

# 2021- 2022

# Annual Report

Missouri Developmental  
Disabilities Council



# Table of Contents

<b>3</b>	Words to Know
<b>4</b>	About MODDC
<b>6</b>	Goals
<b>7</b>	DD Network & Funding
<b>9</b>	Equity, Inclusion & Intersectionality
<b>11</b>	Goal 1
<b>14</b>	Goal 2
<b>21</b>	Goal 3
<b>23</b>	Partners in Policymaking
<b>24</b>	Disability Rights Legislative Day
<b>26</b>	Council Members
<b>27</b>	Get Involved

# Words to Know



**Self Advocacy:** When you share your experience with people making decisions. Advocacy is also providing information.



**Self Determination:** The ability to make your own decisions and choices.



**Systems Change:** Changing a process to make someone's life better.



**Competitive and Integrated Employment:** People with disabilities have jobs at the same places as people without disabilities. Employees with disabilities are paid the same as employees without disabilities.

# Impacting Real People



The Missouri Developmental Disabilities Council's (MODDC) mission is to assist individuals, families, and the community to include all people with developmental disabilities (DD) in every aspect of life.

- DD Councils are groups that advocate for change. This change brings more equity to people with developmental disabilities. Each state has a DD Council.
- MODDC is led by and for people with disabilities and their families. The work of the Council is guided by the experiences of individuals and families navigating Missouri systems.
- MODDC works to make processes equal for Missourians with DD and Missourians without DD.
- This is accomplished by funding innovative projects and partnering with universities, non-profits, and state government agencies.





# Welcome

## Message from the Director, Vicky Davidson



Dear Friends,

Through the dedication of MODDC members and hard-working team, we are glad to present you with the annual report, highlighting some of the work accomplished by the Council.

We appreciate the many collaborative relationships that have made the work of the Council possible. Our gratitude extends to our DD Network Partners of UMKC-IHD and Protection and Advocacy as we continue to collaborate on a variety of projects.

We look forward to forging new partnerships throughout the year as we continue to develop

innovative approaches that will have a positive impact for people with developmental disabilities and their families.

## Message from the Council Chair, Animesh Shah

Dear Council Members and fellow citizens,

It is my pleasure to present the annual report for the Missouri Developmental Disabilities Council for the past year. During this period, we have made significant progress towards our mission of assisting the community, through advocacy and policy change, of improving the lives of people with developmental disabilities in our community.

I would like to thank all the members and the staff of this council for the hard work and dedication. Your tireless efforts have helped us to achieve some remarkable outcomes over the past year. We have achieved many successes over the past year, but there is still much work to be done.

I look forward to continuing our efforts in the coming year and beyond. Thank you all for your hard work, dedication, and commitment to improving the lives of people with developmental disabilities in our community.



# Our Goals

The Council developed a state plan with goals that focus on self-advocacy, quality of life across the lifespan, and leading systems change. The plan also places health equity, racial bias, and discrimination at the forefront of its activities to achieve these goals.

1

## **Self-Advocacy Advances Rights and Inclusion**

Effective self-advocacy strategies secure the rights to self-determination and inclusion for people with developmental disabilities.

2

## **Healthy, Educated, and Connected People Thrive**

Missourians with developmental disabilities live in safe communities that enhance the quality of life across the lifespan. This includes, but is not limited to, barrier-free access to transportation, technology, healthcare, education, employment, housing, social services, cultural activities, and recreation.

