

*Pennsylvania Developmental Disabilities Council
2007 Annual Report*

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*(Representing the Secretary of
Public Welfare)*

Amy Deluca, Pittsburgh
(Representing the Secretary of Education)

Katrine Erie, Butler

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*(Representing the Institute on Disabilities
at Temple University)*

Barbara Fenton, West Newton

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Joan Ober

Roxann Wright



This annual report is being issued at the start of our new, five-year state plan, providing an ideal opportunity to reflect on the accomplishments of our previous plan.

Many of the outcomes and the numerical enumeration of our accomplishments are written in this report according to federal "Areas of Emphasis." These are the broad aspects influencing the lives of people with disabilities in which we engage in our advocacy, capacity building and systems change work. Beyond those accomplishments are lessons that we have learned working on the previous plan, which in turn informs our new state plan, as well as the plan that will follow it beginning in 2011.

One thing we have learned is that sometimes our work does not fit neatly into particular areas of emphasis. Transition of youth with disabilities to adult life, for example, spans education, employment, housing, recreation and health. Capitalizing on the skills of lawyer's touches many areas of people's lives, and even something as apparently discrete as work with faith communities, touches lives in many and various ways.

Another thing we have learned is that there is an ongoing dynamic in our work. We have had many projects that started out as local demonstrations, which led to recommendations and advocacy for large systems change. At the same time, we there are instances where we have worked to make great systems ideas actually work "on the ground," at a local level. Our work with personal care homes is a good example. Without showing how seventeen people residing in personal care homes could change their lives, there would have been no impetus to demonstrate the need to change the way the personal care allowance follows people as they move from such settings. Without changing the way the money flows, we would not have been able to support sustainable personal change beyond the period of our funding.

Lastly and in all humility, we have learned that the benefits and changes resulting from the Council's initiatives and funding, are not solely due to our organization, or even necessarily occur during the period of our involvement. Dedicated others take these ideas and work with imagination and energy to see them bear fruit for years to come. With time, they take these new ideas far beyond what we ourselves could ever do. Many of these contributors are our grantees; some are our members; and some are our allies in the disability community. It is to our friends and partners, who take our initiatives and make them grow, and keep growing, that we dedicate this report.

sincerely,
Graham Mulholland
Executive Director

Life Goal: Quality Assurance

- T**he focus of the Council's Quality Assurance activities took three, overlapping forms:
- Development of advocacy and leadership skills to promote self-determination and empowerment for people with developmental disabilities or their families.
 - Participation in an extensive array of groups and task forces which impact the quality of service systems, and;
 - Information sharing, coalition building, and cross disability exchanges to promote quality and enhance opportunities.

For example, the Council's leadership development and self-advocacy initiatives raised awareness of self-advocacy and created self-advocacy groups where few existed before. Additionally, the C2P2 program graduated 38 youth and parents from its intensive leadership program focused on transition to adult life. High quality disability rights educational opportunities and support for parent group formation significantly supported the Council's quality assurance goal. Participation in groups and committees was widespread, involving those at all levels of the Council, including Council members, staff, and grantees. Many of these groups and committees grew out of past initiatives of the Council and its grantees. New quality assurance activities included the initiation of a grassroots "Money Follows the Person" movement in support of people living in personal care homes; an abuse prevention curriculum for people with intellectual disabilities; cultural competency improvement plans for all grantees, and Council representation on a newly created Governor's Disability Cabinet alongside 14 cabinet Secretaries.

Quality Assurance Outcomes

People benefiting from quality assurance efforts of the Council:
2,134

People trained in quality assurance:
1,400

People trained in systems advocacy:
1,554

People trained in leadership, self-advocacy, and self-determination:
2,326

Entities participating in coalitions as a result of the Council's efforts:
193

People with disabilities and family members who served as board members of local IM4Q programs:
248

Life Goal: Community Supports

The Council's goal in the area of community supports is one that encompasses many unique aspects of community life. One targeted area of community support focus for the Council was on transition of youth with disabilities from school to adult life. Grantees created person-centered transition models, demonstrated individualized support concepts, and disseminated "how to" materials in support of youth with disabilities as they transition. A conference called Beyond Barriers to Passion and Possibilities was held and was attended by 600 students and 250 educators, with 60 employers participating in the conference's job fair.

