

Good Afternoon,

My name is Crystal Redner. My husband and I live in South East Rural Colorado in the Arkansas Valley with our have 5 children. Our son Trevin, is 9 and has Prader-Willi Syndrome. I am a director at the only childcare center for Bent County and my husband is a behavior analyst, working with special need adults. We both were previously elementary teachers for a combined total of over 40 years.

Trevin, is a kind, caring and loving boy who brightens everyone's life around him. He is positive force in life but unfortunately, he has many real life challenges. He has persistent hungry, as a result, he has to be watched constantly, with everything locked in the house, so he doesn't steal food, seek food in trashes or garbage disposals. He was diagnosed with PWS at 6 weeks. The medical appointments, procedures and therapies were overwhelming both mentally, physically and financially. Though insurance helped, not being able to have medicaid, caused extreme financial hardship which led to our having to file bankruptcy to cover the medical bills from the first five years of his life.

I am here to talk about the hardship in rural Colorado in regards to the process of signing up for Medicaid. My husband and I both hold a master's degree in education and this process was very challenging and frustrating for us. We both struggled for weeks to complete all the requirements and figure out what the application was needing. With that being said, I can not imagine how most families in our 100-mile radius accomplish this daunting task. Our county is the 3rd poorest in Colorado, we have an 87% free and reduced lunch count rate. We are an area of very high poverty. With this being said, reading, comprehending, writing and completing this process is near impossible for most, as those with education are the minority.

The problem with our area is that most people do not have access to internet or up-to-date technology. The lack of educational resources play a big role in the inequities in rural Colorado. These individuals, that are not highly educated, do not have the means or the ability to apply for the medicaid

services because the paperwork is extremely lengthy and time consuming. The people who can fill out the lengthy application, cannot qualify because they are in the working class and do not qualify for disability. In the Arkansas Valley, I know of three families who have small children with PWS. None of them have home computers, smartphones or internet access. With the challenges of a PWS child, these limitations affect the way parents are not able to provide or afford quality, effective and efficient services.

Prader-Willi syndrome currently has no cure and is a life long battle and struggle that families endure daily throughout their child's life. It starts at birth and can become harder and harder to cope and deal with the struggles let alone the financial burden it places on families. If medicaid services would have been automatically granted at birth, families could provide the necessary means to receive the best possible care for their children without the financial worry and hardship placed on them while waiting for medicaid approval. In Trevin's situation, he would have received better services, therapies and the needed medications that could have offset the issues we deal with on a daily basis.

Thank you for your time today. We greatly appreciate your support for this bill as Trevin, along with all Prader Willi Syndrome individuals and families would greatly benefit from maximum medical care!

Dear Senator Fields:

Gina Hopkins Flowers contacted you because she would like to meet with you to discuss amending the Colorado Governmental Immunity Act (CGIA). In her letter, Ms. Flowers explained that her son was killed by a volunteer firefighter who was driving to a fire. The firefighter was speeding and hit her son while he crossed a dark rural road. Ms. Hopkins Flowers was seeking civil damages from the firefighter, but was advised that, in accordance with the CGIA and Colorado Supreme Court decision, *Ceja v. Lemire, 06 SC 375*, the firefighter was covered by the CGIA since he was driving his own vehicle and not a vehicle owned or leased by the fire district. Since I cannot respond on your behalf about whether or not you want to meet with Ms. Flowers, I am providing you with information about the Supreme Court case *Ceja v. Lemire, 06 SC 375* and the CGIA for your review.

In the *Ceja v. Lemire* case, Mr. Lemire, a county employee, and Mr. Ceja were involved in a motor vehicle accident. Mr. Ceja brought a negligence lawsuit against both Mr. Lemire and the county. The trial court concluded that the county had immunity under the CGIA, but Mr. Lemire was not entitled to immunity. Both Mr. Ceja and Mr. Lemire appealed this ruling. The Court of Appeals affirmed the trial court's order regarding the immunity of the county and reversed the ruling against Mr. Lemire. The Court of Appeals ruled that Mr. Lemire also enjoyed immunity under the CGIA since he was driving his own vehicle rather than a vehicle owned or operated by the county. Mr. Ceja appealed this decision to the Supreme Court. The Supreme Court case held that Mr. Lemire, who was driving his personally owned vehicle within the course and scope of his employment at the time of the accident, was entitled to governmental immunity under the CGIA. The court indicated that a public employee's immunity for injuries arising out of the course of employment is waived only if the injuries resulted from the employee's operation of a vehicle owned or leased by a public entity.

The CGIA, which became law in 1971, governs the circumstances under which tort claimants may take action against public entities or their employees (i.e., the state, counties, municipalities, and their political subdivisions). The act establishes governmental immunity against all actions of a public entity that lie in tort except for injuries or damages resulting from the following eight general areas:

- operation of a motor vehicle owned or leased by a public entity, by a public employee while in the course of employment;
- operation of a public hospital, correctional facility or jail;
- a dangerous condition of any public building;
- a dangerous condition of a public highway, road or street;
- a dangerous condition of any public hospital, jail, public facility located in any park or recreational area maintained by a public entity, or public water, gas, sanitation, electrical, power, or swimming facility;
- the operation and maintenance of any public water facility, gas facility, sanitation facility, electrical facility, power facility, or swimming facility by such public entity;
- the operation and maintenance of a qualified state capital asset that is the subject of a leveraged leasing agreement; and
- failure to perform an education employment required background check as required by law.

Where governmental immunity is waived, Colorado law sets forth maximum limitations that may be recovered in tort claim cases against public entities. The maximum amount that may be recovered for injury to one person in any single occurrence is \$350,000. A maximum of \$990,000 may be recovered

Hello, my name is Charlotte Peterson. My husband, Mike, and I are the parents of three daughters and we live in Monument. Mike retired from the Navy after 21 years spent mostly as a naval aviator. I volunteer, and take care of our family, often acting as a single parent while Mike was deployed.

Our middle child, Roxy, has Prader-Willi syndrome. This disability affects her muscle tone, her cognitive processing, and especially her behavior. She is in a typical high school, but requires an IEP for extra support academically and to help her reach behavioral goals since she often blurts out in class and says inappropriate things. The most challenging aspect of PWS for us has been her insatiable appetite. She is a sophomore in high school where she keeps up fairly well academically with her peers, but is distracted and driven by her constant hunger to seek food.

