

Finding Your Voice:

**Use your Personal Strengths to Build your Advocacy Skills
for People with Disabilities and their Families**

Circles of Life Conference -- May 8, 2025
Cheryl Funmaker, Kody Funmaker, Molly Cooney

Overview

- Introductions
- Self Advocacy
 - Kody's story
- Individual Advocacy
 - Advocacy styles
- Systems Advocacy
 - Serving on boards and committees
- Building Advocacy Skills



Japresanaca'tiga
Cheryl Funmaker Ph.D.

- *Ho-Chunk Tribal member
- *American Indian Educator
- *Blessed with family

Kody Funmaker

- Bachelor Science Graduate of Cutting Edge Edgewood College
- Washington D.C. advocacy day representative: White House Disability Pride and 34th Anniversary of the Americans with Disabilities Act
- LOV, Inc. family events participant
- Enjoys living in Madison with 2 roommates with independent living supports
- Works at Feist as a job coach

Molly Cooney -- Wisconsin Board for People with Developmental Disabilities

❖ We are a statewide advocacy and innovation organization

❖ We aim to:

- Identify most pressing needs of people with developmental disabilities and their families
- Develop innovative and cost-effective ways to meet these needs
- Advocate for positive change

❖ [BPDD website](#); [Subscribe here](#)



WISCONSIN BOARD FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES

Types of Advocacy

- Self-Advocacy: The ability to speak up for yourself and the things that are important to you.
- Individual advocacy: Supporting or speaking out for a cause, idea, group or person.
- Systems advocacy: Influencing or changing rules, policies or laws that impact how people live their lives

Self-Advocacy

Understanding your strengths and needs, identifying your personal goals, knowing your legal rights and responsibilities, and communicating these to others.

Self-Determination YouTube Channel



Check out the complete "[Know your Rights](#)" video playlist on the channel.

Kody's Experience: It took me awhile to find my voice

We need to talk

- How I came to be brave...it took a lot of encouragement and confidence to do it. You kind of just have to do it. People want you to talk. If you don't talk, people will be like, "I guess this is what he wants."

What stopped me from using my voice

- My self-hating era – "I don't need accommodations. I don't want to be seen with the kids with disabilities because I'd seen bullying and how people with more visual disabilities got treated. I didn't want to be a part of that. It was a miserable time. It took a lot of work to accept who I was. I came out of it by deciding what I wanted instead of looking for my classmates' approval. There are mean people and why do I want their approval anyways."

A different way to look at disability

- Nice to have people tell me about our teachings: taught me, as a person with a disability, that we don't see disability as something to be ashamed of. Back in the day they'd figure out what they can do: what can they do to help out with the community. Part of the community without being outcast.
- The peer pressure always got to me. It's always good to have parents remind you that you are accepted. It took awhile as a kid to get out of that phase.

Advice for students and parents

- Advice for parents: try to encourage your kid to talk about what they need and want
- Advice for kids: might be scary to talk about stuff like this – it was scary for me—but what I want you to do is be brave and want to emphasize that your voice is important
- Kids should know how important THEY are in this process...because it's basically about them. So it's important to get their voice in this.
- Keep on going no matter.
- Nice to have people who supported me. Always have people who support you no matter what...could be your parents, friends, teachers. Find your safe people and safe space.
- Ho-Chunk sister would help find safe space at school.
- Good relationship with case managers at school.
- Good experiences and has developed voice....have support now through IRIS and Cutting Edge Alumni and job coaching
- School turns into work and living. Things shift as you get older. Now you have to share things and things that frustrate you.

Bullying & Strategies to build into IEP

Students with disabilities are at elevated risk for bullying...here are some strategies to consider:

- Keep students apart (don't want child to be near the bully)
- Have 1 person leave the classroom before the other so that they are not together alone
- Have an adult stationed in problem areas like the restroom or locker room
- Have a safe place for the student to go to if feeling afraid
- As a family member, you can ask for a safety plan and add it to the IEP
- Include an IEP goal on self-advocacy

Individual advocacy

Parent Involvement

No Child Left Behind Act of 2001 (NCLB)

“...requires schools to work with parents to develop policies for parental involvement”

Shepard et.al 2016

Individuals with Disabilities Act 2004 (IDEA)

“...parents serve as an accountability mechanism to ensure their child receives appropriate services and supports. Indeed, IDEA has an expectation for parents to advocate.”

