breaking STOUM WINTER 2023 ISSUE 116



Partners in Policymaking®: Developing Leaders in Tennessee's Disability Community for 30 Years



2023 FALL ISSUE

breaking ground



ON THE COVER: Partners in Policymaking graduate Jen Vogus founded AbleVoices to amplify the voices of youth and adults with disabilities through the powerful medium of photography and foster more inclusive communities. (Read more on page 14 about the ripple effects of her Partners training.) In 2021, the Council provided funding to AbleVoices for their weekly Photography for Self-Expression course. AbleVoices photography club members are pictured on the cover at an outing to Chattanooga to photograph the waterfront and aquatic life at the Tennessee Aquarium.

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Personal Perspective: How I Improved Access to 911

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With this issue of *Breaking Ground*, the Tennessee Council on Developmental Disabilities is celebrating 30 years of Partners in Policymaking® in Tennessee. Partners is a national, competency-based curriculum that was established by the Minnesota Council on Developmental Disabilities in 1987. Tennessee was proud to adopt the model as its flagship leadership training and begin its first cohort in fall of 1993. Since that first group, more than 600 individuals with disabilities and family members have completed the curriculum in Tennessee.

The Council's guidepost, the Developmental Disabilities Act, says that our role is to empower individuals with developmental disabilities and their families to help shape the policies that impact their lives. We know of no better way to do this than to give people the tools they need to amplify their voices. Everywhere.

Partners graduates are leaders in the disability community across our state. They are running non-profit agencies, working on legislation to improve the lives of people with disabilities and families, conducting workshops, and serving on boards and councils that shape disability policy and services. They are also leaders of groups that don't focus on disability. Partners graduates are represented on energy boards, PTAs, faith-based groups and art societies. They bring the disability voice and experience to the table in every corner of community life. This is the power of Partners in Policymaking.

Through the years, our Council has been honored to have 3 amazing leaders as director of the program. In these pages, you'll find articles from Kevin Wright and Ned Andrew Solomon, our first 2 directors. Both had a foundational impact in developing and growing our program in Tennessee. Both leaders are still involved, in concrete ways, in improving policies and practices across the service system for people with disabilities and families.

Cathlyn Smith, our Director of Leadership Development, shares her vision for Partners. She looks at how the training can evolve to stay relevant and current to meet the needs of a more diverse community of self-advocates and families – for the next 30 years of Partners and beyond.

In its 30 year history, every person on the Council staff has played a vital role in supporting our Partners in Policymaking program. Former staff members Errol Elshtain and Jaye Deakin led the first 2 classes before we had a full-time director for the program. Since 2004, Mildred Sparkman on our team has kept the behind-the-scenes administrative pieces flowing. The Arc of Davidson County, The Arc TN, and United Cerebral Palsy of Middle Tennessee have helped us at various times through the years with logistical pieces. It truly takes a village, and we are thankful for the staff support and community collaborations that have made Partners possible.

We are grateful to every person who has completed our Partners in Policymaking program in the last 30 years. You have trusted us with your limited time and precious energy. The impact you have on the lives of people with disabilities and families is witnessed across this state, in tangible ways, every day. We are also excited to meet the future cohorts and to share tools and resources to assure your critical voices for change are heard in every community across Tennessee.

Cheers for the next 30 years! Lynette Porter Deputy Director



Lynette and Partners Director Ned Andrew Solomon celebrate with 2013 Partners graduate Jerry McMullin.



Kevin Wright met Justin Dart in April 1995, when the "Godfather of the ADA" visited Nashville. Kevin remembers, "We had a great conversation about the ADA and its impact."

It's hard to believe that Partners in Policymaking® is celebrating 30 years in Tennessee! For me, the launch of Partners seems like yesterday.

Like many college students, I approached graduation as a point in my life where all my education, employment preparation, and theory was about to become real. I realized that I had to decide what path would both fulfill my desire to contribute to the world while also paying the bills. Through various volunteer or part-time roles, I met and regularly crossed paths with Wanda Willis, the Executive Director of the Tennessee Council on Developmental Disabilities. She became a friend and mentor. She not only jump-started my career – she served as a leader, guide, and often voice of reason in a sometimes-unreasonable world.

Wanda and I worked together on various projects. By 1994, I must have made some type of positive impression, because she asked if I'd be interested in moving to Nashville to lead a new Council leadership program. It would focus on helping individuals and parents learn how to advocate for themselves and their families while navigating a fragmented, complex, and often very confusing system of disability related supports.

I accepted the role, and from 1995 until 2000, I was honored to serve as the Director of Tennessee Partners in Policymaking. Through my tenure, I saw the program grow to include a youth component known as the Tennessee Youth Leadership Forum. I also saw Partners in Policymaking scholars grow their knowledge, skills, competencies, and most importantly, themselves. While there are many examples of this, a few general moments will forever be part of my Partners memory bank.

For many of the adult scholars with disabilities, Partners was the first time in their life they had an opportunity to give real thought and practice of true self-advocacy. Up to that point, they had loving, caring supports in their life who helped them navigate through school, first social events, and other parts of life without wanting their loved one to "fail." It was refreshing, while sometimes surprising, to scholars when the light bulb moment happened during a session as they realized that it is okay to "fail" - and in fact, can be a moment of real growth. The second "ah-ha" moment often was when they realized that much of the advocacy provided for them and protections afforded during their youth shifts from others to them. They would realize that they now have, with support where and when needed, responsibility for their own life navigation, which isn't always easy. Being a part of those moments was special.

