Date of Hearing: June 11, 2024

ASSEMBLY COMMITTEE ON HUMAN SERVICES
Alex Lee, Chair
SB 1463 (Niello) – As Amended May 16, 2024

SENATE VOTE: 38-0

SUBJECT: Developmental services: Self-Determination Program: Deputy Director of Self-Determination

SUMMARY: Requires the Governor to appoint a Deputy Director of Self-Determination, subject to Senate confirmation, responsible for overseeing the successful implementation and operation of the Self-Determination Program administered by the Department of Developmental Services (DDS) and regional centers.

EXISTING LAW:

1) Establishes the Lanterman Developmental Disabilities Act (Act), which states that California is responsible for providing an array of services and supports sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, at each stage of life, and to support their integration into the mainstream life of the community. (Welfare and Institutions Code [WIC] § 4500 *et seq*.)

2) Establishes a system of nonprofit regional centers, overseen by the 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. (WIC § 4620(a))

3) Establishes a statewide Self-Determination Program 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 Individualized Program Plan (IPP). (WIC § 4685.8(a))

FISCAL EFFECT: According to the Senate Committee on Appropriations on May 16, 2024, "The DDS estimates annual General Fund costs of $432,000 for the Deputy Director position and a position to provide support to the Deputy Director."

COMMENTS:

Background: *Lanterman Developmental Disabilities Act* originally became statute in 1969. The Act provides entitlement to services and supports for individuals ages three and older who have a qualifying developmental disability. Qualifying disabilities include autism, epilepsy, cerebral palsy, intellectual disabilities, and other conditions closely related to intellectual disabilities that require similar treatment. To qualify, an individual must have a disability that is substantial that began before the age of 18 and is expected to be lifelong. There are no income-related eligibility criteria. Direct responsibility for implementation of the Act's service system is shared by DDS and a statewide network of 21 regional centers, which are private, community-based nonprofit entities, that contract with DDS to carry out many of the state's responsibilities.

As of August 2023, the 21 regional centers served 459,395 consumers, providing services such as: information and referral; assessment and diagnosis; counseling; lifelong individualized planning and service coordination; purchase of necessary services included in the IPP; resource development; outreach; assistance in finding and using community and other resources; advocacy for the protection of legal, civil and service rights; early intervention services for at risk infants and their families; genetic counseling; family support; planning, placement, and monitoring for 24-hour out-of-home care; training and educational opportunities for individuals and families; and, community education about developmental disabilities.

Regional center's services vary at each location. One location might offer one program and the next might offer what they consider an alternative or offer nothing comparable.

Regional Centers' Responsibilities. Direct responsibility for implementation of the Act's service system is shared by the DDS and a statewide network of 21 private regional centers, and community-based nonprofit entities, established pursuant to the Act, that contract with DDS to carry out many of the state's responsibilities. Regional centers are governed by a Board of Directors (Board) who are a part of the community, receive services, or a representative of someone who receives services from the regional center. The Board is responsible for hiring (and firing) the Executive Director who is tasked with the day-to-day management of the regional center. DDS establishes contracts with regional centers that include specific, measurable, performance objectives. Every year, DDS reviews each regional center's performance data for compliance with their contracts and posts them on their website. By design, regional centers implement services differently in each region including the Self-Determination Program

History of the Self-Determination Program. The concept of facilitating a way for individuals with developmental disabilities to choose their own services and supports, rather than be prescribed a list of customized services began in the mid-1990s. According to a 2007 Robert Wood Johnson Foundation report, the growing move toward de-institutionalization and the home and community-based waivers associated with that move allowed states to serve more people. However, most states did not have the resources to meet the long-term care needs of everyone who sought help.

The foundation created a "Self-Determination for Persons with Developmental Disabilities Program" in 1996 to help 18 states implement a more cost-effective system, while simultaneously giving consumers and their families more choice in determining the services they receive. The program – inspired by the success of a 1993 self-determination grant that the foundation gave to the state of New Hampshire – authorized grant funding of up to $5 million nationwide. While each program was unique, they had common tenets, including person-centered planning, an independent support broker, individual budgets, and a designated fiscal intermediary.

The state's efforts to provide a self-determination option to consumers in the developmental services system began with what were intended to be three-year pilot projects launched at five regional centers in January 1999, and was subsequently reauthorized by the Legislature through 2004. A subsequent report to the Legislature showed that the participants were happy and had experienced more freedom and responsibility in controlling the direction of their services and their life choices. The report also indicated that good self-determination practices required intensive person-centered planning, collaboration, and follow-along support.

The 2005-06 Budget Act included a new Self-Directed Services Program, which was intended to expand the original pilot program statewide, contingent upon approval of a federal waiver for self-directed services. The waiver application was submitted in 2008, but was subsequently stalled when Centers for Medicare and Medicaid Services (CMS) invoked rules that would have required a redesign of the state's payment structure for developmental services; DDS would have had to assume responsibility for paying providers directly rather than allowing the regional centers to serve as fiscal intermediaries. Consequently, CMS never approved the Self-Directed Services waiver, and the program was never implemented. With the renewal of California's principal Home and Community Based Services waiver in 2012, CMS redefined DDS as an Organized Health Care System, thereby allowing the state to continue to pay approved service providers through the regional centers rather than requiring direct payment from DDS.

As part of the 2009-10 Budget Act, which included the suspension of various non-medical regional center services, the Legislature approved the development of an “Individual Choice Budget;” another attempt to provide individual consumers and their families increased flexibility in access to services, including those that had been suspended. Although DDS convened a budget advisory group to discuss what the Individual Choice Budget would entail, it was never implemented, as DDS was not able to certify that the Individual Choice Budget would result in the savings target proposed in the law.

