

Senate Engrossed

developmental disabilities; Prader-Willi syndrome

State of Arizona
Senate
Fifty-sixth Legislature
Second Regular Session
2024

SENATE BILL 1191

AN ACT

AMENDING SECTION 36-551, ARIZONA REVISED STATUTES; RELATING TO
DEVELOPMENTAL DISABILITIES.

(TEXT OF BILL BEGINS ON NEXT PAGE)

1 Be it enacted by the Legislature of the State of Arizona:

2 Section 1. Section 36-551, Arizona Revised Statutes, is amended to
3 read:

4 36-551. Definitions

5 In this chapter, unless the context otherwise requires:

6 1. "Adaptive behavior" means the effectiveness or degree to which a
7 person meets the standards of personal independence and social
8 responsibility expected of the person's age and cultural group.

9 2. "Adult developmental home" means a residential setting in a
10 family home in which the care, physical custody and supervision of the
11 adult client are the responsibility, under a twenty-four-hour care model,
12 of the licensee who, in that capacity, is not an employee of the division
13 or of a service provider and the home provides the following services for
14 a group of siblings or up to three adults with developmental disabilities:

15 (a) Room and board.

16 (b) Habilitation.

17 (c) Appropriate personal care.

18 (d) Appropriate supervision.

19 3. "Adult household member":

20 (a) Means a person who is at least eighteen years of age and who
21 resides in an adult developmental home, child developmental home or other
22 home and community based service setting for at least thirty days or who
23 resides in the household throughout the year for more than a cumulative
24 total of thirty days.

25 (b) Does not include a person who is receiving developmental
26 disabilities services from the department.

27 4. "Advisory council" means the developmental disabilities advisory
28 council.

29 5. "Arizona training program facility" means a state-operated
30 institution for clients of the department with developmental disabilities.

31 6. "Attributable to cognitive disability, epilepsy, cerebral palsy
32 or autism" means that there is a causal relationship between the presence
33 of an impairing condition and the developmental disability.

34 7. "Autism" means a condition characterized by severe disorders in
35 communication and behavior resulting in limited ability to communicate,
36 understand, learn and participate in social relationships.

37 8. "Behavioral-supported group home" means a community residential
38 setting that meets all of the following:

39 (a) Is for not more than six persons with developmental
40 disabilities.

41 (b) Is operated by a service provider under contract with the
42 department.

1 (c) Provides room and board, daily habilitation, assistance in
2 self-administering medication and medication administration and behavioral
3 health services for clients with dual disorders, including psychiatric
4 disorders and developmental disabilities, who engage in behaviors that are
5 disruptive, socially inappropriate or harmful or dangerous to self or
6 others, that interfere with functioning and quality of life or that may
7 cause destruction of property.

8 9. "Case management" means coordinating the assistance needed by
9 persons with developmental disabilities and their families in order to
10 ensure that persons with developmental disabilities attain their maximum
11 potential for independence, productivity and integration into the
12 community.

13 10. "Case manager" means a person who coordinates the
14 implementation of the individual program plan of goals, objectives and
15 appropriate services for persons with developmental disabilities.

16 11. "Cerebral palsy" means a permanently disabling condition
17 resulting from damage to the developing brain that may occur before, after
18 or during birth and that results in loss or impairment of control over
19 voluntary muscles.

20 12. "Child developmental certified home" means a regular foster
21 home as defined in section 8-501 that is licensed pursuant to section
22 8-509 and that is certified by the department pursuant to section
23 36-593.01.

24 13. "Child developmental home" means a residential setting in a
25 family home in which the care and supervision of the child are the
26 responsibility, under a twenty-four-hour care model, of the licensee who
27 serves as the developmental home provider of the child in the home setting
28 and who, in that capacity, is not an employee of the division or of a
29 service provider and the home provides the following services for a group
30 of siblings or up to three children with developmental disabilities:

- 31 (a) Room and board.
- 32 (b) Habilitation.
- 33 (c) Appropriate personal care.
- 34 (d) Appropriate supervision.