Minority led organizations continued their work to identify service gaps and disparities as well as demonstrate culturally competent community services. For example, one program created a model of educational support for children with sickle cell disease who have difficulty staying current with school amid frequent illness and/or hospitalization. Another project offered culturally competent support to Korean families who have children with disabilities.

In the area of criminal justice, the Council was able to write and disseminate a position paper, made widely available through the Council's website. Additionally, a video was produced by a grantee and titled, "Under Arrest: Understanding the Criminal Justice System." The goal of this product was to educate people with developmental disabilities about the potential experiences of offenders in the criminal justice system.

Finally, a new initiative began creating a cross-disability training for first responders in order to meet the emergency needs of people with disabilities. The first responder initiative has garnered a great deal of interest and community support in a short period of time.

Community Support Outcomes

Individuals who benefited from formal/informal supports as a result of Council's efforts:

1,870

Children with sickle cell disease who received community educational support:

32

Families of Korean descent who received information, referral and advocacy support:

30

Community supports programs/policies created or improved:

112

People trained in official/informal community supports:

558

People trained in systems advocacy about formal and informal community supports

1,208

Building or public accommodations that became accessible:

47

Criminal justice DVD's and training manuals distributed:

100

Parents with developmental disabilities who received parenting skills training:

120

Youth with circle's of support to assist in transition to adult life:

39

Transition to adult life manuals distributed:

260

"Transitioning is difficult for everyone, not just people with disabilities. Individuals should not have to go through the process alone; they should have a circle of support. Realistic dreams and achievable goals will help make transitions easier and more successful"

Matthew DiMarco, Project Manager

Life Goal: Employment

Several project objectives focused on the Council's employment goals. In order to determine the usage of financial incentives, a grantee developed a web site for employers to reference and download forms (<http://www.employmentincentives.com>). Additionally, a manual explaining incentives as well as other employment related information was compiled and distributed widely. Within the Business Leaders Network established by Council funding, free teleconferences were created to share specific disability related information. Business callers could receive individualized technical assistance and networking support. A ten-week public relations campaign was instituted statewide with 30-second commercials promoting employment and the BLN. Additionally, a project began that will create, promote and maintain entrepreneurial opportunities for people with disabilities.



Employment Outcomes

Employment programs and policies
created or improved:
207

People trained in employment:
1,185

People trained in systems advocacy
about employment:
703

Employment incentive manuals distributed:
101,366

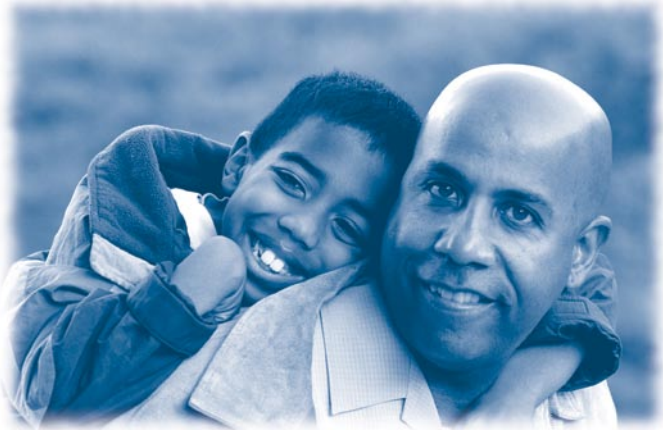
Commercials shown on employment of
people with disabilities:
180

Businesses participating in the Pennsylvania
Business Leaders Network:
250

People with developmental disabilities
employed as systems monitors
through the IM4Q program:
189

Life Goal: Education and Early Intervention

Two new educational rights projects started their work to provide information and mentoring to families of children with developmental disabilities regarding educational rights. In the first six months, one project held a successful statewide inclusive education conference and another project was well underway in the creation of a training module for inclusive education in area districts. Parent mentors were identified in both projects. Other grantees provided families and other stakeholders with information about public policy, legislation, and regulatory matters related to early intervention and education and facilitated communication on these matters with state policy makers.



