

Second Regular Session  
Seventy-first General Assembly  
STATE OF COLORADO

INTRODUCED

LLS NO. 18-0553.01 Jane Ritter x4342

SENATE BILL 18-074

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SENATE SPONSORSHIP

Todd, Court, Holbert, Martinez Humenik, Merrifield, Zenzinger

HOUSE SPONSORSHIP

Hansen,

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Senate Committees  
Health & Human Services

House Committees

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A BILL FOR AN ACT

101 CONCERNING ADDING INDIVIDUALS WITH PRADER-WILLI SYNDROME  
102 TO THE LIST OF PERSONS WITH INTELLECTUAL AND  
103 DEVELOPMENTAL DISABILITIES WHO ARE MANDATORILY  
104 ELIGIBLE FOR SERVICES AND SUPPORTS.

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Bill Summary

*(Note: This summary applies to this bill as introduced and does not reflect any amendments that may be subsequently adopted. If this bill passes third reading in the house of introduction, a bill summary that applies to the reengrossed version of this bill will be available at <http://leg.colorado.gov>.)*

Current law does not guarantee that an individual who has the genetic condition known as Prader-Willi syndrome will receive crucial services and supports that are available for persons with intellectual and

Shading denotes HOUSE amendment. Double underlining denotes SENATE amendment.  
Capital letters or bold & italic numbers indicate new material to be added to existing statute.  
Dashes through the words indicate deletions from existing statute.

developmental disabilities. The bill adds Prader-Willi syndrome to the list of persons who have mandatory eligibility for services and supports and also to the definition of an "intellectual and developmental disability" for the purpose of receiving services and supports.

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1 *Be it enacted by the General Assembly of the State of Colorado:*

2 **SECTION 1.** In Colorado Revised Statutes, 25.5-6-402, **amend**  
3 (1) introductory portion; and **add** (4) as follows:

4 **25.5-6-402. Legislative declaration - Prader-Willi syndrome.**

5 (1) The general assembly ~~hereby~~ finds and declares that it is the purpose  
6 of this part 4 to provide services for persons with INTELLECTUAL AND  
7 developmental disabilities ~~which~~ THAT would foster the following goals:

8 (4) (a) THE GENERAL ASSEMBLY FURTHER FINDS AND DECLARES  
9 THAT:

10 (I) PRADER-WILLI SYNDROME IS A GENETIC CONDITION THAT  
11 OCCURS IN APPROXIMATELY ONE IN FIFTEEN TO TWENTY-FIVE THOUSAND  
12 PEOPLE WORLDWIDE, AND THERE ARE UP TO THREE HUNDRED  
13 SEVENTY-FIVE INDIVIDUALS LIVING WITH THIS SYNDROME IN COLORADO;

14 (II) BECAUSE PRADER-WILLI SYNDROME IS A GENETIC DISORDER,  
15 INDIVIDUALS EITHER HAVE IT OR THEY DO NOT. FURTHER, BECAUSE THERE  
16 IS NO CURE, INDIVIDUALS WHO HAVE PRADER-WILLI SYNDROME WILL  
17 HAVE IT FOR LIFE.

18 (III) THIS DISORDER AFFECTS MEMBERS OF EVERY CULTURE,  
19 RELIGION, ECONOMIC CLASS, RACE, AND SOCIAL ORDER;

20 (IV) THE MOST CRITICAL HALLMARK OF PRADER-WILLI SYNDROME  
21 IS OVEREATING. INDIVIDUALS WITH PRADER-WILLI CANNOT TELL WHEN  
22 THEY ARE FULL AND WILL CONTINUE TO EAT WITHOUT STOP, LEADING TO  
23 RUPTURED STOMACHS AND EVEN DEATH. OTHER SYMPTOMS INCLUDE

1       SIGNIFICANT DEVELOPMENTAL AND COGNITIVE DELAYS, SKIN PICKING,  
2       SLEEP PROBLEMS, OBSESSIVE-COMPULSIVE BEHAVIORS, HYPOTHYROIDISM,  
3       HYPOGONADISM, AND LOW MUSCLE TONE.

4               (V) THE STATE OF COLORADO DOES NOT CURRENTLY RECOGNIZE  
5       PRADER-WILLI SYNDROME AS AN INTELLECTUAL AND DEVELOPMENTAL  
6       DISABILITY FOR THE PURPOSE OF RECEIVING MUCH-NEEDED SERVICES AND  
7       SUPPORTS. THIS SEVERELY LIMITS THE CARE OPTIONS FOR INDIVIDUALS  
8       WITH PRADER-WILLI SYNDROME BECAUSE IT FORCES FAMILIES TO  
9       NAVIGATE MULTIPLE TIME-INTENSIVE ADMINISTRATIVE HOOPS, OFTEN  
10       INCLUDING MULTIPLE DENIALS OF SERVICES AND BENEFITS, BEFORE THESE  
11       FAMILIES ARE ABLE TO RECEIVE THE SERVICES THEY NEED.