It wasn't just adult scholars who had their own realizations. I remember many light bulb moments with parents, as well. Those usually came outside of the formal sessions, during rare downtime or social/mealtime conversations. I, as a new, young professional with life experiences was coaching, and sometimes mentoring, moms and dads with many more years behind them. Those usually included tough conversations about allowing for "safe failure." We talked about ensuring that their son or daughter was included and had a voice in all the advocacy work that the parent was doing. I saw parents realize that without their child being a significant part of the process, not only would they not have as much investment in their own future as adults with a disability, but they would be at an even greater disadvantage in life's navigation.

When I think of these moments and other efforts. I know Tennessee is stronger because of the work that takes place through Partners in Policymaking. Partners allows parents and adults to enrich their lives with knowledge, skills, and lifelong connections to others who share their journey's challenges. It is a place where real solutions are developed, and old solutions evolve.

My advice to all former, current, and future Partners in Policymaking scholars is: Take advantage of all that Partners has to offer. Learn from it. Grow, and use the connections with each other and the professionals who serve as guides at each session to make your and your family's journey as friction free and satisfying as it can be. You only get one chance at this. Make it count!



Kevin Wright is currently Assistant Commissioner for the Division of Rehabilitation Services, TN Dept. of Human Services. Prior to being appointed to his current role, he served as the division's Director of Operations for six years. Kevin holds a BS degree in communications from the University of Tennessee at Martin.









Reflecting on 30 Years of Partners in Tennessee: Growth and Expansion

By Ned Andrew Solomon, Director of Tennessee Partners in Policymaking®, 2000 – 2019

Ned Andrew poses at the State Capitol with the 2008 Partners class.

I am honored to be asked about my experience as one of the Council's directors of its Partners in Policymaking Leadership Institute for this special issue of *Breaking Ground*. Partners is and always has been one of my favorite topics!

Learning curve and mentorship

I was hired by the Council in December of 2000 to lead this program, which had been a core Council program since 1993. I was excited (and nervous) about acquiring some new skills, like overseeing a program budget, handling all aspects of event planning, and developing contracts with participants, speakers, and hotel sites where the weekend meetings would take place. Although I faced a steep learning curve, I did know something about what I was getting into, since I was a Partners participant myself in 1995. The Partners director at that point, Kevin Wright, became my mentor, spending countless, generous hours teaching me the ropes. I will be forever in Kevin's debt for that priceless education!

A shift in focus

When the Partners curriculum was designed originally by Colleen Wieck at the Minnesota Governor's Council on Developmental Disabilities, the focus was on informing young parents of kids with disabilities about their rights and how to advocate for their loved ones. My first "ah-ha" moment as the new director was a keynote presentation I attended by Don Meyers about the importance of siblings in the lives of individuals with disabilities. After hearing this speech and bringing what I had learned back to Wanda Willis, the TN Partners program shifted its focus. No longer an intensive training for just parents of young kids, we recognized the need to inform other family members – adult siblings, aunts, uncles, and grandparents, as long as they played a significant caregiving role. We also confirmed our commitment to helping adults with disabilities become advocates for their own lives.

Diversity is essential

That shift opened up our applicant pool exponentially! It wasn't unusual for us to have 80 applicants for 30 Partners slots. My second goal as director was my desire to have the most diverse Partners classes possible. I worked hard to have a mix of attendees from across the state, comprising different ethnic and cultural backgrounds, representing different disabilities, different ages, and, if possible, near equal numbers of men and women. As a father and stepfather myself of three children with disabilities, I knew the importance of getting fathers and brothers involved. I do believe this was one of my proudest successes as director.

Light bulb moments

I am so grateful for witnessing so many "light bulb" moments during my 19-year tenure as Partners director. It meant the world to me to watch as inspiring speakers struck a nerve with one of the Partners. Sometimes I saw aspects of the Partners "philosophy" around creating inclusive and welcoming environments and providing equal access for all sink in or take hold. I recall a teacher who resigned from serving in a segregated classroom to devote herself to special education advocacy. Another mom realized for the first time that her child was more than capable of making choices and decisions, even though she did not communicate verbally. I remember a father who successfully got legislators to introduce and even pass vital bills that benefited people with disabilities. I remember individuals with disabilities who finally understood the kinds of challenges their parents faced when advocating for their rights. I remember family members who realized, through observations of other Partners, that adults with a wide range of abilities could successfully advocate for themselves, complete homework assignments, and engage socially with their non-disabled peers, which gave them hope for the futures of their own loved ones.

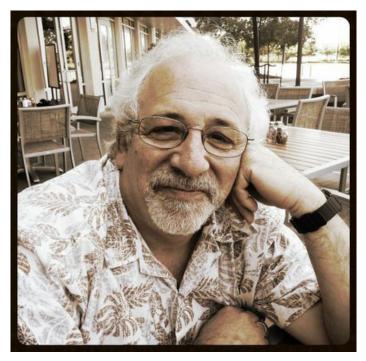
How our state is better because of Partners

Thanks to Partners and the Council's long-term commitment to the program, Tennessee is filled with a large number of informed individuals – family members and people with disabilities – who can educate others,

advocate with policymakers and other stakeholders, and serve and represent the "disability" voice on boards, committees, and task forces. Throughout the long history of the Council on Developmental Disabilities, countless Partners grads have helped shape our state's policies and Council priorities.

