ADDPC Newsletter

March 2023

A few Words from Jon Meyers, ADDPC Executive **Director**

Employment · Self Advocacy · Inclusion

March is **Developmental Disabilities Awareness Month**, an annual recognition of individuals with intellectual and developmental disabilities, or I/DD, in our lives and our communities. It is a time to celebrate and educate, a time to reach out alongside and on behalf of the I/DD community to make certain people with I/DD are not forgotten by policymakers or elected officials. It's also an opportunity to raise the public's consciousness of how people with disabilities contribute to the very fabric of our society. But what is "DD Awareness", really? Is it simply acknowledging that people with I/DD live all around us, and that we appreciate, love, respect, and cherish

them? That we value them and wish them every happiness in life?

In fact, true DD Awareness requires more. It requires that we understand the persistent, often pervasive barriers faced by people with I/DD in education, transportation, housing, healthcare, employment, and far too many other areas of life. It requires that we recognize the threats to personal safety faced by people with I/DD – people who are many times more likely than the general population to be victims of crime, abuse, neglect, or exploitation. It requires that we confront the inequities that beset people with multiple forms of disability and

most especially people with intellectual or developmental disabilities. And it requires that we devise effective, meaningful solutions to these problems. Most important, DD Awareness requires us to take action – as advocates and self-advocates – to build upon the achievements of recent decades and to further the changes that have led to better, though still imperfect, opportunities for individuals with I/DD. DD Awareness cannot, must not, be confined to a single month every year. It must be a daily exercise in improving the conditions that still hold back too many members of the I/DD community, by making our voices heard and bringing our issues to the fore. On behalf of ADDPC, I ask that you continue to

power to create a world that is truly aware of, and truly embraces, people of all

partner with us in this work during March and beyond. Together we have the The Arizona Developmental Disabilities Planning Council continues our profile series to help community members get to know the people who represent Arizonans with disabilities.

Up this month is Council member Bianca Demara

(Pictured from left to right: Janna Murrell, Bill Lucero, Bianca Demara, U.S. Representative Raul Grijalva, Juliana Huerena, Krystal Downie, Michael Leyva 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

focused on expanding the services for the disability community and

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

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

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.

Developmental Disabilities

"This campaign is so important because it seeks to improve understanding about the inclusion of people with developmental disabilities in every facet of community life, as well as awareness of the barriers that people with disabilities still sometimes face in connecting to the Arizona communities in which they live," said Jon Meyers, Executive Director of the Arizona Developmental Disabilities Planning Council. ADDPC, the Arizona Center for Disability Law, University of Arizona Sonoran Center for Excellence in Disabilities and the Institute for Human Development at Northern Arizona University form the Arizona Developmental Disabilities Network. These organizations, authorized under the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106-402), receive funding from the United States Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities.

As part of DD Awareness Month, the partner organizations will host events about, and featuring, people with developmental disabilities. A series of three webinars will highlight the month. Topics will include bullying and intimidation, understanding the impact of a disability, and how the medical community can

Meyers praised the organizations working in partnership to raise awareness

· providing education on disability employment issues and recognizing the

with an intellectual/developmental disability (I/DD).

promoting competitive employment in the general workforce for people living

better serve the disability community.

and their efforts to focus on:

University of Arizona Sonoran Center for Excellence in Disabilities https://sonoranucedd.fcm.arizona.edu/about_us

> March 16, 2023 1:00 PM - 2:15 PM (AZ MST)

Sticks and Stones: **Empowering Youth to Address Bullying and Intimidation**

#DDAM2023

Join presenters Rev. Nicholas Love and Gina Griffiths for a powerful webinar as they discuss the next steps to address bullying within the disability community through the exploration of intersectionality and empowering youth. There is no charge to attend the webinar, but you will need to register to participate. When: Thursday, March 16th Time: 1:00 PM - 2:15 PM Where: Virtual

#DDAM2023 This webinar is about encouraging and helping youth and young adults with disabilities to reach their full potential. It is a message Dr. Gabrielle Ficchi wholeheartedly believes in and the single greatest factor she has found in working with individuals with disabilities and their families is giving them opportunities to be their best selves.