She's been able to manipulate her peers and school staff into giving her food, or money to buy food. She always took a carefully-packed lunch to school, so we had no reason to believe she was sneaking food until she gained weight drastically two years in a row. People with PWS have a slower metabolism in addition to an insatiable appetite, so morbid obesity can occur in little time. I found a box of food in her locker, stacked high with junk food, including a "workout" powder that was a danger to those taking certain medications. We are watching her like a toddler again because of her drive to eat nonstop, and the life-threatening danger this poses to her.

Tricare insurance through the military has been very good for us, covering visits to specialists and various medical procedures. However, Tricare will make a determination at age 21 to see if she qualifies as having a "severe disability"—often a subjective determination. We are very afraid that she will not qualify for services because her test scores don't suggest she is at risk in many ways. But Roxy's constant hunger will require constant supervision and support for the rest of her life.

I am a PHD researcher at National Jewish Health. I received my Doctorate in Molecular Biology from the Anschutz Medical Campus where my research focused on the genetics and epigenetics of birth defects. I currently study the immune system in respiratory disorders and genetic disorders like Down Syndrome and Alpha1 antitrypsin Deficiency.

I am testifying in support of SB 74, adding Prader-Willi syndrome to the list of persons with intellectual and developmental disabilities and are mandatorily eligible for support services.

First, as a chromosomal disorder, there is no cure for these patients, and they will have it for life. It is not an inherited disorder, but a segmental deletion or other random occurrence. There is no way to test for predisposition to this genetic abnormality.

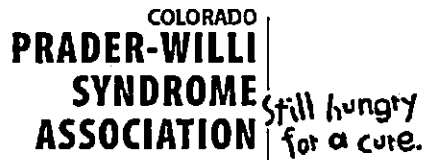
Second, the diagnosis for Prader Willi syndrome consist of a routine cytogenetic lab test knows as Fluorescence IN Situ Hybridization (FISH) or a molecular genetic tests like DNA methylation tests. These test are available in about a week and cost about \$350. Insurance companies and medicare cover these tests. Because of the rapid turnaround time, parents and patients can have fast answers and now have to enter a tedious application process for medicare benefits.

Third, early detection and treatment enables positive outcomes for disease course and treatment. As an example, the average age for Down Syndrome patients was 5 years old decades ago. Today, the average age is 60 years old. PRader-Willi patients have shown decreased morbidity rate to 1.25% per year with improved management.

With this bill, recognition of the disorder will increase among health care providers and maybe the general population. Again, increased knowledge, early diagnosis, and improved management mean reduced morbidity and mortality for these individuals.

Thanks for your vote on this bill.

Laura Harmacek



Prader Willi syndrome Facts

What is Prader-Willi syndrome?

Prader-Willi syndrome (PWS) is a genetic disorder due to an abnormality on the 15th chromosome that affects the brain and results in a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity.

Because PWS is a genetic disorder, individuals either have it or do not. PWS affects members of every culture, religion, economic class, race and social order equally. Also, because it is genetic, PWS is a lifelong condition for which there is no cure.

Those who have PWS need intervention and strict external controls – sometimes including padlocking access to food – to maintain normal weight and to help save their lives.

How does Prader-Willi syndrome affect people?

Individuals with PWS are characterized by weak muscle tone, feeding difficulties, poor growth, and delayed development. Beginning in childhood, affected individuals develop an insatiable appetite, which leads to chronic overeating, obesity, and, if uncontrolled, type 2 diabetes and death.

People with PWS typically will also have mild-to-moderate intellectual impairment and learning disabilities. Behavioral problems are common, including temper outbursts, stubbornness, and compulsive behaviors. Additional elements of this condition include distinctive facial features such as a narrow forehead, almond-shaped eyes, and a triangular mouth; short stature; and small hands and feet.

How many people in Colorado have Prader-Willi syndrome?

Approximately one in 20,000 people worldwide has PWS. Based on an estimated 5.6 million people in the state, there are an estimated 225-300 individuals living with Prader-Willi syndrome in Colorado. Many people with PWS are undiagnosed, especially in rural parts of Colorado.

Why legislation?

The state of Colorado does not currently recognize PWS as a disability. This severely limits the care options for those with PWS because it forces families to jump through many time-intensive administrative hoops, often including multiple denials in requests for benefits, before these families can receive the services they need. These administrative hurdles most directly impact the less affluent, the less educated, and urban and rural families who do not have the time or financial means to care for their family and fight an administrative process. Designating PWS as a disability will remove many of these administrative barriers and allow individuals with PWS to be eligible for Medicaid, Supplementary Security Income, and Home and Community-Based Services. Recognition will also reduce barriers to care faced by individuals with PWS and help them obtain individualized learning plans at schools,

For more information on Prader Willi syndrome please visit www.PWSACO.org

manage their weight, and ensure proper residential placement. Additionally, it will increase access for families and caregivers in need of supportive services.

What are the financial ramifications of this legislation?

Most individuals with PWS already qualify for the benefits, but only after jumping through many administrative hoops. This legislation will cover the few who are not already covered. For most individuals, this will avoid cost-prohibitive processes. Thus, the fiscal impact of this bill will be very low.

Is there precedent for this legislation?

Yes. Nine other states have passed similar legislation. These states are Connecticut, Florida, Maine, Massachusetts, Minnesota, New York, Oklahoma, Utah, Virginia and Wisconsin.

Won't every other small disease want legislation like this?

Research into other states has shown that this occurrence does not happen. In Wisconsin, for example, who passed this legislation in 1997, there has not been a similar bill presented since then.

Why now?

For years the Prader-Willi Syndrome Association of Colorado (PWSACO) has worked every other angle to support this individuals and families dealing with PWS. PWSACO has implemented support groups and clinics to train medical providers and families on options. However, PWASCO cannot move forward in better supporting people with PWS without the legal designation of PWS as a disability. We must act now to ensure a safe future for people affected by PWS and designate Prader-Willi syndrome as a disability.

How much have you learned? Please circle the correct answer, true or false.

1. PWS is a genetic order. True False
2. PWS can have a false positive. True False
3. There is a cure for PWS. True False
4. People with PWS always feel hungry. True False
5. There are thousands of people with PWS in Colorado. True False
6. Colorado does not currently recognize PWS as a disability. True False
7. Colorado can reduce administrative hurdles, help Coloradoans who need assistance, and not take a significant financial hit by just changing legislation defining PWS as a disability. True False

Answers:
1.T; 2.F; 3.F; 4.T; 5.F; 6.T; 7. Definitely True!



