

Autism Lifeline Links Transitions to Texas A&M University-San Antonio College of Education and Human Development

The Kronkosky Charitable Foundation, Autism Lifeline Links and Texas A&M University-San Antonio have entered into an agreement to transition Autism Lifeline Links to the College of Education and Human Development. Autism Lifeline Links (ALL) is a special initiative that was launched and funded by the Kronkosky Charitable Foundation in 2016 to improve the lives of those on the autism spectrum. It brings together hundreds of stakeholders and 14 different organizations serving individuals with autism and intellectual or developmental disabilities (IDD) and their families to increase collaboration and improve the system of care in the San Antonio region.

"Foundation initiatives, like ALL, stem from discussions with our community stakeholders to identify an issue that can be improved with appropriate funding and support," **said J. Tullos Wells, Managing Director of the Kronkosky Charitable Foundation.** "We seed and feed these programs until they create a sustainable model of care and impact and then we look for a new home where they can continue to grow. Texas A&M University-San Antonio and ALL will be perfectly aligned to continue this level of work and engagement. We are also thrilled to announce that the new director of ALL at A&M-San Antonio will be **Hugo Hernandez**. Hugo has been an integral partner since the Foundation first convened community conversations on autism in April 2015. He served as one of the 14 Leadership Committee members to ALL and the Chair of the ALL Community Engagement Workgroup. Through his past work as CEO of Any Baby Can, he has become a thought leader and a trusted advocate for families of children with autism and IDD."

"Texas A&M University-San Antonio College of Education and Human Development will offer ALL the opportunity for future expansion, publication in scholarly journals, and it will continue to be a model of community engagement and public policy impact across the nation," said Cara Magrane, ALL Executive Director and Director of Initiatives & Special Projects at Kronkosky Charitable Foundation. "This is the model of amplification and true systems change from bottom up that Kronkosky Charitable Foundation aims to invest in."

Dr. Carl Sheperis, Dean of the College of Education and Human Development, and his team have a strategic plan to create an autism institute at A&M-San Antonio. This is a multi-phased plan to create a lifespan approach for people with autism that includes early identification of children with autism, primary and secondary education, family and self-advocate advocacy, and therapeutic interventions to improve the quality of life for people with autism and those who care for them.

"The addition of ALL to Texas A&M University-San Antonio will allow the autism institute to build upon the remarkable work completed under the leadership of Cara Magrane and the Kronkosky Charitable Foundation – creating a model of care and provider collaboration for our most vulnerable Texans – those with autism and IDD – and their caregivers. We look forward to building upon the Foundation's visionary leadership and investment and the opportunities ahead," said Dr. Cynthia Matson, President of Texas A&M University-San Antonio.

"As both an advocate and the father of a young adult with autism, I've been impressed with both ALL leadership and ALL's advocacy workgroup since my first meeting," said Dr. Carl Sheperis, Dean of the University's College of Education and Human Development. "After seeing the results of the adult study by Community

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Information: Now (2019) on the cost of care and gaps in services for adults with autism and IDD in our community, I knew ALL was a game changer."

In 2015, two autism and IDD providers and advocates, Kim Jefferies (Brighton Center) and Cynthia Hamilton (Autism Treatment Center), approached the Kronkosky Charitable Foundation to ask for assistance to address both the rising number of children diagnosed with autism and the gaps in the current system of care for the autism population. In late 2016, the Foundation and its stakeholders formally established Autism Lifeline Links. Working collectively, Autism Lifeline Links:

- 1. Deployed a HIPAA compliant, cloud-based referral platform to coordinate services and electronic referrals among 14 agencies. This provides a single point of entry into a coordinated system of services and care, with the assistance of a care coordinator who assesses needs and helps people connect with providers and resources. The platform allows providers to collaborate on a level previously unrealized in the autism sector. Data from providers also allows members to assess barriers to care and gaps in autism services and pursue solutions.
- 2. Established four workgroups consisting of over 100 autism and IDD stakeholders that meet monthly to dig deeper into existing systems and challenges, create alignment across the community, and identify solutions.
- 3. Commissioned two studies: Capital Healthcare (2016) to assess the prevalence of autism, available practitioners for the population, and cost of care in the community; and Community Information Now (CI: Now) (2019) to assess and quantify the number of adults with autism and IDD and available services, which was the first known study of its kind in the United States. These studies indicate there are more than 30,000 people living with autism/IDD in the San Antonio region, including more than 21,000 adults.
- 4. Coordinated care for over 3,400 members with almost 76,000 activities. The top 3 needs identified are: case management/care coordination; parent and caregiver education; and access to care, support, transportation and legal services. These reflect over 9,100 electronic referrals between partners.
- 5. During the 85th and 86th Texas Legislative Session, ALL partners aligned with local and state stakeholders to collaboratively pass legislation to ensure licensure of Texas practitioners delivering interventions for special populations and to include these practices in the Medicaid Service Array- ensuring our most vulnerable Texans have equal access to treatment/interventions to improve success and quality of life.

During the 87th session period ALL partners teamed up with Texas Department of Human Service-Early Childhood Intervention (ECI) to modify the Texas Administrative Code (TAC) to inform parents of children more formally with IDD to have access to future service.

"Of all the work we've achieved in just four short years, the most significant is the workgroups," said Magrane. "The autism and IDD space is rife with inequity and siloed solutions. By engaging people who are working 'boots on the ground,' family advocates and self-advocates, we have been able to take a collaborative, transparent and less siloed approach to solving issues related to these vulnerable populations."

By presenting clear data and a unified approach with other local and state organizations, ALL successfully advocated for several key legislative changes. Among them, in collaboration with Texas Association for Applied Behavior Analysis Public Policy Group (TxABA PPG), was ensuring the licensure of Licensed Applied Behavior Analyst (ABAs) in Texas and adding ABA to the Medicaid service array.

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"Early intervention has a significant impact on the quality of life for people with autism and their families," said Dr. Berenice de la Cruz, Assistant Professor and Program Coordinator of A&M-San Antonio's ABA Program and TxABA PPG Treasurer. "Licensing Behavior Analysts in Texas was the first step in obtaining ABA therapy for children and adolescents with autism on Medicaid. Since last legislative session, we have continued to work with Texas Health and Human Services to bring this benefit to families as soon as possible and ensure access to care. Once fully implemented, this bill will allow for more equitable access to care and improved quality of life for children and adolescents with autism and their families in Texas."

This year, ALL is advocating for an update to the Texas Administrative Code regarding notification of families by Early Childhood Intervention of the importance of registering for Long Term Services & Supports Medicaid (LTSS) Waivers. These LTSS waivers enable people with autism/IDD to remain living in community settings rather than in costly institutional care. This variance averages (roughly) \$50,000 a year for community living support compared to (roughly) \$320,000 a year for institutional care. The average wait time for some of these waivers is approximately 17 years.

"This change is critical because families need to get on the 'interest list' for LTSS as early as possible so that when their child moves into adulthood, they can access the right support to enable their child to live a full life," said Kim Jefferies, CEO of the Brighton Center.

Autism Lifeline Links - Partner Agencies

Brian Lopez	Down Syndrome Association South Texas
Brad Benoit	Center for Health Care Services-Intellectual and Developmental Disability & Long Term Care
Cici Osonma	Special Reach
Elyse Bernal	Any Baby Can-SA
Jacob Ulczynski	AACOG-Local Intellectual and Developmental Disability Authority (LIDDA)
Kim Jefferies	Brighton Center
Larry Mejia	Respite Care of San Antonio
Leslie Bellieu	Southwindfields
Maria Duncan	Autism Treatment Center-San Antonio
Melanie Cawthon	disABILITYsa
Mike Bennett	Arc of San Antonio
Susan Osborne	CAMPcamp
Melissa Svoboda	Children's Hospital of San Antonio-Autism Clinic
Tiffany Fresher	Autism Community Network

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