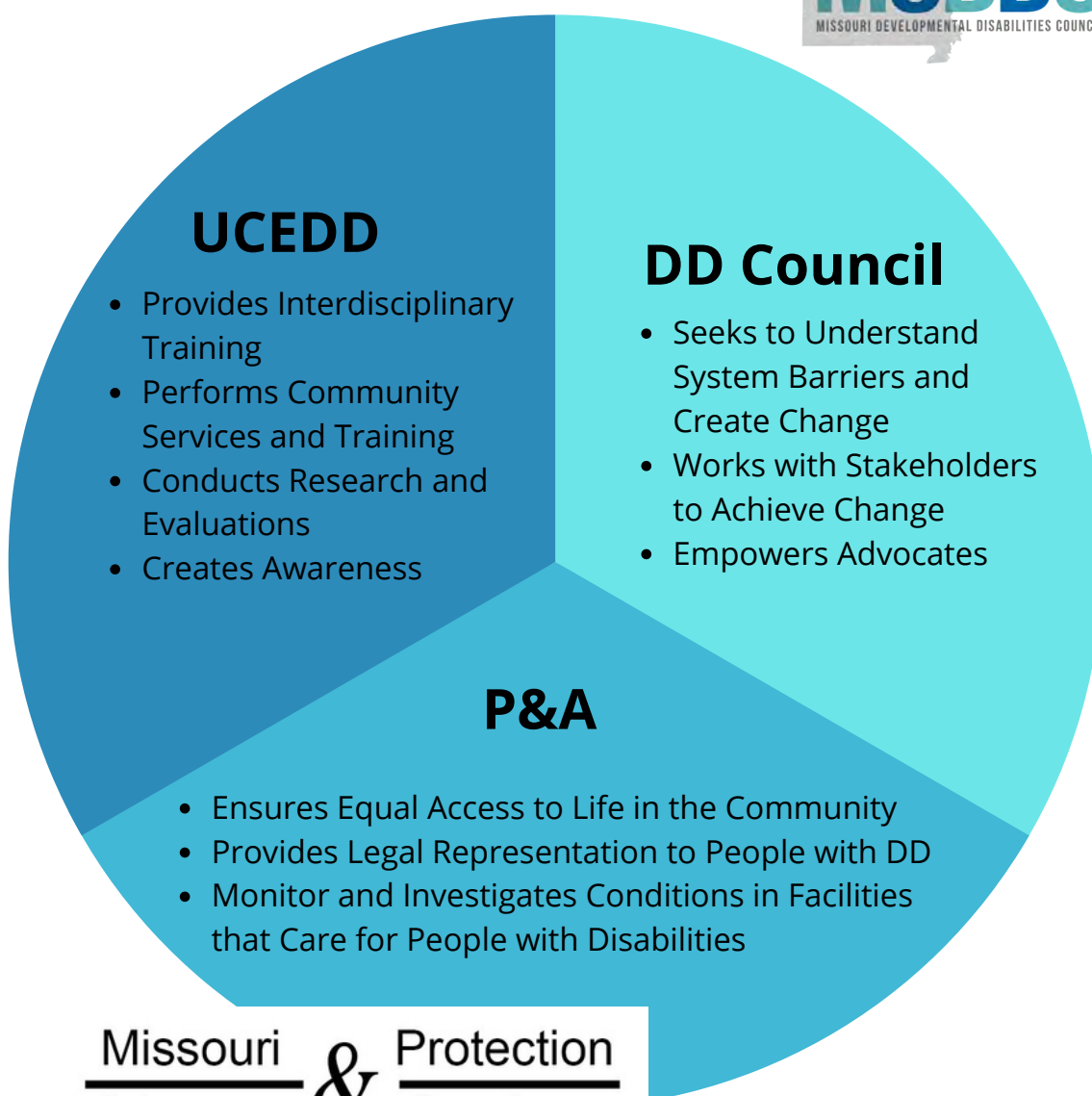
3

## **Informed Leaders Make Change Happen**

People with developmental disabilities and family members guide changes to Missouri laws, policies, and practices by informing decision-makers and educating the public about challenges and solutions.

