



Who is MODDC?

Missouri Developmental Disabilities Council

- 23 Member Council
 - Self-Advocates,
 - Families,
 - State Departments
- Appointed by the Governor



Mission

**To assist individuals, families,
and the community to include
all people with developmental
disabilities (DD)
in every aspect of life.**

Missouri Developmental Disabilities Council | MODDCouncil.org



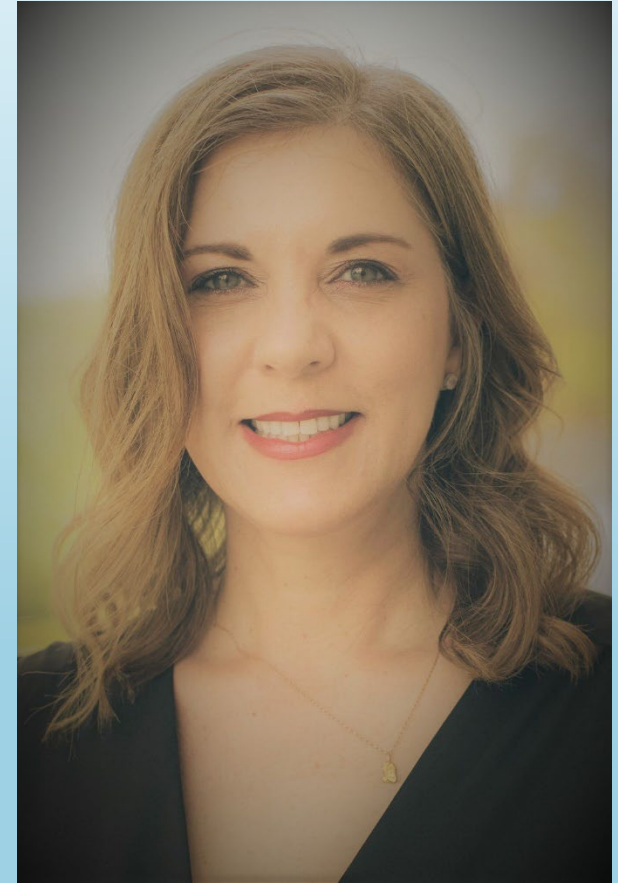
Partners in Policymaking

Training leaders for positive, long-lasting change

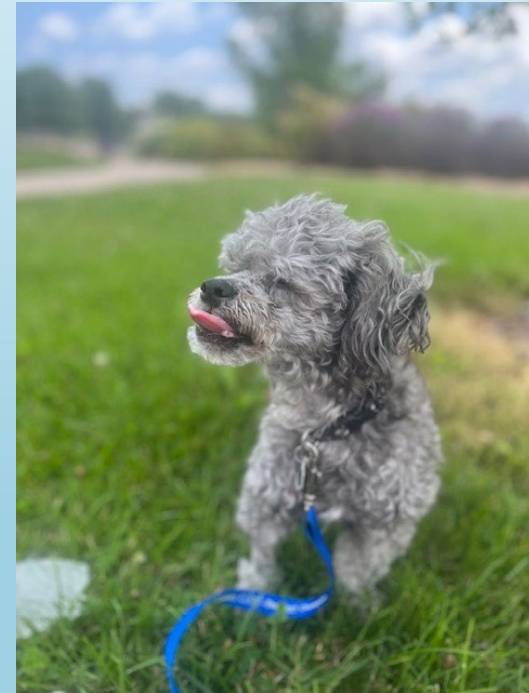
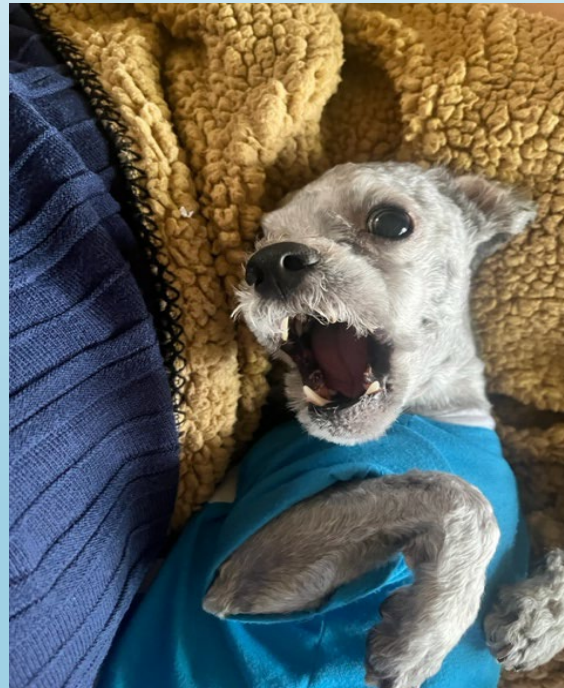
- Created by the Minnesota Governor's Council on Developmental Disabilities in 1987.
- A leadership training program for adults with disabilities and parents of young children with developmental disabilities.
- Over 400 Partners Graduates in Missouri

