REFERENCE TITLE: developmental disabilities; Prader-Willi syndrome

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

SB 1191

Introduced by Senator Wadsack

AN ACT

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

(TEXT OF BILL BEGINS ON NEXT PAGE)

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

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

36-551. <u>Definitions</u>

In this chapter, unless the context otherwise requires:

- 1. "Adaptive behavior" means the effectiveness or degree to which a person meets the standards of personal independence and social responsibility expected of the person's age and cultural group.
- 2. "Adult developmental home" means a residential setting in a family home in which the care, physical custody and supervision of the adult client are the responsibility, under a twenty-four-hour care model, of the licensee who, in that capacity, is not an employee of the division or of a service provider and the home provides the following services for a group of siblings or up to three adults with developmental disabilities:
 - (a) Room and board.
 - (b) Habilitation.
 - (c) Appropriate personal care.
 - (d) Appropriate supervision.
 - 3. "Adult household member":
- (a) Means a person who is at least eighteen years of age and who resides in an adult developmental home, child developmental home or other home and community based service setting for at least thirty days or who resides in the household throughout the year for more than a cumulative total of thirty days.
- (b) Does not include a person who is receiving developmental disabilities services from the department.
- 4. "Advisory council" means the developmental disabilities advisory council.
- 5. "Arizona training program facility" means a state-operated institution for clients of the department with developmental disabilities.
- 6. "Attributable to cognitive disability, epilepsy, cerebral palsy or autism" means that there is a causal relationship between the presence of an impairing condition and the developmental disability.
- 7. "Autism" means a condition characterized by severe disorders in communication and behavior resulting in limited ability to communicate, understand, learn and participate in social relationships.
- 8. "Behavioral-supported group home" means a community residential setting that meets all of the following:
- (a) Is for not more than six persons with developmental disabilities.
- 41 (b) Is operated by a service provider under contract with the 42 department.

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- (c) Provides room and board, daily habilitation, assistance in self-administering medication and medication administration and behavioral health services for clients with dual disorders, including psychiatric disorders and developmental disabilities, who engage in behaviors that are disruptive, socially inappropriate or harmful or dangerous to self or others, that interfere with functioning and quality of life or that may cause destruction of property.
- 9. "Case management" means coordinating the assistance needed by persons with developmental disabilities and their families in order to ensure that persons with developmental disabilities attain their maximum potential for independence, productivity and integration into the community.
- 10. "Case manager" means a person who coordinates the implementation of the individual program plan of goals, objectives and appropriate services for persons with developmental disabilities.
- 11. "Cerebral palsy" means a permanently disabling condition resulting from damage to the developing brain that may occur before, after or during birth and that results in loss or impairment of control over voluntary muscles.
- 12. "Child developmental certified home" means a regular foster home as defined in section 8-501 that is licensed pursuant to section 8-509 and that is certified by the department pursuant to section 36-593.01.
- 13. "Child developmental home" means a residential setting in a family home in which the care and supervision of the child are the responsibility, under a twenty-four-hour care model, of the licensee who serves as the developmental home provider of the child in the home setting and who, in that capacity, is not an employee of the division or of a service provider and the home provides the following services for a group of siblings or up to three children with developmental disabilities:
 - (a) Room and board.
 - (b) Habilitation.
 - (c) Appropriate personal care.
 - (d) Appropriate supervision.
- 14. "Client" means a person receiving developmental disabilities services from the department.
- 15. "Cognitive disability" means a condition that involves subaverage general intellectual functioning, that exists concurrently with deficits in adaptive behavior manifested before the age of eighteen and that is sometimes referred to as intellectual disability.
 - 16. "Community residential setting":
- (a) Means a residential setting in which persons with developmental disabilities live and are provided with appropriate supervision by the service provider responsible for operating the residential setting.

