thirty years of vision & achievement

Maryland

Developmental Disabilities

Council

1971-2001
The Maryland Developmental Disabilities Council advocates for public policy and supportive practices and opportunities that promote the full inclusion of all people with developmental disabilities in community life.
The Maryland Developmental Disabilities Council is a self-governing body whose appointed members include people with developmental disabilities, family members, service providers, state agency representatives, and representatives of Maryland’s protection and advocacy system and University Center on Developmental Disabilities. The majority of the Council’s members are people with developmental disabilities and family members. The Council is in a unique position to bring together people with diverse perspectives, experiences and knowledge in meaningful partnerships.

Established through federal law in 1971, the Council has been a leader in developing innovative and emerging ways to support individuals and families to lead lives of their choosing. The Council has successfully demonstrated new ideas, policies and practices that encourage communities to include and support all citizens. In partnership with other individuals and organizations, we bring about systemic change and improved public policy by:

- Focusing on a shared vision
- Advocating and building influence
- Designing, supporting and funding innovative projects and demonstration projects
- Providing technical assistance
- Educating and informing policymakers and the general public
- Supporting individuals with developmental disabilities and their families to speak for themselves

The Council’s past initiatives, accomplishments, and partnerships are the foundation on which we will build a future where not one person is living in an institution, where all children are included and supported in their neighborhood schools and all people with developmental disabilities and their families lead lives of their choosing, with the support they need and want.
All children, including children with intensive support needs, deserve the love, care and security of a family.

Families must be supported to raise their children at home, for they are the greatest resource their children have.

Supports should build on family and social networks and community resources and assist families to meet their unique needs in ways they choose.

Family support is a sound investment that helps families stay together.

These are among the Maryland DD Council’s strongest beliefs.

The Council has worked for many years to bring these principles to life in Maryland.
Schools must welcome and include all children.

When educational supports and accommodations are provided for children with disabilities, they can fully benefit from their educational experience.

Teachers and schools must receive training and support to truly make this happen.

Input from parents should be valued so they can be true partners with schools in setting the course for their children’s education. Including children with disabilities early on in all aspects of life instills mutual understanding and respect.

Commonalities and differences are appreciated and all children are valued, building the foundation for future relationships.

Laws opened school doors to all children in the 1970s. While this was a critical first step, the DD Council has persisted in working to help children with disabilities move through the door, take their place among classmates and be included in the full life of their schools.
One of the greatest influences on our quality of life is satisfaction with work. Most Americans, including people with significant disabilities, value the freedom to choose their work, earn a living wage, and receive job benefits.

People with developmental disabilities must have opportunities for real jobs in the community with individualized support.

Through their jobs, people develop friendships, gain life experiences, build economic self-sufficiency and contribute to society.

Income creates opportunity.

The DD Council will continue to break down barriers to employment that individuals with developmental disabilities face through demonstration, innovation, and advocacy activities.
People with developmental disabilities want to live full lives in the community where they have opportunities to experience all that life offers — a wish we all share. This means equality in everyday life.

Society is enriched when it embraces and values all of its diverse members.

For this to happen, people with developmental disabilities must have control over their own lives. Community supports and services must honor people’s choices — including risks they wish to take — and assist them to connect with their communities.

Full community participation encompasses all aspects of life — housing, transportation, work, health, recreation, spirituality, and personal relationships.

This holds true for all people — including those with the most extensive and challenging needs. DD Council initiatives promote ways to fully include all people with developmental disabilities in all areas of community life.
Nothing is more powerful and liberating than determining the course of your own life. Self-advocacy is about speaking up for what you believe in and knowing that you are the true expert when it comes to your life. No one should be denied self-determination, even if they need support with making decisions.

Advocacy is also about working collectively to impact issues that are important to all people with disabilities. People with developmental disabilities must be at the table, fully involved as effective advocates and leaders in their own lives and in our communities.

The DD Council believes that people with developmental disabilities and their families must be supported and empowered to speak for themselves — individually and collectively.

They must not only be listened to — they must be heard.
The past three decades have brought extraordinary changes in the lives of people with developmental disabilities and in the systems that provide them support. However, these changes have not come easily. In many ways people with disabilities and their families have witnessed significant improvements, but much work remains. Determined advocacy, collaborative efforts and strong leadership have brought about more choices and opportunities and greater empowerment. And these changes are just the beginning.