Trainor 2010

“... while educational decision making is enhanced when parents’ voices are included, the reality is that participation and partnership are complex constructs that require intentional approaches to skill development among both school professionals and parents.”

Shepard 2016

Special Education Advocacy

Advocacy Styles

- *Intuitive “knowing my child”
- *Disability Expert
- *Agents of Change “create easier paths for other parents of children with disabilities”
- *Strategist “knowledge of special education documents procedures and parental rights”

How can we be more responsive to other advocacy styles?

- Some teams are more responsive to certain types. Can you think of a time when a team was less responsive to a family because of their advocacy style?

Growing in our advocacy

- Families have to grow into advocacy. Many communities reach the table and have been taught that the schools are experts so we defer to their expertise and don't have an opinion. This includes Latinos and indigenous people.
- Invite people to come with you to meetings: a family member or someone from a supportive organization. Some districts have advocates or personnel to support families, like a WSPEI-trained staff (Wisconsin Statewide Parent-Educator Initiative).
- Tap into people who are **strategists**, like a family navigator, because they have knowledge of how to maneuver in the system.
- Tap into **disability experts** because they have ideas for how to meet needs. They can often make recommendations of outside therapies, available programs, etc. that you explore.

Growing in our advocacy continued...

- Try using the pronoun “we” instead of “you” during IEP meetings.
- Connect with other families for support, learning, and collective power.
- Attend school-wide or district-wide meetings. Go with a friend for support.

Systems advocacy

Advocating to change systems - Local

- Talk to the District Family Engagement Liaison (a WSPEI representative) if your district has one. This is a trained parent who can attend IEPs with families. Or see if your district has a family navigator who knows the resources.
 - Make sure you have the building blocks of the system. Before changing the system, you need to understand it.
- Attend a school board meeting to voice your concerns
- Talk to your alderperson, county board supervisor, and mayor
- Join a community board or council
- Run for school board
- Vote!

Advocating to change systems - State

- Call or meet or email or write your state representative and state senator to share your story: [Who Are My Legislators?](#)



Advocating to change systems - State

- Prepare your story – Remember, you are the expert.
 - Ex.: Medicaid [English storytelling sheet](#); [Spanish storytelling sheet](#)
- Attend “Advocacy for Change” and “Disability Advocacy Day”
- Join an advisor committee, board, or council for a statewide organization. Check out [Serving on Groups](#) materials.
- Follow organizations and share on social media
- [BPDD website](#); [Subscribe here](#); [Facebook](#)

Medicaid Matters to Me



Hi, My name is _____ and I live in _____.

I am _____. (Ex.: Person with a disability. Family member of a person with a disability. Care provider to a person with a disability.)

Here is what my life looks like now. Ex. I live in my home in the community, not an institution, I work, I volunteer etc.	Medicaid makes it possible. Ex. I need caregiver to get me out of bed, help support me at my job, to get medications, to get to appointments and other places)	With Medicaid as it is I am not always able to: Ex. Find enough caregivers, get transportation in the evenings, get support on my job.	If Medicaid is cut, and I have less support than I have now: I/the person I support will not be able to: Ex. Live where I want, get out of bed, get to work, keep up on medications, etc.

Ask: If there is less money for Medicaid, the daily lives and health of people like me will be impacted. Don't make cuts that will mean less Medicaid money for states. Thank you for your time.

Medicaid me importa



Hola, mi nombre es _____ y vivo en _____.

Soy _____. (Ej.: Persona con discapacidad. Familiar de una persona con discapacidad. Proveedor de atención a una persona con discapacidad.)

