



ARIZONA STATE SENATE
Fifty-Sixth Legislature, Second Regular Session

FACT SHEET FOR S.B. 1191

developmental disabilities; Prader-Willi syndrome

Purpose

Expands the definition of *developmental disability* to include a severe, chronic disability that is attributable to Prader-Willi syndrome for the purpose of receiving services through the Department of Economic Security (DES) Division of Developmental Disabilities (DDD).

Background

Prader-Willi syndrome is the most common of the genetic disorders that cause life-threatening obesity in children. Prader-Willi syndrome is caused by genetic changes on an *unstable* region of chromosome 15 that affects the regulation of gene expression, or how genes turn on and off. After infancy, symptoms of Prader-Willi syndrome include uncontrolled eating and delays in reaching physical activity milestones, such as standing and walking ([NIH](#)).

A *developmental disability* is either a strongly demonstrated potential that a child who is under six years of age has or will develop a developmental disability, as determined by a prescribed test or by other appropriate tests, or a severe, chronic disability that: 1) is attributable to a cognitive disability, cerebral palsy, epilepsy, Down syndrome or autism; 2) is manifested before the age of 18; 3) is likely to continue indefinitely; 4) 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; and 5) results in substantial functional limitations in three or more areas of major life activity. Areas of major life activity include: 1) self-care; 2) receptive and expressive language; 3) learning; 4) mobility; 5) self-direction; 6) capacity for independent living; and 7) economic self-sufficiency ([A.R.S. § 36-551](#)).

The Director of DES is responsible for developing and annually revising a statewide plan and initiating statewide programs and services for persons with developmental disabilities. Services include child, adult, residential and resource services. An Arizona resident with a developmental disability, supported by medical and psychological documentation, is eligible to apply for developmental disabilities programs, services and facilities operated, licensed and supervised by DES (A.R.S. §§ [36-554](#) and [36-559](#)).

DDD is the division of DES that empowers individuals with developmental disabilities to lead self-directed, healthy and meaningful lives. DDD provides support and services for eligible Arizonans diagnosed with one of the following developmental disabilities: 1) autism; 2) cerebral palsy; 3) epilepsy; 4) cognitive or intellectual disability; and 5) Down syndrome. Children under the age of six who are at risk of having a developmental disability may also qualify. DDD serves more than 40,000 people with developmental disabilities and their families throughout Arizona each year ([DDD](#)).

If there is a cost associated with expanding DDD services to provide for individuals with Prader-Willi syndrome, there may be a fiscal impact to the state General Fund associated with this legislation.

Provisions

1. Expands the definition of *developmental disability* to include a severe, chronic disability that is attributable to a pathogenic genetic mutation associated with neurodevelopmental disabilities, including Prader-Willi syndrome.
2. Defines *Prader-Willi syndrome* as 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.
3. Makes conforming changes.
4. Becomes effective on the general effective date.

Prepared by Senate Research

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MM/KS/slp