Good afternoon. My name is Robin Grey, I live in Lafayette and I thank you for the opportunity today discuss a topic I feel passionate about which is helping families better provide for and manage the important care needed when caring for individuals with a devastating genetic disorder, Prader Willi Syndrome. I am the very proud mother of Chase Grey, a beautiful 13. yr. old who was diagnosed with this devastating disorder when he was 6 weeks old. The reality is that our family was immediately thrown into a world where we had to fight and advocate for him constantly to get proper care, and that is on top of caring for my son, who needs constant oversight. It has been moving from one crisis to another much of his life starting with spending two weeks in NICU, trying to get him to simply get enough oxygen and nutrition when he was baby, then on to all the specialist doctors, and the speech, physical and occupational therapy that was necessary. .Prader Willi Syndrome kids and adults have a very wide variety of symptoms that leave them with an inability to control their appetites, poor motor skills, reduced cognitive abilities, delayed development and learning, less emotional control, behavioral challenges, and a lack of social skills, often are on the autistic spectrum. Today, he is a young man who loves school, playing special needs ice hockey, Boy Scouts, walking our dogs, jamming to Justin Beiber and life in general. He is only able to do all these things with intensive intervention and round the clock care, that we have provided him from day one.

My husband and I have spent many, many hours on behalf of our son making sure he gets appropriate education, health care, access to doctors, services, OT, PT, speech, nutritionists, specials needs tutors, babysitters, etc.. He has pretty intense anxiety and OCD and asks a a hundred questions a day just trying to figure things out. He has scoliosis and had a spinal fusion

2 years ago which included an extremely long recovery period with many doctor and hospital and therapy follow ups, in part due to his poor muscle tone and contracting a severe staph infection. We are lucky that we have the resources to figure out what needs to be done to make services available to my son. Not all parents are in that situation and I know that the hardest years are still likely in front of us. This syndrome doesn't get better or go away – it is lifelong. All PWS parents devote a great amount of time and financial resources to simply piece together the best they can the complicated puzzle of how to get help for their kids, just trying to ensure these beautiful kids can fulfill the most basic of ideas: being safe and growing up to be able to contribute to this world in their own way, with their own unique talents, insights, and challenges.

Based on the years I have watched parents struggle, sometimes heartbreakingly, to get proper care for their loved ones with Prader Willi, I respectfully request that the state of Colorado add individuals with Prader-Willi syndrome to list of people with intellectual and developmental disabilities. This will bring much needed and deserved relief to parents who have been trying so hard to do the right thing for their special needs family member.

Letter of Support in Favor of SB 18-74

February 15, 2018

Dear Senate Health and Human Services Committee,

I am writing in support of Senate Bill 18-074 to add Prader-Willi Syndrome (PWS) as a disability in the state statutes. I am a physician at the University of Colorado Hospital and mother of an affected child, Mira, now age 6.

Mira was a “floppy” baby, exhibiting low muscle tone at birth, but it wasn’t until she started choking and gagging on her milk at 1 month that we realized she had a problem. Our pediatrician referred us to Children’s Hospital since she was failing to thrive. It was during the week there, that she declined, needing both respiratory and feeding support. She was poked and prodded, but we left without an exact answer, only knowing that our child could not eat or breathe entirely on her own, feeding tube and oxygen tube in place.

At a follow up appointment when she was 4 months old, we finally had the blood tests proving that her DNA was abnormal. She was found to have a characteristic deletion in the paternally-inherited copy of chromosome 15 that was indicative of Prader-Willi Syndrome.

PWS is a rare, inherited, genetic condition affecting all genders and races. Those affected are plagued by an insatiable hunger, coupled with an intrinsically slow metabolism and decreased lean muscle mass. In other words, they feel like they are starving ALL THE TIME and their body composition is primed to gain weight. It’s a wicked combination. Their low tone doesn’t just involve their skeletal muscles, but also their smooth muscles including in their digestive tracks so they are prone to intestinal blockages and stomach rupture, especially since low tone prohibits their ability to throw up when they overeat, a protective mechanism that those of us with normal muscle tone have.

In addition to the metabolic and appetite derangements, PWS individuals typically have decreased cognitive functions as well, many qualifying as “mentally retarded”. Disruptive behaviors--anxiety, tantrums, and defiance-- often manifest too, especially when it comes to their being denied the food. However, you have to control their access and intake of food in order to prevent morbid obesity and its complications. Or to prevent them from choking to death when they try to gorge themselves. Or to prevent them from eating rotten or spoiled food or poisonous items as some as compelled to do. So how does this disorder affect our day to day life? Like most families, we have to count Mira’s calories and restrict her access to food. That means no food on counters and refrigerators and pantries must always be locked. We have to vet all outings and public spaces in terms of food safety. We have to anticipate when food may be present at an event or venue (like kindergarten orientation, birthday parties, or EVERYWHERE) and make plans ahead of time to supervise her around the food, prevent her from taking too much, possibly bring an alternative if incompatible with her caloric intake, and have a plan in place for the anxiety and tantrum that inevitably ensues when she is denied food. And sometimes we skip things since it’s just easier for us given that food is ubiquitous to every human celebration and get-together. It takes round the clock eyes to keep her safe so the whole family has to be involved, including her siblings who have unfortunately, had to become great spies, alerting us when she is trying to sneak food.

As for school, Mira is on an IEP (individualized educational program) since we need her teacher and her whole school to be mindful of how she is affected by food. Their preoccupation with food (and other

behaviors) affects their success and concentration. There have to be guidelines in place to keep her safe from food-seeking and to help with her other behaviors related to PWS.

I consider us lucky to have gotten a diagnosis as early as we did so we had a name, some prognostic information, and could start to intervene early. She was developmentally delayed and did not meet the usual milestones in the usual time. She could not eat normally until after 6 months. She could not walk until she was just over 2 years old. She needs PT, OT and speech therapy. With an early diagnosis, she has been able to benefit from having injections of Human Growth Hormone, the staple treatment to help with her tone and growth abnormalities. There is NO CURE. So early identification of these developmentally delayed children with PWS and initiation of therapeutic interventions is the best chance to optimize their health and futures. Our kids suffer when diagnosis and treatment options are delayed.

PWS is a disability and a disadvantage. Modifications and accommodations have to be made at home, school, etc. to monitor and keep kids food safe and deal with accompanying behaviors. You have to look at the world through a whole new lens. It should also be remembered that Mira and folks like her can't help it or just simply ignore their Hunger. It is a malfunction of the signals in their brain due to an omission in their DNA. They can never be trusted not to give into their compulsion to eat and need lifelong supervision. Food is a symbol of community, universal and necessary for life, but potentially deadly for our child. In our house and in Mira's life, food is the enemy.