The Council is celebrating achievements of the last 30 years that have been realized through an unwavering commitment to inclusion and through many partnerships. The following pages highlight some of the Council’s work and initiatives that have had the greatest impact over the past three decades and hold promise for the future.
Thirty years ago, families had few ways to get resources and support concerning a child’s developmental disability. Many families were simply told by health professionals and others to expect little of their child and that their best option was to admit their child to an institution or other out-of-home placement. Knowing that many families want and need support to raise their children at home, the Council undertook a successful long-term commitment to building, improving and expanding family supports and services in Maryland. This has entailed a multi-pronged approach with many strategies.

**Highlights**

**Demonstrating Best Practices**

In the 1980s, no part of the state’s developmental disabilities budget was allocated to help families raise their children with developmental disabilities at home. Families were mostly on their own. This changed in 1983 when the Council funded the start-up of Family Support Services (FSS) through a three-year demonstration grant. Family Support Services work with each family to identify and acquire services and resources that will best meet their needs. Services are individualized, flexible and family-centered.

**Legislative Advocacy**

Having demonstrated the value and effectiveness of FSS, the Council — in collaboration with families and other organizations — advocated with the state legislature and other policy makers to commit state funds to support families raising children with developmentally disabilities. The effort paid off: in 1986 the Maryland General Assembly passed legislation to establish and fund an ongoing Family Support Services program within the Developmental Disabilities Administration.

**Improved Practices**

After the state funded program had been in operation for about a decade, the Council conducted a comprehensive study in 1997 to evaluate how well Family Support Services were assisting parents and reaching underserved families. A Council task force made up of an array of stakeholders, including parents, guided this effort. The study resulted in a set of recommendations that were adopted by the state, resulting in program improvements. The Council has also invested in testing out other promising family support ideas through numerous innovative grants. These include demonstrating a Cash Assistance Program, developing a Parent to Parent support network and increasing respite options through Partners Plus.

**Increased Funding**

The Council’s FSS study concluded that funding for support to families was severely inadequate. A range of Council efforts including mobilizing families to tell their stories, educating legislators and policymakers, and partnerships with other leading advocacy and state organizations, played a significant role in increasing Family Support Services funding sevenfold over five years — enabling many more families to raise their children with developmental disabilities at home. In 2002, DDA invested over $7M in FSS.

**Reaching Unserved and Underserved Families**

In 2000, the Council launched a project called Family NET Works. The project focuses on: improving and increasing family-directed supports and services available throughout Maryland; increasing families’ knowledge and understanding of a wide range of supports, and reaching families that have been traditionally underserved. The needs of families from rural areas, concentrations of poverty and various cultures are being addressed through unique outreach, training and networking. These communities are now more informed, empowered and able to access needed family supports.

**Supporting Parents**

In keeping with a strong belief in empowering parents, the Council sponsored the establishment of The Parents’ Place of Maryland in 1990. The Parents’ Place is a parent-governed organization that supports and empowers parents through training, information and educational advocacy throughout the state.

In 2001, the Council launched the Special Education Leadership Project. The project supports and empowers parents to develop partnerships and impact systemic education issues through local Special Education Citizen Advisory Committees. Parents and students are mobilized to maximize their participation in, and influence over, the design, funding, implementation, and evaluation of local special education services.

**Supporting Students and Teachers**

The Council has sponsored several projects to provide resources to students, parents and schools. The Tech for Tots project provided students with disabilities the opportunity to try out computer hardware and software and choose the technology that works best in their educational program. The ATLAS project expanded access to assistive technology services by evaluating student needs, establishing a lending library of a.t. resources, and providing training and support to students, their families and school personnel in the use of the technology. The Connections project expanded and refined a co-teaching model in general education classrooms by adapting curricula and extracurricular activities using assistive technology.

**Supporting Child Care and Pre-School Inclusion**

In partnership with the MD State Department of Education, the Council has sponsored projects that provided resources, training and technical assistance to parents, preschools, child care centers, and family day care providers — critical to successful including children with developmental disabilities. Other organizations have expanded on these activities throughout the state. The Council continues to impact childcare policy, training and education in collaboration with the Child Care Administration, parents and other stakeholders.