Project Coordinator – Stacy Morse

- Employment, transportation, & Partners in Policymaking
- Chief of Staff to Missouri State Senator
- Administrator of Virtual Education
- 5th grade teacher
- MA in Human Development and Family Studies.
 - Public Policy and Administration
- Adjunct Professor at MU
 - Advocacy for Children and Families
- Children's author



Maxie



Administrative Coordinator – Sara Williamson

- Former Family Support Coordinator at National Guard
- Sets up Zoom meetings, posts recordings
- Sends accessible documents
- Mails resources
- Manages printing and book ordering



Partners in Policymaking Leadership Opportunity

- Details about the program.
- Who can participate.
- When it is held.
- How to apply.
- Partners Graduates feedback
- Graduates leadership
- <https://moddcouncil.org/partners-in-policymaking/>

Purpose

- Teach best practices and competencies needed to influence public policy
- Develop partnerships between people who need and use services and those who are in a position to make policies and laws.

What is Partners in Policymaking?

Learn how to create change, not about how to “get more services”.

Systems and policies have not served people with disabilities and their families.

- FREE online course
- National speakers
- Held in Zoom
- Material in Canvas
- Optional in-person session at State Capitol March 13th

What is the Goal?

Goal: to create a group of people who can support one another and bring a range of talents to their state.

An organized way to improve the way things are currently done by educating and influencing.

Topics

- History of Disability
- Disability Movements
- Inclusive Education
- Employment
- Housing
- Person-Centered Planning
- Positive Behavior Supports

Topics

- State/Federal Policy and Legislative Issues and the Process
- Supported Decision Making
- Guardianship
- Assistive Technologies
- Remote Supports
- Victimization
- Sexuality
- Emergency Preparedness
- Community Organizing and Coalition Building

Expectations

- Attend virtually Between January and September
- Complete homework assignments
 - Letter to legislator
 - Reflect on short film
 - Find local resources/ordinances
- Complete a major project
- Complete evaluation forms
- Post-graduation surveys

Who can be a “Partner?”

- Adults with intellectual or developmental disabilities (I/DD)
- Parents/guardians of children 14 years old and younger with I/DD

Examples of DD

- ADHD
- Autism spectrum disorder
- Cerebral palsy
- Hearing loss
- Intellectual disability
- Learning disability
- Vision impairment

Schedule (once per month)

Thursday	6:00 pm - 9:00 pm
Friday	12:00 pm - 5:00 pm
Saturday	8:30 am - 2:30 pm

When Does Partners Meet?

- **Fridays: 12:00 noon to 5:00 p.m.**
- **Saturdays: 8:30 a.m. to 2:30 p.m.**

- January 12 & 13
- February 2 & 3
- March 1, 2
- March 13: Disability Rights Legislative Day
- April 5 & 6
- May 3 & 4
- June 7 & 8
- July 12 & 13
- August 2 & 3
- September 6 & 7