35 14. "Client" means a person receiving developmental disabilities
36 services from the department.

37 15. "Cognitive disability" means a condition that involves
38 subaverage general intellectual functioning, that exists concurrently with
39 deficits in adaptive behavior manifested before the age of eighteen and
40 that is sometimes referred to as intellectual disability.

41 16. "Community residential setting":

42 (a) Means a residential setting in which persons with developmental
43 disabilities live and are provided with appropriate supervision by the
44 service provider responsible for operating the residential setting.

1 (b) Includes a child developmental home or an adult developmental
2 home operated or contracted by the department or the department's
3 contracted vendor, a group home operated or contracted by the department
4 or a behavioral-supported group home or nursing-supported group home
5 contracted by the department.

6 17. "Consent" means voluntary informed consent. Consent is
7 voluntary if not given as the result of coercion or undue influence.
8 Consent is informed if the person giving the consent has been informed of
9 and comprehends the nature, purpose, consequences, risks and benefits of
10 the alternatives to the procedure, and has been informed and comprehends
11 that withholding or withdrawing consent will not prejudice the future
12 provision of care and services to the client. In cases of unusual or
13 hazardous treatment procedures performed pursuant to section 36-561,
14 subsection A, experimental research, organ transplantation and
15 nontherapeutic surgery, consent is informed if, in addition to the
16 foregoing, the person giving the consent has been informed of and
17 comprehends the method to be used in the proposed procedure.

18 18. "Daily habilitation" means habilitation as defined in this
19 section, except that the method of payment is for one unit per residential
20 day.

21 19. "Department" means the department of economic security.

22 20. "Developmental disability" means either a strongly demonstrated
23 potential that a child who is under six years of age has a developmental
24 disability or will develop a developmental disability, as determined by a
25 test performed pursuant to section 36-694 or by other appropriate tests,
26 or a severe, chronic disability that:

27 (a) Is attributable to a cognitive disability, cerebral palsy,
28 epilepsy, ~~Down syndrome or~~ autism OR OTHER PATHOGENIC GENETIC MUTATION
29 ASSOCIATED WITH NEURODEVELOPMENTAL DISABILITIES, INCLUDING DOWN SYNDROME
30 OR PRADER-WILLI SYNDROME.

31 (b) Is manifested before the age of eighteen.

32 (c) Is likely to continue indefinitely.

33 (d) Results in substantial functional limitations in three or more
34 of the following areas of major life activity:

35 (i) Self-care.

36 (ii) Receptive and expressive language.

37 (iii) Learning.

38 (iv) Mobility.

39 (v) Self-direction.

40 (vi) Capacity for independent living.

41 (vii) Economic self-sufficiency.

42 (e) Reflects the need for a combination and sequence of
43 individually planned or coordinated special, interdisciplinary or generic
44 care, treatment or other services that are of lifelong or extended
45 duration.