**Inclusive Education**

The Council funded the establishment of, and has provided long-term support to, the Maryland Coalition for Inclusive Education. MCIE was established to help increase inclusive policies and practices in Maryland’s schools for children with severe disabilities. MCIE provides training and legal representation for families and empowers parents to advocate for the least restrictive educational setting for their children. Over 4,000 families have been served.
Opportunities for work were virtually non-existent in 1971 for individuals with developmental disabilities. Other people’s expectations, outright discrimination and limited training, support and transportation kept many people with disabilities out of the workforce. By 1985, Maryland had an extensive network of activity centers and sheltered workshops. Vocational services became focused on supported employment. The system expanded so that over 3500 people with developmental disabilities were virtually non-existent in 1971 for individuals with developmental disabilities. Other people’s expectations, outright discrimination and limited training, support and transportation kept many people with disabilities out of the workforce. By 1985, Maryland had an extensive network of activity centers and sheltered workshops. Vocational services became focused on supported employment. The system expanded so that over 3500 people with developmental disabilities were supported employment services nationwide. The supported employment system of supported employment that had: incentives for converting existing programs to supported employment; an increased capacity to serve people; and an emphasis on making a successful transition to meaningful work in the community. To achieve this goal, the Council used a variety of approaches including: designing and funding demonstration projects; providing leadership to bring best and promising practices to Maryland; and advocating for increased state funding.

**Maryland Supported Employment Project**

The Council partnered with Kennedy Krieger Institute, private business, state agencies, and other advocates in 1985 to implement the Maryland Supported Employment Project. Through Council support, this project developed a comprehensive system of supported employment that had: incentives for converting existing programs to supported employment; an increased capacity to serve people; and an emphasis on making a successful transition from school to work. Supported employment was expanded statewide to serve 1300 people with developmental disabilities. The capacity of the system expanded so that over 95% of service providers began offering supported employment as an option for people with developmental disabilities and state funded vocational services became focused on supported employment.

**Business Sponsored Supported Employment**

Supports for employees with disabilities are typically provided by an outside agency. In 1988, the Business Sponsored Supported Employment project demonstrated that given initial assistance and philosophical commitment, a business would provide supported employment services through its own internal expertise. With funding from the Council, the project provided training to hotel managers, supervisors and co-workers to support individuals with developmental disabilities to be successful in the workplace.

**Sheltered Workshop Conversion**

Realizing that systemic change requires a variety of approaches, the Council funded several projects in the late 1990’s to convert segregated vocational and day programs to employment services that are more responsive to individual preferences and abilities.

The PDQ Project provided supported employment and integrated community opportunities to individuals who had been served in a sheltered workshop, thereby closing the workshop. This project focused on developing supports for individuals with the most extensive support needs. The Career Development Project restructured an entire agency’s vocational and day habilitation services to increase community-based employment, paid apprenticeships and volunteer opportunities with local businesses.

**Information and Training**

Many people with disabilities do not work because they fear losing their health care and other public benefits. In response, the Council launched the Benefits Resource Network in 1989 and the Benefits Resource Network in 1999 to provide information, advocacy and direct assistance to people with disabilities so that they understand Social Security benefits and effectively use work incentive programs. These projects assisted over 3500 people and laid the foundation for services to be provided to many more people through funding from the Social Security Administration.

**Reliance on institutions reached its peak in the 1960s, segregating people from their families and communities. A shift occurred over the next three decades as Maryland began building educational and community service systems for children and adults with developmental disabilities. Over three thousand people with developmental disabilities once lived in Maryland state institutions. In 2001, approximately 500 people still did. This is 500 too many.**

The service system has begun to support people in ways that not only assure their safety and well-being, but also assist them to experience and engage in all that the community has to offer. For over 30 years, the Council has taken an active lead in promoting the full inclusion of people with developmental disabilities in all aspects of life. Services and supports must continue to evolve in order to ensure that people with developmental disabilities have opportunities to live their lives the way they choose, involved and connected with their families and communities. Without this, segregation and isolation continue.