12              (VI) THESE ADMINISTRATIVE HURDLES MOST DIRECTLY IMPACT  
13       THE LESS AFFLUENT, THE LESS EDUCATED, AND URBAN AND RURAL  
14       FAMILIES WHO DO NOT HAVE THE TIME OR FINANCIAL MEANS TO CARE FOR  
15       THEIR FAMILIES AND ALSO FIGHT A COMPLEX ADMINISTRATIVE PROCESS.

16              (b) THE GENERAL ASSEMBLY FURTHER DECLARES THAT  
17       DESIGNATING PRADER-WILLI SYNDROME AS AN INTELLECTUAL AND  
18       DEVELOPMENTAL DISABILITY AND DESIGNATING INDIVIDUALS WITH THE  
19       SYNDROME AS AUTOMATICALLY ELIGIBLE FOR SERVICES WILL REMOVE  
20       MANY OF THE ADMINISTRATIVE BARRIERS THAT CURRENTLY EXIST TO  
21       RECEIVING MUCH-NEEDED SERVICES. DESIGNATING PRADER-WILLI  
22       SYNDROME AS AN INTELLECTUAL AND DEVELOPMENTAL DISABILITY WILL  
23       ALLOW INDIVIDUALS AND FAMILIES AFFECTED BY THE SYNDROME TO BE  
24       ELIGIBLE FOR MEDICAID, SUPPLEMENTARY SECURITY INCOME, HOME- AND  
25       COMMUNITY-BASED SERVICES, AND SUPPORTIVE SERVICES, AS WELL AS  
26       HELP THEM OBTAIN INDIVIDUALIZED EDUCATION PROGRAMS AT SCHOOLS,  
27       MANAGE THEIR WEIGHT, AND ENSURE PROPER RESIDENTIAL PLACEMENT.

1           **SECTION 2.** In Colorado Revised Statutes, 25.5-5-101, **amend**  
2 (1) introductory portion and (4); and **add** (1)(n) as follows:

3           **25.5-5-101. Mandatory provisions - eligible groups.** (1) ~~In~~  
4 ~~order~~ To participate in the medicaid program, the federal government  
5 requires the state to provide medical assistance to certain eligible groups.  
6 Pursuant to federal law and except as provided in subsection (2) of this  
7 section, any person who is eligible for medical assistance under the  
8 mandated groups specified in this section shall receive both the  
9 mandatory services that are specified in sections 25.5-5-102 and  
10 25.5-5-103 and the optional services that are specified in sections  
11 25.5-5-202 and 25.5-5-203. Subject to the availability of federal financial  
12 participation, the following are the individuals or groups that are  
13 mandated under federal law to receive benefits under this ~~article~~ ARTICLE  
14 5 and articles 4 and 6 of this ~~title~~ TITLE 25.5:

15           (n) INDIVIDUALS DIAGNOSED BY GENETIC TESTING AS HAVING  
16 PRADER-WILLI SYNDROME.

17           (4) An asset test ~~shall~~ **MUST** not be applied as a condition of  
18 eligibility for individuals or families described in ~~paragraphs (b), (c), (d),~~  
19 ~~and (e) of subsection (1)~~ SUBSECTIONS (1)(b), (1)(c), (1)(d), (1)(e), AND  
20 (1)(n) of this section.

21           **SECTION 3.** In Colorado Revised Statutes, 25.5-6-403, **amend**  
22 (1), (2)(a) introductory portion, (2)(a)(I), (2)(a)(II), (2)(a)(IV), (3.3)(a),  
23 (3.3)(c)(II), (4), and (5)(a)(II) as follows:

24           **25.5-6-403. Definitions.** As used in this part 4, unless the context  
25 otherwise requires:

26           (1) "Developmentally disabled person" means a person with an  
27 intellectual and developmental disability as defined in ~~section~~

1 ~~25.5-10-202~~ SUBSECTION (3.3)(a) OF THIS SECTION.

