

**The Florida Senate**  
**BILL ANALYSIS AND FISCAL IMPACT STATEMENT**

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

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Prepared By: The Professional Staff of the Appropriations Subcommittee on Health and Human Services

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BILL: CS/SB 1040

INTRODUCER: Children, Families, and Elder Affairs Committee and Senator Brodeur

SUBJECT: Special Persons Registry

DATE: February 21, 2022

REVISED: \_\_\_\_\_

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	<u>Delia</u>	<u>Cox</u>	<u>CF</u>	<u>Fav/CS</u>
2.	<u>Gerbrandt</u>	<u>Money</u>	<u>AHS</u>	<u>Pre-meeting</u>
3.	<u>                    </u>	<u>                    </u>	<u>AP</u>	<u>                    </u>

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**Please see Section IX. for Additional Information:**

COMMITTEE SUBSTITUTE - Substantial Changes

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**I. Summary:**

CS/SB 1040, known as the “Protect Our Loved Ones” Act, requires the Florida Department of Health (DOH) to develop and maintain a database, known as the “Special Needs Registry”, of persons who may have developmental, psychological, or other disabilities or conditions.

Parents, guardians, and caregivers may voluntarily enroll individuals in the registry. The registry may include:

- An enrollee’s demographic and contact information, and information related to the enrollee’s disability or condition;
- Contact information of caregivers who have enrolled individuals on the registry; and
- Certain information requested by the DOH or the Florida Department of Law Enforcement (FDLE).

The bill requires the FDLE to provide information from the registry to law enforcement officers to assist in performance of their official duties.

The costs of creating and maintaining the registry will have a significant fiscal impact on the DOH. See Section V. Fiscal Impact Statement.

The bill takes effect March 1, 2023.

## II. Present Situation:

### Developmental Disabilities

Developmental disabilities<sup>1</sup> include autism, cerebral palsy, spina bifida, intellectual disabilities, Down syndrome, Prader-Willi syndrome, and Phelan-McDermid syndrome.<sup>2</sup>

Cerebral palsy<sup>3</sup> is 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.<sup>4</sup>

Spina bifida<sup>5</sup> is a birth defect in the vertebral column in which part of the spinal cord, which is normally protected within the vertebral column, is exposed. Spina bifida is caused by the failure of the neural tube to close during embryonic development. The neural tube is the embryonic structure that gives rise to the brain and spinal cord. People with spina bifida can have difficulty with bladder and bowel incontinence, cognitive (learning) problems, and limited mobility.<sup>6</sup>

Individuals suffering from intellectual disabilities have significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior, which manifests before the age of 18.<sup>7</sup> Such individuals have certain limitations in both mental functioning and in adaptive skills such as communicating, self-care, and social skills. These limitations will cause a person to learn and develop more slowly. People with intellectual disabilities may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating.<sup>8</sup>

Down syndrome is a genetic disorder caused when abnormal cell division results in extra genetic material from chromosome 21. This genetic disorder, also known as trisomy 21, varies in severity, causes lifelong intellectual disability and developmental delays, and, in some people, causes health problems.<sup>9</sup>

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<sup>1</sup> Developmental disability is defined as 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.

<sup>2</sup> Agency for Persons with Disabilities, *Long-Range Program Plan (2021)*, available at <http://floridafiscalportal.state.fl.us/Document.aspx?ID=23172&DocType=PDF> (last visited February 3, 2022) (hereinafter cited as “The Long-Range Plan”).

<sup>3</sup> Section 393.063(6), F.S.

<sup>4</sup> *Id.*

<sup>5</sup> Spina bifida is defined in statute as a medical diagnosis of spina bifida cystica or myelomeningocele. Section 393.063(41), F.S.

<sup>6</sup> The Long-Range Plan, p. 79.

<sup>7</sup> Section 393.063(24), F.S. For the purposes of this definition, the term “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. The term “significantly sub-average 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.

<sup>8</sup> *Id.* at 73.

<sup>9</sup> *Id.* Down syndrome is defined in statute as a disorder caused by the presence of an extra chromosome 21. Section 393.063(15), F.S.