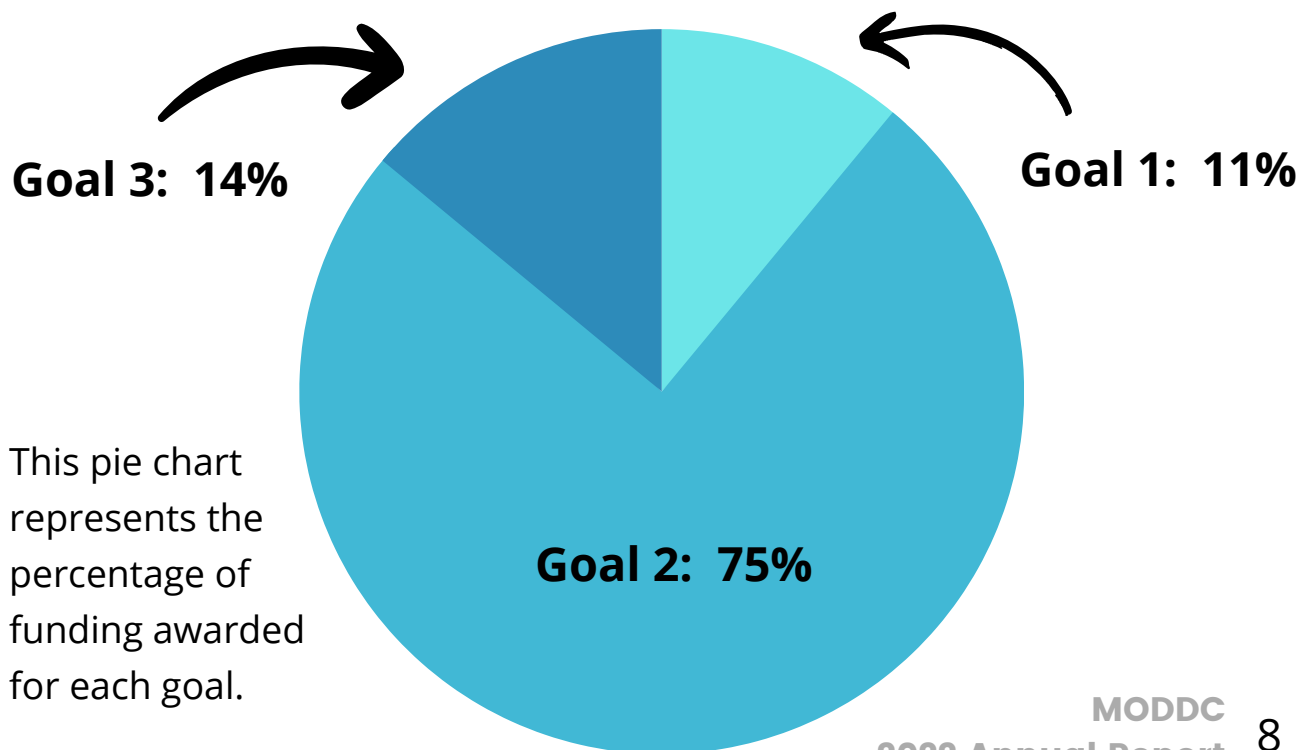
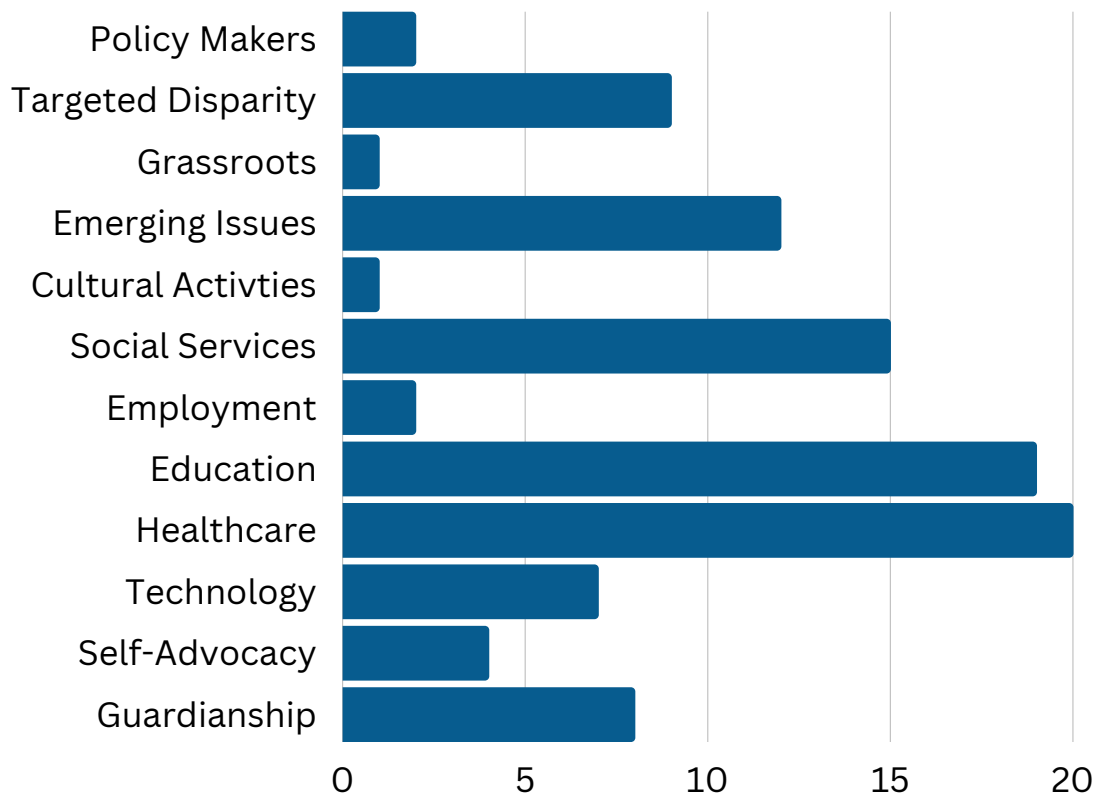
# DD Network

The Council is funded under the Developmental Disabilities Act. The Council works as a partner with University Centers for Excellence and Developmental Disabilities (UCEDDs) and Protection and Advocacy (P&A).