In the long term, most of our kids cannot live independently. It is an extremely sad prospect, but I try to remain hopeful and focus on one day at a time. At 4 months old when we got her diagnosis, I grieved for the "normal" life she would not have and have shifted my focus on educating and advocating on her behalf and others affected by PWS. It is an endless, tiring, but necessary job. So this measure before you, to include this disorder in the disability statutes, is extremely important.

Thank you for your consideration.

Sincerely,

Kristin E. McKinney, M.D.
Kristin.mckinney@ucdenver.edu
303-910-4103



**COLORADO
PRADER-WILLI
SYNDROME
ASSOCIATION** | *Still hungry
for a cure.*

Founded in 2004 by a group of parents of children with Prader-Willi syndrome, the Prader-Willi Syndrome Association of Colorado (PWSACO) is committed to improving the lives of those affected by Prader-Willi Syndrome ("PWS") through four programs:

- Family Support - PWSACO provides support to families in the Rocky Mountain Region affected by Prader-Willi syndrome. These include:
 - Information and referral services
 - Scholarships for treatment beyond a family's means or not covered by medical insurance
 - Individualized Education Plan support
 - Social gatherings
- The PWS Clinic – this is a multi-disciplinary clinic for Prader Willi Syndrome families. The clinic occurs at The Children's Hospital in Aurora, CO every other month.
- Research – PWSACO raises money to supports research efforts implemented by the Foundation for Prader-Willi Research. This research is directed at improving diagnosis, quality of life, and most importantly, finding a cure.
- Long Term Care - PWSACO's newest venture is looking into long term care in Colorado for individuals with Prader Willi syndrome.

For more information please email info@pwsaco.org.

9 / 21

COLORADO
**PRADER-WILLI
SYNDROME
ASSOCIATION** | Still hungry
for a cure.

Legislation from Other States

Table of Contents:
New York – Page 1
Maine – Page 3
Connecticut – Page 4
Florida – Page 5
Massachusetts – Page 11
Minnesota – Page 12
Oklahoma – Page 13
Utah – Page 15
Virginia – Page 15
Wisconsin – Page 17

New York

Senate Bill S1219

SIGNED BY GOVERNOR

2017-2018 Legislative Session

Adds Prader-Willi to the definition of developmental disorder

SPONSORED BY

Robert G. Ort

(R, C, IP) 62ND SENATE DISTRICT

CURRENT BILL STATUS VIA A5974 - SIGNED BY GOVERNOR

See Assembly Version of this Bill: A5974

Law Section: Mental Hygiene Law

Laws Affected: Amd §1.03, Ment Hyg L

S1219 - SUMMARY

Adds Prader-Willi to the definition of developmental disorder.

BILL NUMBER: S1219

TITLE OF BILL: An act to amend the mental hygiene law, in relation to adding Prader-Willi syndrome to the definition of developmental disability

PURPOSE OR GENERAL IDEA OF BILL:

This legislation adds Prader-Willi to the list of disabilities under the definitions of developmental disability.

SUMMARY OF SPECIFIC PROVISIONS: :

Section 1 amends Subparagraph 1 of paragraph (a) of subdivision 22 of section 1.03 of the mental hygiene law by adding Prader Willi syndrome to the list of disabilities under the definition of developmental disability.

Section 2 is the effective date.

JUSTIFICATION:

Prader-Willi is a genetic condition that occurs in approximately 1 in 12,00-15,000 people. The most critical hallmark of Prader-Willi is overeating. Individuals with Prader-Willi cannot tell when they are full and continue to eat without stop leading to ruptured stomachs and death. Other symptoms include: development and cognitive delates, skin picking, sleep problems, obsessive-compulsive behavior, hypothyroidism, hypogonadism, low muscle tone and other traits.

Individuals who suffer from Prader-Willi receive services from the Office of People with Developmental Disabilities (OPWDD). However, many times they initially are rejected for services as the individual may have an IQ that is slightly too high to qualify initially. However, upon appeal by the individual they will then qualify for OPWDD services. Unfortunately, many individuals and their families will not appeal and therefore do not receive services. This legislation aims to streamline this process and make it easier for individuals with Prader-Willi to receive services.

PRIOR LEGISLATIVE HISTORY: New Bill.

FISCAL IMPLICATIONS: To be determined

EFFECTIVE DATE: This act shall take effect immediately.

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. Subparagraph 1 of paragraph(a)of subdivision 22 of section 1.03 of the mental hygiene law, as amended by section 4 of part MM of chapter 58 of the laws of 2015, is amended to read as follows:

(1) is attributable to intellectual disability, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia, PRADER-WILLI SYNDROME or autism;

S 2. This act shall take effect immediately.

Maine

Presented and passed during the SECOND REGULAR SESSION January 4, 2012 to May 31, 2012

THE EFFECTIVE DATE FOR SECOND REGULAR SESSION NON-EMERGENCY LAWS IS AUGUST 30, 2012

PUBLISHED BY THE REVISOR OF STATUTES IN ACCORDANCE WITH THE MAINE REVISED STATUTES ANNOTATED, TITLE 3, SECTION 163-A, SUBSECTION 4.

§3187. Principles of reimbursement; rules

The department shall meet annually with providers of community-based intermediate care facilities for persons with intellectual disabilities to review current principles of reimbursement under the federal Social Security Act, Title XIX, 42 United States Code, Chapter 7, and discuss necessary and appropriate changes.

Principles of reimbursement established for intermediate care facilities for persons with intellectual disabilities must ensure maximum flexibility enabling facilities to shift variable cost funds within accounts established pursuant to the principles. These principles may not set any artificial limits on specific variable cost accounts as long as facility totals are met.

Rules regarding principles of reimbursement for intermediate care facilities for persons with intellectual disabilities adopted pursuant to section 3173 are major substantive rules as defined in Title 5, chapter 375, subchapter 2-A, except that rules adopted to establish an approval process for capital expenditures to renovate or construct intermediate care facilities for persons with intellectual disabilities are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

~~Sec. A-36: 22 MRSA §3573, sub-§1, ¶B, as enacted by PL 2003, c. 602, §1, is amended to read:~~
B: "Mental and physical impairments" includes, but is not limited to, the following conditions: mental retardation, intellectual disability, autism, cerebral palsy, Asperger syndrome, mental illness, Prader-Willi syndrome and epilepsy.

