WEST VIRGINIA LEGISLATURE
REGULAR SESSION, 1991

ENROLLED
Com. Sub. for Com. Sub. for
SENATE BILL NO. 29

(By Senator Burdette, Mr. President, et al)

PASSED March 7, 1991
In Effect July 1, 1991
AN ACT to amend chapter forty-nine of the code of West Virginia, one thousand nine hundred thirty-one, as amended, by adding thereto a new article, designated article four-a, relating to providing services to families of people with developmental disabilities through the West Virginia family support program; setting forth findings; defining terms; specifying services which may be provided under the program; setting forth eligibility criteria; setting forth the primary focus of the program; specifying the administering agency and setting forth its duties; providing for the establishment of a state and regional family support council; and providing for the reimbursement of certain expenses.

Be it enacted by the Legislature of West Virginia:

That chapter forty-nine of the code of West Virginia, one thousand nine hundred thirty-one, as amended, be
amended by adding thereto a new article, designated article four-a, to read as follows:

ARTICLE 4A. WEST VIRGINIA FAMILY SUPPORT PROGRAM.

§49-4A-1. Findings.

(a) The West Virginia Legislature finds that families are the greatest resource available to individuals with developmental disabilities, and they must be supported in their role as primary caregivers. It further finds that supporting families in their effort to care for their family members at home is more efficient, cost effective and humane than placing the developmentally disabled person in an institutional setting.

(b) The Legislature accepts the following as basic principles for providing services to support families of people with developmental disabilities:

1. The quality of life of children with developmental disabilities, their families and communities is enhanced by caring for the children within their own homes. Children with disabilities benefit by growing up in their own families, families benefit by staying together and communities benefit from the inclusion of people with diverse abilities.

2. Adults with developmental disabilities should be afforded the opportunity to make decisions for themselves, live in typical homes and communities and exercise their full rights as citizens. Developmentally disabled adults should have the option of living separately from their families but when this is not the case, families of disabled adults should be provided the support services they need.

3. Services and support for families should be individualized and flexible, should focus on the entire family and should promote the inclusion of people with developmental disabilities in all aspects of school and community life.

4. Families are the best experts about what they need. The service system can best assist families by supporting families as decision-makers as opposed to
making decisions for them.

(c) The Legislature finds that there are at least ten thousand West Virginians with developmental disabilities who live with and are supported by their families, and that the state's policy is to prevent the institutionalization of people with developmental disabilities.

(d) To maximize the number of families supported by this program, each family will contribute to the cost of goods and services based on their ability to pay, taking into account their needs and resources.

(e) Therefore, it is the intent of the Legislature to initiate, within the resources available, a program of services to support families who are caring for family members with developmental disabilities in their homes.


(a) "Family or primary caregiver" means the person or persons with whom the developmentally disabled person resides and who is primarily responsible for the physical care, education, health, and nurturing of the disabled person. The term does not include hospitals, sanitariums, nursing homes, personal care homes, or any other such institution.

(b) "Legal guardian" means the person who is appointed legal guardian of a developmentally disabled person and who is responsible for the physical and financial aspects of caring for such person, regardless of whether the disabled person resides with his or her legal guardian or another family member.

(c) "Family support" means goods and services needed by families to care for their family members with developmental disabilities and to enjoy a quality of life comparable to other community members.

(d) "Family support program" means a coordinated system of family support services administered by the department of health and human resources through initial contracts with agencies within four of the state's behavioral health regions.
(e) "Developmental disability" means a severe, chronic disability of a person which:
  (1) Is attributable to a mental or physical impairment or a combination of mental and physical impairments;
  (2) Is manifested before the person attains age twenty-two;
  (3) Results in substantial functional limitations in three or more of the following areas of major life activity: (A) Self care, (B) receptive and expressive language, (C) learning, (D) mobility, (E) self-direction, (F) capacity for independent living and (G) economic self-sufficiency; and
  (4) Reflects the person's need for services and supports which are of lifelong or extended duration and are individually planned and coordinated.

The term "developmental disability", when applied to infants and young children, means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

(f) "Regional family support council" means the council established by the regional family support agency under the provisions of section six of this article to carry out the responsibilities specified in this article.

(g) "State family support council" means the council established by the department of health and human resources under section six of this article to carry out the responsibilities specified in this article.

§49-4A-3. Family support services.

(a) The regional family support agency, designated under section five of this article, shall direct and be responsible for the individual assessment of each developmentally disabled person which it has designated and shall prepare a service plan with such developmentally disabled person's family. The needs
and preferences of the family will be the basis for
determining what goods and services will be made
available within the resources available.

(b) The family support program may provide funds
to families to purchase goods and services included in
the family service plan. Such goods and services
related to the care of the developmentally disabled
person may include, but are not limited to:

(1) Respite care;
(2) Personal and attendant care;
(3) Child care;
(4) Architectural and vehicular modifications;
(5) Health-related costs not otherwise covered;
(6) Equipment and supplies;
(7) Specialized nutrition and clothing;
(8) Homemaker services;
(9) Transportation;
(10) Utility costs;
(11) Integrated community activities; and
(12) Training and technical assistance.

