#### SENATE JUDICIARY COMMITTEE Senator Thomas Umberg, Chair 2021-2022 Regular Session

SB 518 (Laird) Version: April 13, 2021 Hearing Date: April 27, 2021 Fiscal: Yes Urgency: No JT

## **SUBJECT**

### Developmental services: Self-Determination Program

### DIGEST

This bill aims to increase the use of the Self-Determination Program (SDP) for people with developmental disabilities by creating the Office of the SDP Ombudsperson, providing for the collection of more data, and increasing training relating to the SDP.

## **EXECUTIVE SUMMARY**

Under the Lanterman Developmental Disabilities Services Act (Act), the Department of Developmental Services (DDS) contracts with 21 private nonprofit corporations known as regional centers to coordinate services and support for individuals with developmental disabilities. The SDP is a voluntary alternative to the traditional way of providing regional center services. The SDP allows participants to have more control over selecting their services and supports. To date, there have been numerous challenges with the implementation of the statewide SDP.

This bill aims to increase the use of the SDP by increasing the data that is gathered on the SDP, requiring training on the SDP for regional center staff, and requiring the DDS to create an Office of the SDP Ombudsperson to assist persons with intellectual and developmental disabilities in overcoming barriers to entering the SDP, and to assist SDP participants in overcoming barriers to full participation and inclusion. The Ombudsperson would be an independent and autonomous entity in the DDS and would be responsible for the implementation of specified objectives and assisting regional center clients, SDP consumers, and their families in order to promote full participation in the program.

The bill is co-sponsored by Disability Rights Coalition and Disability Voices United and is supported by Cal-TASH. The bill has no known opposition. The bill passed the Human Services Committee by a vote of 5-0.

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## PROPOSED CHANGES TO THE LAW

## Existing law:

- 1) Establishes the Lanterman Developmental Disabilities Services Act, which states that California is responsible for providing an array of services and supports to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, and at each stage of life, and to support their integration into the mainstream life of the community. (Welf. & Inst. Code § 4500, et seq.)<sup>1</sup>
- 2) Defines a "developmental disability" to mean a disability that originates before an individual attains 18 years of age which continues, or can be expected to continue, indefinitely and constitutes a substantial disability for that individual, including intellectual disability, cerebral palsy, epilepsy, and autism and related conditions, but excluding other conditions that are solely physical in nature. (§ 4512(a).)
- 3) Establishes a system of nonprofit regional centers, which contract with DDS to provide fixed points of contact in the community for all persons with developmental disabilities and their families, and to coordinate services and supports best suited to them throughout their lifetime. (§ 4620(a).)
  - a. Requires the contracts to include annual performance objectives that the DDS determines are necessary to ensure the regional center is rendering services in accordance with applicable laws. (§ 4629(a), (b), (c).)
  - b. Requires the DDS and the regional centers to annually collaborate to compile data in a uniform manner related to purchase of service authorization, utilization, and expenditure by each regional center with respect to certain demographic characteristics of consumers, as provided. (§ 4519.5(a).)
- 4) Requires that an individual program plan be developed through a specified process for each person who is eligible for regional center services. (§ 4646.)
- 5) Requires the DDS to implement a statewide Self-Determination Program (SDP). (§ 4685.8(a).) The SDP must be available in every regional center catchment area to provide participants and their families, within an individual budget, increased flexibility and choice, and greater control over decisions, resources, and needed and desired services and supports to implement their individual program plan.

## This bill:

1) Finds and declares that the people of the State of California have benefited from the establishment of a long-term care ombudsperson pursuant to Section 9710 of the Welfare and Institutions Code, a child care ombudsperson program pursuant to

<sup>&</sup>lt;sup>1</sup> All further statutory references are to the Welfare and Institutions Code, unless otherwise specified

Section 1596.872a of the Health and Safety Code, and a foster child ombudsperson program pursuant to Section 16161 of the Welfare and Institutions Code.