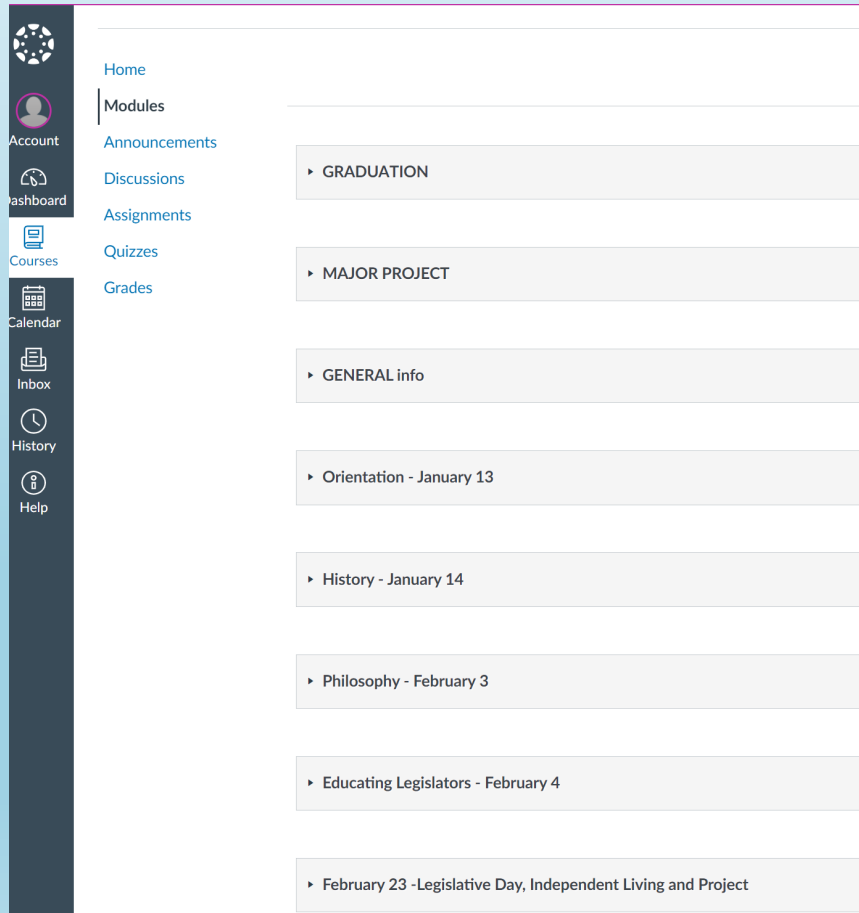
When Does Partners Meet?

- **Thursdays: 6:00 p.m. to 9:00 p.m.**
- February 22
- March 28
- April 25
- May 23
- June 27
- July 25
- August 22

Where does Partners Meet?


- ZOOM
- Same link for every class
- Building skills as an advocate
- Trainings and advocacy done in Zoom


Canvas – Learning Management System





- Materials
- Speaker presentations
- Resources
- Quizzes
- Announcements
- Homework
- Email
- Recordings


Canvas Module






Account



Dashboard


Courses


Calendar


Inbox


History


Help

Home

Modules









Announcements

Discussions

Assignments

Quizzes

Grades

▼ History - January 14
 1. Agenda January 14
 Speaker - Colleen Wieck
 Our History Part 1 Accessible FINAL.pdf
 Our History Part II 1900-Today Accessible FINAL.pdf
 History and Philosophy materials
 Ed Roberts Segment
 Speaker Poll - Colleen Wieck 1 pts
 PARTNERS IN POLICYMAKING2023.ppt

Link to Partner's Application

[Partners in Policymaking Application](#)

Deadline is November 1, 2023.

Application Questions

- Why you think you would be a good candidate?
- Why are you interested?
- What experience do you have advocating for people with I/DD?
- How did you learn about Partners in Policymaking?
- What services are you or your child currently receiving?
 - (ie. First Steps, School Services, Respite Care, Support Coordination, Employment Services, Housing, Attendant Care, etc.)
- List two references

Tech Support for Partners

- Through a grant with Community Partnership of the Ozarks (CPO)
 - Francine and Nasser
- Hotspots
- Ipad
- Tech phone and email support
- Saving documents
- Using Zoom or Canvas

Major Project Examples

Guide to Autism Diagnosis



Parent Concerns

Address any concerns regarding development with your child's pediatrician such as:

- poor eye contact,
- lack of speech,
- not responding when called, etc.