Missouri & Protection  
Advocacy Services

## 2021 – 2022 Funding Awarded



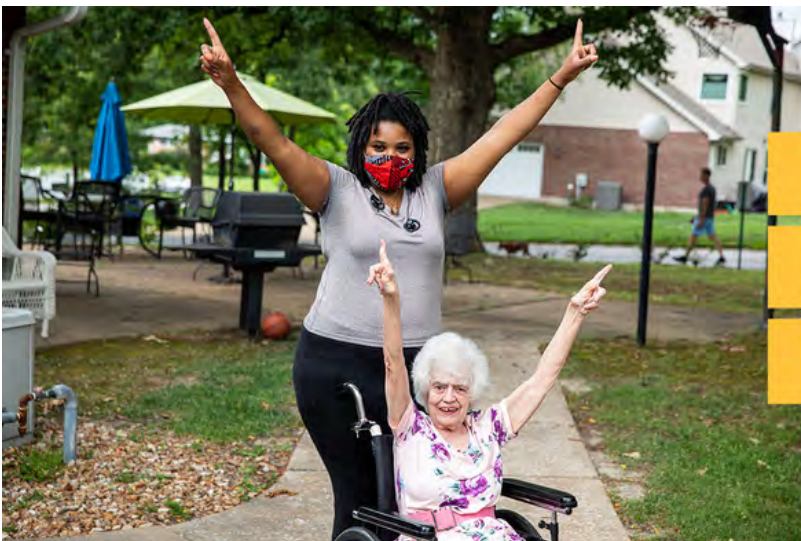


# Equity, Inclusion, and Intersectionality

MODDC embraces disability as a powerful identity group. Disability is a natural part of life and is a valued part of our diversity. People with disabilities intersect all other identity groups. So, MODDC funds projects to create systems change. The change we create impacts all diverse communities of Missouri.

Inclusion and full participation is a matter of social justice for everyone. MODDC works to remove barriers and inequities of the disability experience and the experiences of other groups.

MODDC collaborates with allies and partners, in a common struggle, to create change that empowers everyone.



**THERE IS  
POWER  
IN THE  
UNITY OF  
HUMANITY**

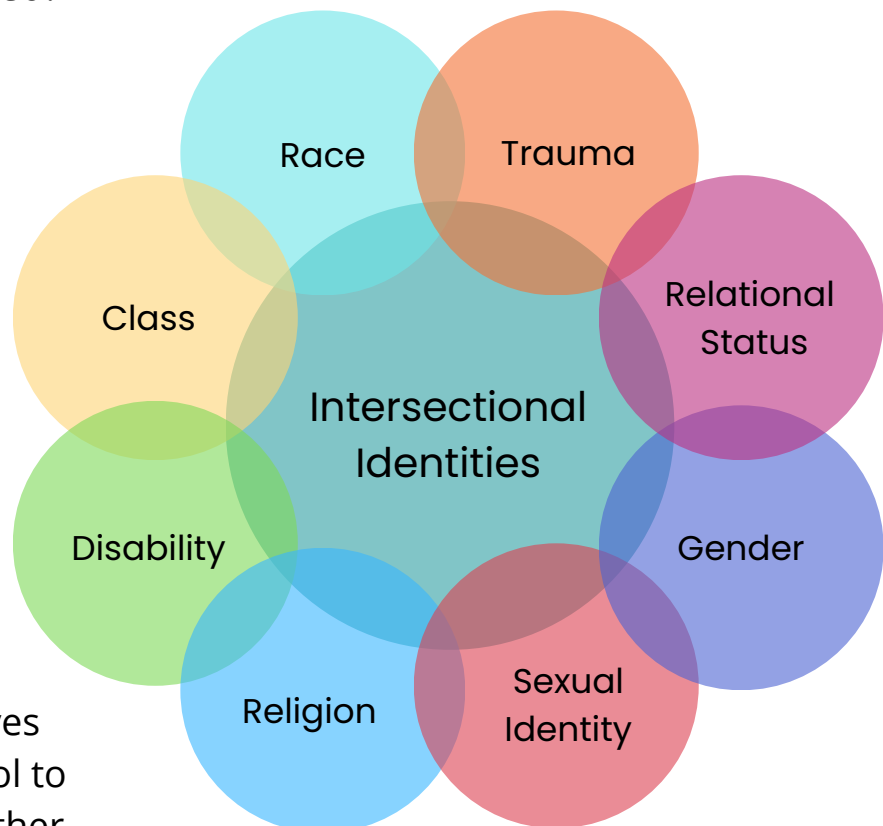
Power in Unity was the theme for Disability Rights Legislative Day 2022.

