



PENNSYLVANIA DEVELOPMENTAL DISABILITIES COUNCIL
2012-16 **STATE PLAN**

OUR VISION

We **envision** a Commonwealth comprised of **inclusive communities** where all people with disabilities are **valued** and **thrive**.

The Council engages in **advocacy, systems change** and **capacity building** for people with developmental disabilities and their families in order to:

- SUPPORT** people with disabilities in taking control of their own lives.
- ENSURE** access to goods, services and supports.
- BUILD** inclusive communities. **PURSUE** a cross disability agenda.
- CHANGE** negative societal attitudes toward people with disabilities.

In so doing we will bring about **benefits** to individuals with disabilities other than developmental disabilities and, indeed, to **all people**.

OUR MISSION



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WHAT IS THE DD COUNCIL?

The Pennsylvania Developmental Disabilities Council is a group made up of people with disabilities, family members, advocates, and cabinet secretary representatives who work to create favorable conditions for people with developmental disabilities and their families in the Commonwealth. Created and funded by federal law and appointed by the Governor, the Council is both a planning and advisory group and a funding body for new approaches to systems change, advocacy and capacity building for people with disabilities and the public, social and cultural systems that surround them.

WHAT IS THE STATE PLAN?

The Council is charged by federal law to create a five year state plan outlining how it will fulfill its responsibilities under the federal Developmental Disabilities Act (PL 106-402). This booklet describes our plan for the years 2012 through 2016.

STATEMENT OF VALUES

Generic Change. The Council has a responsibility to change communities in the broadest, most generic sense. Our work improves the lives, not only of people with disabilities, but of all Pennsylvanians. Our energy is increasingly directed at ensuring that the systems and supports that are available to the community in general are made equally available, with appropriate accommodation, to Pennsylvanians with disabilities. We prefer to improve disability services by making them available in the context of the systems and supports that exist for all people.

Systems Change. The Council has a responsibility to change the systems that impact people with disabilities in Pennsylvania. We are less and less interested in models of accommodation which rely on the person with the disability being the person doing the changing, or which provide temporary help in the context of systems that are broken. All our work, viewed over time and in the context of our interlocking strategies and approaches, must contribute to our broad view of systems change. We do not believe that we can change Pennsylvania one sub-system at a time. We view systems in a wide-reaching way; not just as human service systems, but as the broader and generic social systems and cultures which have an effect on people with disabilities in Pennsylvania.

Natural Part of the Human Condition. The Council believes that disability is a natural part of the human condition. We are not sympathetic to medical models of understanding disability. While we do not deny the importance of medical treatment and medical need, we are more sympathetic to understandings of disability as a social construct imposed on people with disability labels rather than as a quality inherent in the person with a disability. We are not impressed by the model of trying to “help” people with disabilities by making them more like people without disabilities.

Inclusion. The Council is deeply committed to inclusion and integration. We do not like approaches which are segregated, and will not fund “special programs for special people.” We prefer activities to be alongside and integrated with people without disabilities, in regular and generic settings in regular communities. Groups of people with different disabilities congregated together do not constitute “inclusion.”

Cross-Disability. The Council is cross-disability in nature; we try to fund approaches that affect all people with disabilities in common areas of their lives, such as housing, health, employment, community inclusion, etc., and we are especially interested in the cross-disability impact of shared stigma and segregation. Having said this, we are acutely conscious of the vital and important differences in priorities and emphases between different disability communities, and seek to provide opportunities for communication and the sharing of different disability experiences.

Cultural Competence. The Council believes that the skills involved in understanding disability are closely related to the skills which lead to other forms of cultural competence. We believe that disability competence cannot take place in isolation from the embrace of all human diversity. Therefore we seek alliances with all those who are excluded or dispossessed on the grounds of poverty, race, ethnicity or sexuality.

Empowerment. The Council seeks to engage in activities which meaningfully involve people with disabilities, or, if they cannot speak for themselves, their chosen family members, in all areas of their conception, preparation and implementation. We oppose activities which could be construed as doing things for, to, or on behalf of people with disabilities rather than under their direct leadership. We do not fund projects which portray people with disabilities as deserving pity; which, even unconsciously, endorse stigmatization of people with disabilities, or which incorporate portrayals of people with disabilities as the objects of charity or “the least of these.”