Education and Early Intervention Outcomes

Students who have the education and support they need to reach their educational goals through Council efforts:

970

People facilitated inclusive education:

1,848

People active in systems advocacy about inclusive education:

1,749

Parents or guardians trained regarding their child's education rights:

913

School Districts trained in inclusive education issues:

100

“Ultimately, our project will create a ripple effect because we will train parents to train other parents and teachers, who will in turn train other parents and teachers, and so on. Collaboration among parents and educators is our focus.”

*Lindsey Walker,
PEAC Project Manager*

Life Goal: Housing

In the area of housing, the Council's work focused on two primary areas:

- Coordination and technical assistance for housing and
- Housing transition for people living in personal care homes.

The housing coordination grantee provided individuals with disabilities, families, and local housing affiliates with training on new resources, financing, design, and accessibility for affordable housing options. A popular website for information on housing was highly used throughout the report period. Through advocacy and individual support, people living in personal care homes transitioned successfully into community life and new housing options of their own choice. Advocacy efforts focused on allowing available funding to 'follow the person' to support individual home choices rather than \$ being tied to a program or building.

Housing Outcomes

People trained in housing:
613

People trained in systems advocacy
about housing:
489

Individuals who have homes of their choice
as a result of Council efforts:
17

Average monthly website visits to learn
about housing opportunities:
2,500



*"I've been through a lot in my life and have not lived on my own
or with my family for a long time.*

*My mother taught me how to cook, clean, do my laundry
and keep myself looking nice.*

When I lived in a personal care home I didn't get to do these things for myself.

*At first I was scared that I had lost all the skills
that my mother had taught me,*

but after moving in here and I found that I hadn't lost those skills at all.

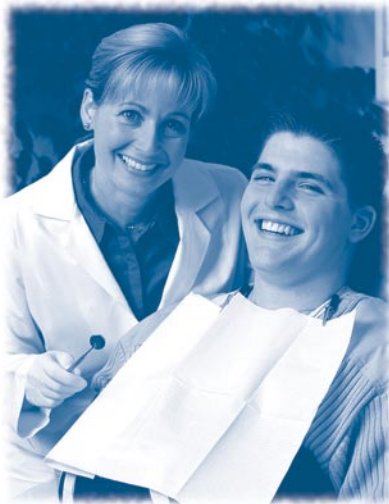
That made me so happy. I didn't expect that my life could be so good."

RT

(after moving from a personal care home to a home of his own)

Life Goal: Health

Several crucial health-related areas received the Council's attention. First through a variety of opportunities, grantees provided advocacy and training for people with disabilities and families on rights, responsibilities, and grievance procedures under managed care. A consumer evaluation of the Health Choices managed care was conducted through focus groups with individuals using the program. A report of the results was produced and distributed. Finally, adult primary care physicians, family practitioners, adult specialty practices, youth with disabilities or chronic medical conditions, and families received materials and education so that young adults with disabilities and/or chronic health conditions successfully transition from pediatric providers into the adult medical care system.