When: Thursday, March 23rd

Time: 1:00 PM - 2:00 PM MST

Click here to register for Making the Shift

Where: Virtual

AHCCCS Medicaid resumes regular renewal process beginning April 1, 2023 Beginning April 1, 2023, the Arizona Health Care Cost Containment System (AHCCCS) is required to resume the regular renewal process and disenroll ineligible individuals from AHCCCS and KidsCare. Over the course of 12 months, AHCCCS will complete a full eligibility renewal for all 2.5 million enrolled members, following a careful plan designed to make sure that no eligible members are wrongly disenrolled, and that anyone who no longer qualifies for Medicaid is referred to other health care insurance options. The return to

Attention AHCCCS and **Kidscare Members!** Regular Member renewals begin April 1.

According to the Centers for Disease Control and Prevention, cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. CP is the most common motor disability in childhood. Cerebral means having to do with the brain. Palsy means weakness or problems with using the muscles. CP is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control his or her muscles.

The symptoms of CP vary from person to person. A person with severe CP might need to use special equipment to be able to walk, or might not be able to walk at all and might need lifelong care. A person with mild CP, on the other hand, might walk a little awkwardly, but might not need any special help. CP does not get worse over time, though the exact symptoms can change over a

All people with CP have problems with movement and posture. Many also have related conditions such as intellectual disability; seizures; problems with vision, hearing, or speech; changes in the spine (such as scoliosis); or

United Cerebral Palsy of Central Arizona leaders assert that CP is a diagnosis that has not received adequate federal or state funding. Due to passionate families, clinicians, and researchers, progress is being made in early CP diagnosis and treatment. As with all paradigm shifts, the challenge of change is difficult. The passage of the 2023 Appropriations Act was a positive move

research and surveillance. While cerebral palsy is the most common physical disability among children, with 1 in 343 children being born with CP in the United States, the need is great. The United Cerebral Palsy Central Arizona's Motor Disorder Clinic aims to be a center of excellence to bring precise,

forward, but more federal support is needed to pay for cerebral palsy

evidence-based services to the children of Arizona.

person's lifetime.

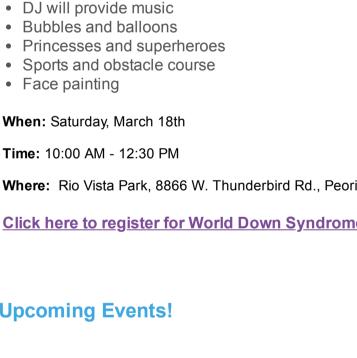
joint problems (such as contractures).

March is National Cerebral Palsy Awareness Month

In 2017, international guidelines for early diagnosis and intervention for cerebral palsy were published. A systematic review of evidence found that early recognition of cerebral palsy should occur as early as possible so that an infant can receive diagnosis-specific early intervention and surveillance to optimize neuroplasticity and prevent complications (Novak et al. 2017). A cocktail of standardized tools, including a neurological exam, brain imaging, and a developmental motor assessment, can diagnose cerebral palsy as early as three months with 95% accuracy. Although still pervasive, the wait-and-see approach to developmental delay is outdated and it hinders potentially transformative care by as much as one to two years for children with cerebral palsy (CDC, 2019). In Arizona, children with cerebral palsy and other neurodevelopmental motor disabilities lack targeted services that are customized to their needs. UCP of Central Arizona's Motor Disorder Clinic strives to be the primary place where families can obtain innovative, cuttingedge, diagnosis-specific evaluations and therapeutic interventions.

