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SECRETARY OF STATE

## WEST VIRGINIA LEGISLATURE

REGULAR SESSION, 1991

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# ENROLLED

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

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

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PASSED March 7, 1991

In Effect July 1, 1991 Passage

**ENROLLED**

COMMITTEE SUBSTITUTE

FOR

COMMITTEE SUBSTITUTE

FOR

**Senate Bill No. 29**

(BY SENATORS BURDETTE, MR. PRESIDENT, HOLLIDAY, M. MANCHIN, PRITT, WEHRLE AND J. MANCHIN, *original sponsors*)

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[Passed March 7, 1991; to take effect July 1, 1991.]

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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.**

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

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

12 (1) The quality of life of children with developmen-  
13 tal disabilities, their families and communities is  
14 enhanced by caring for the children within their own  
15 homes. Children with disabilities benefit by growing  
16 up in their own families, families benefit by staying  
17 together and communities benefit from the inclusion  
18 of people with diverse abilities.

19 (2) Adults with developmental disabilities should be  
20 afforded the opportunity to make decisions for them-  
21 selves, live in typical homes and communities and  
22 exercise their full rights as citizens. Developmentally  
23 disabled adults should have the option of living  
24 separately from their families but when this is not the  
25 case, families of disabled adults should be provided the  
26 support services they need.

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

32 (4) Families are the best experts about what they  
33 need. The service system can best assist families by  
34 supporting families as decision-makers as opposed to

35 making decisions for them.

36 (c) The Legislature finds that there are at least ten  
37 thousand West Virginians with developmental disabili-  
38 ties who live with and are supported by their families,  
39 and that the state's policy is to prevent the institution-  
40 alization of people with developmental disabilities.

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

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

**§49-4A-2. Definitions.**

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

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

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

18 (d) "Family support program" means a coordinated  
19 system of family support services administered by the  
20 department of health and human resources through  
21 initial contracts with agencies within four of the  
22 state's behavioral health regions.

23 (e) "Developmental disability" means a severe,  
24 chronic disability of a person which:

25 (1) Is attributable to a mental or physical impair-  
26 ment or a combination of mental and physical  
27 impairments;

28 (2) Is manifested before the person attains age  
29 twenty-two;

30 (3) Results in substantial functional limitations in  
31 three or more of the following areas of major life  
32 activity: (A) Self care, (B) receptive and expressive  
33 language, (C) learning, (D) mobility, (E) self-direction,  
34 (F) capacity for independent living and (G) economic  
35 self-sufficiency; and

36 (4) Reflects the person's need for services and  
37 supports which are of lifelong or extended duration  
38 and are individually planned and coordinated.

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

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

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

**§49-4A-3. Family support services.**

1 (a) The regional family support agency, designated  
2 under section five of this article, shall direct and be  
3 responsible for the individual assessment of each  
4 developmentally disabled person which it has desig-  
5 nated and shall prepare a service plan with such  
6 developmentally disabled person's family. The needs

7 and preferences of the family will be the basis for  
8 determining what goods and services will be made  
9 available within the resources available.

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

- 15 (1) Respite care;
- 16 (2) Personal and attendant care;
- 17 (3) Child care;
- 18 (4) Architectural and vehicular modifications;
- 19 (5) Health-related costs not otherwise covered;
- 20 (6) Equipment and supplies;
- 21 (7) Specialized nutrition and clothing;
- 22 (8) Homemaker services;
- 23 (9) Transportation;
- 24 (10) Utility costs;
- 25 (11) Integrated community activities; and
- 26 (12) Training and technical assistance.

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

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

40 (e) The family support program shall conduct out-

41 reach to identify families in need of assistance and  
42 shall maintain a waiting list of individuals and families  
43 in the event that there are insufficient resources to  
44 provide services to all those who request them.

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

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

**§49-4A-4. Eligibility; primary focus.**

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

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

**§49-4A-5. Program administration.**

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

4 (b) The department of health and human resources  
5 shall initially implement the family support program  
6 through contracts with an agency within four of the  
7 state's behavioral health regions, with the four regions  
8 to be determined by the department of health and  
9 human resources in consultation with the state family

10 support council. These regional family support agen-  
11 cies of the family support program will be responsible  
12 for implementing the provisions of this article and  
13 subsequent policies for the families of persons with  
14 developmental disabilities residing within their respec-  
15 tive regions. Each regional family support agency must  
16 serve at least twenty-five families from each fifty  
17 thousand dollars allocated. The total appropriation  
18 from general revenue funds for this program shall not  
19 exceed two hundred thousand dollars for the fiscal  
20 year beginning the first day of July, one thousand  
21 nine hundred ninety-one.

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

25 (1) Development of annual budgets;

26 (2) Program specifications;

27 (3) Criteria for awarding contracts for operation of  
28 regional family support programs and the role of  
29 regional family support councils;

30 (4) Annual evaluation of services provided by each  
31 regional family support agency, including consumer  
32 satisfaction;

33 (5) Coordination of the family support program and  
34 the use of its funds, throughout the state and within  
35 each region, with other publicly funded programs,  
36 including medicaid;

37 (6) Performance of family needs assessments and  
38 development of family service plans;

39 (7) Methodology for allocating resources to families  
40 within the funds available; and

41 (8) Resolution of grievances filed by families pertain-  
42 ing to actions of the family support program.

43 (d) The department of health and human resources  
44 shall submit a report to the governor and the Legisla-  
45 ture on the family support program, by the fifteenth  
46 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.

**§49-4A-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

38 expenses related to the developmentally disabled  
39 person shall also be reimbursed. Members of regional  
40 councils who are eligible for expense reimbursement  
41 shall be reimbursed by their respective regional  
42 family support agencies.

The Joint Committee on Enrolled Bills hereby certifies that the foregoing bill is correctly enrolled.

*Somer Heck*  
.....  
Chairman Senate Committee

*Ernest C. Moore*  
.....  
Chairman House Committee

Originated in the Senate.

To take effect July 1, 1991

*Parsell*  
.....  
Clerk of the Senate

*Donald L. Kopp*  
.....  
Clerk of the House of Delegates

*Will Burdette*  
.....  
President of the Senate

*Bob Clark*  
.....  
Speaker House of Delegates

The within *is approved* this the *18th*  
day of *May*, 1991.

*Yaston Caperton*  
.....  
Governor