

PROSPECTUS ON DISABILITY
for the
COMMONWEALTH OF PENNSYLVANIA
prepared by the
PENNSYLVANIA COUNCIL
ON
INDEPENDENT LIVING

INTRODUCTION

Even the most casual of observers has noticed our arrival. We have arrived not at a place, but a time. It is a time of dramatic change in our attitude about ourselves and, to a lesser extent, the attitudes of others about us. We are Pennsylvanians who have disabilities. We number in the hundreds of thousands. Anyone can join our ranks at -any time, and most people do so as they age.

We have emerged from centuries of social isolation and a resulting dependence. So strong is our desire for independence that a worldwide movement has resulted and **we are the leaders**. We have begun to reshape public policy regarding disability and will - continue to do so. Policies made by others without our concurrence have been based upon "charity" and "segregation" forcing us to compete with each other for limited resources. Our input is essential in developing strategies that allow us to empower ourselves.

We are redefining the problem of disability to look at the person as a resource, with barriers as the handicapping condition. These barriers are sometimes architectural, but more often are reflective of the attitudes and prejudices that have been reinforced for generations. They have deterred us from working, have left most in poverty, and too often have forced the State to house us in institutions. The economic advantages of examining disability from our perspective makes great sense for the Commonwealth and, more importantly, for us.

Ours is the newest of the social equality and civil rights movements. Many of us never before recognized our collective abilities and are still learning to speak with a unified voice. Our movement has a clear philosophical base with guiding principles and agenda for change. We intend to enter the twenty-first century as equal partners with our non-disabled counterparts, enjoying the same options and opportunities in housing, employment, recreation, transportation, etc. This goal will be accomplished with the help of our colleagues in government, business, industry and community.

GUIDING PRINCIPLES

The Commonwealth of Pennsylvania is rapidly emerging as the national leader in effectively addressing the needs of its citizens with disabilities. This is particularly true of the state's Vocational Rehabilitation, Attendant Care and Independent Living Center programs. Most recently, Pennsylvania has applied for federal Medicaid waivers that allow recipients to manage and control the services that they receive. Each of these initiatives are exceptional due to their adherence to an established set of guiding principles that simultaneously empower the consumer and free the state of unnecessary control over the individual. Extension of the following ten principles into all programs and services is a necessity for citizens with disabilities to become and remain equal partners in society.

Cross Disability Emphasis. As a matter of practice, offices, programs and services designed to assist individuals with disabilities should provide services without regard for the type of disability. Thus, the specific condition is de-emphasized and attention shifted to promoting ability and self-sufficiency.

Consumer Direction. People with disabilities should direct and manage the organizations that provide services to them. Further, qualified individuals with disabilities should hold key posts in government, particularly in the departments and offices that administer disability related programs.

Consumer Control. People with disabilities must be afforded the opportunity to fully direct and control the individual services that they receive, including responsibility for the desired outcome.

Access. People with disabilities must be afforded access to the same programs, services, facilities and opportunities as the general population as required by the Americans with Disabilities Act (ADA). The segregation of disability related initiatives should be avoided.

Skill Acquisition. Services and supports should be provided in a manner that promotes the acquisition of the skills necessary to achieve maximum independence and self-determination as defined by the person with a disability.

Peer Approaches. People with disabilities should mentor their counterparts in defining and obtaining goals for social, functional and economic independence.

Choice. People with disabilities must be afforded the right to make informed choices as to how they live, work and play that are comparable to their non-disabled counterparts. This includes the opportunity to take any risks and responsibilities associated with their decisions.

Civil Rights. Programs, services and opportunities must be afforded in a manner that - promotes, and does not subrogate, individual civil rights.

Self Reliance. Programs, services and opportunities must be afforded in a manner that ensures individual determination and the corresponding reliance on ones own skills and abilities.

Empowerment. Participation in the community by an individual with a disability should be an empowering experience with programs, services and opportunities structured accordingly.

There is an undeniable inter-dependence among each of these ten guiding principles, whereby, the absence of any one diminishes the realization of the others. Regrettably, traditional approaches toward disability, and the corresponding public policy, are rarely compatible with these principles. While some change has been realized, established systems in government, health care, insurance and long term care contain an extremely strong bias toward protective, prescriptive and paternalistic methods of assisting individuals with disabilities. Substantial and prolonged efforts will be necessary for the integration of all these guiding principles into every aspect of society.

MAJOR CHALLENGES

Several recent national studies conducted by Louis Harris and Associates Inc. reveal the following:

- Two -thirds of all Americans with disabilities between the ages of 16 and 64 are not working. Of those working, only 1 in 4 work full time, another 10% work part time.
- Sixty -six percent of working age people with disabilities who are not working say they would like to have a job.
- Six out of ten people with disabilities who are not working depend on insurance payments or government benefits for support. The majority of these individuals provide the primary financial support in their household.
- The group receiving government benefits tend strongly to have less education, less money and be more significantly disabled.
- Ninety- two percent of all people believe decreasing barriers and increasing access is the least society can do to help people with disabilities.
- Ninety-eight percent of Americans believe everyone, including people with disabilities, should have equal opportunity to participate in society, and most are willing to spend the money it takes to integrate people with disabilities into mainstream America.

