



2022 Annual Report



***Hold my hand and walk with me.
We must break the back of social inequity;
We must empower every individual with a disability
To live with dignity in an inclusive society.
— William E. Lightbourne***

Introduction

The Arizona Developmental Disabilities Planning Council (ADDPC) serves Arizona residents with intellectual and developmental disabilities (I/DD), along with their families, providing original research, education, advocacy, and financial support to disability-serving organizations that encourages Arizonans with I/DD to advocate for themselves and create more inclusive communities.

The Council receives funding from the federal government to do this work. Along with other responsibilities, Council Members vote to determine which projects can use these funds to improve the lives of Arizonans with I/DD.

To embody the words of William E. Lightbourne and the views of the Council, in 2022 ADDPC added two new goals and redefined those already being pursued. The five current goals are: Self-Determination, Meaningful Careers, Inclusion with Engagement, Safety, and System Access and Navigation. As you read through the following pages you will see some of the remarkable things the Council and its grantees have accomplished this year to move these goals forward and to ensure that individuals with I/DD in Arizona can live with dignity in an inclusive society. This report covers the 2022 federal fiscal year (October 2021 – September 2022).

The best advice I can give people is don't give up, whatever your circumstances are.

- Kristina Lopez, Council Member and Self-Advocate

Self-Determination

To expand advocacy among people with intellectual and developmental disabilities so that they can live more self-determined lives, fully engaged, and included in all aspects of community life.

The aim of this Goal is to help people with disabilities and family members lead more self-determined lives so that individuals with disabilities, especially individuals with I/DD, can reach whatever dreams and aspirations they have. Overall, Self-Determination activities involved

476 self-advocates, 69 family members, and 1,447 professionals or other members of the public.

The Council continued to support alternatives to guardianship during 2022. This included Supported Decision-Making (SDM). SDM is simply asking for help to make everyday choices. The individual still decides on his or her own, however, the individual uses the information provided by supporters to help make the decision. Supported decision-making is all about receiving the right support at the right time so that the individual may live or work as independently as possible. The key to this concept is that the individual is in the driver's seat.

Since 2018, the Council has funded a partnership between the Southwest Institute for Families and Children (SWI), The Arc of Arizona, and the Arizona Center for Disability Law (ACDL) to educate the public on supported decision-making and to try to get legislation passed that recognizes SDM in Arizona statute. It is worth noting that SDM legislation does not have to be passed in order for a person to make an SDM agreement. Legislation had not been passed as of the end of the fiscal year, but in 2022 the partnership educated families and individuals through the Supported Decision-Making Academy and a variety of other trainings and presentations.

Supported Decision-Making Academy

SWI promoted a new training for families in 2022, the Supported Decision-Making Academy. Five courses were held, in which 11 participants met to learn about SDM and how to create an SDM agreement. The Academy offered families 1-on-1 support and technical assistance from the staff of SWI, The Arc, and ACDL to develop a plan tailored for the person with I/DD and to minimize any barriers to implementation. ADDPC will continue promoting SDM through a new grant-funded project beginning in 2023 while also sharing information about all currently developed trainings on our website and in future newsletters.

Self-Advocacy Solutions

Self-Advocacy Solutions is a coalition of self-advocacy groups and allies throughout Arizona, led by Southwest Institute for Families and Children under a contract from ADDPC. Its goal is to strengthen self-advocates to speak up for themselves and others by working together through the statewide self-advocacy network.

During 2022, SWI was able to:

- Host semimonthly Zoom meetings, referred to as Let's Talk. These meetings were the primary way SWI helped various self-advocates with leadership development, issue or goal planning, bylaws development, social media utilization, and membership/coalition building. During the meetings, self-advocates were encouraged to speak up about issues that were important to them.

Security is mostly a superstition. It does not exist in nature, nor do the children of men as a whole experience it.

