

Bianca Demara, a native of Yuma, Arizona, is a family member representative with the Council, representing her two autistic brothers, Josh and Isaac. She is also the co-guardian of Isaac. A few years ago, Bianca was also diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD), which made her disability advocacy journey even more personal. "My passion for being involved in disability policy and advocacy came from my personal experience growing up in a Mexican American household in rural Arizona with my two younger, autistic brothers," she says. "Their experiences, and our experience as a family navigating various state, educational, and healthcare systems, are the foundation of why I care about disability justice in our state. It is also what ultimately led me to join the Council."

Bianca holds a Master's degree in Public Health Policy and Management from the University of Arizona. She currently works as a clinical research associate monitoring compliance and data integrity in clinical trials across the Western region of the United States. Bianca previously worked in a rural health clinic as the director of a center for children with disabilities in Somerton, AZ, where she focused on expanding the services for the disability community and collaborated with other local nonprofit organizations. In 2018, she attended the Disability Policy Seminar in Washington, DC, as part of the University of Arizona Leadership Education in Neurodevelopmental and Related Disabilities (Arizona LEND) program, where she met Michael Leyva, an ADDPC staff member. She also had the pleasure of meeting with U.S. Representative Raúl Grijalva (D-Tucson, pictured together at the top of the article along with Michael Leyva and Janna Murrell, a fellow Council member). In addition to her family, Bianca credits one of her mentors, Dr. Jamie Edgin, a former Council member, for inspiring her to join the Council when she was an undergraduate research associate and research staff member in the Memory Development and Disorders Laboratory/Down Syndrome Research Group under Dr. Edgin.

Although she knows she will never fully understand the experiences of her brothers as autistic people, Bianca nevertheless feels a responsibility, as the eldest daughter of an immigrant family living in a U.S.-Mexico border community, to represent them and share what she has gained from her academic, professional, and personal experiences. She says that she chose to go into public health because she wanted to make an impact at the systemic level for the disabled community in Arizona, especially the underserved and minority members and their families. One thing about which she is most proud is that disability work has been a family focus: Her mother, Gloria, also works in the disability community as a Family Support Specialist with Raising Special Kids (RSK). RSK serves as Arizona's Family-to-Family Health Information Center, and Arizona's Parent Training and Information Center, helping parents access information about healthcare, community resources, and support services so they can make informed decisions regarding their children's care. Gloria is a pillar of strength and wisdom for Bianca, and she credits her mother's perseverance and experience as a single mother, advocating for Bianca's younger brothers, as an immense source of inspiration to also work on behalf of the disability community.

"Some of the biggest barriers that the I/DD community faces are systemic in nature," Bianca also stated. "For one, our state continues to face challenges with equitable access to disability services in our rural communities. However, barriers also persist in providing and promoting services for the I/DD community that provide support across the lifespan. This includes opportunities for self-advocacy, employment, and independent/community-based living arrangements. Additionally, the I/DD community is one of the most vulnerable to discrimination and bias. When members of this community are also part of other vulnerable groups, such as being of advanced age, LGBTQIA+, minority race/ethnicities, or living in poverty, these vulnerabilities can be, and are often, compounded."

Bianca is excited to work with ADDPC's System Access and Navigation Committee to specifically work on resources for individuals with disabilities dealing with across-the-lifespan issues. She believes there needs to be more resources for individuals as they age through life. She also believes that individuals

should live as independently as possible, while also acknowledging some individuals, like her brother, may require guardianship or additional community support.

On a personal note, Bianca's favorite activities include spending time with loved ones, finding new places to eat in Tucson, and exploring bookstores. She has a wide range of interests and hobbies, and currently, she is building and collecting Lego sets, particularly from the Botanical Collection. She is also an Arizona Diamondbacks fan. When asked how she would describe herself in one sentence, Bianca noted that she considers herself an "Arizonan Latina who is passionate about person-centered healthcare and the well-being of people with disabilities across their lifespan." She wants others to understand that the best way to help individuals with disabilities is to listen to them and ensure they have a seat at the table. The best experts are individuals with disabilities, and we should include them in all decision-making aspects of their lives.