Prader-Willi syndrome<sup>10</sup> is a complex genetic condition that affects many parts of the body. In infancy, this condition is characterized by weak muscle tone, feeding difficulties, poor growth, and delayed development. Beginning in childhood, affected individuals develop an insatiable appetite and chronic overeating. As a result, most experience rapid weight gain leading to obesity. People with Prader-Willi syndrome typically have an intellectual disability or a learning disability and behavioral problems.<sup>11</sup>

Phelan-McDermid syndrome<sup>12</sup> is a rare condition due to a chromosomal abnormality. Symptoms vary in range and severity but often include low muscle tone, difficulty moving, absent-to-severely delayed speech, autistic features, moderate-to-profound intellectual disability, and epilepsy.<sup>13</sup>

### ***Autism***

Autism is a pervasive, neurologically-based developmental disability of extended duration that has onset during infancy or childhood, which causes severe learning, communication, and behavioral disorders.<sup>14</sup> Autism spectrum disorder (ASD) includes autism, Asperger's syndrome, and any other pervasive developmental disorder.<sup>15</sup> The Centers for Disease Control and Prevention (CDC) estimates that approximately one in 44 children has ASD.<sup>16</sup> The CDC also estimates that over 5.4 million adults have ASD.<sup>17</sup>

### ***Interactions with Law Enforcement for Individuals with Autism***

A person's developmental disability may make interactions with law enforcement more challenging. For example, identifying a person with an ASD can be confusing to any person unfamiliar with the condition, including law enforcement. Law enforcement can mistake the signs of autism with behaviors typically associated with those of criminals.<sup>18</sup> Common attributes of autism are communication differences and behaviors or thinking that are repetitive or restricted to an area of interest. These traits could be interpreted by law enforcement as not being compliant with questioning or direct instructions. A characteristic of ASD known as escalation

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<sup>10</sup> Prader-Willi syndrome is defined in statute as 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. Section 393.063(29), F.S.

<sup>11</sup> *Id.*

<sup>12</sup> Phelan-McDermid Syndrome is defined in statute as 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. Section 393.063(28), F.S.

<sup>13</sup> *Id.*

<sup>14</sup> Section 393.063(5), F.S.

<sup>15</sup> Section 627.6686(2)(b), F.S.

<sup>16</sup> The Centers for Disease Control and Prevention (The CDC), *Data & Statistics on Autism Spectrum Disorder*, available at <https://www.cdc.gov/ncbddd/autism/data.html> (last visited February 3, 2022).

<sup>17</sup> The CDC, *Key Findings: CDC Releases First Estimates of the Number of Adults Living with Autism Spectrum Disorder in the United States*, available at <https://www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html> (last visited February 3, 2022).

<sup>18</sup> Randy Lambert, *How Changing the Wes Kleinert Fair Interview Act and Establishing Law Enforcement Academy Training Standards Will Help the Autism Community*, *Child and Family Law Journal*, p. 48 (2018), available at <https://lawpublications.barry.edu/cflj/vol6/iss1/3> (last visited February 3, 2022).

poses a particular problem in encounters with law enforcement.<sup>19</sup> Escalation describes the response of a person with ASD under stress or in an unfamiliar situation.<sup>20</sup> Overwhelmed by the barrage of sensory information, a person with ASD may attempt to flee the uncomfortable situation, become combative, or simply shut down.<sup>21</sup> The individual may cover his or her ears and shriek, not knowing how or where to get help.<sup>22</sup> The presence of police lights and sirens, uniforms, loud and unfamiliar voices, or barking dogs often makes a difficult situation worse by contributing to the individual's sensory overload.<sup>23</sup>

### **Mental Health and Mental Illness**

Mental health is a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to his or her community.<sup>24</sup>

The primary indicators used to evaluate an individual's mental health are:

- **Emotional well-being-** Perceived life satisfaction, happiness, cheerfulness, peacefulness;
- **Psychological well-being-** Self-acceptance, personal growth including openness to new experiences, optimism, hopefulness, purpose in life, control of one's environment, spirituality, self-direction, and positive relationships; and
- **Social well-being-** Social acceptance, beliefs in the potential of people and society as a whole, personal self-worth and usefulness to society, sense of community.