- Helen Keller

➤ Establish a statewide network totaling 8 self-advocacy groups, whose members met and worked regularly with SWI. The groups included People First of AZ, Inclusive Empowerment Network, and Seeking Equality Leading to Fairness (S.E.L.F.), all in the Phoenix area; Self-Direction (Nogales); Northern Arizona Tribal Disability Coalition (Tuba City, on the Navajo Nation); and 3 Special Olympics Arizona-sponsored groups, Athletic Input Councils (various locations). These 8 groups were comprised of approximately 91 self-advocates advocating for all Arizonans with disabilities. The main objective was to get individuals with disabilities to speak out more about their lives.

Arizona Peer and Family Coalition

The Arizona Peer and Family Coalition (APFC) project funded by ADDPC since 2020 finalized its third year of self-advocacy leadership training geared for persons with I/DD who use and engage with the behavioral health system. A successful promising program, advocates included peers with I/DD as well as family members and professionals working alongside those with I/DD. Ten trainings were conducted over the grant period, with 154 individuals trained. For the final year of funding, APFC trained a total of 84 individuals with I/DD in one of its three Civic Leadership Development trainings, as well as 27 family members trained. Peer-to-peer mentoring was a key part of the program and a total of 120 hours of peer-to-peer mentoring to 13 unique individuals with I/DD took place. In addition, 13 mentees and five mentors completed APFC's Leadership Advocacy Mentorship Program.

Pictured at right is one of the self-advocacy leadership trainings conducted by the Arizona Peer and Family Coalition (APFC).



Meaningful Careers

We will increase the career potential of people who have intellectual and developmental disabilities (I/DD) and link them with resources needed to achieve their career goals.

A lot of the state systems still put people with disabilities in a box suggesting that they can only fit in working certain types of jobs as opposed to really looking at their goals and their strengths and maximizing those.

- J.J. Rico, ADDPC Vice-Chair

In 2022, the conversation was no longer just about employment. People who have I/DD want to attend college, explore alternative career paths, obtain, and retain positions where they earn competitive wages, and have the opportunity for advancement. If they need resources, these should be readily available. This expanded goal is focused on providing easily accessible resources and supports to people with I/DD to reach their career dreams.

ADDPC worked with the Arizona DD Network - Arizona Center for Disability Law, Institute for Human Development at Northern Arizona University, and Sonoran Center for Excellence in Disabilities at University of Arizona - Association of People Supporting Employment First (APSE) Arizona Chapter, AZ Employment First, Department of Economic Security-Division of Developmental Disabilities (DDD) and DES-Rehabilitation Services Administration (Vocational

Rehabilitation), the business community, and other stakeholders on multiple tasks to ensure young adults with I/DD and their families and caretakers are aware that a career choice is an option for them. Each person with I/DD should have conversations with their parents, caregivers, school counselors, and others on what a meaningful career looks like for them. ADDPC believes this conversation should begin at an early age so there are champions in place for them, supporters who see the ability in each person with I/DD and are willing to advocate and assist them on their journey.

Creating a Successful Path

During 2022 the Council initiated a monthly webinar series, titled *Creating a Successful Path*, which began in April and ended in September. David Murahashi, an individual



with a disability, was a featured presenter for one of the webinars that focused on the importance of Person-Centered Planning. A total of 529 individuals participated in the webinars; in addition, webinar sessions have been viewed more than 700 times on YouTube. The webinar with the highest attendance was “Apprenticeships and Career & Technical Education (CTE),” which had 105 participants. Participants came from all over Arizona and some even attended from out-of-state.

Technology Enabled Employment Skills Training project at Northern Arizona University – Institute for Human Development (NAU-IHD)

ADDPC funded a Technology Enabled Employment Skills Training project at Northern Arizona University’s Institute for Human Development, one of the two University Centers of Excellence in Developmental Disabilities, or UCEDDs, serving Arizona. During the pandemic, many people with I/DD lost employment (at least temporarily) because various workplaces closed. One of the key aims of this project was to test the viability of the Daivergent training program in helping people with I/DD in rural/isolated areas obtain technology skills and then, using those skills, seek employment that

CHRISTOPHER’S STORY:

Christopher was a client at the Hozhoni Foundation in Flagstaff, where he was studying for a career in hotel management. His counselor had worked with him for years and always felt like he could benefit from a strong mentor. When she learned of Daivergent's program at NAU-IHD, she encouraged Christopher to apply for the program and assumed the role of his champion throughout the process.