when abnormal cell division results in an extra full or partial copy of chromosome 21. This extra genetic material causes the developmental changes and physical features of Down syndrome. Down syndrome varies in severity among individuals, causing lifelong intellectual disability and developmental delays. It is the most common genetic chromosomal disorder and cause of learning disabilities in children. It also commonly causes other medical abnormalities, including heart and gastrointestinal disorders. Among the frequent participants in World Down Syndrome Day from Arizona is Maquela "Lala" Bussey, who lives in Sierra Vista with her parents, Brian and Carmen, and her younger brother and sister. Maquela loves to dance, eat, and hang out with friends and family. She also has an outgoing personality and loves being the center of attention. Eventually, she would like a place of her own where she can live as independently as possible and even would like

to become a mom. She has a friend named Andrew whom she has known since they were about five or six. He also has Down syndrome and lives in Sierra Vista with his family. Maquela refers to Andrew as her boyfriend, although her dad does not like for her to use the term boyfriend.



successes of implementing Employment First in Arizona. This is an opportunity for YOU to bring your questions, comments, and concerns to an informal meeting with Sonoran Center professionals and practitioners. WHO IS THIS FOR? Open to Supported Employment Professionals, Vocational Rehabilitation

Counselors, DDD Support Coordinators, Educators, Providers, Job Coaches,

19TH ANNUAL

Gathering Native Voices to Learn from the Past, Prepare for the Future.

Where: This event is free of charge and can be attended online or in person at the Desert Willow Conference Center, located at 4340 E Cotton Center

3RD ANNUAL AMERICAN INDIAN YOUTH DISABILITY SUMMIT

Blvd., Phoenix, AZ 85040. Registration in advance is required.

American Indian Youth Disability Summit

Click here to register for the American Indian Disability Summit

Click here to register for Monday Mindset Chats

American Indian Disability Summit

Click here to register for the Youth Summit Service Provider Training: Addressing Sexual Violence in I/DD Communities Presented by the Arizona Coalition to End Sexual and Domestic Violence (ACESDV). This free 4-hour training provides vital information on how to prevent, recognize and respond to sexual violence in I/DD communities. It will be

Youth Town Hall: Centering the Voices of Youth with Disabilities Come join the Institute for Educational Leadership for a thoughtful conversation where young people with disabilities discuss challenges they are facing in school and how adults can shift their practices to alleviate these challenges.

When: Thursday, March 30th

Time: 4:00 PM MST

Where: Virtual

CONFERENCE SATURDAY, APRIL 29, 2023 IE FALL, FIGHT, AND RISE FOR MORE INFORMATION: SWIFAMILIES.ORG/2023SACONFERENCE The 2023 Self-Advocates Conference will bring together self-advocates, family members, caregivers, and professionals serving the Arizona disability community from around the state to learn and talk about the issues important to all of us. The conference will include:

Visit Disability Data Hub Here See ADDPC website for more events. Click here. Manage your preferences | Opt Out using TrueRemove™ Got this as a forward? Sign up to receive our future emails. View this email online.

Click here for updates on the Self-Advocates Conference G 0 0 0 3 0 % 0 andergryteninner: 🔛 tilt. 💿 Altt: 🙎 ACCVI. O TORNOO TRUM MONIGORED AND GIVEN TRANS COURSE transport Apparent age the: 2,088,117 brokeyed With a Disastry, 111,555

3839 N. 3rd Street Suite 306 | Phoenix, AZ 85251 US

This email was sent to . emma To continue receiving our emails, add us to your address book. Subscribe to our email list.

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 selfadvocacy, 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 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

March is Developmental Disabilities Awareness Month! The 2023 Theme is "Beyond the Conversation"

Awareness Month 2023 **Beyond the Conversation** #DDAM2023 Governor Hobbs proclaims March 2023 **Developmental Disabilities Awareness Month** Highlighting the need for broader acceptance and inclusion of people with intellectual and developmental disabilities, or I/DD, in communities across the state, Governor Katie Hobbs proclaimed March 2023 to be Developmental Disabilities Awareness Month. The Arizona Developmental Disabilities Planning Council (ADDPC), in partnership with the Arizona Developmental Disabilities Network (ADDN), the Arizona Association of People Supporting Employment First (AZ APSE) Chapter, and Arizona's Vocational Rehabilitation program will celebrate the abilities and contributions of people with developmental disabilities in Arizona throughout March. This year's theme for DD Awareness Month is "Beyond the Conversation: It's not just talking; it's about action." Governor Hobbs's proclamation is designed to increase Arizonans' appreciation of how people throughout the state share their abilities and contribute positively to all aspects of life.