(c) As part of the family support program, the
regional family support agency, designated under
section five of this article, shall provide case manage-
ment for each family to provide information, service
coordination and other assistance as needed by the
family.

(d) The family support program shall assist families
of developmentally disabled adults in planning and
obtaining community living arrangements, employ-
ment services and other resources needed to achieve,
to the greatest extent possible, independence, produc-
tivity and integration of the developmentally disabled
adult into the community.

(e) The family support program shall conduct out-
reach to identify families in need of assistance and shall maintain a waiting list of individuals and families in the event that there are insufficient resources to provide services to all those who request them.

(f) The family support program may provide for differential fees for services under the program or for appropriate cost participation by the recipient families consistent with the goals of the program and the overall financial condition of the family.

(g) Funds, goods or services provided to eligible families by the family support program under this article, shall not be considered as income to those families for any purpose under this code or under the rules and regulations of any agency of state government.

§49-4A-4. Eligibility; primary focus.

(a) To be eligible for the family support program, a family must have at least one family member who has a developmental disability as defined in this article living with the family.

(b) The primary focus of the family support program is supporting: (1) Developmentally disabled children, school age and younger, within their families; (2) adults with developmental disabilities who choose to live with their families; and (3) adults with developmental disabilities for whom other community living arrangements are not available and who are living with their families.

§49-4A-5. Program administration.

(a) The administering agency for the family support program is the department of health and human resources.

(b) The department of health and human resources shall initially implement the family support program through contracts with an agency within four of the state’s behavioral health regions, with the four regions to be determined by the department of health and human resources in consultation with the state family...
support council. These regional family support agencies of the family support program will be responsible for implementing the provisions of this article and subsequent policies for the families of persons with developmental disabilities residing within their respective regions. Each regional family support agency must serve at least twenty-five families from each fifty thousand dollars allocated. The total appropriation from general revenue funds for this program shall not exceed two hundred thousand dollars for the fiscal year beginning the first day of July, one thousand nine hundred ninety-one.

(c) The department of health and human resources, in conjunction with the state family support council, shall adopt policies and procedures regarding:

1. Development of annual budgets;
2. Program specifications;
3. Criteria for awarding contracts for operation of regional family support programs and the role of regional family support councils;
4. Annual evaluation of services provided by each regional family support agency, including consumer satisfaction;
5. Coordination of the family support program and the use of its funds, throughout the state and within each region, with other publicly funded programs, including medicaid;
6. Performance of family needs assessments and development of family service plans;
7. Methodology for allocating resources to families within the funds available; and
8. Resolution of grievances filed by families pertaining to actions of the family support program.

(d) The department of health and human resources shall submit a report to the governor and the Legislature on the family support program, by the fifteenth day of January, one thousand nine hundred ninety-

47 two, and by the fifteenth day of September every year
48 thereafter, so long as the program is funded.

§ 40A-6. Regional and state family support councils.

1 (a) Each regional family support agency shall estab-
2 lish a regional family support council comprised of at
3 least seven members, of whom at least a majority shall
4 be persons with developmental disabilities or their
5 parents or primary caregivers. Each regional family
6 support council shall meet at least quarterly to advise
7 the regional family support agency on matters related
8 to local implementation of the family support program
9 and to communicate information and recommenda-
10 tions regarding the family support program to the
11 state family support council.

12 (b) The secretary of the department of health and
13 human resources shall appoint a state family support
14 council comprised of at least twenty-two members, of
15 whom at least a majority shall be persons with
16 developmental disabilities or their parents or primary
17 caregivers. A representative elected by each regional
18 council shall serve on the state council. The state
19 council shall also include a representative from each of
20 the following agencies: The state developmental
21 disabilities planning council, the state protection and
22 advocacy agency, the university affiliated center for
23 developmental disabilities, the office of special educa-
24 tion, the association of community mental health/
25 mental retardation programs and the early interven-
26 tion interagency coordinating council.

27 (c) The state council shall meet at least quarterly.
28 The state council will participate in the development
29 of program policies and procedures, annual contracts
30 and perform such other duties as are necessary for
31 statewide implementation of the family support
32 program.

33 (d) Members of the state and regional councils who
34 are a member of the family or the primary caregiver
35 of a developmentally disabled person shall be reim-
36 bursed for travel and lodging expenses incurred in
37 attending official meetings of their councils. Child care
expenses related to the developmentally disabled person shall also be reimbursed. Members of regional councils who are eligible for expense reimbursement shall be reimbursed by their respective regional family support agencies.
The Joint Committee on Enrolled Bills hereby certifies that the foregoing bill is correctly enrolled.

Homer Flick
Chairman Senate Committee

Ernest C. Moore
Chairman House Committee

Originated in the Senate.

To take effect July 1, 1991.

Donald R. Kepp
Clerk of the Senate

Clerk of the House of Delegates

President of the Senate

Speaker House of Delegates

The within is the 18th day of , 1991.

Governor

Yoston Caperton