Follow your instincts and don't be dismissed with the "let's wait and see". Ask for a referral for an autism evaluation.

Autism Diagnosis

The evaluation for an autism diagnosis includes:

- a parent interview regarding development stages,
- parent concerns,
- observation of the child at play, and
- child interacting with the evaluator.

The diagnosis can be obtained from a neurologist, developmental pediatrician, or a psychologist.



Finding Supports

After receiving the diagnosis of autism, determine what supports your child needs and which services your child will benefit from the most. Discuss your developmental concerns with your pediatrician and ask for a referral or recommendation to an appropriate provider that can provide a treatment plan to address those concerns.

Typical therapies are

1. speech & language,
2. behavioral therapy (ABA),
3. occupational therapy,
4. food therapy, and
5. physical therapy.

Working with Schools

Age 0-3

A child ages 0-3 qualifies for Missouri First Steps which is an early intervention program for children with developmental delays. Through this program a child can receive speech therapy, occupational therapy, and behavioral therapy. To learn more visit www.mofirststeps.com.

Age 3+

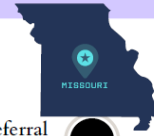
A diagnosis for a child over age 3 then contact your school (pre-school, elementary, etc) regarding obtaining an Individualized education plan (IEP) to determine what type of supports and services your child can receive at school to be successful in the general education setting.



*While on a wait list for an autism diagnosis you can seek out therapies to support your child.

*Find a support group in person or online.

The Road to Special Education



Request for Initial Evaluation and Referral

- Express concerns
- Request qualification for specialized education under any of the disability categories under IDEA
- School district has **30** days to consider request and decide if a disability is suspected



If disability is not suspected, the district will provide a Notice of Action (NOA) which explains the reason for declining to test.

1

Review of Existing Data (RED)

- If disability is suspected, current information is gathered and assessed by an IEP team
- Used to get a full understanding of the child's strengths/challenges and determine if other evaluation/data is needed to make a decision about special education

2

Evaluation

- NOA informs you that the school wants to test your child to help decide eligibility, written permission required
- Testing must identify all educational needs & describe abilities
- School must administer testing and meet with parents to review results within **60** days of receiving permission

3

Eligibility Conference

- Evaluation results are shared including what tests were used, why, scoring, and what the scores mean



Students found not eligible will receive NOA explaining the reasons and a copy of the report

4

Eligibility

- NOA for initial services and a copy of the evaluation process provided
- Your child is a "child with a disability as defined by IDEA AND is in need of special education services because of the disability
- School district must meet with IEP team within **30** days

5

If you disagree with the results or conclusions, you have the right to request an Independent Educational Evaluation (IEE)

IEP Meeting

- Individualized Education Plan
- Must be based on child's unique needs
- SMART goals developed and measurement and expectations for success are defined

6

The IEP team must review and revise IEP at least once a year to decide whether the yearly goals are being met, but can be reviewed and changed more often if you or school staff asks for a review



Creating a Nonprofit 501(c)(3) Organization

A Step-by-Step Guide

By: Elizabeth T Bennett
Partners in Policymaking
Major Project 2023

Major Project



Concept Map
By Colletta Daniels

Partners in
Policymaking 2023

1 Primary Goal

The initial goal was to improve the practices and policies around the inclusive education of K-12 students with developmental disabilities in St. Charles and St. Louis County. This was based on Dr. Paul Kluth and Patrick Schwarz' presentations.

2 Research

I researched several state and local agencies and services that aligned to my major project that could be done in my timeline. This initially included MPACT and LEAP.



I was initially excited by the idea of serving on the policy committee of my son's school district - Francis Howell (FHSD), unfortunately, the Policy Committee is exclusive to staff members. Instead I joined the PTA.

Partners in Policymaking 2023

Made with PosterMyWall.com

Attempted Projects

- ❑ FHSD Policy Committee
- ❑ SEAP
- ❑ St. Louis ARC
- ❑ LASE

I unsuccessfully attempted to work in conjunction with these groups as a member or volunteer in order to fulfill my goal.