Christopher's life goal was to become a technical support provider. He wanted to assist people in resolving computer hardware issues. His Virtual Support Professional (VSP) noticed this early on after spending hours with Christopher discussing desktop processors, technology brands, and newly released gaming consoles. Given the VSP's experience and training from his time with Daivergent, he knew exactly what was needed to lead Christopher closer to his dreams. The VSP recommended several courses to Christopher, including Google's Technical Support Fundamentals course and learning modules from Daivergent's learning library. Daivergent covered the full cost of the Google Certification Program.

Every week, the VSP would meet with Christopher to discuss his progress. Afterward, the pair would take some time to discuss Christopher's personal issues, such as his confidence and propensity to be sidetracked. At one point, Christopher fell nearly 3 weeks behind and expressed his desire to quit both the course and Daivergent's program; when asked why, his response was simple: Christopher didn't want his VSP, his counselor, or his family to view him as a failure.

After hearing this, the VSP reassured Christopher, letting him know he was not a failure and reminding him of the amazing progress he made. The conversation allowed Christopher to put everything in perspective and encouraged him to keep moving forward. Following weeks of hard work and dedication, Christopher successfully completed the course and earned his Google Certification. The day he passed his exam, his father printed and framed his certificate, and it now hangs on the wall in their home.

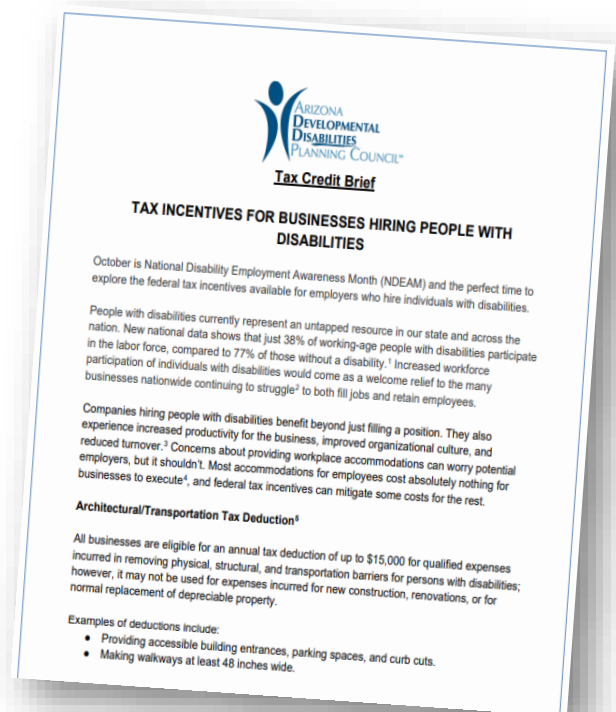
would not require them to be tied to a physical location. This would make them less vulnerable in the future to loss of site-specific employment.

Christopher takes great pride in his new credential, as it is a reminder to himself that anything is possible for those who are dedicated and work hard. “The certificate I received will allow me to secure a job much faster,” said Christopher.

A Community Advisory Board was formed to provide oversight of the project and its evaluation processes. A total of 13 participants were recruited, all of whom were affiliated with either the Division of Developmental Disabilities, Vocational Rehabilitation, or other transition services; 15% of the participants identified as American Indian; and 62% of the participants lived in rural areas. All 13 participants received personalized services from Daivergent, from 3-9 months in duration. The personalized services included an initial assessment of interests, virtual work simulations of technology-enabled jobs of interest, and virtual social groups. Each participant was paired with an online coach, called a Virtual Support Professional (VSP). The VSP met weekly with each participant and communicated in between virtual sessions to ensure goals were met. As a result of this project funding and the company’s ability to demonstrate the effectiveness of its services, Daivergent is now a vendor for Arizona Vocational Rehabilitation.