Connecticut

2013 Connecticut General Statutes

Title 17a - Social and Human Services and Resources

Chapter 319b - Department of Developmental Services

Section 17a-227 - (Formerly Sec. 19a-467). Licensing and regulation of residential facilities for persons with intellectual disability, Prader-Willi syndrome or autism spectrum disorder.

Universal Citation: CT Gen Stat § 17a-227 (2013)

(a) No person, firm or corporation shall operate within this state a community living arrangement or community companion home which it owns, leases or rents for the lodging, care or treatment of persons with intellectual disability, Prader-Willi syndrome or autism spectrum disorder unless such person, firm or corporation, upon written application, verified by oath, has obtained a license issued by the Department of Developmental Services.

(b) The commissioner shall adopt regulations, in accordance with the provisions of chapter 54, to insure the comfort, safety, adequate medical care and treatment of such persons at the residential facilities described in subsection (a) of this section. Such regulations shall include requirements that: (1) All residential facility staff be certified in cardiopulmonary resuscitation in a manner and time frame prescribed by the commissioner; (2) records of staffing schedules and actual staff hours worked, by residential facility, be available for inspection by the department upon advance notice; (3) each residential facility develop and implement emergency plans and staff training to address emergencies that may pose a threat to the health and safety of the residents of the facility; (4) department staff verify during quality service reviews and licensing inspections, that (A) staff is adequately trained to respond in an emergency, and (B) a summary of information on each resident is available to emergency medical personnel for use in an emergency; and (5) not less than one-half of the quality service reviews, licensing inspections or facility visits conducted by the department after initial licensure are unannounced.

(c) After receiving an application and making such investigation as is deemed necessary and after finding the specified requirements to have been fulfilled, the department shall grant a license to such applicant to operate a facility of the character described in such application, which license shall specify the name of the person to have charge and the location of each facility operated under the license. Any person, firm or corporation aggrieved by any requirement of the regulations or by the refusal to grant any license may request an administrative hearing in accordance with the provisions of chapter 54. If the licensee of any such facility desires to place in charge thereof a person other than the one specified in the license, application shall be made to the Department of Developmental Services, in the same manner as provided for the original application, for permission to make such change. Such application shall be acted upon not later than ten calendar days from the date of the filing of the application. Each such license shall be renewed annually upon such terms as may be established by regulations and may be revoked by the department upon proof that the facility for which such license was issued is being improperly operated, or for the violation of any of the provisions of this section or of the regulations adopted pursuant to this section, provided the licensee shall first be given a reasonable opportunity to be heard in reference to such proposed revocation. Any person, firm or corporation aggrieved by such revocation may request an administrative hearing in accordance with the provisions of chapter 54. Each person,

firm or corporation, upon filing an application under the provisions of this section for a license for a community living arrangement, shall pay to the State Treasurer the sum of fifty dollars.

(d) The Department of Developmental Services may contract, within available appropriations, with any qualified provider for the operation of a community-based residential facility, provided the qualified provider is licensed by the department to operate such facilities. The department shall include in all contracts with such licensed qualified providers, provisions requiring the department to (1) conduct periodic reviews of contract performance, and (2) take progressive enforcement actions if the department finds poor performance or noncompliance with the contract, as follows: (A) The licensed qualified provider may be placed on a strict schedule of monitoring and oversight by the department; (B) the licensed qualified provider may be placed on a partial-year contract; and (C) payments due under the contract may be reduced by specific amounts on a monthly basis until the licensed qualified provider complies with the contract. If compliance cannot be achieved, the department shall terminate the contract.

(e) The department may contract with any person, firm or corporation to provide residential support services for persons with intellectual disability, Prader-Willi syndrome or autism spectrum disorder who reside in settings which are not licensed by the department. The commissioner shall adopt regulations, in accordance with the provisions of chapter 54, to ensure the safety, adequate supervision and support of persons receiving such residential support services.

(f) Any person, firm or corporation who operates any facility contrary to the provisions of this section shall be fined not more than one thousand dollars or imprisoned not more than six months or both. Any person, firm or corporation who operates any facility contrary to the regulations adopted pursuant to subsection (b) of this section shall be fined not more than one thousand dollars.

Florida

The 2017 Florida Statutes

Title XXIX
PUBLIC HEALTH

Chapter 393
DEVELOPMENTAL DISABILITIES

[View Entire Chapter](#)

393.063 Definitions.—For the purposes of this chapter, the term:

(1) “Adult day training” means training services that take place in a nonresidential setting, separate from the home or facility in which the client resides, and are intended to support the participation of clients in daily, meaningful, and valued routines of the community. Such training may be provided in work-like settings that do not meet the definition of supported employment.

(2) “Agency” means the Agency for Persons with Disabilities.

(3) "Algorithm" means the mathematical formula used by the agency to calculate budget amounts for clients which uses variables that have statistically validated relationships to clients' needs for services provided by the home and community-based services Medicaid waiver program.

(4) "Allocation methodology" is the process used to determine a client's iBudget by summing the amount generated by the algorithm, and, if applicable, any funding authorized by the agency for the client pursuant to s. 393.0662(1)(b).

(5) "Autism" means a pervasive, neurologically based developmental disability of extended duration which causes severe learning, communication, and behavior disorders with age of onset during infancy or childhood. Individuals with autism exhibit impairment in reciprocal social interaction, impairment in verbal and nonverbal communication and imaginative ability, and a markedly restricted repertoire of activities and interests.

(6) "Cerebral palsy" means a group of disabling symptoms of extended duration which results from damage to the developing brain that may occur before, during, or after birth and that results in the loss or impairment of control over voluntary muscles. For the purposes of this definition, cerebral palsy does not include those symptoms or impairments resulting solely from a stroke.

(7) "Client" means any person determined eligible by the agency for services under this chapter.

(8) "Client advocate" means a friend or relative of the client, or of the client's immediate family, who advocates for the best interests of the client in any proceedings under this chapter in which the client or his or her family has the right or duty to participate.

(9) "Comprehensive assessment" means the process used to determine eligibility for services under this chapter.

(10) "Comprehensive transitional education program" means the program established in s.393.18.

(11) "Developmental disabilities center" means a state-owned and state-operated facility, formerly known as a "Sunland Center," providing for the care, habilitation, and rehabilitation of clients with developmental disabilities.

(12) "Developmental disability" means a disorder or syndrome that is attributable to intellectual disability, cerebral palsy, autism, spina bifida, Down syndrome, Phelan-McDermid syndrome, or Prader-Willi syndrome; that manifests before the age of 18; and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.