2 (2) (a) "Eligible person" means a person with ~~developmental~~  
3 ~~disabilities~~ AN INTELLECTUAL AND DEVELOPMENTAL DISABILITY:

4 (I) Who meets the definition of categorically needy as defined in  
5 ~~section~~ SECTIONS 25.5-4-103 (4) AND 25.5-5-101 (1)(n);

6 (II) Who is in need of the level of care available in an intermediate  
7 care facility for individuals with intellectual AND DEVELOPMENTAL  
8 disabilities;

9 (IV) For whom it is determined that provision of such services is  
10 necessary to avoid placement in an intermediate care facility for  
11 individuals with intellectual AND DEVELOPMENTAL disabilities.

12 (3.3) (a) "Intellectual and developmental disability" means a  
13 disability that manifests before the person reaches twenty-two years of  
14 age, that constitutes a substantial disability to the affected person, and that  
15 is attributable to ~~mental-retardation~~ AN INTELLECTUAL AND  
16 DEVELOPMENTAL DISABILITY or related conditions, ~~which include~~  
17 INCLUDING PRADER-WILLI SYNDROME, cerebral palsy, epilepsy, autism,  
18 or other neurological conditions when those conditions result in  
19 impairment of general intellectual functioning or adaptive behavior  
20 similar to that of a person with ~~mental-retardation~~ AN INTELLECTUAL AND  
21 DEVELOPMENTAL DISABILITY. Unless otherwise specifically stated, the  
22 federal definition of "developmental disability" found in 42 U.S.C. sec.  
23 15001 et seq., ~~shall~~ DOES not apply.

24 (c) "Child with a developmental delay" means:

25 (II) A person less than five years of age who is at risk of having  
26 ~~a~~ AN INTELLECTUAL AND developmental disability as defined by rule of  
27 the state board.

1 (4) "Plan of care" means a coordinated plan of care for provision  
2 of services in other than a nursing facility or institutional setting,  
3 developed and managed, subject to review and approval pursuant to  
4 section 25.5-6-404, by a community centered board for persons with  
5 INTELLECTUAL AND developmental disabilities. This plan of care ~~shall~~  
6 MUST fully identify the services to be provided to eligible persons. Prior  
7 to the provision of those services, a physician may be required to review  
8 an assessment document to insure that it adequately describes the medical  
9 needs of the eligible person.

10 (5) (a) "Services for persons with intellectual and developmental  
11 disabilities" means those services:

12 (II) Necessary to prevent a person, eligible for services ~~under~~  
13 PURSUANT TO subsection (2) of this section, from being subjected to  
14 placement in an intermediate care facility for individuals with intellectual  
15 AND DEVELOPMENTAL disabilities.

16 **SECTION 4.** In Colorado Revised Statutes, 25.5-10-202, **amend**  
17 (26) as follows:

18 **25.5-10-202. Definitions.** As used in this article 10, unless the  
19 context otherwise requires:

20 (26) (a) "Intellectual and developmental disability" means a  
21 disability that manifests before the person reaches twenty-two years of  
22 age, that constitutes a substantial disability to the affected person, and that  
23 is attributable to ~~mental-retardation~~ AN INTELLECTUAL AND  
24 DEVELOPMENTAL DISABILITY or related conditions, ~~which include~~  
25 INCLUDING PRADER-WILLI SYNDROME, cerebral palsy, epilepsy, autism,  
26 or other neurological conditions when those conditions result in  
27 impairment of general intellectual functioning or adaptive behavior

1 similar to that of a person with ~~mental retardation~~ AN INTELLECTUAL AND  
2 DEVELOPMENTAL DISABILITY. Unless otherwise specifically stated, the  
3 federal definition of "developmental disability" found in 42 U.S.C. sec.  
4 15001 et seq., ~~shall~~ DOES not apply.

5 (b) "Person with an intellectual and developmental disability"  
6 means a person determined by a community-centered board to have an  
7 intellectual and developmental disability and ~~shall include~~ INCLUDES a  
8 child with a developmental delay.

9 (c) "Child with a developmental delay" means:

10 (I) A person less than five years of age with delayed development  
11 as defined by rule of the state board; or

12 (II) A person less than five years of age who is at risk of having  
13 ~~a~~ AN INTELLECTUAL AND developmental disability as defined by rule of  
14 the state board.

15 **SECTION 5. Act subject to petition - effective date.** This act  
16 takes effect at 12:01 a.m. on the day following the expiration of the  
17 ninety-day period after final adjournment of the general assembly (August  
18 8, 2018, if adjournment sine die is on May 9, 2018); except that, if a  
19 referendum petition is filed pursuant to section 1 (3) of article V of the  
20 state constitution against this act or an item, section, or part of this act  
21 within such period, then the act, item, section, or part will not take effect  
22 unless approved by the people at the general election to be held in  
23 November 2018 and, in such case, will take effect on the date of the  
24 official declaration of the vote thereon by the governor.