# Equity, Inclusion, and Intersectionality

Intersectionality consists of the many identities that make us who we are. Knowing and seeking to understand them gives a better picture of who we are.

It is important to remember that:

- Some identities are visible while others are not.
- Characteristics like race, ethnicity, gender, sexual orientation, disability, class, occupation, and others can make up a person's identity.
- These identities have the most impact in the areas in which we are marginalized.



Recognizing intersectionality gives us an important tool to understand each other.

# Goal 1: Self-Advocacy Advances Rights and Inclusion

## People First of Missouri (PFMO)

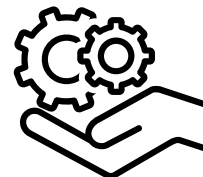
- Self-advocates engage in cross-disability and culturally diverse coalitions.
- 24 PFMO representatives serve on 15 statewide or regional coalitions.
- PFMO Steering Committee Members consist of self-advocate leaders from 20 statewide chapters.
- Through funding to support PFMO Steering Committee, MODDC is engaging and supporting self-advocacy in 5 specific areas: (1) Guardianship and Supported Decision Making, (2) Transportation, (3) Financial Wellness, (4) Self Determination, and (5) Housing.

**24**

PFMO reps.  
serve on

**15**

statewide or  
regional coalitions



**Effective self-advocacy strategies secure the rights to self-determination and inclusion for people with I/DD.**

# Goal 1: Self-Advocacy Advances Rights and Inclusion

## People First of Missouri (PFMO)

- A chapter of PFMO hosted a voting summit for their community. At the event, 2 self-advocates registered to vote and one changed their address. All 15 in-person participants were able to test accessible voting equipment for their county.
- 23 People First Steering Committee Members from across the state met with 16 legislators and advocated for specific topics that were important to them. Topics included, transportation, housing, equal opportunities to marry without losing benefits, guardianship and supported decision making, and the DSP crisis.

**23**

PFMO reps.  
met with

**16**

legislators  
for advocacy

### *People First of Missouri Voting Summit*





# Goal 1: Self-Advocacy Advances Rights and Inclusion

## Alternatives to Guardianship

1. **Consultation and Mediation** - Provide information and resources on alternatives to guardianship.
2. **Training and Education** - Develop and provide training to educators, families, and students throughout the state. Training will be virtual and in-person.

# 88%

of people consulted moved forward with alternatives to guardianship

# 50+

more than 50 people trained and educated on alternatives to guardianship

*Advocates educated policy makers on laws and proposed legislation on adult guardianship at Disability Rights Legislative Day (DRLD) at the Capitol.*





# Goal 2: Healthy, Educated, and Connected People Thrive

## WE CARE – Aging into Adulthood

WE CARE (Wellness, Education, Confidence, Assessment & Recognizing Emergencies): This project, in partnership with the Association on Aging with Developmental Disabilities, will provide the knowledge and skills for people with disabilities and their families to be mutual caregivers. This will prolong a person with I/DD the ability to remain in their natural home.

## Health Disparities Advisory Council

The development of a health advisory council of medical professionals, self-advocates and family members to identify measures of health and well-being of people with I/DD in the state. It reviews data and informs the work of the project.

## Developmental Disabilities Network Project

In partnership with UMKC-IHD, the research project looks at the differences and similarities between people with I/DD and the general population. The project will consider overall health and disease, as well as intersectionality factors like: race, ethnicity, social standing, where they live, and gaps in healthcare for people with I/DD.

## Advocacy through Technology (ATT)

Project grantee Community Partnership of the Ozarks provided increased access to learning and participation in advocacy activities such as Partners in Policymaking, Disability Rights Legislative Day and MODDC meetings. Technology supports increased people with I/DD working in competitive and integrated employment (CIE).

## Goal 2: Healthy, Educated, and Connected People Thrive

### SToPP: Disrupting the School to Prison Pipeline

SToPP: Disrupting the School to Prison Pipeline is a new project that will create trainings for educators and community members to support students in positive, social-emotional learning; rather than relying on punishment. Students should not be referred as often to the juvenile justice system and will more likely experience a more inclusive, equitable education.



Grantee:  
Missouri Juvenile  
Justice Association

### Community Alliance Summit (Planning for Oct. 14, 2023)

Community Alliance Summit (CAS): This project was awarded to Alliance for Leadership, Advancement and Success (ALAS). This is a one-day summit for all individuals to learn from one another and explore opportunities for partnerships and collaboration in our systems change advocacy. Participants will explore the marginalization of persons with disabilities along with other diverse communities. MODDC hopes to learn more about the disability experience and how it intersects other oppressed communities to create change and enhance lives.