Federal Business Tax Incentives Brief

The Council created a Tax Credit Brief and Press Release in October 2022 to help support National Disabilities Employment Awareness Month (NDEAM). The brief and press release were directed at the numerous Chambers of Commerce across the state – including messaging that people with disabilities represent an untapped resource and tax incentives are available for businesses hiring people with disabilities. ADDPC encouraged the Chambers to share the information with their members – primarily small businesses. This is the first time the Council conducted a targeted campaign to the business community.



Inclusion With Engagement

We will support communities and agencies across Arizona to include and engage people of all ages and backgrounds who have intellectual and developmental (I/DD) disabilities.

The Council is committed to going beyond the mere placement of individuals with I/DD in community-based settings. Instead, through this goal, ADDPC envisions community inclusion that offers opportunities for people with disabilities to be active participants in the life of their community. Moreover, ADDPC is stating a commitment to recognize needs and opportunities will vary from location to location and culture to culture, given Arizona's diversity – its numerous distinct Tribal communities, extensive Hispanic/Latino population, and the growing number of refugees from many parts of the world.

Continuing Medical Education (CME)

The University of Arizona-Sonoran Center for Excellence in Disabilities (Sonoran Center) was funded to develop an online continuing medical education (CME) program consisting of a series of training videos for primary care providers to support their work with individuals with I/DD in promoting personal healthcare decision-making. The principal population of interest was primary care providers (physicians and nurse practitioners) who provide regular preventive care to adults with I/DD. As reported in a 2020 ADDPC survey, educating medical providers on the healthcare needs of the disability community (specifically individuals with I/DD) and communicating with them in "a way that I can understand" was identified as a top priority.

The Sonoran Center was able to create a steering committee that included an individual with I/DD, a family member, a provider in the I/DD community, and several representatives from the medical community. This group developed new partnerships, brainstormed on the module concept, developed scripts, featured self-advocates in the videos, and shared the information with the larger public. (More information can be found by visiting the [learning hub](#) on the Sonoran Center's website.)

Healthcare that is appropriate for individuals with I/DD is an urgent need in Arizona and across the nation. In each of the fields of physical, oral, and mental health, too little is done to ensure clinicians have the necessary knowledge, training, and incentives to provide high-quality care



for individuals with unique needs. Instead, they are typically treated by general practitioners who are underequipped for this task. Circumstances are especially dire in rural or isolated communities where far fewer care resources can be found.

Moreover, as extensive media coverage has recently shown, many clinicians simply refuse – whether overtly or covertly – to treat patients with disabilities. Steps must be taken to prepare a larger and more dedicated body of medical professionals who are proficient in serving patients with I/DD. The Council’s intent in funding this CME project was to ensure this tool can be used as a step in the right direction.

Safety

We will expose and reduce instances of abuse and neglect against individuals with intellectual and developmental disabilities (I/DD) of all ages while working toward a systemic focus on prevention.

Individuals with I/DD are extremely vulnerable and are subject to abuse, exploitation, neglect, physical and emotional violence, and other forms of maltreatment at rates several to many times greater than those for the general population. ADDPC's Safety goal was created to address these issues through engagement of a diverse, informed, and dedicated array of disability advocates and self-advocates, as well as family members, caregivers, service providers, abuse response professionals, and others who play a role in ensuring the well-being of the I/DD community.

ADDPC recognizes this is a long-term effort, not a set of activities that will result in transformation of systems in a single, or even a few, years. The Council foresees dedicating resources over the long term to maintain progress in addressing these critical Safety issues.

I/DD service provider trainings on sexual abuse, preventing abuse, and reducing traumatization of people with I/DD

The Council funded a training program implemented by the Arizona Coalition to End Sexual and Domestic Violence (ACESDV) to increase knowledge among I/DD service providers about sexual abuse, to improve prevention efforts, and to reduce traumatization or re-traumatization among survivors with I/DD.