- 1 21. "Director" means the director of the department of economic
2 security.
- 3 22. "Division" means the division of developmental disabilities in
4 the department of economic security.
- 5 23. "Down syndrome" means a genetic disorder caused when abnormal
6 cell division results in extra genetic material from chromosome 21,
7 affecting a person's cognitive and physical abilities and causing
8 developmental issues.
- 9 24. "Epilepsy" means a neurological condition characterized by
10 abnormal electrical-chemical discharge in the brain. This discharge is
11 manifested in various forms of physical activities called seizures.
- 12 25. "Group home":
- 13 (a) Means a community residential setting for not more than six
14 persons with developmental disabilities that is operated by a service
15 provider under contract with the department and that provides room and
16 board and daily habilitation and other assessed medically necessary
17 services and supports to meet the needs of each person.
- 18 (b) Does not include an adult developmental home, a child
19 developmental home, a behavioral-supported group home, a nursing-supported
20 group home or an intermediate care facility for individuals with
21 intellectual disabilities.
- 22 26. "Guardian" means the person who, under court order, is
23 appointed to fulfill the powers and duties prescribed in section 14-5312.
24 Guardian does not include a guardian pursuant to section 14-5312.01.
- 25 27. "Habilitation" means the process by which a person is assisted
26 to acquire and maintain those life skills that enable the person to cope
27 more effectively with personal and environmental demands and to raise the
28 level of the person's physical, mental and social efficiency.
- 29 28. "Indigent" means a person with a developmental disability whose
30 estate or parent is unable to bear the full cost of maintaining or
31 providing services for that person in a developmental disabilities
32 program.
- 33 29. "Individual program plan" means a written statement of services
34 to be provided to a person with developmental disabilities, including
35 habilitation goals and objectives, that is developed following initial
36 placement evaluation and revised after periodic evaluations.
- 37 30. "Intermediate care facility for individuals with intellectual
38 disabilities" means a facility that primarily provides health and
39 rehabilitative services to persons with developmental disabilities that
40 are above the service level of room and board or supervisory care services
41 or personal care services as defined in section 36-401.
- 42 31. "Large group setting" means a setting that in addition to
43 residential care provides support services such as therapy, recreation and
44 transportation to seven or more persons with developmental disabilities
45 who require intensive supervision.

1 32. "Least restrictive alternative" means an available program or
2 facility that fosters independent living, that is the least confining for
3 the client's condition and that provides service and treatment in the
4 least intrusive manner reasonably and humanely appropriate to the
5 individual's needs.

6 33. "Likely to continue indefinitely" means that the developmental
7 disability has a reasonable likelihood of continuing for a protracted
8 period of time or for life.

9 34. "Manifested before the age of eighteen" means that the
10 disability must be apparent and have a substantially limiting effect on a
11 person's functioning before the age of eighteen.

12 35. "Nursing-supported group home" has the same meaning prescribed
13 in section 36-401.

14 36. "Physician" means a person who is licensed to practice pursuant
15 to title 32, chapter 13 or 17.

16 37. "Placement evaluation" means an interview and evaluation of a
17 person with a developmental disability and a review of the person's prior
18 medical and program histories to determine the appropriate developmental
19 disability programs and services for the person and recommendations for
20 specific program placements for the person.

21 38. "PRADER-WILLI SYNDROME" MEANS A GENETIC DISORDER THAT IS
22 CHARACTERIZED BY SHORT STATURE, COGNITIVE IMPAIRMENT, HYPOTONIA,
23 ABNORMALLY SMALL HANDS AND FEET, HYPOGONADISM AND UNCONTROLLED APPETITE
24 LEADING TO EXTREME OBESITY.

25 ~~38.~~ 39. "Psychologist" means a person who is licensed pursuant to
26 title 32, chapter 19.1.

27 ~~39.~~ 40. "Respite services" means services that provide a
28 short-term or long-term interval of rest or relief to the care provider of
29 a person with a developmental disability.

30 ~~40.~~ 41. "Responsible person" means the parent or guardian of a
31 minor with a developmental disability, the guardian of an adult with a
32 developmental disability or an adult with a developmental disability who
33 is a client or an applicant for whom no guardian has been appointed.

34 ~~41.~~ 42. "Service provider" means a person or agency that provides
35 services to clients pursuant to a contract, service agreement or qualified
36 vendor agreement with the division.

37 ~~42.~~ 43. "State operated service center" means a state owned or
38 leased facility that is operated by the department and that provides
39 temporary residential care and space for child and adult services that
40 include respite care, crisis intervention and diagnostic evaluation.

41 ~~43.~~ 44. "Subaverage general intellectual functioning" means
42 measured intelligence on standardized psychometric instruments of two or
43 more standard deviations below the mean for the tests used.

1 ~~44.~~ 45. "Substantial functional limitation" means a limitation so
2 severe that extraordinary assistance from other people, programs, services
3 or mechanical devices is required to assist the person in performing
4 appropriate major life activities.

5 ~~45.~~ 46. "Supervision" means the process by which the activities of
6 an individual with developmental disabilities are directed, influenced or
7 monitored.