***"I am so grateful with all the information and knowledge that has been shared with me in my own language. MODDC cares about people with disabilities and their families. It is so hard to find resources, activities and other help when you don't speak English. Thank you for doing this and being open to diversity. Don't stop doing this work and give more opportunities and help from different backgrounds and different cultures. We are all one, so if we practice cooperation instead of competition we would group all together to live in a better world."***  
***- CAS Anonymous Participant***

# Goal 2: Healthy, Educated, and Connected People Thrive

## Telehealth Dental Visits

- In partnership with the Missouri Coalition for Oral Health, the promising practice of teledentistry was implemented in the first of three pilot programs.
- MO passed into law a Dental Medicaid Rate Increase as part of the state budget - the largest provider rate increase in state history.

*Enable Dental reported dental patients with I/DD voice "a feeling of comfort" when they realize the provider will come to them versus having to go to a clinic.*

## MoLEAP: Lay Education Advocacy Project

- Provides online training and resources to support individuals in advocacy for students with I/DD.



Scan to Learn More

*"We eventually were able to get a Certified Lay Education Advocate. Once the school found out we had an advocate the games stopped... we finally felt supported for the first time in this fight for our child. ... Our child is doing better this year than he has ever done. I cannot say enough as to how MoLEAP has helped us in this journey. Their support, knowledge, and encouragement have helped give us hope when we had none." - MoLEAP Anonymous Participant*

# 25

people with I/DD  
trained on Teledentistry

# 28

family members of  
people with I/DD  
trained on Teledentistry

# 257

people trained online

# 40

hours of mentoring  
provided by Lay Education  
Advocates

## Goal 2: Healthy, Educated, and Connected People Thrive

### First Responder Disability Awareness Training (FRDAT)

- MODDC, in partnership with Niagara University, continued to invest in First Responder Disability Awareness Training to improve response of responders to people with disabilities to address their needs in a safe manner.
- The following law enforcement agencies built the First Responder Disability Awareness Training into their Basic Course:
  - Missouri Sheriff Association
  - Missouri State Highway Patrol
  - Kansas City Police Department
  - Joplin Police Department
  - Blue Ridge Community College

**310**

people participated in disability awareness trainings

**Launched online trainings for Emergency Medical Services (EMS) and Law Enforcement in Missouri.**

### 2022 Disaster Preparedness Survey

- MODDC collected data on how prepared people with disabilities are for a disaster using an online survey, asking about past plans, future plans, and types of disasters.
- The survey informs stakeholders on areas for improvement and the preparedness level of people with disabilities in our state.

**163**

survey respondents

**68%** of respondents have an emergency plan in place.

## Goal 2: Healthy, Educated, and Connected People Thrive

### Sensory Inclusive Pop-Up Vaccination Events and Training

- MODDC Collaborated with our DD Network Partners (P&A and UMKC-IHD), the Department of Health and Senior Services and Kulture City.
- Kulture City provided a sensory inclusive space that was used to hold 10 pop-up vaccination events across the state.

# 109

MO vaccinators participated in online training to provide vaccinations to people with sensory disabilities.

After the pop-up events were held throughout the state, Kulture City and Dr. Julian Maha donated the sensory space to the state. This space will have long-lasting impact for people with sensory disabilities and be used for future vaccination clinics.





## Goal 2: Healthy, Educated, and Connected People Thrive

### Transportation Task Force

- Agencies collaborated to research all transportation funding streams.
- The task force identified overlap and gaps in funding to find opportunities where accessible transportation services can be funded.
- The task force hosted a virtual summit. Summit attendees learned best practices from nationwide experts to build statewide and regional frameworks for transportation.

**65**

task force members

**132**

people registered for the annual summit

### Disability Benefits 101 (DB101)

- DB101 is an estimation tool that shows a person how benefits are affected when working in competitive and integrated employment.
- Visit **[www.MO.DB101.org](http://www.MO.DB101.org)** to learn more!

**500**

users visit the DB101 website on average per month

**48** family members of people with disabilities were trained on DB101 and reported they planned to use DB101. This was 100% of people who responded to the survey.



Scan to Learn More

## Goal 2: Healthy, Educated, and Connected People Thrive

### Family to Family (F2F)

- Provides people with I/DD and their families with the information, skills, opportunities, and support that lead to independence, productivity, self-determination, integration and inclusion.