Health Outcomes

People trained in health policies or systems advocacy about health:
1,304

Health programs and policies created or improved:
44

Individuals receiving training on health transition and medical home model:
390

Adult care medical providers in process of becoming medical home practices:
17

Life Goal: Childcare

Inclusive childcare for children with disabilities has received intensive focus from the Council in recent years. During this report year, the Council's grantee provided statewide training and technical assistance to childcare providers. Efforts focused on the identification of family mentors who will be prepared to work with child care staff to provide family perspectives as centers develop inclusive practices. Consultants, mentors, and state service systems were trained in inclusive practices and universal design for learning (UDL). A video that outlines principles of inclusive childcare, UDL, and a virtual tour of their "Best Practices" Reibman Children's Center was produced and distributed.



Childcare Outcomes:

People facilitating
inclusive childcare:
148

People active in systems advocacy
about child care:
75

Childcare policies improved
or created:
62

Life Goal: Recreation

The Council grantees in the area of recreation worked to build relationships, friendships, and team spirit through inclusive leisure activities. While new projects had just several months to operate during this report year, they successfully provided community training on inclusive recreation opportunities. Additionally, projects made connections with generic community recreation or leisure organizations such as Girl Scouts, YMCA's and community centers with the goal of building partnerships to enable full participation for children and adults with disabilities in their self-determined areas of interest. Finally, a Council grantee began its focus on providing consultants to event planners for one time or annual community events, such as festivals, to assure the events were inclusive and accessible for people with disabilities.

Recreation Outcomes

People trained in aspects of
inclusive recreation:
169

Groups interested in providing
recreation opportunities:
25



Life Goal: Transportation

During the report year, the Council's successful "Rural Transportation" project ended. Due to the grantee's work, 77,000 riders from 4 counties in Pennsylvania were served. The Council's "Transportation To and From Work" grantee initiated advocacy that resulted in the rural transportation program being expanded statewide in the next (08-09) fiscal year. Looking to the future, in October 2008 the program anticipates completing the one millionth ride since the inception of the Council's efforts.

Transportation Outcomes

People who have transportation
services through Council's efforts:
10,512

Dollars leveraged from transportation:
\$4,800,000

People active in systems advocacy
for transportation:
367



Council Internal Activity and Participation

In order to comprehensively address all of its goals, the Council participated in a multitude of stakeholder groups, committees, and planning teams. Below is a sample of those entities:

- Human Relations Commission
Disability Stakeholder Committee
- Governors Disability Cabinet
- Office of Public Health Preparedness'
Special Populations Workgroup
- Statewide Independent Living Council
- Community Advocacy Coalition
- Institute on Disabilities Community
Advisory Council
- State Interagency Coordinating Council
- Disability Rights Network of Pennsylvania
Mental Health Advisory Council
- IM4Q Statewide Steering Committee
- Advisory Council on Deaf Blindness
- Office of Developmental Programs PAC
- Stakeholders Planning Team

In an effort to assess the impact of our work to inform the general public and relevant policy-makers, all Council funded projects collected outcomes regarding information sharing. Some of the notable outcomes included over 5000 copies of 5 issues of public policy newsletters were distributed. Over 2000 copies each of 4 general Council newsletters, as well as an electronic version of this newsletter were produced. These newsletters covered issues ranging from Criminal Justice to Collective and Local Advocacy. There was a major redesign of the site received 58,260 page-views from 35,260 unique visitors during the report period. New website features included enlarged print feature, visual controls, enhanced calendar, link manager

and a RSS feed. The RSS feed is a way to easily distribute headlines and updates from the website, helping those with a high interest in the Council's work to find the updates quickly.