(13) "Direct service provider" means a person 18 years of age or older who has direct face-to-face contact with a client while providing services to the client or has access to a client's living areas or to a client's funds or personal property.

(14) "Domicile" means the place where a client legally resides and which is his or her permanent home. Domicile may be established as provided in s. 222.17. Domicile may not be established in Florida by a minor who has no parent domiciled in Florida, or by a minor who has no legal guardian domiciled in Florida, or by any alien not classified as a resident alien.

(15) "Down syndrome" means a disorder caused by the presence of an extra chromosome 21.

(16) "Express and informed consent" means consent voluntarily given in writing with sufficient knowledge and comprehension of the subject matter to enable the person giving consent to make a knowing decision without any element of force, fraud, deceit, duress, or other form of constraint or coercion.

(17) "Family care program" means the program established in s. 393.068.

(18) "Foster care facility" means a residential facility licensed under this chapter which provides a family living environment including supervision and care necessary to meet the physical, emotional, and social needs of its residents. The capacity of such a facility may not be more than three residents.

(19) "Group home facility" means a residential facility licensed under this chapter which provides a family living environment including supervision and care necessary to meet the physical, emotional, and social needs of its residents. The capacity of such a facility shall be at least 4 but not more than 15 residents.

(20) "Guardian" has the same meaning as in s. 744.102.

(21) "Guardian advocate" means a person appointed by a written order of the court to represent a person with developmental disabilities under s. 393.12.

(22) "Habilitation" means the process by which a client is assisted in acquiring and maintaining those life skills that enable the client to cope more effectively with the demands of his or her condition and environment and to raise the level of his or her physical, mental, and social efficiency. It includes, but is not limited to, programs of formal structured education and treatment.

(23) "High-risk child" means, for the purposes of this chapter, a child from 3 to 5 years of age with one or more of the following characteristics:

(a) A developmental delay in cognition, language, or physical development.

(b) A child surviving a catastrophic infectious or traumatic illness known to be associated with developmental delay, when funds are specifically appropriated.

(c) A child with a parent or guardian with developmental disabilities who requires assistance in meeting the child's developmental needs.

(d) A child who has a physical or genetic anomaly associated with developmental disability.

(24) "Intellectual disability" means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior which manifests before the age of 18 and can reasonably be expected to continue indefinitely. For the purposes of this definition, the term:

(a) "Adaptive behavior" means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of his or her age, cultural group, and community.

(b) "Significantly subaverage general intellectual functioning" means performance that is two or more standard deviations from the mean score on a standardized intelligence test specified in the rules of the agency.

For purposes of the application of the criminal laws and procedural rules of this state to matters relating to pretrial, trial, sentencing, and any matters relating to the imposition and execution of the death penalty, the terms "intellectual disability" or "intellectually disabled" are interchangeable with and have the same meaning as the terms "mental retardation" or "retardation" and "mentally retarded" as defined in this section before July 1, 2013.

(25) "Intermediate care facility for the developmentally disabled" means a residential facility licensed and certified under part VIII of chapter 400.

(26) "Medical/dental services" means medically necessary services that are provided or ordered for a client by a person licensed under chapter 458, chapter 459, or chapter 466. Such services may include, but are not limited to, prescription drugs, specialized therapies, nursing supervision, hospitalization, dietary services, prosthetic devices, surgery, specialized equipment and supplies, adaptive equipment, and other services as required to prevent or alleviate a medical or dental condition.

(27) "Personal care services" means individual assistance with or supervision of essential activities of daily living for self-care, including ambulation, bathing, dressing, eating, grooming, and toileting, and other similar services that are incidental to the care furnished and essential to the health, safety, and welfare of the client if no one else is available to perform those services.

(28) "Phelan-McDermid syndrome" means a disorder caused by the loss of the terminal segment of the long arm of chromosome 22, which occurs near the end of the chromosome

at a location designated q13.3, typically leading to developmental delay, intellectual disability, dolicocephaly, hypotonia, or absent or delayed speech.

(29) "Prader-Willi syndrome" means an inherited condition typified by neonatal hypotonia with failure to thrive, hyperphagia or an excessive drive to eat which leads to obesity usually at 18 to 36 months of age, mild to moderate intellectual disability, hypogonadism, short stature, mild facial dysmorphism, and a characteristic neurobehavior.

(30) "Relative" means an individual who is connected by affinity or consanguinity to the client and who is 18 years of age or older.

(31) "Resident" means a person who has a developmental disability and resides at a residential facility, whether or not such person is a client of the agency.

(32) "Residential facility" means a facility providing room and board and personal care for persons who have developmental disabilities.

(33) "Residential habilitation" means supervision and training with the acquisition, retention, or improvement in skills related to activities of daily living, such as personal hygiene skills, homemaking skills, and the social and adaptive skills necessary to enable the individual to reside in the community.

(34) "Residential habilitation center" means a community residential facility licensed under this chapter which provides habilitation services. The capacity of such a facility may not be fewer than nine residents. After October 1, 1989, new residential habilitation centers may not be licensed and the licensed capacity for any existing residential habilitation center may not be increased.

(35) "Respite service" means appropriate, short-term, temporary care that is provided to a person who has a developmental disability in order to meet the planned or emergency needs of the person or the family or other direct service provider.

(36) "Restraint" means a physical device, method, or drug used to control dangerous behavior.

(a) A physical restraint is any manual method or physical or mechanical device, material, or equipment attached or adjacent to an individual's body so that he or she cannot easily remove the restraint and which restricts freedom of movement or normal access to one's body.

(b) A drug used as a restraint is a medication used to control the person's behavior or to restrict his or her freedom of movement and is not a standard treatment for the person's medical or psychiatric condition. Physically holding a person during a procedure to forcibly administer psychotropic medication is a physical restraint.

(c) Restraint does not include physical devices, such as orthopedically prescribed appliances, surgical dressings and bandages, supportive body bands, or other physical

holding necessary for routine physical examinations and tests; for purposes of orthopedic, surgical, or other similar medical treatment; to provide support for the achievement of functional body position or proper balance; or to protect a person from falling out of bed.

(37) "Seclusion" means the involuntary isolation of a person in a room or area from which the person is prevented from leaving. The prevention may be by physical barrier or by a staff member who is acting in a manner, or who is physically situated, so as to prevent the person from leaving the room or area. For the purposes of this chapter, the term does not mean isolation due to the medical condition or symptoms of the person.

(38) "Self-determination" means an individual's freedom to exercise the same rights as all other citizens, authority to exercise control over funds needed for one's own support, including prioritizing these funds when necessary, responsibility for the wise use of public funds, and self-advocacy to speak and advocate for oneself in order to gain independence and ensure that individuals with a developmental disability are treated equally.