**7,000**

sessions on  
MO F2F website

*"When I called F2F you were just what I needed, you LISTENED, you were compassionate, gave me guidance and followed up to be sure my ability to secure my family's needs resulting in positive plans and movement for my family. I don't know what I would have done without MoF2F's Life Navigator!" - F2F Anonymous Participant*



Scan to Learn More

### MoABLE Savings Accounts

- The Missouri Achieving a Better Life Experience (MoABLE) savings and investment program provides greater independence and financial security for people with disabilities.
- People with disabilities and their families can save and invest, tax-free, without losing their federal benefits like Supplemental Security Income (SSI) and Medicaid.

**2,850**

active accounts

*"My wife and I setup a MO-ABLE account for our grown son. It gave us peace of mind that we could save for his future and be sure his needs were taken care of in the immediate timeframe, as well as when we are no longer here. To be able to make those long term plans was reassuring and it gave us confidence that he would be taken care of. It has a tremendous impact for our family." - Former Missouri State Senator David Pearce*

# Goal 3: Informed Leaders Make Change Happen

## Supporting Language Access in Schools

- This project was awarded to the National Association of Educational Translators and Interpreters of Spoken Languages (NAETISL).
- This project will improve language access in schools for families and students with Spanish and other language backgrounds; especially those with developmental disabilities.
- This will include access to interpreters at important meetings, translated documents, training for school leaders, and more.

NAETISL



## Learning with MODDC

- Learning with MODDC is a free, live, and interactive webinar series that covered solutions to challenges and barriers for people with disabilities.

Guest Speaker: J.R. Reed



# 278

people registered and were provided follow up recordings and resources

STORY  
Muse★

Guest Speaker:  
Shannon M. Turner



# Goal 3: Informed Leaders Make Change Happen

## Educational Voting Videos

- The project created short videos of the 5 most used types of accessible voting equipment in the state of Missouri.
- The videos, with self-advocates as actors, are meant to help combat lack of confidence by poll workers and voters in using accessible voting equipment. Videos were produced in English and Spanish.

# 519

video views as of 9/30/22.



Scan the QR Code  
or visit  
[moddcouncil.org/voting](https://moddcouncil.org/voting)



# Partners in Policymaking

Partners in Policymaking is a national leadership training program for adults with I/DD and parents of children with I/DD.

20

Partners Graduates were trained on leadership skills and techniques to help develop positive partnerships. These partnerships include elected officials, school personnel, and other individuals who make policy decisions about services that participants and their family use.

***"Before Partners, I never imagined I could go to the state capitol and affect state legislation just by telling my story Now, I feel empowered to work with my school board, city council, elected officials, and grassroots organizations to protect the rights of people with disabilities." - Partners Graduate***

***"I will help my neighbors vote and work to increase accessible transportation and try to create state legislation to require schools to give more accessible info to parents." - Partners Graduate***

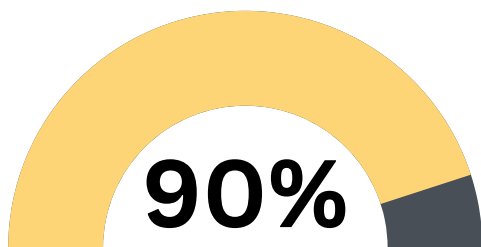
***"I love the knowledge and practical applications for living my best life in the ID/DD world. I really love the idea that it just takes one voice to make a change and how to best advocate and fight for things you believe in through the legal process." - Partners Graduate***

***"I went into this program not understanding my voice was important, and thinking my experience was isolated. To realize I am not alone in the struggle and our experience is not unique- that was very empowering, and led me to understand my voice is a representation of so many in the disability community." - Partners Graduate***

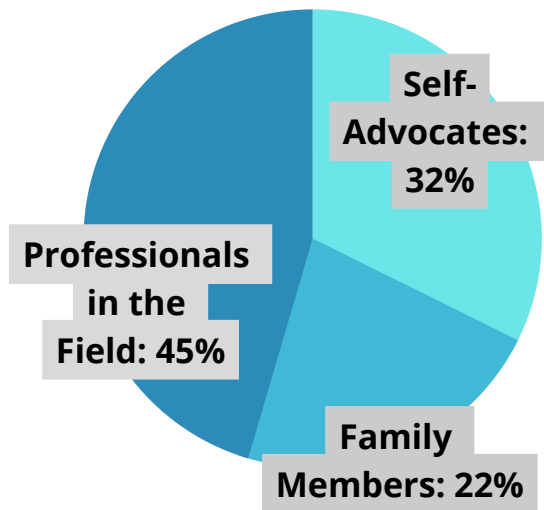


# Disability Rights Legislative Day

On March 9th, 2022, hundreds of self advocates and families attended Disability Rights Legislative Day (DRLD) in-person at Missouri's Capitol and virtually to show Power In Unity.



