

No. 2004-198

AN ACT

HB 2270

Providing for the development and implementation of pilot projects with the goal of establishing a Statewide system of family support services program for families of persons with disabilities; and providing for the powers and duties of the Department of Public Welfare.

The General Assembly finds and declares as follows:

(1) The families of people with disabilities are searching for ways to empower themselves to keep their family members with disabilities in their homes and in their communities.

(2) Many families experience exceptionally high financial outlays and significant physical and emotional challenges in meeting the special needs of persons with disabilities.

(3) Family members who could be part of their family and community have been forced to live in out-of-home placements, often at public expense, due to the financial disincentives to care for persons with a disability at home. The result is a loss both to these families and to this Commonwealth as a whole. Supporting these families to keep their family members at home is efficient and cost effective and improves quality of life.

(4) There are insufficient resources to replace family caregivers with paid workers.

(5) Most families do not have access to family-centered and family-directed services to support them in keeping their family together.

(6) There is a need for a comprehensive system of support for families of people with disabilities. This system must support families' cultural identities and be family centered and family directed. It must be readily accessible and individualized to meet family and individual needs. This system must address all disabilities and prevent gaps in services to families across this Commonwealth, should avoid duplication and use existing resources efficiently. Existing resources include those designed for the nondisabled population as well as those resources that are specialized for the disabled.

(7) Pennsylvania's categorical family support services program for persons diagnosed with mental retardation has been successful in making a positive difference in the lives of families and keeping them together. Pennsylvania's Caregiver Program for families with persons over 60 years of age has made significant difference in helping families since its inception. This act will enable families of persons with disabilities who need similar services to obtain such assistance and will facilitate the coordination of those services.

(8) The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106-402, 42 U.S.C. § 15001), also referred to as the

Families of Children With Disabilities Support Act of 2000, recognizes that there is a need in each state to strengthen, expand and coordinate a system of family support for children with disabilities. The goals of that act are to provide the necessary family support services to enable families of children with disabilities to enjoy and nurture their children at home and to make informed choices and informed decisions regarding services.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Family Support for Persons with Disabilities Act.

Section 2. Purpose and policy.

(a) Purpose.—The purpose of this act is to promote and strengthen the implementation of a Statewide program of family support services for families of persons with disabilities that are family centered and family directed, that promote leadership by families in planning, development, implementation and evaluation of family support services and that promote interagency coordination and collaboration between agencies providing the services.

(b) Policy.—It is the policy of the Commonwealth that the family support services created by this act shall be carried out in a manner that is consistent with the following principles:

- (1) Family support must focus on the needs of the entire family.
- (2) Families should be supported in determining their own needs and in making their own decisions concerning services.
- (3) Families should have the opportunity not only to choose and direct the services provided to them but also to direct the development and operation of the service system.
- (4) Family support must offer options that are flexible and responsive to the unique and changing needs and to the strengths and cultural values of individual families.
- (5) Families must be supported in their efforts to promote the integration and inclusion of their family member with a disability in all aspects of community life.
- (6) The family support service program must be easily accessible to families and maintain accountability without creating unnecessary administrative burdens.
- (7) The family support service program should enhance, but not duplicate, other service programs and utilize existing community resources, both those which are specialized and those which are used by the general community.
- (8) Eligibility for family support services should not be limited to certain disabilities but should be open to all disabilities. This program

must bridge the gaps in service eligibility that are created by requirements for specific disabilities.

(9) The family support system should be proactive and not used solely to respond to crisis.

Section 3. Definitions.

The following words and phrases when used in this act shall have the meanings given to them in this section unless the context clearly indicates otherwise:

“Culturally competent.” Services, supports or other assistance that are conducted or provided in a manner that:

(1) Is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of those persons receiving services:

(2) Has the greatest likelihood of ensuring participation of such persons.

“Department.” The Department of Public Welfare of the Commonwealth.

“Disability.” A severe, chronic condition of a person that:

(1) Is attributable to a mental or physical impairment or a combination of mental and physical impairments.

(2) Is likely to continue indefinitely.

(3) Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living or economic self-sufficiency.

(4) Reflects the person’s need for a combination and sequence of special, interdisciplinary or generic services, individualized supports or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

When applied to children who are under nine years of age, this term means persons who have substantial developmental delay or specific congenital or acquired conditions, who¹ may be considered to have a disability without meeting three or more of the criteria if the person, without services and supports, has a high probability of meeting those criteria later in life.

“Family.” A person with a disability and the people with whom the person lives, including, but not limited to, mother, father, brother, sister, spouse, significant other, son or daughter, grandparent, aunt, uncle, cousin, legal guardian or legal custodian. The term may include a person providing foster care or a home under the family living program. The term does not include a person who acts in a paid employment capacity and provides services in hospitals, State centers, nursing homes, personal care boarding homes, domiciliary care, community living arrangements or other such facilities.