Advice for future Partners

Partners is a gift, not to be taken lightly. Partners class members are given access to fantastic presenters and notebooks full of important information. Yes, for a few participants, Partners meant a no-cost weekend at a lovely hotel, eating delicious food, and getting some respite from their complicated lives at home. But for the majority, Partners was life changing. Like any experience, those who give their all – showing up for every training weekend on time, listening intently, and asking great questions – get the most out of it. Long live Tennessee Partners!



Ned Andrew Solomon is a writer, speaker, consultant, and musician. He lives in Brentwood with his wife, Gina Lynette, who is also a Partners grad. They share four adult children, three grandchildren, and four cats.









Partners class of 2003

Partners class of 2009

Partners class of 2011

"My hope is that with continued input from our graduates, we will be able to keep enhancing TN Partners in Policymaking® to meet the needs of Tennesseans. We plan to offer the most up-to-date information from agencies that serve people with disabilities. We plan to keep innovating in how we use technology to reach more participants across our state, including in rural and underserved communities."



Reflecting on 30 Years of Partners in Tennessee: Forward to 2053 and Beyond!

By Cathlyn Smith, Director of Leadership Development, 2020 to Present

I cannot begin to tell you how honored I am to help celebrate 30 years of Partners in Policymaking® in Tennessee. This historic feat took great leadership, focus, and support, along with the belief that Tennesseans with disabilities would benefit from this training.

The Partners story

Partners in Policymaking® was originally conceived in 1987 by the Minnesota Council. It has since been implemented nationally and internationally. The program overall has developed leaders that have affected local, state, federal, and international policies and communities.

No one had a crystal ball to see into the future. But our previous Executive Director, Wanda Willis, took a cue from the Minnesota Council on Developmental Disabilities and the Developmental Disabilities Act (the federal law that created councils like ours). Wanda felt that self-advocates deserved a space to learn about advocacy, how to impact policies, and, more importantly, use their voices and stories to make and create change in our state for individuals with disabilities and their family members.

Wanda shared with me that, "Partners in Policymaking is at the heart of all that the Council on Developmental Disabilities does. Partners graduates, Tennesseans with disabilities and their family members, drive Council priorities and are the most effective spokespersons on disability issues and needs. For these reasons, Partners will always be a priority for the Council."

The past leaders of this program, Kevin Wright and Ned Andrew Solomon, laid a strong foundation which expanded and strengthened Partners over the years.

Partners graduates laid the groundwork for future progress and acceptance for individuals with disabilities and their family members. We were so very fortunate to have had their guidance and tenacity. Their footsteps and strides are everlasting!

A trajectory of change

The growth and expansion of Partners was linked to broader change in disability services. Many of us personally experienced the hardships, misunderstandings, and sacrifices of living with disability. For a new parent or someone with a new, life-changing disability diagnosis, there was no easily found roadmap to resources, medical understanding, attentive ears, and benefits. We have witnessed big changes over the past 30 years. But I would be remiss not to acknowledge that we are only 8 years out from the closure of Tennessee's last large residential care facility, Clover Bottom.

Since then, more change has come. Many people who previously were served in institutional settings are now being served in their homes with family or are living independently with community supports. There is greater emphasis now on:

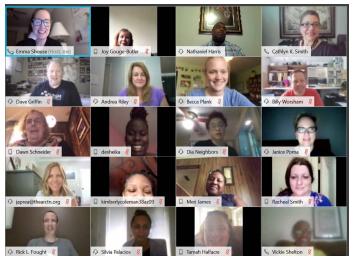
- sustainable employment and hiring,
- · safer independent living environments,
- increased higher education learning opportunities,
- early intervention programs, and
- mainstream learning and behavioral supports.

We have Partners grads and leaders working in all these areas, continuing to make known the needs of people with disabilities. Their voices will ensure more people with disabilities can be challenged, inspired, and put on the path to success.

It was Partners' voices who helped us see the need to create Tennessee Disability Pathfinder, together with the Vanderbilt Kennedy Center. Now, Pathfinder is funded by six different state agencies. It serves as a central portal to help the new parent or person with a new diagnosis find the information and services they need. We need YOU to help continue to share this great resource within your communities!

The continued power of Partners

I am constantly amazed at the confidence and enthusiasm Partners graduates still have from this program. That was true for the Partners grads I met before coming to work for the Council, and it's true for the Partners classes I've had the honor to lead. I've had opportunity to witness a timeline of growth from individuals who were shy or felt they didn't have anything to share. I've watched them blossom into non-stop advocates who tell their stores, tell businesses/agencies what they need, sit down and have engaged and informed conversation with legislators and local leaders – the list goes on. I share with Partners classes what I shared with my own daughter as she began to understand her own disabilities: When it comes to telling your story, no one can do that but YOU!



A virtual Partners session with members of the class of 2020-21

Toward the future

So, what will the next thirty years bring for Partners? My hope is that with continued input from our graduates, we will be able to keep enhancing TN Partners in Policymaking® to meet the diverse needs of Tennesseans. We plan to offer the most up-to-date information from agencies that serve people with disabilities. We plan to keep innovating in how we use technology to reach more participants across our state, including in rural and underserved communities.

We also plan to use the LifeCourse framework to focus our curriculum on the core areas that are necessary for a good life. We will keep central the values of the Developmental Disabilities Act and continue to emphasize advocacy skills



that transfer to any situation our scholars may face. We'll build an understanding of how all the parts of a person's identity may affect their support needs and the barriers they face.