Así es como se ve mi vida ahora. Ex. Vivo en mi casa en la comunidad, no en una institución, trabajo, soy voluntario, etc.	Medicaid lo hace posible. Ex. Necesito un cuidador que me levante de la cama, me ayude en mi trabajo, para conseguir medicamentos, para ir a citas y otros lugares)	Con Medicaid tal como está, no siempre puedo: Ex. Encontrar suficientes cuidadores, conseguir transporte por las noches, conseguir apoyo en mi trabajo.	Si se recorta Medicaid y tengo menos apoyo del que tengo ahora: Yo/la persona a quien apoyo no podré: Ej. Vivir donde quiero, levantarme de la cama, ponerme a trabajar, mantenerme al día medicamentos, etc

Pregunte: Si hay menos dinero para Medicaid, la vida diaria y la salud de personas como yo se verán afectadas. No haga recortes que signifiquen menos dinero de Medicaid para los estados. Gracias por tu tiempo.

Advocating to change systems - National

- Email, Call, Meet or Write your national representative and state senators to share your story: Who are my Members of Congress?
- Your Congressional Representative (Look up Washington DC mailing address)
- U.S. Sen. Tammy Baldwin,
141 Hart Senate Office Building
Washington DC 20510
- U.S. Sen. Ron Johnson
328 Hart Senate Office Building
Washington DC 20510



District 1: Bryan Steil
Phone: 202-225-3031



District 5: Scott Fitzgerald
Phone: 202-225-5101



District 2: Mark Pocan
Phone: 202-225-2906



District 6: Glenn Grothman
Phone: 202-225-2476



District 3: Derrick Van Orden
Phone: 202-225-5506



District 7: Tom Tiffany
Phone: 202-225-3365



District 4: Gwen Moore
Phone: 202-225-4572



District 8: Tony Wied
Phone: 202-225-5665



US Senator: Ron Johnson
Phone: 202-224-5323



US Senator: Tammy Baldwin
Phone: 202-224-5653

Serving on committees and boards

- People with lived experience bring, to any committee or board they join,...
 - Unique perspectives
 - Direct experience using a service or support – insider experience with how something works
 - Creative ideas for solving problems
- Learn about the committee or board to decide if its values align with yours
- Lots of resources available! Check out “Resources” and our tips sheet

Build your Advocacy Skills with...

- **Wisconsin Family Leadership Institute – WIFLI** (Winter-Spring): <https://familyvoiceswi.org/wisconsin-family-leadership-institute-wifli/>
 - Foundations
 - Advanced
- **Partners in Policymaking** (Fall-Spring): <https://wi-bpdd.org/index.php/partners-in-policymaking/>
- **Youth Leadership Forum** (July): <https://wi-bpdd.org/index.php/wisconsin-youth-leadership-forum/>
- **Advocacy for Change** (March): <https://familyvoiceswi.org/advocacy-for-change/>
- **Disability Advocacy Day** (March): <https://www.survivalcoalitionwi.org/index.php/events/>
- **Wisconsin Transition Improvement Grant (TIG):** [Online Tools Self-Advocacy](#)

Resources

- **Serving On Groups**: guidebook and modules in English and Spanish by WI Family Assistance Center for Education, Training, and Support - <https://servingongroups.org/>
- **Serving on Groups that Make Decisions: A Guide for Families** by Family Voices and SPAN Parent Advocacy Network - <https://familyvoices.org/wp-content/uploads/2019/05/NCFPP-Serving-on-Groups-Presentation-English.pdf>
- **Your Voice Counts: Joining a Committee – Thought for Families** by Family Voices of Wisconsin - <https://familyvoiceswi.org/resource-library/your-voice-counts-5-joining-a-committee-thoughts-for-families/>

Resources continued...

- Wisconsin Office of Children's Mental Health created **Use Your Voice** resources for parents and young adults wanting to impact systems change.
<https://children.wi.gov/Pages/LivedExperience/BecomeALeader.aspx>
- **Living Well Blueprint: A Healthy, Safe and Connected Approach to Quality Home and Community-Based Services** includes sections for individuals with disabilities, agencies, and states.
 - Check out the on **Self-Advocate Leadership and Engagement for Individuals**.
<https://wi-bpdd.org/index.php/living-well-blueprint/>
- Green Mountain Self-Advocates: <https://gmsavt.org/self-advocacy>
- Family Voices of Wisconsin – Early Choices Matter:
<https://familyvoiceswi.org/learn/>

Questions?

Thank you!

Cheryl Funmaker; Cheryl.Funmaker@ho-chunk.com

Kody Funmaker

Molly Cooney; molly.cooney@wisconsin.gov