diverse contributions of Arizona's workers with disabilities. developing a statewide network of self-advocacy organizations led by persons with I/DD. In addition, personal stories and videos will be shared, and a robust social media campaign will run on YouTube, Facebook, Instagram, and Twitter. To see all events and get more information, follow ADDPC's Facebook page. For more information about ADDPC's goals and efforts around Arizona, visit the Council online at https://addpc.az.gov/about. For more information about our partners, visit their website: Arizona APSE https://apse.org/chapter/arizona-apse/ Arizona Vocational Rehabilitation: https://des.az.gov/services/employment/rehabilitation-services/vocationalrehabilitation-vr Arizona Center for Disability Law - https://www.azdisabilitylaw.org/about-us/ Institute for Human Development at Northern Arizona University https://nau.edu/ihd/about-ihd/

Click here to register for Sticks and Stones webinar March 23, 2023 1:00 PM - 2:00 PM (AZ MST) Making the Shift: Seeing disability as something you have, to seeing disability as part of who you are

regular renewal processes will be the first time in three years that Medicaid and Arizona's Children's Health Insurance Program (CHIP) members who no longer qualify for Medicaid will be disenrolled. Members will be notified of their eligibility renewal prior to their month of renewal. What AHCCCS Members Can Do To Prepare for Renewal: The most important thing AHCCCS members can do right now is **update** their contact information in Health-e-Arizona Plus (www.healthearizonaplus.gov). To update contact information, log in to www.healthearizonaplus.gov or call Health-e-Arizona Plus at 1-855-432-7587, Monday through Friday 7:00 AM - 6:00 PM. Sign up for text/email notification alerts from AHCCCS and respond to all AHCCCS requests for information in a timely manner. To sign up for text/email alerts of AHCCCS notifications, log in to www.healthearizonaplus.gov, go to "Message Center" on the toolbar, and click on "Manage My Alerts and Letters." Look for a letter from AHCCCS and respond if needed.

At what age are most children diagnosed with CP or other motor disorders? In the United States, the average age is 2 years old for CP, but in rural areas, it is 5 years old. The diagnosis is made when a child misses consecutive developmental-motor milestones or is found to have abnormal movement patterns. For more information on UCP of Central Arizona's baby clinic, click here. March 21st is World Down Syndrome Day

Meet Maquela Bussey, a 19 year old living in Sierra

World Down Syndrome Day (WDSD), March 21st, is a global awareness day

The date for WDSD, the 21st day of the 3rd month, was selected to signify the uniqueness of the triplication (trisomy) of the 21st chromosome which causes

The Mayo Clinic definition of Down syndrome is a genetic disorder caused

which has been officially observed by the United Nations since 2012.

Vista, AZ, who has Down syndrome

Down syndrome.

As a freshman in a public high school, Maquela was involved in an incident that led her parents to remove Maquela from the school and enroll her in SKILLS Private Academy., founded by Maquela's middle school teacher, Kelly Mangan. The relationship flourished in high school. In the past, she rarely spoke about the schoolwork that she was given. Brian and Carmen felt that Maquela was not provided the opportunity to share her academic skills at school. Now, Maquela is excited to discuss what she has learned in school and even enjoys her homework. Maquela has three siblings with whom she has great relationships: Josiah is 14, Judea is 8, and Elijah is 22. Elijah is in his senior year at the Air Force Academy in Colorado Springs, Colorado, following in the footsteps of his dad (an officer in the US Army) by joining the military. Elijah remains one of Maquela's biggest cheerleaders as he was able to help watch over her recovery when she had heart surgery at three months of age. Maquela has recovered well from her heart surgery and has no complications. Despite her medical history, she is now healthy and participates in WDSD celebrations in

Tucson with her family. Maquela is excited about her future and is determined

SAT, MAR 18 @ 10am - 12:30pm Rio Vista Park - Peoria

This free event is like a family picnic! Information and resource tables will be

on hand. There will be entertainment and activities for all ages:

DSNetwork

to live life on her own terms.