We've heard from many of our graduates with input on the path ahead. We will strive to build on the legacy of this program, investing in best practices that will propel our Partners graduates to be the best community leaders and advocates for our state. While our grads have a specific emphasis on the needs of the disability population, I am hopeful that their voices will be heard for all people.

Since I started with the Council, I've had the opportunity to speak with Colleen Wieck (one of the founders of Partners) on several occasions. She shared with me her thoughts about Partners moving forward:

"In 30 years, we will be celebrating the 100th anniversary of the Parent Movement, the 90th anniversary of the Independent Living Movement, and the 80th anniversary of the Self-Advocacy Movement. My hope is that in 2053, people will look back at our history and understand the immense struggles that we faced every day. In 2053, the vision and hope of every federal law will come true. Every



Cathlyn Smith with 2023 grad Nidhi Mali

person will be treated with **dignity and respect**. Every person will have the services and supports that match needs, requirements, and expectations. Every person will have the assistive technology to maintain **independence**, **productivity**, and **self-determination**. For babies born with disabilities in 2053, no family will ever feel alone. The path toward **inclusion** and **belonging** will be universally understood. Adults with disabilities will be treated as equal citizens. Ed Roberts, founder of the Independent Living Movement, believed that the impact of the Americans with Disabilities Act would not be felt for three generations, and he may be right in his prediction."

While we're still working toward the full fruition of the Americans with Disabilities Act and the Developmental Disabilities Act, we've made great strides toward that goal. However, there is still much to do. You are still needed every step of the way. As you've probably heard me say before...YOUR VOICE TRULY MATTERS!

The Charting the LifeCourse framework is an approach and set of tools created to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. For more, visit www.LifeCourseTools.com.

SCAN TO VISIT THE LIFE COURSE TOOLS WEBSITE



Cathlyn Smith is Director of Leadership Development for the Council on Developmental Disabilities. In addition to Partners in Policymaking, she oversees the Council's Leadership Academy for Excellence in Disability, a ground-breaking training for leaders of state disability services. She also manages the Council's Scholarship Fund, which helps people with disabilities and their family members attend educational opportunities and take on leadership roles in their communities. She is a proud wife, mother/ stepmother to four young adults, one with disabilities, and one fantastic grandson. She enjoys gardening, watching movies, and spending time with her family.

A Partners in Policymaking® Video Library

Over the years, Partners graduates have featured prominently in a host of Council videos. Some have shared their stories about disability issues or services that are important to them. Others have shared their experiences with Partners. All of them have been powerful voices for education, advocacy, and change.

We're pleased to present this special retrospective of Partners graduates on video, doing what they do best: advocating for what matters.







https://bit.ly/FaithAndDavid

Partners in Policymaking Celebrates 30 Years





https://bit.ly/Partners30Video

How do our Council members create





https://bit.ly/CouncilMemberVideo

The Coleman Family's Story





https://bit.ly/ColemanFamilyVideo

Chrissy's Story





https://bit.ly/ChrissyStory

Supported Decision-Making with the Browns





https://bit.ly/BrownsSDM

By the Numbers: Evaluating Tennessee's Partners in Policymaking® Leadership Institute

By Bruce Keisling, Executive Director, The UT Center on Developmental Disabilities

The University of Tennessee's Center on Developmental Disabilities has had the privilege of evaluating the attitudes and outcomes of hundreds of Partners in Policymaking® graduates over the years. This process includes surveying groups of participants at the beginning and end of their leadership experience. It has also taken the form of looking back with focus groups and self-report questionnaires for graduates years after completing the program. Regardless of when or how we ask graduates, we consistently hear that participation in Partners in Policymaking results in long-lasting gains in:

- self-confidence and empowerment,
- knowledge,
- advocacy skills,
- professional and social networking,
- community inclusion,
- and quality of life for those connected by the experience of disability.

Partners graduates report being actively involved in system changes within their communities. This continues many years after they finish the leadership training program. A few examples of community improvements and system change Partners graduates have worked on include:

- developing a training course for first responders who encounter persons with developmental disabilities,
- creating integrated and competitive employment opportunities,
- · founding a minority-owned transportation business, and
- establishing an accessible and ADA-compliant sports complex.

In addition, Partners in Policymaking graduates have significantly contributed to shaping public policy in Tennessee in ways that improve outcomes for people with developmental disabilities and their families. These policy efforts have included:

- leading legislative advocacy efforts to phase out subminimum wages across private, public, and nonprofit organizations and
- championing the creation of the Tennessee Council on Autism Spectrum Disorder. The Autism Council works to establish a long-term plan for a coordinated system of care for people with autism and their families.

In 2021, 135 Partners graduates from 1993 to 1998 were surveyed about the lasting impact the leadership institute has had on their ongoing disability work. Even years after completing the Partners program, alumni reported increased leadership skills, greater ability to impact disability-related policy work, and improved quality of life.

Partners graduates we surveyed overwhelmingly (99%) said that the training experience improved their ability to define their desired services and supports. For those currently participating in disability-related advocacy, 74% attributed their degree of engagement and success to their participation in the Partners in Policymaking program.

Ninety-two percent (92%) of graduates said that Partners helped increase their ability to access their community, and 89% reported an increase in their knowledge of disability issues. Eighty percent (80%) of Partners graduates said their sense of being connected to others with similar life experiences improved, increasing their ability to find resources for themselves and others.