I was inspired by Bryon Koster's (MO-PA) presentation about disability rights and high-level advocacy. I applied to be on the Missouri Special Education Advisory Panel (SEAP) and I was not selected. I moved on to St. Louis ARC. I completed orientation and background check to be a ARC Volunteer. However, after reviewing the calendar of volunteer activities, I realized that they would not allow for any system level change for children with developmental disabilities. I recalibrated and began the Lay Educational Advocate Program coursework. I completed that and applied to be a part of the the Missouri Educational Advocacy. As of August 2023, I am awaiting their response. As an ongoing project, I am in conversation with Lutheran Association for Special Education about better supports and programming for their students with developmental disabilities.

3 Finding a Path

After much reflection and consultation with Stacy Morse (Partners Program Coordinator), I realized that I had many ideas but no target audience and no clear end goal. I wanted to impact system level change but I was attempting it too broadly. Therefore, I narrowed it down to providing a support for parents/caregivers.

4 FACT SHEET



I decided to develop a one page fact sheet with hyperlinks that guides parents/caregivers to state and local advocacy services.

PARENT IEP GUIDE

Scan the QR codes with your phone's camera for more information.

Acronyms:

IEP - Individualized Education Program (the plan for how your kid will receive special education)

FAPE - Free Appropriate Public Education (Your kid's needs should be met, & your kid should benefit from school.)

LRE - Least Restrictive Environment (**Inclusion is the law!** Your kid should be in the regular classroom as much as possible.)

LEA - Local Education Agency (your school district)

Learn more acronyms at ...



Know Your Rights:

* **You are an important part of the IEP team!** The school must try to schedule the meeting when you can attend.

* You can bring people with you to every meeting (friends, family, doctor, therapist, free MPACT advocate, paid advocate, etc.)!

* You can put whatever you want in the Parent Concerns section of the IEP! Bring copies to each IEP meeting.

* You can record the audio of every meeting (but not video)!

* There is no time limit for an IEP meeting. Don't feel rushed, but be willing to schedule multiple meetings if needed.

* The IEP team must meet at least once a year, but you can ask for a meeting at any time.

Prepare for the meeting:

- Ask someone to come with you.

- Learn the parts of the IEP.



- Fill out an IEP Preparation Form.



- Write your Parent Concerns **before** the meeting.

- Get an audio (sound) recording app on your phone.

- Start an IEP binder or folder.



Learn more of your rights:



Need help?



SSD FACE
Free support & workshops
ssdmo.org/face
314-989-8460



MPACT
Get a free advocate & go to free trainings
MissouriParentsAct.org
800-743-7634



MOF2F
Free support & resources
MoFamilytoFamily.org
800-444-0821

created by Lindsay K. Woods
MO Partners in Policymaking 2022



Partners in Policymaking Final Project Hospice Volunteer

BY ANDREA WEISENBORN

Post Graduation....

- Annual survey of new advocacy
- Attend Disability Rights Legislative Day:
 - [DRLD 2023](#)
- [Signup for MODDC News](#)
- Attend training webinars
- Partners Graduate Facebook page
- Partners Graduate Listserve

Employment Services for Competitive Integrated Employment

- Employment First Law, Representative Melanie Stinnett
- Pre-Employment Transition Services
- Vocational Rehab
- Rehabilitation Services for the Blind
- Missouri Job Centers
- Employment Services

**The Partners in Policymaking
Employment Summit**
Competitive Integrated Employment

THIS WED. AND THURS.

Support Services for Competitive Integrated Employment

- Waiver Services
- SB40 Support Services for Case Management
- Services from the Department of Social Services
- Job Accommodation Network (JAN)
- Centers for Independent Living
- Benefits Planning

What are Missouri Partners Graduates Doing?

- Ambassador, and the Community Relations Director for the Autism Alliance of NWMO.
- Hired as an Inclusion Educator with a provider agency.
 - Co-presented at the Charting the LifeCourse Showcase.
- Working with federal legislators to get a MO state bill passed as a national law; the Autism and Health Care Bill (“Therapy for All”).
 - If passed, the bill would allow people with Autism and maybe other DD to receive more therapies thru their private insurance.
- Elected as the next President of MO AAIDD (American Association on Intellectual and Developmental Disabilities).