Food trucks and popsicles

Game trucks and train rides

Raffle baskets

event!

Where: Virtual

When: Thursday, March 9th

When: Thursday, April 6th

Time: 10:00 AM - 1:00 PM

Monday Mindset Chat

and Job Developers.

When: Friday, March 24th

Where: Virtual

informed response.

Where: Virtual

Where: Virtual

1. When: Tuesday, March 21st

2. When: Thursday, May 18th

Time: 1:00 PM - 4:00 PM MST

Time: 9:00 AM - 1:00 PM MST

During this training, DB101 experts will:

Time: 8:00 AM - 4:00 PM MST

Time: 10:00 AM - 12:30 PM MST

Tie-dye socks craft

Where: Rio Vista Park, 8866 W. Thunderbird Rd., Peoria, AZ Click here to register for World Down Syndrome Day **Upcoming Events! FAMILY CAREGIVER** DAY AT THE CAPITOL Hosted by

Arizona Caregiver Coalition

The virtual Family Caregiver Day at the Capitol is for family caregivers, friends, and supporters to learn about current issues and policies affecting caregiving. Please join the Arizona Caregiver Coalition for this amazing annual

The **in-person Family Caregiver Day at the Capitol** will be held April 6th for family caregivers, friends, and supporters. Come to downtown Phoenix to show your support for family caregivers in Arizona. We will invite media and our State legislators. Come to hear speakers on policy issues and shared

Where: In-Person at Wesley Bolin Plaza, 1700 W. Washington Street, Phoenix

Presented by the Sonoran Center for Excellence in

SUPPORTED **EMPLOYMENT IN ARIZONA**

Every Second

Monday Noon-1 PM

Join us for monthly chats focused on addressing the challenges and

Click here to register for the virtual Family Caregiver Day

caregiver stories. We'll have sandwiches and snacks. For program information, contact the Arizona Caregiver Coalition at 1-888-737-7494.

Click here to register for the in-person Family Caregiver Day

Disabilities at the University of Arizona

American Indian Youth Disability Summit will highlight voices of American Indian youth with disabilities and focus on aspects of American Indian life, history, culture and heritage that can help you address today's challenges. When: Saturday, March 25th Time: 10:00 AM - 4:00 PM MST offered twice virtually, on March 21st and May18th. Presenters will discuss the dynamics and traumatic impact of sexual violence and how to recognize abuse, as well as explore strategies for a trauma-

This training is for disability service providers who serve the I/DD community

and can be used for Direct Care Worker continuing education.

Click here to register for Sexual Violence in I/DD Communities

Disability Benefits 10

Arizona Disability Benefits 101 (DB101) provides training for professionals on benefits, health coverage, and employment supports to reduce the myths that are barriers to employment and financial self-sufficiency for people with

Click here to register for the Youth Town Hall SAVE THE DATE
023 SELF ADVOCATES

 Describe Supplemental Security Income/ Social Security Disability Insurance rules and work incentives, Medicaid and Medicare, and employment impact on state/federal benefits Complete and explain Estimator results of the impact of specific earnings on Explain motive and support plans for employment and transition to selfsufficiency When: Wednesday, March 23rd Time: 1:00 PM MST - 4:00 PM MST Where: Virtual Click here to register for DB101 You are invited to Arizona's 2023 **Statewide Transportation Technology Summit** Could technology help older adults get to their doctor more easily? As an important partner in transportation and health care, the Statewide transportation Technology Summit cordially invites you to attend a free statewide summit to identify technology projects that help older adults better access rides to health care appointments. This event is hosted by Age Friendly Arizona, the Northern Arizona Council of Governments (NACOG), and the National Center for Applied Transit Technology (N-CATT). When: Tuesday, March 28th Time: 9:00 AM - 4:00 PM MST Where: Virtual Click here to register by March 21st for the Technology Summit

-Self-advocate keynote speakers -Presentations on issues important to self-advocates -Introduction to self advocacy groups across Arizona -Online fun and games