But the benefits don't stop there – 98% of Partners graduates have served as a member of a cross-disability coalition, policy board, advisory board, governing body, or leadership position. For graduates who participated in community organizations, 69% said their involvement in Partners in Policymaking improved their effectiveness in these community-based disability activities.

As an overall quality of life measure, 86% of graduates reported that their life has improved after participating in Partners in Policymaking. This sentiment is echoed throughout this special edition of Breaking Ground, where you'll find many personal testimonies and examples of the wonderful outcomes of this program.



Bruce Keisling is a clinical psychologist and professor in the Departments of Pediatrics and Medical Education at the University of Tennessee Health Science Center (UTHSC). He holds the endowed Herbert A. Shainberg Professorship in Developmental Pediatrics and is the Executive Director of the UTHSC Center on Developmental Disabilities.

From our Partners in Policymaking® News

Our Partners graduates are subscribed to a monthly newsletter just for them. Features include:

- Thoughts and resources from Cathlyn Smith, Director of Leadership Development
- Updates on the work Partners grads are doing across the state
- Ways to get involved and offer feedback on important issues
- First-to-know updates on Council projects and opportunities, including Partners-related events
- And more!

in their communities.

If you're a Partners grad:

- Aren't getting this newsletter? Contact us at
- TNDDC@tn.gov, and we'll make sure you're subscribed!
- Wish your name was here? Send us an update or post to social media using #PartnersTN30. We'd love to hear from folks in classes further back – we know many of you are still using your Partners know-how to lead and advocate!

As a special feature for this Partners 30th anniversary edition of Breaking Ground, we're sharing a few highlights from recent Partners newsletters, highlighting grads doing great work

April 2023 Feature: Partners Grad Desiree Dyer, Class of 2022

"Last month, I was officially appointed to the board of directors for Autism Tennessee. I'll be serving on two committees, programs and fundraising. I'll also be putting my IT experience to good use as part of the team getting the new website up and running. During my interview process, one of the things I talked about was the fact that if Autism Tennessee wishes to grow its budget and fundraising capabilities, one growing edge that stands out for me is storytelling shared with the community by families and autistic self-advocates. I am hoping to use my Partners in Policymaking experience and lessons around storytelling to do quarterly trainings for Autism TN members, staff, and the board. The initial feedback has been enthusiastic.

"In August, I got a new job as Network and Computer Systems Administrator with the Nashville Symphony. One of the things I've taken on here is working with Chrissy Hood (a fellow 2022 Partners grad) to try to bring an adult-sized changing table to the Schermerhorn Center.

"Around the same time I started in Partners in Policymaking, I was also selected by the Upper Mattaponi Tribal Council to be a part of the Constitution Committee to create a government for our newly formed sovereign nation.

"I'm so excited about the advocacy work I'm doing in the autism and wider disability communities as well as the work I'm able to do on behalf of my Upper Mattaponi people. When Partners was wrapping up in the spring of last year, I had no idea how I'd translate the lessons I learned into action. But here I am, and I can't wait to let you know how all these efforts pay off."

July 2023 Feature: Partners Grad Peach Chinratanalab, Class of 2022

Peach Chinratanalab is still young but has long been a policy advocate for people with disabilities. She's a Vanderbilt Next Steps graduate, an employee at Bubble Love Nashville, and a 2022 Partners in Policymaking graduate.

These days, Peach is passionate about accessible transportation. Her parents serve as her primary form of transportation, driving her to work and medical appointments in their accessible van.

Peach says that more accessible public transportation would allow her greater independence. She has met with her state legislators to talk about her concerns. She asks for more investment in accessible transportation options. "I want to see people with disabilities be able to get where they need to go just like anyone else," she says. "Most public transportation or private ride services like Uber or Lyft aren't accessible to people who use a power wheelchair. I am advocating for more options for people like me, who need to get to work and want to be out in the community."



August 2023 Feature: Partners Grad Kimberly Coleman, Class of 2021

Council staff recently attended an Advocates in Motion (AiM) Person-Centered Training in Nashville. Kimberly Coleman was one of the trainers and did a fabulous job. She's been an AiM trainer for five years and said she LOVES it. The 7 attendees, who are Tennesseans with disabilities, reflected on what is important to them, discussed their future dreams, and created a vision board with images f their goals.

Background: The Council funds Advocates in Motion, which is coordinated by the TN Dept. of Intellectual and Developmental Disabilities. Check out this video for more about the program: https://bit.ly/AdvocatesInMotion



And from the same issue: Partners Grad Carol Shehan, Class of 2015

"Going through the Partners program was such an enlightening, meaningful, and positive experience for me! Since graduating, my main focus has been advocating for my daughter, who is 43 and has cerebral palsy. I continue to encourage other parents/caregivers to seek out how to be the best advocate they can be, as well as passing on vital information and resources for them to help further their or their loved one's goals. Medical issues prevent me from working, but I do volunteer work, which includes being an Ombudsman for the state of TN. I advocate where and when I can."

October 2023 Feature: Partners Grad Monica Everett, Class of 2023

Monica Everett has been using information, skills, and relationships gained through Partners to make lots of great things happen in her community! She is the mom of two young boys with autism.

Monica shared with us that since graduating in April, she helped create and serves as co-leader of the new "Labeled and Loved Memphis Sisterhood Circles Pilot Program."