THE PLANNING PROCESS

The Council's planning process is on ongoing one. Throughout the last plan cycle we worked with the Pennsylvania Disability Rights Network and Temple University's Institute on Disabilities, our sister agencies under the federal Developmental Disabilities Act, to hold public forums to determine the interests of Pennsylvanians with disabilities and sent out a number of requests, in the form of New Initiatives enquiries, to find out what was not in our plan that people thought we ought to have been doing. The Council and its staff attended meetings and gatherings where interested individuals discussed current problems and issues. Our grantees also worked to evaluate the successes, challenges and impact of their efforts to further inform the planning process.

The formal planning process started with a retreat in the fall of 2009, when we reviewed our work over the last fifteen years, using the Route to Success model, to determine where we had more work to do, where our work had been picked up by others, and where we had reached the logical conclusion of our work in any particular area. We also heard from state and national speakers about impending issues affecting the disability community, families and self advocates, and considered national priorities set by our funding sources and looked at the work and priorities of other Councils around the country.

This led to a year long process of roundtables, ‘listening tours’ and other requests for public input to gather information about themes and patterns of concerns for individuals with developmental disabilities of all ages and their families in Pennsylvania, leading to the development and clarification of the work it was important for us to do in the new plan cycle.

Simultaneously we embarked on a Comprehensive Review and Analysis—looking at qualitative and quantitative data describing the situation of Pennsylvanians with disabilities, and using this “state of the state” to determine where we needed to work, where we could have the most impact, and how we could determine our success.

In the fall of 2010 all of these data—the current situation of people with disabilities, threats to the disability community, our past successes, the types of things we do well, and the priorities gathered from the disability public—were coalesced into a draft plan for the 2012–2016 cycle.

We conducted a listening tour to get initial feedback on our ideas and used the feedback to further refine and revise our plan, which was approved by the Federal government and is presented to you in this document as the culmination of our work.

THE CHALLENGES OF THE NEXT FIVE YEARS

Here are some of the things we learned will be important in the lives of Pennsylvanians with disabilities in the next five years:

- Service Gaps and Waiting Lists
- Disparities in Service
- Changing Demographics—Aging Parents and Human Resource Shortages
- Financial strictures and threats to funding
- Non-Service models of support
- Person Directed Services
- The misuse of medication
- Increases in Autism Diagnoses
- The failure of Employment services
- Abuse and neglect of people with disabilities—Adult Protective Services
- Olmstead, the Community Imperative and Deinstitutionalization
- The shortage of affordable, accessible housing
- The lack of a disability voting block
- Barriers to cross-disability systems—“silo” models
- Poorly developed Quality systems—failure to combine Quality Management and Quality Improvement systems

In addition to these issues, which will affect the service and support system, we also considered the following likelihoods:

- People will continue to try to effect change by changing people with disabilities rather than systems
- Diversity, including disability diversity, will continue to be seen as a challenge rather than a strength
- Disability will continue to be stigmatized and pride in disability identities will be hard to achieve
- Paternalism, disdain and rejection will continue to be the predominant public attitudes towards disability

DOING WHAT WE DO BEST

We wanted only to do things where we could succeed, and considered some of the potentialities that seemed to go into making our past work a success. As a result, we asked the following questions when considering what we would include in this plan:

- Is this Council’s mission, vision and values-related business?
- Does this draw on Council’s unique perspective, capacity and historical strengths?
- Does it move our work forward?
- Is it radical? (Is it a new idea; is no-one else doing it?)
- Is it systemic in its design on at least some level/in at least some context?
- Is it someone else’s business/does it have a home elsewhere?
- Does it have potential for generic impact and change?

HOW OUR WORK PROGRESSES OVER TIME, PLAN CYCLES AND DIFFERENT STRATEGIES

Through its efforts, the Council has learned that systemic change takes significant time and an investment of many different resources. The Council has also learned that the efforts that have been the most successful generally follow a pattern of strategies. Once potential issues and themes are identified, the next step in our strategy “cycle” is often to research a subject or topic to learn more about it. We frequently observe that change starts with small grassroots efforts and thus “demonstration” is the Council’s next strategic step. Grassroots groups that the Council funds experiment to work out the kinks in their ideas and make changes to ensure success.

The Council supports these “first stages” of change through its demonstration or grassroots advocacy projects. It is a crucial step in figuring out new ideas and best practices.

Often, after funding a number of local demonstration projects and seeing what is successful, the Council looks to disseminate this information. Thus, the next stage of the evolutionary process is to “expand and replicate” and it may include:

- Funding additional demonstrations
- Looking for opportunities for projects to share their efforts with others through technical assistance, or
- Disseminating information about the project, its outcomes, and implications for others

After the Council has done its fact finding, research, supported demonstrations of new ideas, and overseen the expansion and/or replication of those ideas, the Council’s final step is to work with stakeholders in their activities which advocate for systems change at a larger level. The Council often brings together larger groups of people, through project gatherings, stakeholder groups, roundtables and the like. Coalition building begins or existing coalitions become engaged in the new ideas and efforts.