“Family-centered” or “family-directed.” A system in which families are empowered to identify their needs, participate in the development of any

¹ “who” omitted in enrolled bill.

service plan, determine which services they want delivered, select the service provider and the services that are responsive to the needs of the entire family in a timely and appropriate manner and are easily accessible to and usable by the family.

“Family support.” Supports, resources, services and other assistance that are designed to support and are provided:

(1) To families in their efforts to maintain family unity and keep persons with disabilities in the family home and participating in their community.

(2) To prevent inappropriate and unwanted out-of-home placement.

(3) When possible, to reunite persons with disabilities who have been placed out of the home by their family.

The term includes voucher or reimbursement systems. For the purpose of this definition, “services” include respite care in and out of the home, recreation, assistive technology as defined in section 3 of the Assistive Technology Act of 1998 (Public Law 105-394, 29 U.S.C. § 3002), information and referral and other services as authorized by the Department of Public Welfare.

Section 4. Powers and duties of department.

The department shall:

(1) Work with stakeholders, including persons with disabilities, family members and advocates, and identify and apply for available public or private funding sources in order to establish and develop pilot projects to provide family supports to eligible families.

(2) Work with stakeholders, evaluate the pilot projects with a goal of expanding the projects throughout this Commonwealth and report to the General Assembly on the plan for Statewide expansion within three months of the completion of the pilot projects.

(3) Establish working relationships, including interagency agreements, with other governmental bodies and public and private agencies as needed to fulfill the purposes of this act.

Section 5. Pilot projects for family support services.

(a) General rule.—The pilot projects shall include the provisions set forth in this section, which provisions shall serve as a basis for Statewide expansion.

(b) Administration.—The department shall administer the project directly or contract with a private disability-related organization or organizations to administer the elements of the project.

(c) Eligibility.—Families residing in this Commonwealth that include at least one person with a disability are eligible for family support services under this act. The department shall give first priority to families not eligible for any other family support services and second priority to those families eligible for, but not currently receiving, any family support services.

(d) Types of services.—

(1) The types of services and supports to be provided and the organization or person to provide them shall be selected, consistent with

the intent of this act, by the family and shall not be prescribed by the department or the administering agency.

(2) Administering agencies may use family support funds to contract directly with providers for necessary services only when the arrangement will facilitate rather than limit family choice. The supports or services which are selected may benefit the family as a whole.

(e) Control.—When a person with a disability becomes 18 years of age, that person shall make decisions regarding family support services unless the person is adjudicated incapacitated. When a person with a disability is under 18 years of age or has been adjudicated incapacitated, the decision making for services shall be shared by appropriate family members, including the person with the disability to the extent of the person's ability.

(f) Payment.—

(1) Each family may choose the payment method, including, but not limited to, cash advances, cash reimbursement and vouchers. In determining the amount of support to be provided, the administering agencies shall consider income, family composition, number of persons with disabilities, the related costs to the family of the disability and the costs of the service being requested from this project.

(2) The family shall be accountable for payments received and complete all reports required by the administering agencies.

(g) Nonduplication.—The family support system required by this act shall be separate from, but parallel to, the Office of Mental Retardation's existing Family Resource Service. The family support system shall serve persons with the full range of disabilities, including mental retardation, but may not be used to pay for services for which funds are available to the family from some other source such as the Office of Mental Retardation program.

(h) Coordination.—The family support program shall coordinate and, when necessary, establish interagency agreements with other related public and private programs.

(i) Advisory committees.—

(1) Each administering entity shall establish an advisory committee to provide guidance and input on all matters pertaining to the delivery of family support services, including, but not limited to, the development of payment policies.

(2) Membership of an advisory committee shall include a majority of persons with disabilities and family members of persons with disabilities. Every effort shall be made to include recipients of family support services and to reflect the diversity of disabilities.

Section 6. Nonsupplantation.

Funding available under this act shall not be used to displace benefits, entitlements or resources available under other programs.

Section 7. Payer of last resort.

Family support funds shall be used only when other funds are not available to pay for the same services or supports.

Section 8. Administrative costs.

The department shall determine allowable administrative costs.

Section 9. State tax.

Funds paid under this act shall not be counted as income for purposes of State income tax.

Section 10. Agreements with other taxing authorities and certain agencies.

The department shall seek agreements with other taxing authorities and agencies issuing benefits so that payments made under this act shall not be reportable as income to the family.

Section 11. Construction.

Nothing in this act shall be construed to create or provide any person with an entitlement to services or benefits.

Section 12. Effective date.

This act shall take effect immediately.

APPROVED—The 30th day of November, A.D. 2004.

EDWARD G. RENDELL