- 2) States it is the intent of the Legislature to provide protections for persons with intellectual and developmental disabilities who seek to become or are already participants in the SDP by establishing an Office of the SDP Ombudsperson.
- 3) Requires the DDS and regional centers to compile data on the individual budget certification, utilization, and expenditure for the SDP participants. Requires that the annual performance objectives included in the five-year contracts of regional center are able to measure progress and report outcomes in implementing the SDP, as provided.
- 4) Requires the DDS to establish an Office of the SDP Ombudsperson to assist: (1) persons with intellectual and developmental disabilities in overcoming barriers to entering the SDP and (2) SDP participants in overcoming any barrier to full participation and inclusion.
- 5) Provides that the Ombudsperson is an independent and autonomous entity in the DDS for the purpose of monitoring the implementation of specified objectives and assisting regional center clients and SDP consumers and their families in order to participate fully in the program, as specified.
- 6) Provides that the Ombudsperson has the following rights and duties:
  - a) Assisting regional center consumers and their families in understanding their rights and facilitating solutions to disagreement regarding eligibility and services.
  - b) Providing information and support to regional center consumers and their families and stakeholders in navigating and understanding the SDP.
  - c) Deciding whether to investigate, or refer to another agency for investigation, certain complaints and alleged violations, and recommending to the DDS strategies to change and improve the SDP.
  - d) Advising and aiding the DDS regarding the creation of public information programs that educate Californians about the SDP and the Ombudsperson's duties regarding the SDP.
  - e) Compiling data relating to complaints and investigations and reporting it to the Legislature and certain advisory bodies; making recommendations to the Legislature and DDS for improving the SDP and changes to relevant laws the Ombudsperson determines to be appropriate.
  - f) Posting on a dedicated website the aggregated and depersonalized data compiled pursuant to the requirement above.
  - g) Establishing a telephone number at which regional center consumers and other stakeholders may contact the Ombudsperson, and a confidential

mechanism to receive feedback on consumer satisfaction in their experience with the Ombudsperson's office.

- h) Maintaining the confidentiality of information obtained by the office from a complaint, regardless of whether it is investigated by the office, referred to another entity for investigation, or determined not to be the proper subject of an investigation, or confidential under relevant state and federal confidentiality laws. Disclosure of information shall occur only as necessary to carry out the mission of the office and as permitted by law.
- 7) Specifies that contacting, assisting, communicating with, providing information to the Self-Determination Program Ombudsperson, or participating in any way in a complaint, investigation, proceeding, or hearing related to the activities of the Self-Determination Program Ombudsperson, shall be considered protected activity.
- 8) Establishes requirements trainings related to the SDP for regional center staff.

# **COMMENTS**

# 1. <u>Author's statement</u>

The author writes:

SB 518 will require the Department of Developmental Services to facilitate an ombudsperson that will have the authority to investigate the Self-Determination Program (SDP) and the authorization to keep investigations confidential. The SDP is based on successful multi-year self-determination pilot projects, which gave individuals with developmental disabilities authentic person-centered planning, choice and control over their services and supports, in addition to better outcomes, with potential long-term cost savings. SB 518 will establish an ombudsperson to ensure successful adoption of self-determination, work to address racial and ethnic disparities, provide opportunities for innovation and increase consumer choice and flexibility.

# 2. The Lanterman Developmental Disabilities Services Act

In 1969, the Act established that individuals with developmental disabilities and their families have a right to receive the necessary supports and services required to live independently in the community. The Act enumerates the rights of individuals with developmental disabilities, the rights of their families, the services and supports available to these individuals, and details how regional centers and service providers must work together to provide these supports and services.

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In California, a developmental disability is defined as one that originates before an individual attains 18 years of age which continues, or can be expected to continue, indefinitely and constitutes a substantial disability for that individual, including intellectual disability, cerebral palsy, epilepsy, and autism and related conditions, but excluding other conditions that are solely physical in nature. (§ 4512(a).) If an individual is determined to have a qualifying condition, then developmental services in California are considered an entitlement to care, regardless of income or public benefit eligibility.

DDS is the state agency that has jurisdiction over the laws relating to the care, custody, and treatment of individuals with developmental disabilities. (§ 4416.) Under the Act, DDS selects nonprofit corporations known as regional centers to determine what services should be provided to individuals with developmental disabilities. In turn, the regional centers contract with various agencies or individuals to provide those services. (§§ 4620, 4630, 4648 & 4651.) DDS oversees and monitors the regional centers for compliance with the Act. (§ 4501.) It also has the authority to ensure that the regional centers operate in a uniform and cost-effective manner by, among other things, developing uniform systems of accounting, budgeting, and reporting (§ 4631(a)), auditing and paying funds to the regional centers might provide (§§ 4680, 4690).