At this point in its strategy cycle, the Council considers how larger, regional or statewide systems, policies, or governmental structures can be changed for the better to support the new approaches and ideas which were demonstrated through small, successful grassroots or local level projects. The projects targeted at this scale of effort are what most people might recognize as the Council’s larger systems change projects. They might look at passage of legislation, changing regulations, standards or funding practices, or addressing stigma and public awareness across the Commonwealth.

THE ROUTE TO SUCCESS

The Route to Success is a model which we used in analyzing old and new ideas for our systems change work. It is a model we developed over the last seven years, along with the Human Services Research Institute in Massachusetts, and the Institute on Disabilities at Temple University. It delineates the component steps of successful systems change work, and offers up possibilities for both new directions and determinations that our work in a particular area is over. We used it to determine how to advance our work in certain areas, and, on other areas, to determine that there was no more we could do, or that this was not an area in which we could make the best use of our resources. It is described in some detail on our website at www.paddc.org.

THE “CLUSTERS”

The Council, in its planning, viewed its work as arranged in the following “clusters.” These are mostly Areas of Emphasis as determined by the federal government, but some are unique to the Pennsylvania Council. In each cluster, we considered the progression of our work over the last fifteen years and identified incomplete opportunities, redundancies and tasks completed or no longer a best match with the unique skills and capacities of the Pennsylvania Council.

Many of the clusters will interact with each other and it will be our challenge to organize our operational structures to ensure that this is facilitated to the greatest degree possible.

THE “CLUSTERS”:



THE OBJECTIVES

The following are the Objectives of each Council Committee for the 2012-2016 State Plan:

ACHIEVEMENT COMMITTEE

Changing the Cultural Context within Schools

Carry out a series of roundtables, technical assistance opportunities and other forums that would focus on coalition building and changing the cultural context within schools regarding Inclusive Education.

Parent Leadership in Inclusive Education

Develop parent leadership expanded to kids who are off the radar—home schools, charter schools, cyber schools, Private and Parochial schools, etc. This builds on current work.

Best Employment Practices Research

Research and identify employers deemed by people with developmental disabilities to have best practices and attitudes for successful disability employment. The core question is whether there are identifiable employment practices which people with disabilities deem conducive to disability employment. Recommendations will be used as a basis for discussion and implementation of the following objective.

Best Employment Practices Implementation

Recommendations from the above objective will be used as a basis for implementation of this objective. If employment practices conducive to disability employment are identified, these can not only be publicized to people with disabilities but there can be advocacy for generic change, with old and new allies, in the employment practices of all employers.

Health Care Reform

Potential goals of this objective are dependent on a round table discussion to be held in November which will identify areas in which the unique roles and capacities of the DD Council could be applied to ensure the effective implementation of health care reform to the benefit of Pennsylvanians with disabilities.

Transition to Adult Life

Develop a replicable approach to transition to adult life in a statewide, systemic manner, including work on college life transitions, using the strategies/practices identified at a Transition Summit to be held during current plan in conjunction with DD Act partners.

Aging Transitions

Identify issues related to service transitions and life transitions that affect Pennsylvanians with disabilities as they grow older and to make recommendations for further research, demonstrations and advocacy in this area.

EMPOWERMENT COMMITTEE

Grassroots Advocacy Grants

Fund a small grants program which enables grassroots groups and organizations to pursue advocacy goals of a self-determined nature which are consistent with Council's Mission, Vision and values.

Disability Advocacy Support

Support grassroots and other advocacy efforts through trainings, intensive technical assistance and limited networking/coordination activities. Includes emphases on cross-disability approaches and on supporting the organization and networking of parent groups.

Self-Representation on Boards

The Council currently has a grant focused on ensuring that self advocates are meaningfully included on boards, focusing on statewide disability organizations. This grant will continue this work with a focus on generic boards.

Leadership Development

The Council has a long history of funding Leadership Development activities impacting many different audiences over time. The current Leadership Development project focuses specifically on people with disabilities. Past grants have focused on parents of young children, people with disabilities and family members, etc. The Council notes that there has not been a specific effort to address youth becoming leaders but entertains the idea of funding continued efforts to develop parent leaders as well as continuing work to have people with disabilities become leaders.

Self-Advocacy Support

Support the establishment and operations of a statewide self-advocacy network managed and run by people with disabilities.