Responses to the ACESDV Trainings:

- "I would recommend this training to all that can take it. The amount of data was very interesting...Thank you!"
- "All of the information will be useful in my line of work provided the statistic that more than likely, people with disabilities have higher probability of experiencing sexual violence and abuse (and that's only reported). It was noted that people with intellectual disabilities are 7x more likely to experience sexual assault. It was eye-opening just knowing that members I serve are vulnerable but putting it in that perspective makes their protection all the more important."
- "To be honest, all the information [from the training] was very valuable in my opinion."
- "They [our trainers] were patient and answered questions thoroughly."
- "The two trainers were very knowledgeable and presented information in a clear way. Even though the session was virtual they did a great job of getting people involved and keeping me engaged."

After developing the curriculum, then conducting community outreach and sharing information with the Arizona Statewide Independent Living Council (AZSILC), The Arc of Arizona, and The Opportunity Tree, ACESDV offered three trainings to audiences that included staff at group homes, day treatment centers, independent living centers, community-based disability advocacy organizations, and long-term care facilities. Feedback showed that over 95% of the training attendees thought the training was Exceptional or Good, with the attendees indicating that all aspects of the training were useful and meaningful for their work with people with I/DD.

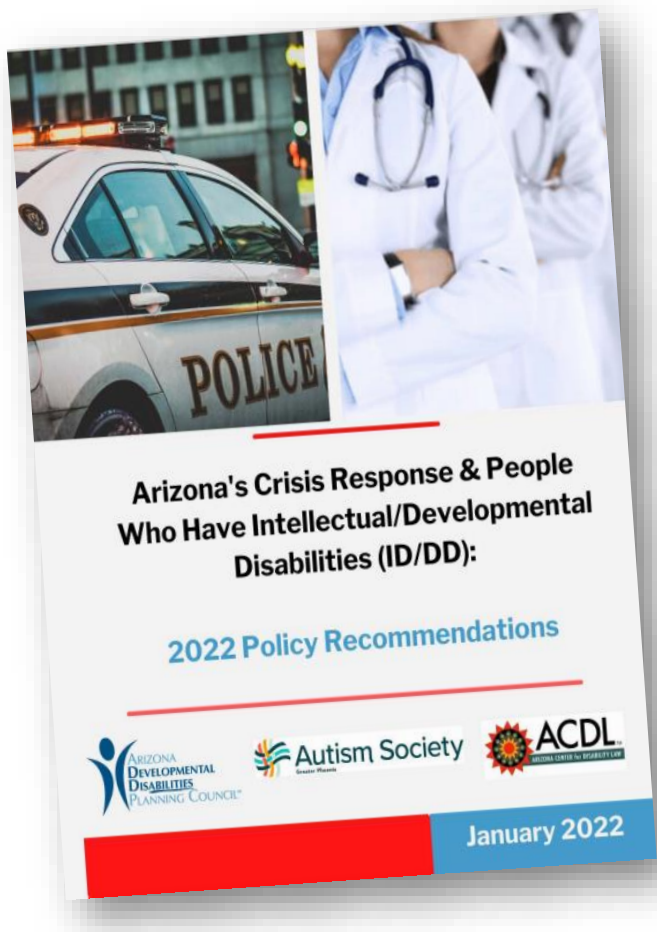
Arizona's Crisis Response & People Who Have Intellectual/Developmental Disabilities (ID/DD): 2022 Policy Recommendations

ADDPC established a Behavioral Health and Crisis Response Committee after the January 2022 release of its report, "[Arizona's Crisis Response and People Who Have Intellectual/Developmental Disabilities \(ID/DD\): 2022 Policy Recommendations](#)". From this committee, a core group was formed to focus specifically on systems-level policies related to

crisis interventions for DDD members.

This core group was charged to meet with each of the Managed Care Organizations (MCOs) providing physical and behavioral health services for DDD members, as well as key players involved in operating Arizona's crisis response systems, in order to 1) identify each organization's role, responsibilities, policies, and procedures; 2) determine where gaps exist that pose a threat to individuals with I/DD when they are experiencing crisis; and 3) advocate for system-wide awareness of the unique intervention needs of the I/DD community.

