnings.

As the Program Manager for the Autism Systems Development Program at the Utah Department of Health and the Chair of the Utah Autism Initiative (UAI) committee, a state inter-agency advisory panel of over 20 experts in the field of Autism, I am very excited about the potential for an adult program specifically for those who are severely affected, as they continue to learn and work towards independence.

The Pingree Center for Autism Learning and Valley Behavioral Health that will provide individualized, research-based programs for adults who need significant supports is desperately needed in our community.

Thank you for all you do for those affected by Autism Spectrum Disorder in Utah.

Colin Kingsbury, MSc
Utah Department of Health
Autism Systems Development Program - Manager
UAI Committee Chair
URADD Oversight Committee Chair



Dear Potential Supporter,

Children with autism grow up to be adults with autism. Adults with autism are found to have extremely high unemployment and underemployment rates of 80-85%. There are also adults with significant needs who are not able to be employed but need a quality program that can continue to provide meaningful opportunities to help them build skills and achieve a higher level of independence. Many parents of individuals with autism know that after their children age out of educational services between the ages of 18 and 22, there is a cliff that they fall off of due to lack of services available for adults with autism. Prevalence studies estimate that there are as many as 1,500 adults with autism and co-occurring intellectual disability in Salt Lake County and as many as 3,500 statewide. These are adults who are not able to access quality programs and continuing personal growth.

We want to expand the Pingree programs to adults. What makes us different? We successfully serve the most difficult and highest acuity population with quality programs. The Carmen B. Pingree Autism Center of Learning currently offers exceptional individualized research-based services based on the principles of Applied Behavior Analysis (ABA). This program will be an extension of this quality programming. There is an unmet need for quality programs specifically for adults with autism. An even greater need is for these types of programs for adults with autism who require significant levels of support. The Pingree programs successfully support the individuals with autism who have lower cognitive skills, lower communication skills, and individuals with significant behavior, such as biting, head banging, running, hitting, etc. While other agencies provide vocational services and day programs for adults, some even serve adults with autism, but there is a critical need for quality services for adults with autism who require this high level of support. This program would be able to appropriately and meaningfully serve this group of individuals.

This program would provide much needed services to adults with autism to provide vocational skills training. The vocational skills training program could support up to 50 individuals with vocational skills training needs. The vocational skills training program will aim to provide supported employment in community agencies when appropriate for the individual. When supported community employment is not appropriate, other skills training and meaningful activities will be available at the training center. We need your support to help create quality services for these individuals who deserve to continue to improve their quality of life.



UTAH VALLEY UNIVERSITY
MELISA NELLESEN AUTISM CENTER

January 10, 2019

To Whom it May Concern,

Utah Valley University has been supporting those working and living with Autism Spectrum Disorders in the community, in a variety of capacities, for nearly a decade. We are aware of available supports for those impacted, and also areas of deficiency, where more attention is required. There are definitely more types of services available now than there have been in the past, but there is still much to be done.

Utah needs more services that address basic essentials for those with Autism Spectrum Disorder over the age of 18. A diagnosis of autism provides a certain amount of support while a child is in the school system, however, research indicates that there is a substantial and obvious "services cliff" that occurs once someone ages out of education. Unfortunately, a person doesn't necessarily "graduate" from autism. Needs and additional support are a lifelong reality. Adulthood lasts much longer than childhood.

We recognize the absence and obvious need for individualized supports strongly embedded with evidence-based approaches for those who require substantial assistance, similar to the program currently being established through the Pingree Center for Autism and Valley Behavioral Health. There are not enough programs in the state of Utah designed to address the needs of those with significant needs and delays.

Sincerely,

Jane Carlson, PhD, BCBA-D, LBA

Director

Melisa Nellesen Center for Autism

Utah Valley University

Laurie Bowen, M.Ed., BCBA, LBA

Associate Director

Melisa Nellesen Center for Autism

Utah Valley University



Department of Educational Psychology

Dear Mr. Larcenaire,

I have worked in the field of education and service provision for individuals with autism spectrum disorder (ASD) over 15 years, and am currently an Associate Professor and the Director of Training of the School Psychology program at the University of Utah. I have worked closely with the Pingree Center for many years, and am writing on behalf of the Pingree Adult Program.

Early intervention has been identified as best practice for individuals with ASD. The Pingree Autism Center of Learning exemplifies best practice for children and adolescents with ASD, providing empirically-based interventions that promote educational, social, and behavioral success. The service that the Pingree Autism Center provides to the community is immeasurable in their ability to provide excellent services to a large number of children and adolescents. The Pingree Autism Center not only enriches the lives of the students that attend the Center and their families, but also provides an invaluable service to the University of Utah. The School Psychology program at the University of Utah has long had a partnership with the Pingree Autism Center, with students in the program gaining experiences in assessment and intervention for individuals with ASD while also providing a service to the center.

Despite the important early intervention services that the Pingree Autism Center provides to children and adolescents with ASD, there remains a serious need for adults with ASD.

Although early intervention services are often essential in improving long-term developmental

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Department of Educational Psychology

trajectories of individuals with ASD, many adults with ASD continue to need supports. At the present time, there are limited resources in Utah that provide the wide-range of services needed by this population. The Pingree Adult Program stands to fill a substantial void, immediately benefitting a large number of adults in the community. Given the high quality services currently being provided at the Pingree Autism Center, there is little doubt that the Adult Program would provide essential supports to a currently underserved population. Such a program would ensure that individuals with ASD have access to services that promote independence and success, regardless of the age of the individual.

I am incredibly encouraged by current efforts to establish the Adult Program, and see it as a resource that would be immediately impactful in the community. Should you have any questions regarding my support of the program, please do not hesitate in contacting me.

Regards,

Keith Radley, Ph.D., BCBA-D, NCSP

Associate Professor and Director of Training

School Psychology Program

University of Utah

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