Mental illness is collectively all diagnosable mental disorders or health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress or impaired functioning.<sup>25</sup> Thus, mental health refers to an individual's mental state of well-being whereas mental illness signifies an alteration of that well-being. Mental illness affects millions of people in the United States each year. Nearly one in five adults lives with a mental illness.<sup>26</sup> During their childhood and adolescence, almost half of children will experience a mental disorder, though the proportion experiencing severe impairment during childhood and adolescence is much lower, at about 22 percent.<sup>27</sup>

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<sup>19</sup> Bernard J. Farber, *Police Interaction With Autistic Persons: The Need For Training*, *Aele Monthly Law Journal*, p. 106 (2009), available at <https://www.aele.org/law/2009all07/2009-07MLJ101.pdf> (last visited February 3, 2022).

<sup>20</sup> *Id.*

<sup>21</sup> *Id.*

<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> World Health Organization, *Mental Health: Strengthening Our Response*, <https://www.who.int/news-room/factsheets/detail/mental-health-strengthening-our-response> (last visited February 4, 2022).

<sup>25</sup> *Id.*

<sup>26</sup> National Institute of Mental Health (NIH), *Mental Illness*, <https://www.nimh.nih.gov/health/statistics/mental-illness> (last visited Feb.4, 2022).

<sup>27</sup> *Id.*

Some examples of common mental health illnesses or disorders that can negatively impact how a person interacts with others, such as law enforcement officers, include schizophrenia, bipolar disorder, borderline personality disorder, and antisocial personality disorder.<sup>28</sup>

### **Alzheimer's Disease**

Alzheimer's disease is a form of dementia, a general term for memory loss. It is a progressive brain disorder that damages and eventually destroys brain cells, leading to memory loss and changes in the functions of the brain. In the early stages of Alzheimer's disease, memory loss is mild; in late-stages, individuals lose the ability to carry on a conversation and respond to their environment. Currently, the disease has no cure, but treatment can temporarily slow the worsening of symptoms.<sup>29</sup>

Florida has an increasing number of individuals with Alzheimer's disease. An estimated 580,000 Floridians have Alzheimer's disease.<sup>30</sup> The projected number of Floridians with Alzheimer's disease is estimated to increase by 24% to 720,000 individuals by 2025.<sup>31</sup>

### ***Interactions with Law Enforcement for Individuals with Alzheimer's and Dementia***

Many behaviors associated with Alzheimer's disease and dementia tend to increase a person's chance of interacting with law enforcement. Because these individuals are often unable to explain their unusual behavior, their actions are more easily misunderstood.<sup>32</sup> Common instances that can cause someone with Alzheimer's disease to interact with law enforcement include wandering, auto accidents, erratic driving, accidental breaking and entering due to confusion, and unintentional shoplifting.<sup>33</sup>

### **Florida Crime Information Center (FCIC) System**

The Florida Crime Information Center (FCIC) system is an electronic database that provides criminal justice agencies with access to federal and state criminal justice information. The FCIC is managed by FDLE and contains information as reported to FDLE by law enforcement agencies through the state.<sup>34</sup>

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<sup>28</sup> See National Alliance Mental Illness, *Mental Health Disorders*, available at <https://www.nami.org/About-Mental-Illness/Mental-Health-Conditions>; Psychiatry Online, *Contact Between Police and People With Mental Disorders: A Review of Rates*, available at <https://ps.psychiatryonline.org/doi/10.1176/appi.ps.201500312> (all sites last visited February 5, 2022).

<sup>29</sup> Alzheimer's Association, *2021 Alzheimer's Disease Facts and Figures*, p. 69, available at <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf> (last visited February 3, 2022).

<sup>30</sup> The Department of Elder Affairs, *2021 Alzheimer's Disease Advisory Committee Annual Report*, p. 4, available at [https://elderaffairs.org/wp-content/uploads/ADAC-Report-2021\\_FINAL.pdf](https://elderaffairs.org/wp-content/uploads/ADAC-Report-2021_FINAL.pdf) (last visited February 3, 2022).