ADDPC's behavioral health/crisis core group was able to bring heightened attention to the needs of key players in the crisis response and I/DD service systems, resulting in commitments to provide better oversight of existing system requirements as they affect the I/DD community. Too often the



contractual obligations requiring MCOs and service providers to coordinate care and communications are not enforced, as are many of the legal responsibilities of state and municipal agencies. Representatives of state Medicaid, health, and DD services agencies demonstrated a willingness to explore new options for meeting the crisis needs of Arizonans with cognitive challenges, including expanding training and funding mechanisms to ensure the most appropriate responders are dispatched to incidents.

System Access and Navigation

We will enhance, strengthen, and expand access to accurate and user-friendly information and the services needed for people with intellectual and developmental disabilities (I/DD) to lead more self-determined lives.

ADDPC created a new goal to address how reliable, accurate, and current information can be gathered and shared within the disability population, especially in unserved and underserved communities. The System Access and Navigation goal will focus on an evaluation process to understand the extent to which created or shared materials are useful and impactful for a family member or individual with I/DD seeking to find the services and supports they need. The committee also aims to ensure individuals with I/DD and their families have optimal access to pertinent information that assists them in navigating the systems within Arizona.

Comprehensive Online Resource Guide

ADDPC collaborated with the Sonoran Center to begin developing a comprehensive online guide that allows families to identify resources and services for people with disabilities from birth to adulthood. Starting in January 2022, an intern working on behalf of the Sonoran Center met weekly with Council staff and the System Access and Navigation chairperson to review progress and discuss the next steps. She also met bimonthly with the System Access and Navigation Committee to update them on her progress and receive feedback.

The project began with the creation of an initial framework, followed by virtual meetings with parents, service providers, and state agencies to develop a list of questions that parents and guardians typically ask while trying to find needed resources and services to support their child's success. Based on the results of these meetings, the scope of work moving forward will focus on the needs of individuals at different key transition points in life.

Once finalized in 2023, the online guide will be available in English as well as a Spanish translation. ADDPC will track how the online guide is utilized in order to update and adapt it, as necessary.

Significant legislation related to individuals with I/DD enacted in 2022

HB2031 HIGHER EDUCATION; INDIVIDUALS WITH DISABILITIES

Community colleges and universities under the jurisdiction of the Arizona Board of Regents are required to adopt policies that are transparent and explicit about the process by which the university or community college determines eligibility for accommodations for an individual with a disability, and that make any of a list of specified documents sufficient to establish that an individual is an individual with a disability.

HB2088 ALTCS; PREADMISSION SCREENING

Preadmission screening conducted by the Arizona Long-Term Care System must be conducted telephonically, unless the Arizona Health Care Cost Containment System Administration determines it is necessary to conduct the assessment in person.

HB2113 DEVELOPMENTAL DISABILITIES; DOWN SYNDROME

Adds Down syndrome to the definition of a developmental disability for the purposes of qualifying to receive support and services through the Arizona Department of Economic Security-Division of Developmental Disabilities and the Arizona Long Term Care System (ALTCS).

HB2157 SUPPLEMENTAL APPROPRIATIONS; COMMUNITY-BASED SERVICES

Supplemental appropriations in FY2021-22: \$30.1 million from the Children's Health Insurance Program Fund and \$1.078 billion of expenditure authority to the Arizona Health Care Cost Containment System Administration to implement the American Rescue Plan Act of 2021 home and community-based services spending plan and to adjust funding formula requirements; \$362.7 million of expenditure authority to the Department of Economic Security Division of Developmental Disabilities to implement the American Rescue Plan Act of 2021 home and community-based services spending plan.

HB2397 EMOTIONAL ABUSE; VULNERABLE ADULTS

For Adult Protective Services statutes, the definition of "abuse" is expanded to include "emotional abuse" (defined).

HB2659 ORGAN TRANSPLANTS; DISABILITIES; DISCRIMINATION; PROHIBITION

Health care providers are prohibited from determining that an individual is ineligible to receive an organ transplant, refusing to place the individual on an organ transplant waiting list, or denying the individual medical or other services related to an organ transplant based solely on the individual's disability. Applies to each stage of the organ transplant process. If an individual believes that a health care provider or facility has violated this prohibition, the affected individual may commence a civil action for injunctive and other equitable relief for the purpose of enforcing compliance.