(39) "Specialized therapies" means those treatments or activities prescribed by and provided by an appropriately trained, licensed, or certified professional or staff person and may include, but are not limited to, physical therapy, speech therapy, respiratory therapy, occupational therapy, behavior therapy, physical management services, and related specialized equipment and supplies.

(40) "Spina bifida" means a person with a medical diagnosis of spina bifida cystica or myelomeningocele.

(41) "Support coordinator" means a person who is designated by the agency to assist individuals and families in identifying their capacities, needs, and resources, as well as finding and gaining access to necessary supports and services; coordinating the delivery of supports and services; advocating on behalf of the individual and family; maintaining relevant records; and monitoring and evaluating the delivery of supports and services to determine the extent to which they meet the needs and expectations identified by the individual, family, and others who participated in the development of the support plan.

(42) "Supported employment" means employment located or provided in an integrated work setting, with earnings paid on a commensurate wage basis, and for which continued support is needed for job maintenance.

(43) "Supported living" means a category of individually determined services designed and coordinated in such a manner as to provide assistance to adult clients who require ongoing supports to live as independently as possible in their own homes, to be integrated into the community, and to participate in community life to the fullest extent possible.

(44) "Training" means a planned approach to assisting a client to attain or maintain his or her maximum potential and includes services ranging from sensory stimulation to instruction in skills for independent living and employment.

(45) "Treatment" means the prevention, amelioration, or cure of a client's physical and mental disabilities or illnesses.

Massachusetts

The Prader-Willi Syndrome Association of New England (PWSANE) is pleased to announce a successful legislative effort. Massachusetts House Bill 4047 was signed into law by Governor Patrick on August 5, 2014. The new disability law includes those with PWS as being eligible for disability services and removes any relationship to IQ measurements. Below is the text:

Person with a developmental disability, (1) an individual 5 years of age or older with a severe, chronic disability that: (i) is attributable to a mental or physical impairment resulting from intellectual disability, autism, smith-magenis syndrome or Prader-Willi syndrome; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (1) self-care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) selfdirection; (6) capacity for independent living; and (7) economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, supports or other assistance that is of a lifelong or extended duration and is individually planned and coordinated; or (2) an individual under the age of 5 who has a substantial developmental delay or specific congenital or acquired condition with a high probability that the condition will result in a developmental disability if services are not provided. A person who has a developmental disability may be considered to be mentally ill; provided, however, that no person with a developmental disability shall be considered to be mentally ill solely by reason of the persons developmental disability.

This legislation is the result of a large state lobbying effort in which PWSANE was an active participant. Funds for a professional lobbyist were raised through an annual walkathon sponsored by Jared and Cindy Wells and PWSANE and the Lens family golf event. The families affected by PWS are grateful to certain legislators and PWSANE members that assisted in this effort.

State eligibility criteria vary by state and fits into one of three categories. Category 1 would be those states that list PWS as an eligibility criteria; Category 2 are those states that have a broader definition of intellectual disability or a definition that includes substantial difficulty in independent living. Category 3 would be those states that strictly limit eligibility criteria to individuals having mental retardation. State PWS Chapters can have a pivotal role in not only changing legislation, but sharing strategies and knowledge to help individuals obtain services in the Category 2 and 3 states. According to a report issued in 2008 by the NASDDDS.org, states that specifically include those with PWS as an eligibility criteria are: AK, CT, DE, DC, FL, GA, MS, MO and now MA. There are many states in Category 2 as they include individuals with substantial limitations in 2 or 3 of the 7 functional living skills regardless of IQ number. This definition typically includes a person with PWS, although it is not an absolute. These states are: AR, CO, HI, ID, LA, MI, NE, NV, NH, NJ, NM, NY, NC, ND, OH, OR, WV, WY. The remaining states list an IQ criterion at 70 or below. Those States are: ME, CA, IL, IN, IO, KS, KY, MN, MT, OK, PA, SD, TN, TX, UT, VT, VA. It is more difficult to qualify for disability services in these Category 3 states particularly if the individual with PWS has an IQ over the threshold. Each state determines how they interpret the Federal guidelines for defining developmental disability. In Massachusetts, the state government was challenged by the disability community a couple of years ago as not meeting Federal guidelines. At that time, the state eligibility criterion was changed through legislation to a Category 2. Now MA has joined 8 other states in recognizing the special challenges of caring for a PWS individual

Minnesota

Minnesota Administrative Rules

Part 9525.0016

- o **Version List**
9525.0016 CASE MANAGEMENT ADMINISTRATION.

Subpart 1.

Intake.

Intake for case management must be conducted according to established county procedures.

§ Subp. 2.

Diagnostic definitions.

For purposes of subpart 3, the terms in items A to E have the meanings given them.

A. "Person with a related condition" means a person who has been diagnosed under this part as having a severe, chronic disability that meets all of the following conditions:

(1) is attributable to cerebral palsy, epilepsy, autism, Prader-Willi syndrome, or any other condition, other than mental illness as defined under Minnesota Statutes, section 245.462, subdivision 20, or an emotional disturbance, as defined under Minnesota Statutes, section 245.4871, subdivision 15, found to be closely related to developmental disability because the condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with developmental disabilities and requires treatment or services similar to those required for persons with developmental disabilities;

(2) is manifested before the person reaches 22 years of age;

(3) is likely to continue indefinitely; and

(4) results in substantial functional limitations in three or more of the following areas of major life activity:

(a) self-care;

(b) understanding and use of language;

(c) learning;

(d) mobility;

(e) self-direction; or

(f) capacity for independent living.

B. "Person with developmental disability" means a person who has been diagnosed under this part as having substantial limitations in present functioning, manifested as significantly subaverage intellectual functioning, existing concurrently with demonstrated deficits in adaptive behavior and who manifests these conditions before the person's 22nd birthday.

Oklahoma

STATE OF OKLAHOMA

1st Session of the 55th Legislature (2015) SENATE BILL 271 By: Halligan

AS INTRODUCED: An Act relating to Prader-Willi syndrome; amending 56 O.S. 2011, Section 1020, which relates to the administration of certain programs; permitting injection of certain drugs by certain persons; directing the Department of Human Services to promulgate certain rules; and providing an effective date. BE IT ENACTED BY THE PEOPLE OF THE STATE OF OKLAHOMA: SECTION 1. AMENDATORY 56 O.S. 2011, Section 1020, is amended to read as follows:

Section 1020.

