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.
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
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<th>Time</th>
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<tr>
<td>Thursday</td>
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<tr>
<td>Friday</td>
<td>12:00 pm - 5:00 pm</td>
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<tr>
<td>Saturday</td>
<td>8:30 am - 2:30 pm</td>
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Schedule
(once per month)
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

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<td>Speaker - Colleen Wieck</td>
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<td>PARTNERS IN POLICYMAKING2023.ppt</td>
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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 these concerns.
Typical therapies are:
1. speech and language,
2. behavioural therapy (RBT),
3. occupational therapy,
4. 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 behavioural 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 or at school to be successful in the general education setting.

www.freddawfordfamilyfoundation.org
The Road to Special Education

1. Request for Initial Evaluation and Referral
   - Expert's concerns
   - Request for special education services under IDEA
   - District has 30 days to consider request and decide if a disability is suspected
   - If disability is suspected, District will provide a Notice of Initial Assessment (NIA) and explain the reason for declining to test

2. Review of Existing Data (RED)
   - If disability is suspected, consult information gathered by an IEP team
   - Used to get a full understanding of the child's strengths and challenges and determine if further evaluations are needed to make a decision about special education

3. Evaluation
   - NIA informs you that the school wishes to test your child to help determine eligibility; written permission required
   - Testing must identify all educational needs & describe abilities
   - School must administer testing and meet with parents to review results within 40 days of receiving permission

4. Eligibility Conference
   - Evaluation results are shared including what tests were used, why scoring, and what the scores mean
   - Parent is given an opportunity to question the results and vote on the IEP
   - NIA includes eligibility for initial services and a copy of the evaluation process provided
   - Child is labeled 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. IEP Meeting
   - Individualized Education Plan
   - Must be based on child's unique needs
   - SMART goals developed to ensure and expectations for success are defined

6. The IEP team must review and revise IEP at least once a year to determine whether the yearly goals are being met, but can be reviewed and changed more often if you or school staff need to do a review
Major Project
Concept Map
By Colletta Daniels

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 Kloth 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.

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.

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 Bryson 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 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.
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.

Need help?

SSD FACE
Free support & workshops
info@fface.org ace
314-689-9660

MPACT
Get a free advocate & go to free trainings
MassachusettsAccep
800-763-7834

MDVF
Free support & resources
MDVF/UniqueIdFamily.org
800-444-0827

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:

created by Lindsey K. Woods
MD 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.
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