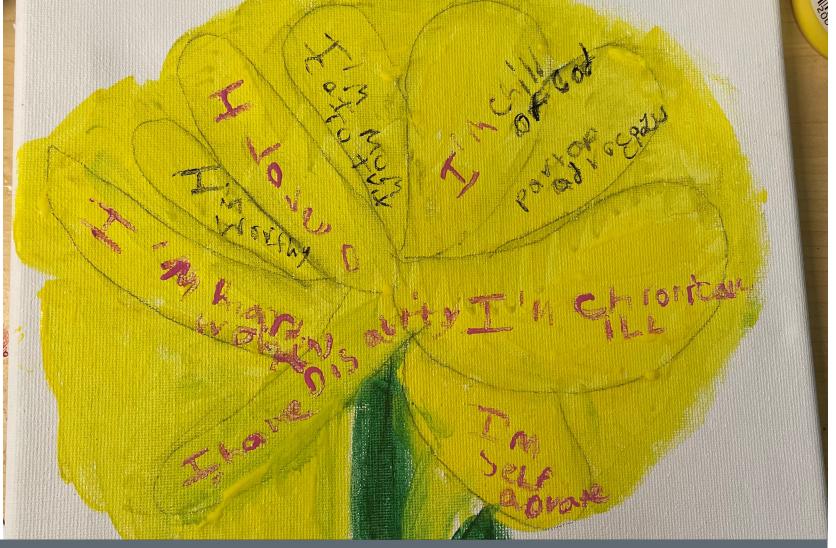
Monica told us: "L & L is a national non-profit organization benefiting mothers and families of people with disabilities. The mission and vision of the sisterhood circle support group is to bring moms of kids with disabilities into a community where they can arrive accepted, feel seen, be celebrated, and find belonging to expand inner strength. Currently, Memphis has more than 40 women participating. It is the first of its kind in the city from a national organization."

Partners classmate Heather Bensch spoke at the group's last meeting about her own journey as mom to a daughter with disabilities. Monica represented the organization on a TV interview on WMC Action News 5 (pictured below at left) about their July "Moms Night Out" event.

You can connect to Monica's efforts by following her Facebook page, "All Aboard for Autism."







Personal Perspective: How Partners Helped My Advocacy Journey

By Katie Moore, 2023 Partners in Policymaking® graduate

I heard from a friend about policymaking classes. I thought I would be a good fit. I checked it out on the Tennessee Council on Developmental Disabilities website. I was able to apply, and I got into the Partners in Policymaking® class.

It started in September 2022 and then ended in April 2023. There were people in the class from all over Tennessee that joined. Our first two classes were in person. Then we met over Zoom a couple times a month.

We heard from a lot of different speakers to be more powerful advocates throughout this class. We heard from The Arc and Tennessee Pathfinder and Our Place Nashville and a lot more organizations.

There were a lot more different things I got to hear about while in the class. We talked about self-esteem and our "I statements," so I can have good health to be a good self-advocate and advocate for others.

We heard from news teams about how we could get our story out to the world so we can share what's on our mind about our problems, so more people can help with it. We heard from a mayor and legislators about how to speak up about what our issue is and how we can get help with it. We always need to speak up and speak out to get the word out about our issues we have.

We had several people join this class with a learning disability or parents join to this class I was in. I have gotten to know them each a different way, some closer than others. And plus, I have gotten to learn a lot from Cathlyn [Smith – Director of Leadership Development] and Lauren [Pearcy – Council Executive Director] and Emma [Shouse Garton – Director of Public Policy]. They were amazing people that selected all the class members in this amazing class I joined.

I enjoyed hearing the different experiences from my classmates. When we had class, Mrs. Cathlyn always asked for updates on how your self-advocate journey was going and had us share anything we have learned or any ideas we want to mention. We always started our classes with that, then our homework – go over that. Some people in my class always had good stuff or hard stuff that they wanted to talk about.

We learned how to talk to state leaders. We need to know what all is out there for disabled people, so we learned a ton while in the class. We learned how to become more, what our story is about, and what we want to self-advocate about.

I have gotten a lot of amazing experience. I got to speak in front of a School of Education class at Union University. That was an awesome experience. It gets my self-advocate journey stronger and better when I go out to talk about my self-advocate journey. I have learned to take time for myself and remember to use my I statements we talked about.

I've gotten be part of so much since being part of the advocacy class. I've been trying to help my friends with chronic illness be better self-advocates. I got voted in on July 4 as part of the Vanderbilt Kennedy Center advisory council. I've been getting better at learning how to talk to my doctors and other people. I heard that what we will be doing in the council advisory board is hearing more about Vanderbilt and giving feedback on the projects they do and learning more about the council. I went to my first Vanderbilt advisory board meeting on September 8. I'm excited to get know those people in the council.

Getting to be part of this training helped me learn more about voting and other things for disability. I shared my artwork in the art magazine [Breaking Ground arts issue]. Plus, I got to be part of Tennessee Disability Coalition as a disability content creator, posting ideas and sharing about voting with a disability, and how it's hard to vote with disability.

I want to get issues out there. Doctors don't understand chronic illness – what we go through on a daily basis. We need to get the word out about disability and wheelchair issues and chronic illness. Our advocacy journey is powerful. We need to remember our "I statements:"



I am awesome and I am a self-advocate and I am strong. I am beautiful.