**Best Practices**

In 1988, the Citizenship Project was at the forefront of supported living services in Maryland by providing individualized supports rather than pre-packaged systems. This Council-sponsored project demonstrated the impact of empowering individuals with the freedom of choice, building community and forming relationships.

Several demonstration projects in the early 1990s, including the Consumer Empowerment Project, continued work toward a more customer-driven service system. These projects encouraged consumer choice and natural supports from the community, and developed individualized supports.

The Council has also undertaken award-winning activities to increase public awareness and support of critical disability issues. Highlights include a radio public service announcement called Slice of Life; Open Minds/Open Doors posters; and Visions of Equality and About Families publications.

**Research**

In 1990, a Council commissioned study illustrated the state’s bias toward funding institutional services while thousands of people waited for community services. The study clearly supported the argument for increased funding for community services and illustrated eventual cost savings through the closure of institutions.

**Expanded Community Resources**

Leading the Home of Your Own Coalition, the Council worked with the Department of Housing and Community Development to develop a mortgage product for people with disabilities and low incomes who otherwise could not afford to own a home — a unique program in the nation. To date, nearly $16M has been committed.

The Council took a lead role in advocating for protections for children and adults with disabilities as the state implemented its managed care system for Medicaid recipients. Continuing advocacy focuses on program implementation and policy development that addresses critical disability healthcare issues.

The Wicomico Transit project has expanded transportation regionally, significantly increasing hours of operation, geographic reach, and the number of people with disabilities with access to work, friends and family, healthcare, and community activities.

**Civil Rights**

In 1999, advocacy led by the Council and 14 cross-disability collaborators resulted in Maryland reversing its decision to join other states in arguing for limited rights for people with disabilities in the U.S. Supreme Court Olmstead case. Many other states followed Maryland’s lead, and refused to support the argument that community options should be limited.
The decade of the seventies saw much social upheaval and advancement in civil rights for women and minorities, while the movement for people with disabilities was in many ways just beginning. This movement became more pronounced in the eighties, culminating in the passage of the Americans with Disabilities Act in 1990. That same year, the reauthorized Developmental Disabilities Act highlighted a movement toward full inclusion of people with disabilities into the broad spectrum of life.

Only through the active involvement of people with developmental disabilities and their families have we seen significant changes in attitudes, laws, programs, and services in all areas of life. The Council has supported people with disabilities and their families in many ways to become empowered, to speak for themselves, and to be at the center of decisions affecting their lives — both personally and at a systems level.

Leadership Development

One of the Council's long-term commitments has been to Partners in Policymaking. Partners builds skilled advocates and leaders through an extensive training program for adults with developmental disabilities and parents of children with disabilities. The project is a partnership between the Council, The Arc of MD and the State Department of Education. Established in 1988 and still active today, the Montgomery Exceptional Leaders project promotes awareness, builds acceptance and empowers students with disabilities to become school and community leaders. The Council has also supported the Youth Leadership Forum, a program for high school students with disabilities emphasizing leadership skills, independence, and career goal setting.

Support of Self-Advocacy Groups

People On the Go's Leadership Now project supported local self-advocacy groups to organize, build, strengthen and sustain their groups and to influence issues important to them.

Support of Advocacy Initiatives

The Baltimore Advocacy Group trained agency staff about the rights of individuals with disabilities and how people with disabilities want to be treated, including making their own choices.

The Campaign for Freedom is a statewide movement to close institutions and support people in the community. Self-advocates are actively involved in legislative advocacy, public awareness, and direct action to accomplish this goal.

Legislative Advocacy

In 2000, the Council established its Legislative Advocacy Support Fund to cover the cost of transportation, personal assistance services and other costs incurred by individuals with disabilities and parents when they participate in the legislative process.

Small Grants

Through small grants, the Council has supported the participation of many people with disabilities and parents at conferences in Maryland and throughout the country where they become informed, network, and impact disability issues.

Self-Determination

The Council sponsored an evaluation of Maryland’s Self-Determination Initiative and a consumer satisfaction survey of individuals who participated in it. The studies noted successes, remaining challenges and made recommendations to expand self-determination practices statewide.

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