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- (b) Includes a child developmental home or an adult developmental home operated or contracted by the department or the department's contracted vendor, a group home operated or contracted by the department or a behavioral-supported group home or nursing-supported group home contracted by the department.
- 17. "Consent" means voluntary informed consent. Consent voluntary if not given as the result of coercion or undue influence. Consent is informed if the person giving the consent has been informed of and comprehends the nature, purpose, consequences, risks and benefits of the alternatives to the procedure, and has been informed and comprehends that withholding or withdrawing consent will not prejudice the future provision of care and services to the client. In cases of unusual or hazardous treatment procedures performed pursuant to section 36-561, subsection Α, experimental research, organ transplantation nontherapeutic surgery, consent is informed if, in addition to foregoing, the person giving the consent has been informed of comprehends the method to be used in the proposed procedure.
- 18. "Daily habilitation" means habilitation as defined in this section, except that the method of payment is for one unit per residential day.
 - 19. "Department" means the department of economic security.
- 20. "Developmental disability" means either a strongly demonstrated potential that a child who is under six years of age has a developmental disability or will develop a developmental disability, as determined by a test performed pursuant to section 36-694 or by other appropriate tests, or a severe, chronic disability that:
- (a) Is attributable to a cognitive disability, cerebral palsy, epilepsy, Down syndrome or autism OR OTHER PATHOGENIC GENETIC MUTATION ASSOCIATED WITH NEURODEVELOPMENTAL DISABILITIES, INCLUDING DOWN SYNDROME OR PRADER-WILLI SYNDROME.
 - (b) Is manifested before the age of eighteen.
 - (c) Is likely to continue indefinitely.
- (d) Results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) Self-care.
 - (ii) Receptive and expressive language.
 - (iii) Learning.
 - (iv) Mobility.
 - (v) Self-direction.
 - (vi) Capacity for independent living.
 - (vii) Economic self-sufficiency.
- (e) Reflects the need for a combination and sequence of individually planned or coordinated special, interdisciplinary or generic care, treatment or other services that are of lifelong or extended duration.

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

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- 32. "Least restrictive alternative" means an available program or facility that fosters independent living, that is the least confining for the client's condition and that provides service and treatment in the least intrusive manner reasonably and humanely appropriate to the individual's needs.
- 33. "Likely to continue indefinitely" means that the developmental disability has a reasonable likelihood of continuing for a protracted period of time or for life.
- 34. "Manifested before the age of eighteen" means that the disability must be apparent and have a substantially limiting effect on a person's functioning before the age of eighteen.
- 35. "Nursing-supported group home" has the same meaning prescribed in section 36-401.
- 36. "Physician" means a person who is licensed to practice pursuant to title 32, chapter 13 or 17.
- 37. "Placement evaluation" means an interview and evaluation of a person with a developmental disability and a review of the person's prior medical and program histories to determine the appropriate developmental disability programs and services for the person and recommendations for specific program placements for the person.
- 38. "PRADER-WILLI SYNDROME" MEANS A GENETIC DISORDER THAT IS CHARACTERIZED BY SHORT STATURE, COGNITIVE IMPAIRMENT, HYPOTONIA, ABNORMALLY SMALL HANDS AND FEET, HYPOGONADISM AND UNCONTROLLED APPETITE LEADING TO EXTREME OBESITY.
- 38. "Psychologist" means a person who is licensed pursuant to title 32, chapter 19.1.
- 39. 40. "Respite services" means services that provide a short-term or long-term interval of rest or relief to the care provider of a person with a developmental disability.
- 40. 41. "Responsible person" means the parent or guardian of a minor with a developmental disability, the guardian of an adult with a developmental disability or an adult with a developmental disability who is a client or an applicant for whom no guardian has been appointed.
- 41. 42. "Service provider" means a person or agency that provides services to clients pursuant to a contract, service agreement or qualified vendor agreement with the division.
- 42. 43. "State operated service center" means a state owned or leased facility that is operated by the department and that provides temporary residential care and space for child and adult services that include respite care, crisis intervention and diagnostic evaluation.
- 43. 44. "Subaverage general intellectual functioning" means measured intelligence on standardized psychometric instruments of two or more standard deviations below the mean for the tests used.

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6 7 44. 45. "Substantial functional limitation" means a limitation so severe that extraordinary assistance from other people, programs, services or mechanical devices is required to assist the person in performing appropriate major life activities.

 $\frac{45.}{100}$ 46. "Supervision" means the process by which the activities of an individual with developmental disabilities are directed, influenced or monitored.

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