<sup>31</sup> *Id.*

<sup>32</sup> Alzheimer's Association, *Alzheimer's Disease Guide for Law Enforcement*, available at [https://www.alz.org/national/documents/safereturn\\_lawenforcement.pdf](https://www.alz.org/national/documents/safereturn_lawenforcement.pdf) (last visited February 3, 2022).

<sup>33</sup> *Id.*

<sup>34</sup> The FDLE, *The FCIC*, available at <https://web.fdle.state.fl.us/pas/restricted/PAS/home/home.jsf> (last visited February 3, 2022).

## Voluntary Registry Systems

Law enforcement agencies nationwide have begun utilizing voluntary registry systems that provide officers with relevant information on individuals with special needs, including those with Alzheimer's disease.<sup>35</sup> Law enforcement agencies have found that such registries can:

- Promote community safety;
- Improve officer safety;
- Increase the speed and efficiency in which officers are able to respond, decreasing department liability;
- Reduce strain on department resources, both human and financial, during emergencies;
- Give community members peace of mind; and
- Promote community partnerships in responding to special needs community members.<sup>36</sup>

Voluntary registry systems allow law enforcement to obtain information that assists in response to calls for service involving individuals with conditions such as Alzheimer's disease.<sup>37</sup>

Voluntary registry systems have also proven helpful in responding to individuals in other special needs populations. Departments utilize the system for community members living with ASD, developmental disabilities, attention deficit/hyperactivity disorder (ADHD), epilepsy, brain injury, mental illness, and other disabilities that may affect the way individuals interact and respond to law enforcement officers and other first responders.<sup>38</sup>

### *Project Safe and Sound*

In 2007, the Polk County Sheriff's Office (PCSO) began utilizing a voluntary registry system, called Project Safe and Sound (PSS), which provides bracelets to registrants in an effort to help identify wandering individuals with Alzheimer's disease and special needs children.<sup>39</sup>

Caregivers choosing to participate are asked to complete an application/authorization form which requires specific information about the child or adult being registered. The agency then enters the information into the PSS database, making the information accessible to all Polk County first responders. After the information is entered, the special needs person will be issued a "Safe & Sound" bracelet, which includes an assigned number. The bracelet also includes emergency contact information engraved on the plate of the bracelet. In the event a special needs child or adult wanders off and is found, responding law enforcement personnel will be able to contact the PCSO and confirm the identity of the individual.<sup>40</sup> First responders will be provided the caregiver's contact information so that the special needs person can be reunited with their caregiver.<sup>41</sup>

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<sup>35</sup> The International Association of Chiefs of Police (IACP), *A Guide to Law Enforcement on Voluntary Registry Programs for Vulnerable Populations*, p. 2, available at

[https://www.theiacp.org/sites/default/files/Alz%20Voluntary%20Registry\\_0.pdf](https://www.theiacp.org/sites/default/files/Alz%20Voluntary%20Registry_0.pdf) (last visited February 3, 2022)(hereinafter cited as "The IACP Guide").

<sup>36</sup> *Id.*

<sup>37</sup> *Id.*

<sup>38</sup> *Id.* at 3.

<sup>39</sup> Polk County Sheriff's Office, *Project Safe & Sound*, available at <http://www.polksheriff.org/programs-services/crime-prevention-programs-for-adults/project-safe-sound> (last visited February 3, 2022).

<sup>40</sup> *Id.*

<sup>41</sup> *Id.*

The PCSO was highlighted in *A Guide to Law Enforcement on Voluntary Registry Programs for Vulnerable Adults* for using existing grant funds to build and sustain the PSS program and leveraging a partnership with a local engraver who engraves PSS bracelets with ID numbers at no cost to the program.<sup>42</sup>

### **Florida Special Needs Registry**

The DOH, in coordination with its county health departments and each local emergency management agency in the state, developed a registry for persons with special needs to register with their local emergency management agency to receive assistance during a disaster. The statewide registry provides first responders with valuable information to prepare for disasters or other emergencies.<sup>43</sup> All records, data, information, correspondence, and communications relating to the registry are confidential and exempt from Florida's public records laws.<sup>44</sup>

### **III. Effect of Proposed Changes:**

The bill creates s. 402.88, F.S., providing that the bill may be cited as the "Protect Our Loved Ones Act." The bill requires the DOH to develop and maintain a database, known as the "Special Needs Registry" of persons who may have developmental, psychological, or other disabilities or conditions that may be relevant to their interactions with law enforcement officers, including but not limited to:

- Autism spectrum disorder;
- Alzheimer's disease;
- Dementia;
- Bipolar disorder; and
- Down syndrome.