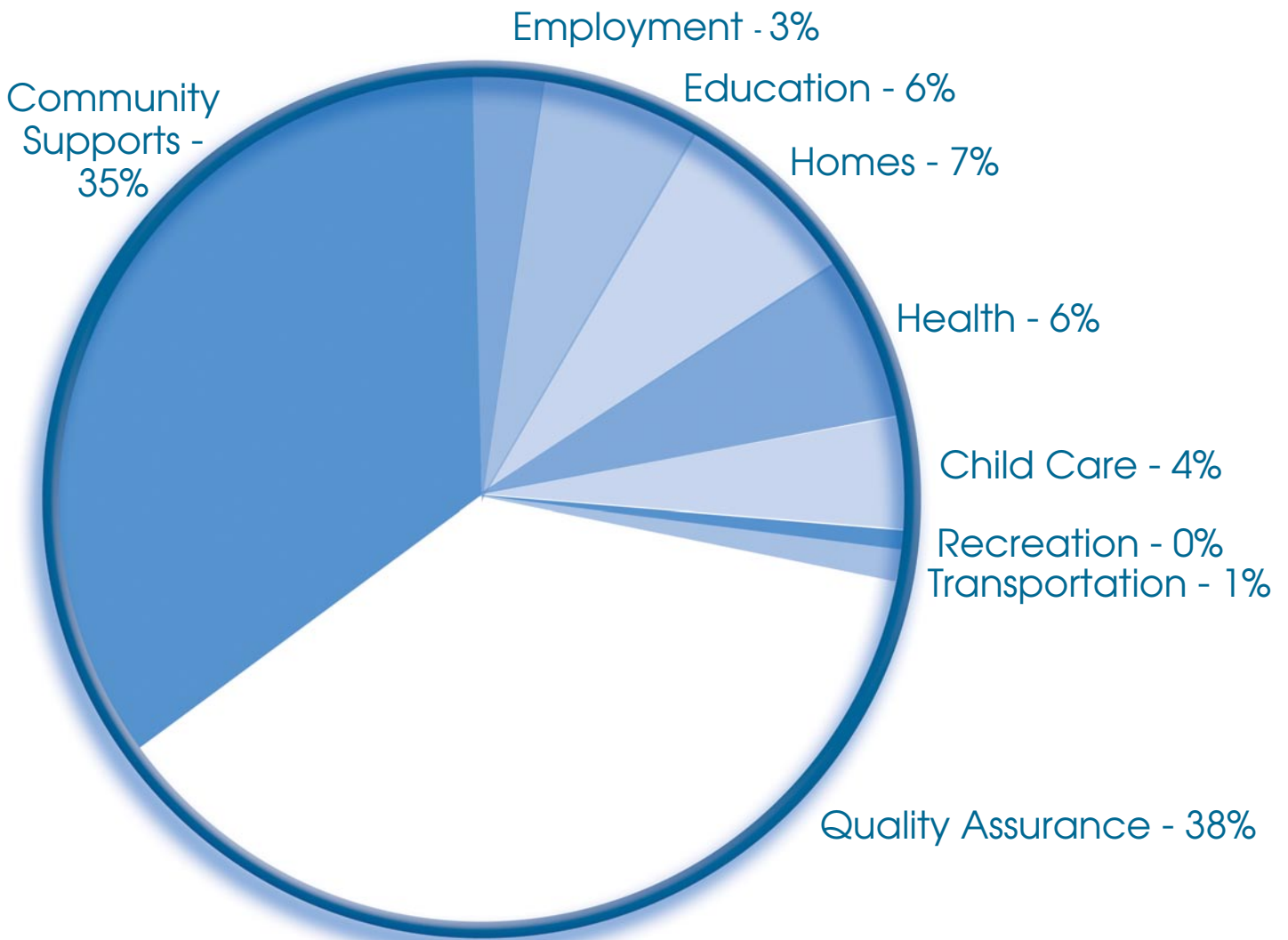
Internal Capacity Outcomes

Public policy makers educated by Council related to Council initiatives:
649

Copies of products distributed to policy makers on issues related to Council's initiatives:
245

Members of the general public estimated to have been reached by Council's public education, awareness and media initiatives:
305,249

Federal Fiscal Year 2006



Employment	\$ 58,060.00
Education	\$ 128,715.00
Homes	\$ 149,631.00
Health	\$ 121,642.00
Child Care	\$ 84,513.00
Recreation	\$ 6,635.00
Transportation	\$ 10,900.00
Quality Assurance	\$ 790,935.00
Community Supports	\$ 790,811.00
Total Grants	\$2,071,842.00
Administrative	\$ 853,176.00