Once a regional center determines that a person is eligible for services, an individual program plan must be developed to determine what services and supports are required, taking into account the needs and preferences of the individual and the family, and promoting independent, productive, and normal lives. The services provided must be effective in meeting the plan's goals, and must also reflect the preferences and choices of the consumer, as well as the cost-effective use of public resources. (§ 4646(a).)

Regional centers can buy services or supports to fulfill a person's individual plan from individuals or agencies who have gone through vendorization, which is the process of contracting for those services after identifying and selecting those who qualify under certain criteria. (§ 4648(a)(3)(A).) Regional centers may reimburse approved vendors if a rate of payment for their services has been established by DDS. The director of DDS "shall adopt regulations governing the vendorization process to be utilized by the department, regional centers, vendors and the individual or agency requesting vendorization." (§ 4648(a)(3)(B).)

## 3. Aims to increase the use of the Self-Determination Program

SB 468 (Emmerson, Ch. 684, Stats. 2013) allowed for the development of a statewide SDP. The California SDP is a voluntary alternative to the traditional way of providing regional center services. The SDP allows participants to have more control over selecting their services and supports. Participants (or their parents or legal representatives) are given a specific budget to purchase the services and supports that they need to make their person-centered plan work better for them. Participants may choose their services and pick which providers deliver those services. Participants are responsible for staying within their annual budget. The program consisted of a three-year phase-in period where the program was only allowed to serve a maximum of 2,500. Later this year, the program will be open to all eligible consumers statewide.

To date, there have been numerous challenges with the implementation of the statewide SDP. At this time, the primary barriers to entry and success in the SDP are unclear. This is due to the low take up rate in the program, which has in turn yielded insufficient data. Co-sponsors Disability Rights California and Disability Voice United write that the SDP "promised to give people with intellectual and developmental disabilities greater control and flexibility over the services they receive." They continue:

However, that early promise has yet to be fully realized. In the eight years since passage of this groundbreaking law, implementation of the Self-Determination program has been subject to substantial delays and barriers to full participation. Although the initial phase-in period allowed up to 2500 participants to enter the program, as of February 2021, regional centers have processed only 500 participants. The Statewide Self-Determination Advisory Committee has documented the numerous implementation barriers including lack of clear and consistent guidance from the Department of Developmental (DDS) to regional centers and participants, and lack of training for regional center staff.

Cal-TASH, writing in support of the bill, adds:

The reason people are dropping out of the Self-Determination program is not because parents/people with disabilities do not want this program, it is because of the difficulties they are having with bureaucracy and push back by the Regional Centers. Parents of/individuals with disabilities do not have the time and resources to fight against the system and should not have to. Their budgets need to be approved in a timely manner and they need to be able to access the services they desire. An Ombudsman is required to remove these administrative roadblocks.

This bill aims to increase the use of the SDP by increasing the data that is gathered on the SDP, requiring training on the SDP for regional center staff, and requiring the DDS to create an Office of the SDP Ombudsperson to assist persons with intellectual and developmental disabilities in overcoming barriers to entering the SDP and to assist SDP participants in overcoming any barrier to full participation and inclusion. The Ombudsperson would be an independent and autonomous entity in the DDS and would be responsible for the implementation of specified objectives and assisting regional center clients and SDP consumers and their families so that they may participate fully in the program. The Ombudsperson would also receive complaints and allegations of violations and decide whether to investigate or refer to the appropriate agency. Subject to confidentiality restrictions, the Ombudsperson would also compile SB 518 (Laird) Page 7 of 7

data related to complaints and investigations and provide it to the Legislature and other interested parties, as well as posting certain aggregated, depersonalized data on a dedicated website. The bill also specifies that contacting, assisting, communicating with, providing information to the SDP Ombudsperson, or participating in any way in a complaint, investigation, proceeding, or hearing related to the activities of the Self-Determination Program Ombudsperson, is a protected activity to ensure that complaints may be submitted without fear of retaliation or denial of services.

### **SUPPORT**

Disability Rights Coalition (co-sponsor) Disability Voices United (co-sponsor) Cal-TASH

### **OPPOSITION**

None known

## **RELATED LEGISLATION**

Pending Legislation: None known.

Prior Legislation: See Comment 3.

#### **PRIOR VOTES:**

Senate Human Services Committee (Ayes 5, Noes 0)

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