Remembering I statements helps keep me strong to share my story. Self-advocates' stories are powerful with all different issues! We need more advocates to share what is going on with issues around the world.

Katie Moore is a graduate of Union EDGE at Union University. She lives in Henderson, TN, and enjoys crafting, volunteering, and the connections she has made through her Partners experience.

More videos from A Partners in Policymaking® Video Library





https://bit.ly/JenVogus







https://bit.ly/CharlotteBynum https://bit.ly/AllsupVideo



Jen at a recent Partners reunion conference in Nashville.

When I began the Partners in Policymaking® leadership program in September 2006, I didn't know what I didn't know. I was a first-time mom of a four-year-old child with both physical and developmental disabilities and an uncontrolled seizure disorder, all of unknown origin. My days were filled with uncertainty and fear. Uncertainty about my son Aidan's health and future. And fear based in my limited experiences with disability.

Like many people of my generation, I grew up in a world where the default was to segregate children and adults with disability. There was little inclusion in schools or throughout the community. With my son's diagnoses, I was consumed by seemingly unanswerable questions: How will Aidan communicate his thoughts and needs to others? Will he have friends? What doctors and service providers can help? What will Aidan's life look like and how can it be meaningful and happy? What will happen to Aidan after my husband and I die? I was overwhelmed by it all. I was even overwhelmed by the alphabet soup of acronyms and the array of programs and services intended to help.

What Partners in Policymaking did for me is develop the understanding and provide the tools for successfully making sense of and navigating the complexity of the

disability world in Tennessee. That included special education, employment, housing, civic engagement, and policy making. But Partners does so much more. It builds a real and enduring community of mutual support. That community gave me not only a network chock-full of information, but a feeling of confidence that I could make decisions to support Aidan in living his best life.

Partners also provides a spark to think and act beyond oneself or one's family to help others in similar situations. Partners showed me that even as an individual parent, I have the power to make positive and transformational change for more than just my child. Partners helped me think through how I can be a force for positive change. That meant thinking about how I could use my new disability knowledge and advocacy skills to help others and pay the gift of Partners in Policymaking forward.

I first used these skills to help Aidan use alternate means for communicating, as his rare genetic condition prevents him from using more traditional ways, such as speaking, writing, or signing. When he started elementary school, I began taking pictures of all that he enjoyed and was capable of doing. He shared these photos across his school day, informing teachers and peers about his favorite activities, toys, and how he spends his time

outside of school. These photographs opened up his world, allowing others to realize he is more alike than different from them. That helped build lasting relationships and friendships with his peers, his teachers, and even his extended family.

The great success Aidan experienced at school due to the photos led me to think about the power of photography for people with disabilities, generally. It was a gift to our family, and I wanted to share it with others. The inspiration from Partners to give back and pay it forward led me to combine my teaching and photography skills. I developed a curriculum for teaching people with disabilities photography so they can share their stories and lives through the photos they take. These stories can be tools of advocacy and break down boundaries between people, just like the photos Aidan took to school did.

In 2019, I founded AbleVoices, a nonprofit organization whose mission is to amplify the voices of youth and adults with disabilities through the powerful medium of photography and foster more inclusive communities. Our flagship program, Photography for Self-Expression, teaches photography as a means for self-expression, empowerment, and disability advocacy in local schools, community organizations, and also virtually. We also offer a year-round photography club where we explore and photograph scenic locations throughout Middle Tennessee.

What is next for AbleVoices? We are excited to build on these offerings to push things even further. We are rolling out a new work-based learning program, thanks to generous funding from the Jackson Foundation. We are creating a structured training and sustainable photo-based production program for AbleVoices photographers. These products will be for sale on our website and at local markets, fairs, and retail stores.

My call to action is that we all use Partners to help ourselves, our families, and our students. But we should also use it as an opportunity to reflect on what we might uniquely offer to make our communities and our world more welcoming and inclusive for people with disabilities.

To learn more, please visit ablevoices.org and follow AbleVoices on Facebook, Instagram, LinkedIn, and You-Tube (@ablevoices). Youth and adults with disabilities, as well as volunteers, can get involved by emailing info@ablevoices.org.

AbleVoices also has 16 AbleVoices photographer prints on exhibit now through April 1, 2024, at the Frist Art Museum. This collection is part of the "Power of Resilience" exhibit, showcasing the work created by more than 80 adult artists with disabilities. Stop by this free exhibit before it ends. You will not be disappointed!

Jen Vogus is a Class of 2007 Partners in Policymaking alum, founder and executive director of the nonprofit organization AbleVoices, and parent of two children, Aidan and Eleanor.

Jen and Aidan at home, reminiscing while looking at images in Aidan's photo books created to help him communicate with others.





Molly's Partners experience was virtual during COVID, but a group of Partners grads met up in person at a recent TN Disability Coalition policy retreat. Molly is second from the left, in the red dress. Also pictured L-R: Omegbhai Uriri, Michelle Gross, Chrissy Hood, Council Executive Director Lauren Pearcy, and Carrie Carlson

Molly Anderson is a Partners graduate and a Governorappointed member of our Council. She has a nonverbal disability and uses assistive technology and American Sign Language to communicate. In this written interview, Molly shares about her advocacy for increased access to 911 emergency services.

in Partners in Policymaking®.

I was in the 2021 class of Partners. It was a great experience getting to understand what services are in Tennessee and how I could be a better advocate for people with disabilities! I would highly recommend applying to be in a Partners in Policymaking class. It changed my world and will change others', too!