HB2865 BUDGET; HUMAN SERVICES; 2022-2023

Establishes the Developmental Disabilities Group Home Monitoring Pilot Program in the Department of Health Services (DHS) and establishes Program requirements. The Program self-repeals on January 1, 2027. During FY2022-23, on or before January 1, 2024, and each year thereafter, the Department of Economic Security (DES) shall provide an annual report to the chairpersons of the Health and Human Services committees of the Senate and the House of Representatives, or their successor committees, the directors of the Arizona Health Care Cost Containment System and the Department of Health Services and the designated entity conducting the developmental disabilities group home monitoring pilot program.

SB1075 INCOMPETENT DEFENDANT; GUARDIAN APPOINTMENT; COSTS

If the court finds that a defendant is incompetent to stand trial and that there is no substantial probability that the defendant will regain competency within 21 months, any party is allowed to request that the court appoint a guardian ad litem (GAL) to investigate whether the defendant is or may be in need of a guardian, a conservator or any other protective order, instead of being allowed to request that the court appoint a guardian. A GAL who determines that protective action is appropriate is required to initiate and prosecute proceedings for the appointment of a guardian, a conservator, or any other protective order. A GAL is entitled to reasonable compensation for the work performed. If the defendant is indigent, the court is authorized to order the county to pay reasonable compensation.

SB1231 INDEPENDENT OVERSIGHT COMMITTEE; DEVELOPMENTAL DISABILITIES

The Division of Developmental Disabilities in the Department of Economic Security (DES) must allow the Independent Oversight Committee on Persons with Developmental Disabilities up to 30 days to review new policies and major policy changes before the Division submits the policies or changes for public comment.

SB1257 LONG-TERM RECREATIONAL VEHICLE PARKS; CAREGIVERS

The requirements for a resident of a long-term recreational vehicle (RV) park to have a caregiver occupy the RV to provide live-in health care to the resident are modified to require the resident to have a disability (as defined elsewhere in statute) and to require the services provided by the caregiver to be necessary to afford the resident equal opportunity to use and enjoy the dwelling. Previously, the resident was required to provide a written treatment plan from the resident's physician every six months for a caregiver to be authorized to do so. Landlords are no longer authorized to require the resident to provide a written renewal of the treatment plan every six months.

SB1542 GROUP HOMES; ELECTRONIC MONITORING

Expanded existing legislation related to electronic (video) monitoring in the common areas of state-contracted group homes to state that all group homes "shall" install video monitoring equipment covering common areas, unless the guardian of a resident or a resident who is