THE COUNCIL'S GRANTEES - January 2008

Abuse Identification and Reporting

Pennsylvania Coalition Against Rape (PCAR),
Enola, PA

Accessible Dental Services

ACHIEVA,
Pittsburgh, PA

Building Inclusive Recreational Opportunities

Lehigh Valley CIL,
Allentown, PA

Community Living and Support Services (CLASS)
Pittsburgh, PA

Arc of York, PA,
York, PA

Business Leaders Network

AHEDD,
Camp Hill, PA

Collective Advocacy Grants Program

Center for Independent Living of
North Central Pennsylvania,
Williamsport, PA

Communications/Publications

Community Living and Support Services (CLASS)
Pittsburgh, PA

Council Archives

Lehigh Valley CIL,
Allentown, PA

Criminal Justice

Temple University, Institute on Disabilities,
Philadelphia, PA

Cultural Competency Standards

AIDS Services in Asian Communities (ASIAC),
Philadelphia, PA

Developing Leaders

Temple University, Institute on Disabilities,
Philadelphia, PA

Disability Rights Advocacy Education

Disability Rights Network,
Philadelphia, PA

Educating Medical Professionals in the Community

PA Academy of Family Physicians,
Harrisburg, PA

Educational Rights

PEAL Center,
Pittsburgh, PA

PA Education for All Coalition,
Norwood, PA

Entrepreneurship

Volunteers of America,
Sharpsburg, PA

Evaluation

Human Services Research Institute,
Cambridge, MA

First Responders Disability Awareness

Family Services Association of Wyoming Valley,
Wilkes Barre, PA

Health Law Education

PA Health Law Project,
Harrisburg, PA

Housing Advocacy Coordination

Self-Determination Housing Project,
Downingtown, PA

Inclusive Child Care

(continued on page 13)

THE COUNCIL'S GRANTEES - January 2008

continued

Northampton Community College,
Bethlehem, PA

Local Advocacy Organizing Coalitions

The Arc of Delaware County,
Swarthmore, PA

Life and Independence for Today,
St. Marys, PA

Mental Health America of Allegheny County,
Pittsburgh, PA

Local Disability Coordination and Training

Disability Rights Network,
Harrisburg, PA

Minority Community Grants

Korean Community Development Services Center,
Philadelphia, PA

South Central Pennsylvania Sickle Cell Council,
Harrisburg, PA

Personal Care Boarding Homes Demonstration Project

Disability Rights Network,
Harrisburg, PA

Policy Information Exchange

UCP of PA,
Camp Hill, PA

Research on Transportation To and From Work

RTR Associates,
Pittsburgh, PA

Self Advocacy and Support

Speaking for Ourselves,
Lansdale, PA

Self Directed Support Corporations

PA Health Law Project,
Harrisburg, PA

Special Projects Grants

The Arc of Chester County,
West Chester, PA

The Arc of Dauphin and Lebanon Counties,
Harrisburg, PA

The Arc of Indiana County,
Indiana, PA

Community Resources for Independence,
Erie, PA

East Suburban Citizen Advocacy,
Murrysville, PA

Lancaster disAbleD for Change and Justice,
Lancaster, PA

Northeast PA Center for Independent Living,
Scranton, PA

Spectrum Community Services Inc.,
Bethlehem, PA

Vision for Equality, Inc.,
Philadelphia, PA

Youth Advocate Programs, Inc.,
Harrisburg, PA

Transition to Adult Life

United Disabilities Services,
Lancaster, PA

Neighbours, Inc.,
Drexel Hill, PA

Transition: School to Adult Life

Berks County Intermediate Unit,
Reading, PA

Transition: Community of Choice

United Disabilities Services,
Lancaster, PA