You have done significant advocacy to establish texting 911 as an option in TN. Why was this important to you?

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When I was a senior in high school, I got into a wreck and could not call 911 for help. This was my first experience where I realized that texting 911 was so important. On student government day my senior year,

we watched a city council hearing in my hometown of Florence, Alabama. I got to speak to the city council about texting 911, and then visited the 911 center and was featured in the local newspaper. Fast forward to 6 years later: I crashed again - this time into a funeral van. Thankfully, no one was hurt. Although the dead guy was okay and only the casket got dented, I still could not **Tell readers a bit about yourself and your experience** call 911. When I FaceTimed my husband, he could not understand me because I was crying, and my signs were everywhere. A bystander, who was so sweet, stopped to help and called 911. It is so scary when I cannot get help.

What was the first step in starting your work on the issue?

Building a relationship with a legislator is the first step to starting any policy work. Since I had developed a relationship with Becky Massey already, I just met with her and told my story. She then worked on the bill.

Where does this effort stand now?

About 80% of the state's population has access to texting 911. I am working with the Tennessee Emergency Board. I am told texting 911 should be statewide by July 2024.

What lessons did you learn during this process?

There are many lessons learned during this process. One lesson was finding solutions that all parties could agree on. With this particular bill, it was stopped in the budget process in the legislature, which means it was passed but didn't go through the budget process. When I realized that the bill had been stopped in the budget process, I decided to work with the Tennessee Emergency Board to find a solution that we all could agree on. Sometimes, working with individual departments can get more accomplished than working with the legislature.

How did going through Partners strengthen your skills to work on issues like this?

I was in the middle of Partners while working on texting 911. It really helped me as an advocate to see the many possibilities and to understand when something is not working, there's usually some kind of compromise that can work.

Molly Anderson is Director of Peer Supports for Family Voices and is a Governor-appointed member of our Council, representing the Southeast TN development district. Molly lives in Chattanooga with her husband, Josh, and their daughter, Lucy - with a second daughter on the way. In her spare time, Mollv loves to run and kayak.

Grants for adult-size changing tables extended through June 2024



Have you been following Partners graduate and Council member Chrissy Hood's work on adult-size changing tables? (See her video on page 8.) If so, you know that Tennessee's legislature created a \$1 million grant program to help businesses and local governments install adult-size changing tables. The program gives locations up to \$5,000 per table to buy and install height-adjustable, adult-size changing tables in family restrooms across the state.

Now, that grant program has been extended for another year. We still need your help! Local residents have the best chance to encourage businesses and public buildings across TN to apply for the grant. Where do lots of families go in your community? That's where tables are needed!

For more details and the link to the online grant application, visit the program's page from the TN Department of Intellectual and Developmental Disabilities: www.tn.gov/didd/for-consumers/adult-size-changing-tables.html

More videos from A Partners in Policymaking® Video Library

Hearing and Supporting McKenzie









Steven Greiner (2013) and Nicholas



Partners



https://bit.ly/GreinerPinter

Pinter (2017)

https://bit.ly/25Partners

A 25th anniversary celebration of

https://bit.ly/HearingMcKenzie https://bit.ly/SupportingMcKenzie

Tennessee Council on Developmental Disabilities

Davy Crockett Tower, 1st Floor 500 James Robertson Parkway Nashville, TN 37243 Return service requested PRSRT STD US POSTAGE PAID NASHVILLE, TN PERMIT NO. 983

Healthy Behavior Check-In





Supporting Well-being for People with Disabilities

Behavior is communication. It can be hard for people with disabilities to say when their needs aren't being met. Sometimes, unmet needs show up through behavior. Sometimes, behavior is a symptom of a medical problem (like a seizure or a urinary tract infection). Supporting well-being for a person with a disability means working to understand what the person's actions and non-verbal cues are telling us they need.

Autonomy & Independence

- Does the person have as much say as possible over their own life? Are they given meaningful choice whenever possible? Are they getting support to understand and make decisions?
- ☐ Are supporters and caregivers speaking directly

 TO the person? Are they paying attention to the
 person's responses (verbal or non-verbal) and
 wishes?
- ☐ Does the person have space to take reasonable risks and make mistakes?
- □ Does the person have time to be alone/do their own thing without direct supervision (as developmentally appropriate)?

Need help in this area? Visit the **TN Center for Decision-Making Support** for information and tools.

Mental health

- ☐ Does the person have professional support for mental health? Do other family members/supporters?
- ☐ Are there mindfulness or other mental wellness tools that could be helpful?
 - ☐ Are there signs that a more complete mental health evaluation is needed?

Physical health

- ☐ Is it possible the person is not feeling well?
- ☐ Are they experiencing pain they can't explain (for example, a urinary tract infection or dental pain)?
- ☐ Are they getting recommended preventive, medical, and dental care?

Medication

- ☐ Is medication being taken as prescribed?
- $\hfill \square$ Have medication dosages been checked recently?
- ☐ Has a doctor checked for possible interactions between different medications the person is taking?
- ☐ Do any of the person's medications have possible negative side effects? Are there other alternatives to try?

Finding the root cause for behavior can sometimes take some real detective work. Learn about a new tool to help people with intellectual/developmental disabilities and their supporters think about the needs behind behavior.

AVISO: Subtítulos disponibles en inglés y español.



SCAN TO VIEW VIDEO