What are Missouri Partners Graduates Doing?

- Led the effort to pass inclusive hiring legislation within the City of Kansas City's workforce; making Kansas City only the 2nd in the nation to adopt inclusive practices. She also served as the MO APSE President.
- Supported her 1st grade daughter with a disability to advocate for an inclusive playground at her school. Her school obtained a parks and recreation outreach grant to update the school playground so she could play with her classmates on the school playground while using her wheelchair. Their advocacy, together, made the evening TV news.

What are Missouri Partners Graduates Doing??

- Started her own advocacy business. She launched her own website and registered her new business with the state.
- Received grant funding for \$25,000 to build an inclusive playground in her local community. It will be named, “Better Together Playground”.
- Earned doctorate in Educational Leadership and passed with distinction.
 - Dissertation: “Acts of Resilience and Resistance: Persistence by Autistic College Students”.

Partner's Experience

MO Partners Graduate Advocating in Washington D.C.

"I will not keep all
this knowledge to
myself! I plan on
telling everyone
in my path!"

ABOUT THE PAC

MEET THE EXECUTIVE COMMITTEE



Rebecca Flieg, President

Rebecca Flieg has been announced as the PAC President. She holds a BA in English Literature from the University of Missouri. Flieg is not only a graduate of the Missouri Department of Developmental Disabilities Partners In Policymaking program but also actively participates as a presenter within the program.

Flieg 's passion lies in advocating for systemic changes that promote inclusivity across all settings for individuals with disabilities. She is deeply committed to supporting legislative efforts aimed at enhancing protection, fostering independence, and providing improved community supports for those with disabilities.

What drives Flieg 's advocacy efforts is her admiration for adult self-advocates who seamlessly integrate as valuable members of their communities. This admiration fuels her determination to push for greater inclusion and the implementation of contemporary self-determination models for students with disabilities within the Rockwood school district. This district is also where she resides, together with her husband of 18 years and their two children.

Graduate with Governor, Senator,
Representative at bill signing.



How has Partners changed your life?

- I improved my **confidence** to advocate for myself and others.
- I know my **rights** better than I did before the course.
- I have **resources** to help me.
- I made great **connections**.

How has Partners changed your life?

- PIP has changed my life to become a better advocate in having a greater accessibility and knowledge in the many various resources locally and nationally, as well as making great connections. I'm left in "Awe" on the many presenters that were given to us and their in-depth knowledge they brought to the table. Things I never even knew were out there and what is being done, makes me have hope and know that we are going in the right directions. **I know change takes time but I feel encouraged and hopeful in that.**

How has Partners changed your life?

- I learned so much, but will also be a better advocate after interactions with presenters and fellow partners!!
- I can say Partners change my life to learn about more resources for my children, learning my rights within my city and **disability laws** and **changes that still need to be made change**. I will also say I am a better advocate than I every was before, and I know how to actually use my voice and a more appropriate way. I also got to meet and **network** with a lot of other parents in my same situation, which gave me more hope with my own situation. **Being reminded that Self-Care is important for myself too.**