90% of post-event survey respondents indicated they were **"Very Likely"** to advocate for disability rights as a result of information received from DRLD.



***"I appreciated the opportunity to participate in DRLD 2022 in a virtual manner - this made participating in both the rally and afternoon sessions with policymakers very accessible. I think it would be beneficial to continue offering the virtual component of DRLD."*** - DRLD Participant



**Scan the QR Code  
for a recap of the day!**

***"The live rally on Youtube was a great option for those unable to attend in person! The legislator mixers after the rally had good participation and allowed for real concerns to be heard."*** - DRLD Participant

MODDC provided a grant to provide a high quality, accessible, virtual experience for those across the state that wished to participate in DRLD but were unable to do so in person.



*People First of Missouri Voting Summit*



*People First of Missouri Voting Summit*



*Disability Rights  
Legislative Day*



*Real Voices Real Choices Conference*

# Council Members

- **Animesh Shah:** Parent Advocate, Council Chair
- **Mike Abel:** University Centers for Excellence in Developmental Disabilities Representative
- **Rachel Baskerville:** Self-Advocate
- **Kennimarie Bell:** Parent Advocate
- **Lisa Crandall:** Title V: Maternal and Child Health Representative
- **Cathy Enfield:** Self-Advocate
- **Jennifer "Allie" Friedrich:** Self-Advocate
- **Allen Haas:** Title XIX (Medicaid) Representative
- **Stacie Holt:** Department of Elementary and Secondary Education
- **Sangyeal Lee:** Parent Advocate
- **Lisa Liss:** Parent Advocate
- **Jelani Logan:** Protection and Advocacy Agency Representative
- **Todd Mayfield:** Parent Advocate
- **Missy McGaw:** Rehabilitation Act Agency Representative
- **Jordanna McLeod:** Division of Senior and Disability Services Representative
- **Lisa Nothaus:** Division of Developmental Disabilities Representative
- **Kit Stahlberg:** Self-Advocate
- **Diana Willard:** Self-Advocate, Chair Elect
- **Sharon Williams:** Parent Advocate

The Council would like to acknowledge the membership of Susan Eckles (Protection and Advocacy Agency Representative), Mike Frazier (Workshop Representative), Allen Nelson (Self-Advocate) and Dana Welch (Department of Elementary and Secondary Education Representative) whose service ended during the 2022 grant year.

## Systems Change Required

There are many ways for you to get involved with MODDC:

- Apply for a grant
- Connect with a project
- Attend a training
- Apply for Partners in Policymaking
- Become a Council member
- Subscribe to our email at [MODDCouncil.org/subscribe](https://MODDCouncil.org/subscribe)

***Thank you for your support of MODDC  
and your interest in enhancing the lives  
of people with disabilities.***

**We want to be a  
resource for you.**

Consider us your DD resource  
in the community.

email: [moddc@moddcouncil.org](mailto:moddc@moddcouncil.org)

call: 573-751-8611

**[www.MODDCouncil.org](https://www.MODDCouncil.org)**







*Disability Rights Legislative Day*



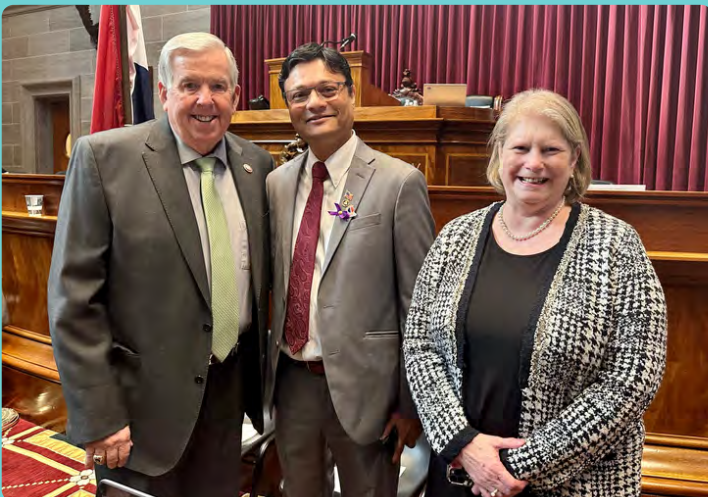
*Disability Rights Legislative Day*



*Take Your Legislator to Work Day*



*Disability Rights Legislative Day*



*Inauguration of State Treasurer  
Vivek Malek*



*Disability Policy Seminar*