Clearly, significant changes to the current system of addressing the needs of Pennsylvanians with disabilities are needed. Much of what exists today is designed around the archaic notions of the past. There exists a strong emphasis on a medical model that is costly and counterproductive. This model emphasizes a "care for the person" mentality that over-encumbers the state with responsibility and a corresponding expense. Approaches must change to assume that the individual is capable of self-determination, thereby reducing the state's responsibility, with a proportionate drop in cost. Resources must be redirected away from care and toward support. The numerous incentives promoting reliance on institutional models of care must be eliminated in favor of policy and regulation that promotes individual choice. Education and advocacy initiatives, implemented by people with disabilities themselves, must complement all systems change activities. Initiatives assisting children with disabilities must be designed based on current best practices, to avoid inflicting outdated notions on yet another generation.

As is the case with any shift in policy, no matter how appropriate or popular, special interest groups will look to delay change. Due to the historical lack of comprehensive approaches, individuals with certain disabilities have been afforded significant supports, while the needs of others have gone unrecognized. A system of "haves and have-nots" is the result. Programs and supports must be modified on a cross-disability basis to assure that all people have access to the services that they require. Further, our current systems tend to be provider driven with a multi-level government structure. Power and control of resources is sometimes as entrenched in bureaucracy as are the attitudes that foster dependence. A commitment to stay-the-course in assuring a cross-disability emphasis is a necessity.

The need for systems change notwithstanding, fully implementing the desired level of consumer direction and control within a state government system is a monumental challenge. However, many of the key components necessary to address this challenge currently exist, and simply require proper coordination. The Pennsylvania General Assembly has demonstrated a keen interest in advancing consumer direction by unanimously adopting The Independent Living Services Act (Act 139 of 1994), which mandates that people with disabilities be fully involved in the planning, management and implementation of the independent living services that they receive.

PRACTICAL APPLICATIONS

The Commonwealth of Pennsylvania must continue those practices that are consistent with the guiding principles set forth previously. Affirmative steps must be taken to integrate these principles into all services, programs, initiatives and departments that touch the lives of individuals with disabilities. Finally, the system must be modified to remove the many and costly disincentives to personal independence by placing control over planning and implementation in the hands of individuals with disabilities. First step initiatives toward operationalizing the guiding principles are as follows:

- **ORGANIZE EXISTING SERVICES INTO A SEAMLESS SYSTEM THAT IS REASONABLY AVAILABLE REGARDLESS OF DISABILITY TYPE, AGE, INCOME AND LIVING ARRANGEMENT.**
- **ADOPT THE GUIDING PRINCIPLES NOTED EARLIER AS COMMONWEALTH POLICY IN ALL DISABILITY RELATED PROGRAMS AND SERVICES.**
- **ESTABLISH AN OFFICE OF DISABILITY SERVICES IN THE DEPARTMENT OF PUBLIC WELFARE WITH THE AUTHORITY AND THE RESPONSIBILITY TO BEGIN THE COORDINATION OF DISABILITY RELATED PROGRAMS AND SERVICES.**
- **APPOINT A DEPUTY SECRETARY ON DISABILITY SERVICES AND POLICY TO OVERSEE THE OFFICE OF DISABILITY SERVICES, TO DEVELOP PLANS FOR SYSTEM IMPROVEMENTS AND TO COORDINATE ACTIVITIES WITH THE EXISTING STATE INDEPENDENT LIVING COUNCIL (SILC).**
- **LEGISLATIVELY EMPOWER THE SILC AS THE PRINCIPAL POLICY GROUP IN DISABILITY RELATED MATTERS.**
- **REQUIRE THE DEVELOPMENT AND ANNUAL REVISION OF A FIVE (5) YEAR PLAN FOR DISABILITY SERVICES, AND LEGISLATIVELY MANDATE CONCURRENCE BY THE SILC.**
- **EMPOWER THE OFFICE OF DISABILITY SERVICES AND THE SILC TO ADVOCATE WITH OTHER OFFICES, DEPARTMENTS AND AGENCIES OF STATE GOVERNMENT, SUCH AS THE GOVERNOR'S ADA COORDINATOR TO ASSURE EQUAL AND APPROPRIATE ACCESS TO PROGRAMS AND SERVICES.**
- **LIMIT THE SIZE AND SCOPE OF STATE INVOLVEMENT IN PROVIDING DISABILITY RELATED SERVICES BY CHANNELING RESOURCES DIRECTLY THROUGH LOCAL CONSUMER DIRECTED ORGANIZATIONS.**
- **UTILIZE WAIVERS, MODIFICATION TO POLICY AND REGULATION TO DIVERT RESOURCES FROM INSTITUTIONS TOWARD COMMUNITY BASED SERVICES THAT ARE CONSISTENT WITH THE GUIDING PRINCIPLES.**
- **LEGISLATIVELY MANDATE THAT ALL SUPPORTS FOR PEOPLE WITH DISABILITIES BE AFFORDED IN A MANNER THAT ASSURES MAXIMUM CHOICE, CONTROL, AUTONOMY AND SELF -RELIANCE.**
- **COLLABORATE WITH FEDERAL OFFICIALS TO ELIMINATE THE REGULATORY AND POLICY BARRIERS TO EFFECTIVELY UTILIZING FEDERAL FUNDS IN PROGRAMS, SERVICES AND INITIATIVES.**