A. The Director of the Department of Human Services shall, within the constraints of funding appropriated to the Department, establish and maintain a community-based program of services that includes, but is not limited to, establishment of foster care and supported living arrangements for persons affected by Prader-Willi syndrome. The purpose of this section of law shall be to improve the

quality of life of persons with developmental disabilities and to integrate such persons into the mainstream of society by ensuring availability of community services.

B. The programs established pursuant to this section shall be administered by the Developmental Disabilities Service Division. The Commission for Human Services shall promulgate rules for the operation of community-based programs for persons with developmental disabilities including, but not limited to, rules regarding the delivery of:

1. Health-related services. As used in this section, health related services means services provided by community services providers or community services workers to persons with developmental disabilities, and includes, but is not limited to:

- a. personal hygiene,
- b. transferring,
- c. range of motion,
- d. supervision or assistance with activities of daily living,
- e. basic nursing care, such as taking the person's temperature, pulse or respiration, positioning, incontinent care, and identification of signs and symptoms of disease. Certain tasks that may be performed as basic nursing care by community services workers require appropriate training provided or approved by the Department, written agreement by the service recipient's personal support team, and the primary care physician's acknowledgment and specific order related to the task. Under such circumstances, basic nursing care may include, but need not be limited to:

- (1) nutrition, including meals by gastrostomy tube or jejunotomy tube,
- (2) blood glucose monitoring,
- (3) ostomy bag care,
- (4) oral suctioning, and
- (5) administration of oral metered dose inhalers and nebulizers;

2. Supportive assistance, which means the service rendered to persons with developmental disabilities that is sufficient to enable such person to meet an adequate level of daily living. Supportive assistance includes, but is not limited to, training and supervision of persons with developmental disabilities, assistance in housekeeping, assistance in the preparation of meals, and assistance in activities of daily living as necessary for the health and comfort of persons with developmental disabilities; and

3. Safe storage and administration of medications, first aid treatments and nutrition by oral, rectal, vaginal, otic, ophthalmic, nasal, skin, topical, transdermal and gastrostomy tube routes by community service workers who have successfully completed competency-based training approved by the Department.

Utah

DISCUSSION AND ANALYSIS The following is a list of legislative intent from the 2008 General Session with the agency's response. The Analyst has no concerns of non-compliance with any intent language issued last year.

1. H.B. 2, Require Case Management Services for Individuals with Prader-Willi Syndrome: The Legislature intends that the Department of Health pay for case management services for individuals affected by Prader-Willi Syndrome out of the existing Medicaid Mandatory Services budget.
2. *Agency Response:* The Division of Health Care Financing is reimbursing case management services provided for Prader-Willi syndrome clients enrolled in the Community Supports Waiver program.

Virginia

CHAPTER 289

An Act to amend and reenact §§ 51.5-116, 51.5-119, 51.5-123, and 51.5-124 of the Code of Virginia, relating to individuals with disabilities; terminology.

[H 1076]

Approved March 24, 2014

Be it enacted by the General Assembly of Virginia:

1. That §§ 51.5-116, 51.5-119, 51.5-123, and 51.5-124 of the Code of Virginia are amended and reenacted as follows:

§ 51.5-116. Definitions.

As used in this chapter, unless the context requires a different meaning:

"Case management" means a dynamic collaborative process that utilizes and builds on the strengths and resources of consumers to assist them in identifying their needs, accessing and coordinating services, and achieving their goals. The major collaborative components of case management services include advocacy, assessment, planning, facilitation, coordination, and monitoring.

"Case management system" means a central point of contact linking a wide variety of evolving services and supports that are (i) available in a timely, coordinated manner; (ii) physically and programmatically accessible; and (iii) consumer-directed with procedural safeguards to ensure responsiveness and accountability.

"Client" means any person receiving a service provided by the personnel or facilities of a public or private agency, whether referred to as a client, participant, patient, resident, or other term.

"Commissioner" means the Commissioner for Aging and Rehabilitative Services.

"Consumer" means, with respect to case management services, a person with a disability or his designee, guardian, conservator, or committee.

"Department" means the Department for Aging and Rehabilitative Services.

"Local board" means a local board of social services established pursuant to Article 1 (§ 63.2-300 et seq.) of Chapter 3 of Title 63.2.

"Local department" means a local department of social services established pursuant to Article 2 (§ 63.2-324 et seq.) of Chapter 3 of Title 63.2.

"Local director" means a local director of social services appointed pursuant to § 63.2-325.

"Older person" or "older Virginian" means a person who is age 60 years or older.

"Physical or sensory disability" means a disability resulting in functional impairment or impairment of the central nervous system, which may include but is not limited to brain injury, spinal cord injury, cerebral palsy, arthritis, muscular dystrophy, multiple sclerosis, Prader-Willi syndrome, and systemic lupus erythematosus (lupus).

"Prader-Willi syndrome" means a specific disorder that is usually caused by chromosomal change, resulting in lifelong functional and cognitive impairments and life-threatening obesity.

"Rehabilitation technology" means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of and address the barriers confronted by individuals with disabilities in areas that include education, rehabilitation, employment, transportation, independent living, and recreation.

§ 51.5-119. Department designated as state agency for purpose of coordinating rehabilitative services.

The Department is designated as the state agency for coordinating rehabilitative services to persons *significant physical or sensory* disabilities. The Department shall provide for the comprehensive assessment of the need for rehabilitative and support services of such persons, identify gaps in services, promote interagency coordination, develop models for case management, and advise the Secretary of Health and Human Resources, the Governor, and the General Assembly on programmatic and fiscal policies and the delivery of services to such persons.

Wisconsin

Mental retardation, see also Community-based residential facility

CIP use of model service contract to receive COP funds required (remedial legislation) - SB495

Confidentiality of certain resident patient records [Sec. 2120, 3010; original bill only] - AB100

Confidentiality of certain resident patient records [Sec. 2120, 3010] - SB77

MA annual review for certain residents of nursing homes and mental disease institutions: requirement eliminated [Sec. 1916] - AB100

MA annual review for certain residents of nursing homes and mental disease institutions: requirement eliminated [Sec. 1916] - SB77

Nursing home as institution for mental disease: DHFS determination requirements revised (remedial legislation) - SB495

Prader-Willi syndrome specified as a developmental disability - AB403

Relating to: specifying that Prader-Willi syndrome is a developmental disability. (FE) relating to: specifying that Prader-Willi syndrome is a developmental disability. (FE) **12/16/1997 - approved by the Governor**