Disability Voting Rights

Continue to grow the disability voting block and expand into general civic engagement. To address barriers to voting for people with disabilities, including physical barriers, barriers to information disseminated by candidates, etc.

Person Driven Services

Person Driven Services would focus on a cross-disability effort to demonstrate that when people have control of their services there are positive outcomes both personally for the individual and financially for the service system providing the resources. This type of demonstration project would be followed up by strong advocacy for systems change.

ENGAGEMENT COMMITTEE

Community Accessibility

Re-visit original intent under the Community Accessibility grant—broadly addressing access throughout all facets of a community. The original Objective was: "To increase inclusion in generic community events, functions and civic opportunities for Pennsylvanian citizens with disabilities."

Stigma

Implement the recommendations of a current project which is identifying best practice in stigma education, cross-disability, cross-nationally and using multiple media, especially new media.

Criminal Justice Disability Awareness

A project to provide information and training curricula to the personnel of the criminal justice system (court officers, prison officers, etc.) in disability awareness, rights and etiquette. Should be applicable across the various criminal justice systems in PA and closely involve criminal justice personnel in its preparation, approval and delivery. Should have curriculum or video and a plan for its dissemination and ongoing availability as a product.

Emergency Preparedness

Ensure that people with disabilities are "at the table" in emergency planning discussions at all levels across the Commonwealth. Ensure that people are not planning for people with disabilities without having direct input from people with disabilities.

Cross-Disability Efforts

Work to replicate conversations from the SILC conference and other venues across geographic communities across the Commonwealth, identifying cross-disability continuities and discontinuities, fostering understanding, and developing a knowledge base about where, when and how different disability groups can work together.

Congregate Care

Preserve the capacity in the plan to continue the internal work being done in identifying what numbers of children are being held in what types of congregate care for how long and at what cost. This would build on the current inter-departmental work.

PIE WORK GROUP

Policy Information Exchange

Support the exchange of information between policymakers and the disability community.

COMMUNICATIONS/PUBLICATIONS WORK GROUP

Communications and Publications

Tell the Council's story through print and other media.

ADMINISTRATIVE

Meetings Coordination

Facilitate meetings, memberships and Council functioning.

REPRESENTATION ON BOARDS AND COMMITTEES

Continue Council representation on policy-making boards and committees, including, but not limited to:

- Governor's Disability Cabinet
- DPW-Stakeholder Planning Team
- State Interagency Coordinating Council
- ODP-Planning Advisory Committee
- PA Transition State Leadership Team
- PDSS Steering Committee
- IM4Q Statewide Steering Committee
- Family Support Advisory Council
- Personal Care Home Coalition

EVALUATING OUR WORK

We view our work as having an impact on much larger systems and processes than those we control directly. We view ourselves as having a marginal, yet sometimes seminal, influence on bigger human, social and cultural systems. This makes it hard to measure the outcomes of our work, because the outcomes, in terms of impact on larger systems, are indirect, convoluted and often take many years to achieve. We work to evaluate our efforts in a variety of ways:

- by testing the efficiency with which we engage in systems change;
- by measuring the outputs of our efforts, and, where possible,
- by evaluating the end effects of changes in the systems we have worked to improve.

We do this by measuring publications and other products developed by grantees, primary and secondary effects, by convening focus groups of our significant stakeholders, and by using the Route to Success model to ensure that the processes in which we are engaged are state of the art in terms of achieving systems change. It is a work in progress, and we invite all those who are interested in our work, our members, stakeholders and grantees, to join with us to ensure that our efforts do not go in vain and work at all times to fulfill our Vision and Mission.

PUBLIC INPUT

Input to our plan is a long term and continuous process, gathered from public forums held with our sister agencies as noted previously throughout the life of the plan, from invited national and state experts, from participation on statewide bodies, from input to our New Initiatives process, and from the learning produced by all our grantees, both large and small. We would particularly like to thank all those who participated in our "Listening Tour" in late 2010, and who commented on our first, draft ideas for this plan. We appreciate your input and hope we have learned from it. You may send comments on this plan to us at any time at info@paddc.org. We look forward to hearing from you.

HOW TO CONTACT US:

PADDCC HARRISBURG OFFICE:

Room 561 Forum Building
605 South Drive
Harrisburg, PA 17120

Phone: 717-787-6057 | Toll Free: 1-877-685-4452

Fax: 717-772-0738 | TTY: 717-705-0819

E-mail: info@paddc.org

PITTSBURGH OFFICE:

8500 Brooktree Road, Suite 100
Wexford, PA 15090
Phone: 724-933-1655

www.paddc.org





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