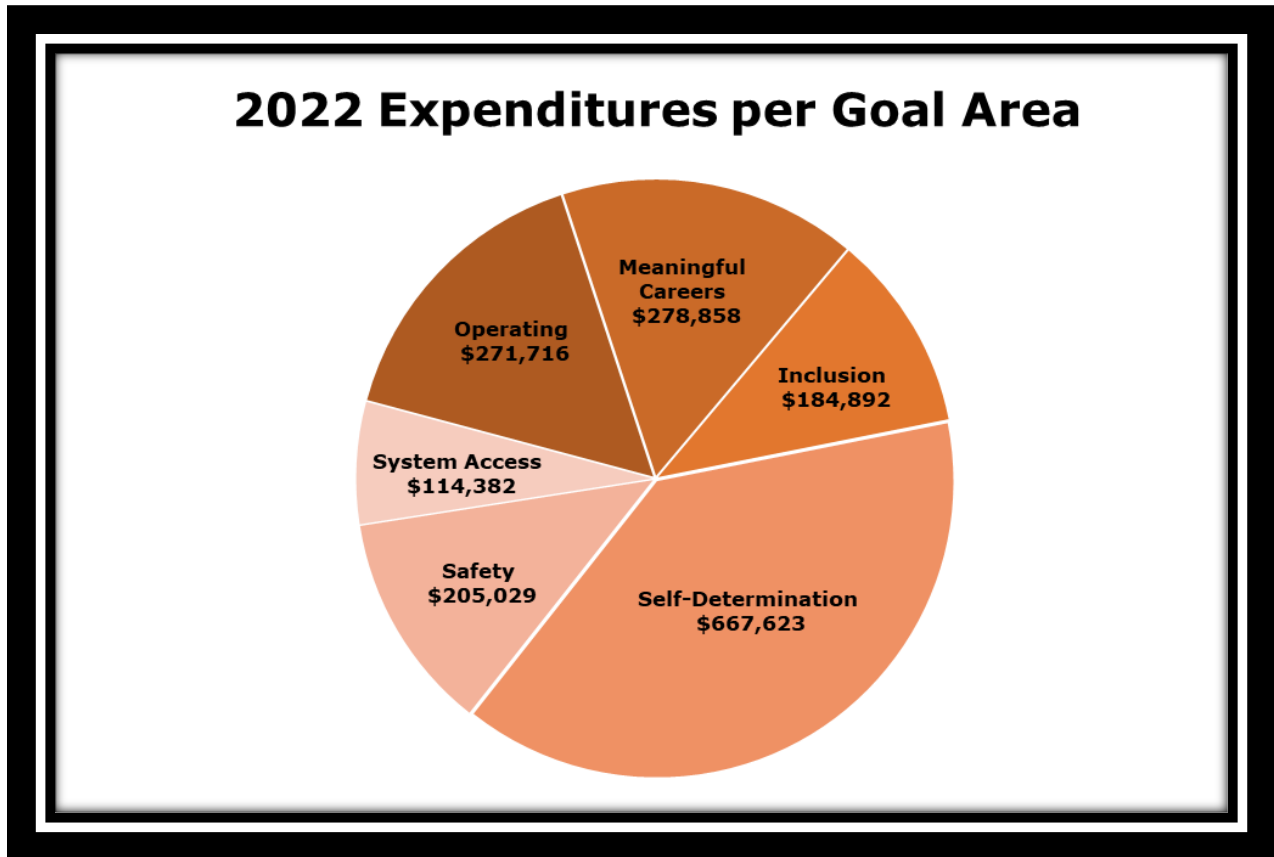
his/her own guardian objects, rather than allowing that group homes "may" install such equipment unless objected to.

State Funding of I/DD and Related Services

The approved state budget for Fiscal Year 2023 (July 2022-June 2023) included more than \$57 million in increased funding for DDD, ALTCS, and the Arizona Early Intervention Program (AzEIP). Several of the fiscal items - most notably facility-based and HCBS provider rate increases and an across-the-board 21% improvement in payments to AzEIP providers - were deemed "permanent" increases.

Agency Funding

In Federal Fiscal Year 2022, the Arizona Developmental Disabilities Planning Council allocated \$1,722,499 to support programs and operations.



GOAL	AMOUNT
Self-Determination	\$ 667,623
Meaningful Careers	\$ 278,858
Safety	\$ 205,029
Inclusion	\$ 184,892
System Access	\$ 114,382
Operating Expenses	\$ 271,716

2022 Council Members



MELISSA VAN HOOK Chair & Family Member

J.J. RICO Vice Chair and Representative, Arizona Center for Disability Law (Protection and Advocacy System)

LAURA LUNA BELLUCCI Representative, Arizona Department of Health Services

KIN CHUNG-COUNTS Family Member

MONICA COOPER Self-Advocate

MICHAEL COEN Representative, Department of Economic Security-Division of Aging & Adult Services

MEGHAN COX Family Member

BIANCA DEMARA Family Member

VANESSA FELIX Self-Advocate

ERIK JENSEN Self-Advocate

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KRISTINA LOPEZ Self-Advocate

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JAMES RIVERA Representative, Arizona Department of Education

KELLY ROBERTS Representative, Northern Arizona University-Institute for Human Development (UCEDD)

VIJETTE SAARI Family Member

MARY SLAUGHTER Family Member

MATEO TREETOP Self-Advocate

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