Parents, guardians, and caregivers may voluntarily enroll individuals in the registry, and persons 18 and older may self-enroll. The registry may include:

- An enrollee's demographic and contact information, and information related to the enrollee's disability or condition;
- Contact information of those who have enrolled individuals on the registry;
- Any additional information provided by an enrollee or their caregiver; and
- Any information requested by the DOH or the FDLE or otherwise held by a:
  - Law enforcement agency;
  - County emergency management agency; or
  - Local fire department for the purpose of assisting any of the following in responding to call for service:
    - Assisting law enforcement officers;
    - Emergency medical personnel; or
    - Fire personnel.

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<sup>42</sup> The IACP Guide at 32 and 24.

<sup>43</sup> Florida Department of Health, *Florida Special Needs Registry*, available at: <https://snr.flhealthresponse.com/> (last visited February 17, 2022).

<sup>44</sup> Sections 252.905, and 252.355(4), F.S., both provide a public records exemption for information related to the Florida Special Needs Registry.

The bill requires the FDLE to provide relevant information from the registry to law enforcement officers in performance of their official duties. The bill also requires the DOH to provide such information to a law enforcement officer engaged in their duties upon an officer's request made through the FCIC.

The information provided to law enforcement officers under the bill may assist officers by preparing them to respectfully and appropriately interact with an individual enrolled in the registry who has a relevant condition.

The bill takes effect March 1, 2023.

#### **IV. Constitutional Issues:**

##### **A. Municipality/County Mandates Restrictions:**

The bill does not appear to require cities and counties to expend funds or limit their authority to raise revenue or receive state-shared revenues as specified by Article VII, Section 18 of the Florida Constitution.

##### **B. Public Records/Open Meetings Issues:**

None.

##### **C. Trust Funds Restrictions:**

None.

##### **D. State Tax or Fee Increases:**

None.

##### **E. Other Constitutional Issues:**

None identified.

#### **V. Fiscal Impact Statement:**

##### **A. Tax/Fee Issues:**

None.

##### **B. Private Sector Impact:**

None.



**C. Government Sector Impact:**

The bill will have a significant negative fiscal impact on the Department of Health. To build a new system or modify the current Florida Special Needs Registry, and maintain and manage the registry the DOH estimates a cost of \$1.2 million over two years and two full-time-equivalent positions. The current Florida Special Needs Registry is funded from federal preparedness grants. Any new system or modifications would require a separate funding source.<sup>45</sup>

According to the Florida Department of Law Enforcement (FDLE) the bill will require the development of an interface with the registry at an estimated cost of \$80,000.<sup>46</sup>

**VI. Technical Deficiencies:**

None.

**VII. Related Issues:**

None.

**VIII. Statutes Affected:**

This bill creates section 402.88 of the Florida Statutes.

**IX. Additional Information:****A. Committee Substitute – Statement of Changes:**

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

**CS by Children, Families, and Elder Affairs on February 8, 2022:**

The Committee Substitute:

- Changes the name of the voluntary registry created by the bill from “Registry of Persons with Special Needs” to the “Special Persons Registry”.
- Changes the entity creating and maintaining the registry from the APD to the DOH.
- Revises the effective date to March 1, 2023.

**B. Amendments:**

None.

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This Senate Bill Analysis does not reflect the intent or official position of the bill’s introducer or the Florida Senate.

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<sup>45</sup> Email from Andrew Love, DOH Legislative Affairs Director (February 17, 2022) (on file with the Appropriations Subcommittee on Health and Human Services).

<sup>46</sup> Florida Department of Law Enforcement, *Senate Bill 1040 Fiscal Analysis* (January 7, 2022)(on file with the Appropriations Subcommittee on Health and Human Services).