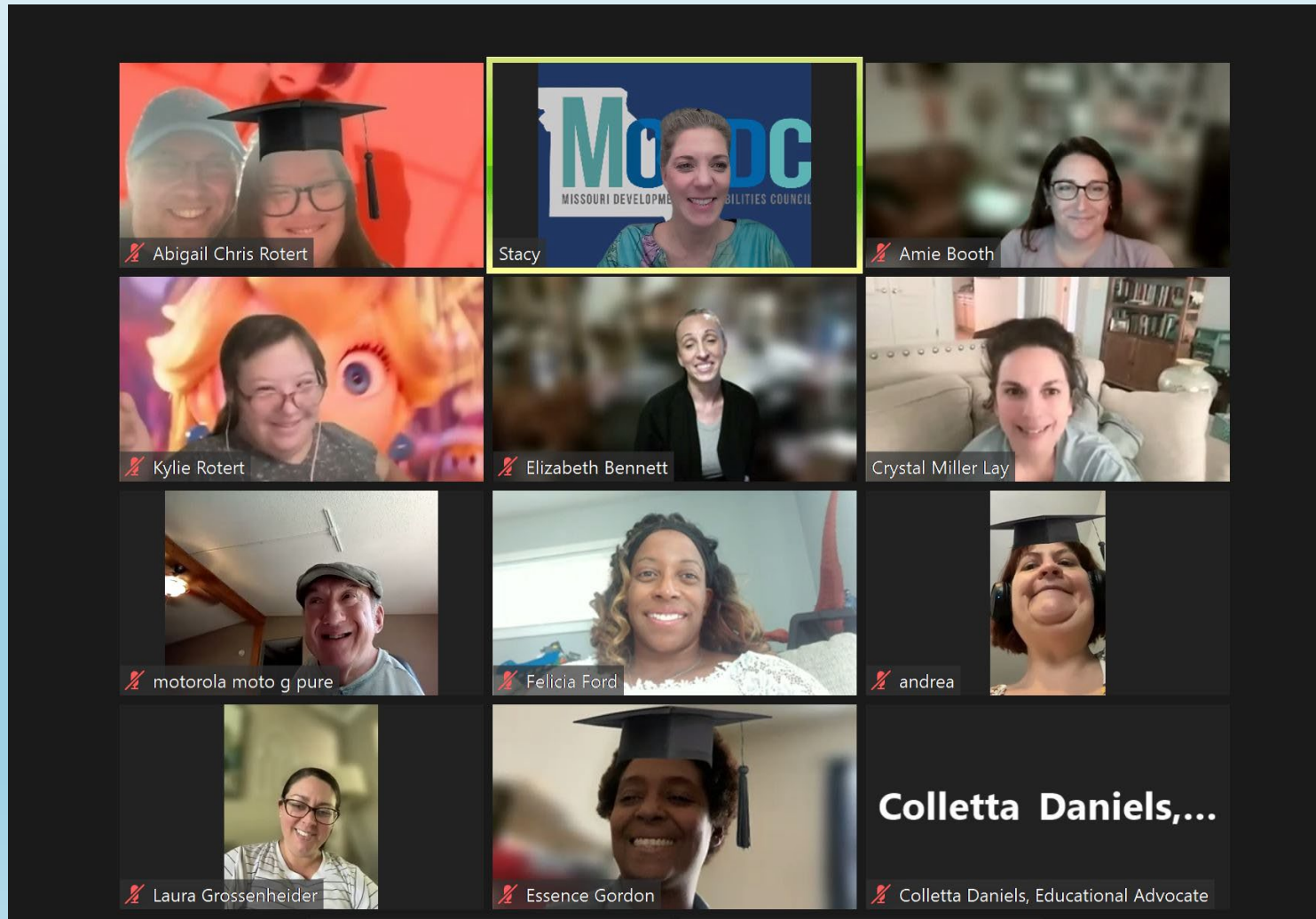
How has Partners changed your life?

- I **gained confidence** in serving as a better advocate for myself and others. I have better knowledge about some of the policies that have to do with people disabilities and the history.
- I'm a better advocate for my family members with special needs and for the teens with autism I help. I've made new connections and learned so much I had no idea existed before this program. I'm **incredibly grateful**.

How has Partners changed your life?

- I have grown my advocacy skills, especially regarding Special Education law. My confidence and networking has also increased and helped me **stand up for families** and teens in our youth ministry who have been hurt by leaders' actions and **UN-inclusive programming**. I also have a full-time job, now, in disability ministry, something I dreamt of but never felt fully qualified.
- **I loved taking this course!** I have learned so much. I have learned to be a better advocate and about the history of advocacy for people with disabilities.
- A better advocate & made **new friends**.

Class of 2023



Partners in Policymaking



Missouri Developmental Disabilities Council

- Stacy Morse
- Program Coordinator
- Phone: 573-522-3613
- Smorse@ModdCouncil.org