The Self-Determination Program Today. After a long history of working toward a Self-Determination Program, in 2013, SB 468 (Emmerson), Chapter 683, Statutes of 2013, was enacted and established a statewide “Self-Determination Program” for individuals with developmental disabilities contingent upon funding.

SB 468 established five principles of self-determination:

1) Freedom, which includes the ability of adults with developmental disabilities to exercise the same rights as all citizens; to establish, with freely chosen supporters, family and friends, where they want to live, with whom they want to live, how their time will be occupied, and who supports them; and, for families, to have the freedom to receive unbiased assistance of their own choosing when developing a plan and to select all personnel and supports to further the life goals of a minor child;

2) Authority, which includes the ability of a person with a disability or family, to control a certain sum of dollars in order to purchase services and supports of their choosing;

3) Support, which includes the ability to arrange resources and personnel, both formal and informal, that will assist a person with a disability to live a life in their community that is rich in community participation and contributions;

4) Responsibility, which includes the ability of participants to take responsibility for decisions in their own lives and to be accountable for the use of public dollars, and to accept a valued role in their community through, for example, competitive employment, organizational affiliations, spiritual development, and general caring of others in their community; and,

5) Confirmation, which includes confirmation of the critical role of participants and their families in making decisions in their own lives and designing and operating the system that they rely on.

Any eligible regional center consumer is eligible to participate in the program on a voluntary basis and can register through their regional center. Regional center individuals who would like to participate in the Self-Determination Program are required to attend a Self-Determination Program

Orientation session. After the IPP is developed which can be in consultation with the regional center coordinator or an independent facilitator, an individual then must request a budget meeting where a 12-month budget is determined and a spending plan based on the IPP needs and goals. Then, a financial management service and payer model is selected. The individual or their representative can then begin hiring service providers.

In 2018, CMS approved the Self-Determination Program waiver and 2,500 individuals were selected in 2018. A second set of participants were selected one year later. The 2020-21 Annual Budget included $4.4 million total funds ($3.1 million General Fund) ongoing to support the administration of the Self-Determination Program. As of July 1, 2021, the Self-Determination Program is available to all eligible individuals receiving services from a regional center. While enrollment has steadily increased since the full rollout, the enrollment broken down into racial and ethnic demographics are not proportionate.

Role of the Self-Determination Program Ombudsperson. The 2021-22 Budget established the Office of the Self-Determination Program Ombudsperson (Office) within DDS to provide information and assist regional center consumers and their families in understanding their rights under the self-determination program. The Office is an independent entity from DDS.

From October 2021 to December 2023, the Office received 2,079 contacts. There are currently 82 cases that remain open. 930 contacts were for information, 839 for a complaint, 115 for referrals, the remainder were either classified as other or didn't respond. The Office also issues recommendations based on complaints received. In the past, recommendations have been issued regarding financial management services, individual budget and spending plans, regional centers, and local volunteer advisory committees. All recommendations posted on their website cite a Directive from DDS addressing the recommendations.

This bill would create a Deputy Director of Self-Determination Program. Typically, Deputy Directors report to either the Director, the Chief Deputy Director, or the Assistant Director. This position would not be a separate entity like the Ombudsperson, and instead would be an extension of DDS.

Author's Statement: According to the Author, "[This bill] seeks to ensure the success of the Self Determination Program (SDP) by bringing accountability and oversight. SDP is driven by the recognition that people with intellectual and developmental disabilities have the same right to, and responsibilities that accompany, self-determination as everyone else. They are entitled to opportunities, respectful support, and the authority to exert control in their lives, to direct their services, and to act on their own behalf. Currently the [DDS] is three years from its 2021 transition of the SDP pilot program into a statewide promise for those that seek the benefits of this voluntary program, yet the delivery of those promises have yet to be realized.

"[This bill] provides for a dedicated senior position at the [DDS] focused solely on the program's success. Having this position will provide for improved accountability over the success of SDP and reaffirm the state's commitment to self-determination."

Equity Implications: The Self-Determination Program has faced challenges since its inception. Racial, socioeconomic, and regional inequities have all been demonstrated as an impediment to accessing this program. This bill creates another position to be dedicated to the program. However, of note, the Self-Determination Program is administered at the regional center level and this bill would not change that. This bill may increase awareness of problems and might allow for more collaboration efforts between regional centers.

RELATED AND PRIOR LEGISLATION:

SB 1281 (Menjivar) of the current legislative session, would require DDS to establish statewide standardized processes and procedures for the Self-Determination Program by January 1, 2026, to ensure those processes and procedures are applied consistently across regional centers, and that enrollment is equitable by race, ethnicity, and regional center. SB 1281 would also define and clarify payment processes related to financial management services providers. *SB 1281 is set for hearing in this committee on June 11, 2024.*

AB 1147 (Addis) of the current legislative session, requires regional centers to inform consumers about the Self-Determination Program during IPP meetings, maintain documentation of a consumer's interest or disinterest in the program, and provide information to interested consumers within five days of request, among other changes to the developmental services system. *AB 1147 is currently on the Senate inactive file.*

AB 136 (Committee on Budget), Chapter 76, Statutes of 2021, a budget trailer bill, established an Office of the Self-Determination Program Ombudsperson as an independent and autonomous entity within DDS.

SB 468 (Emmerson), Chapter 683, Statutes of 2013, see comments above.

AB 131 (Committee on Budget), Chapter 80, Statutes of 2005, a budget trailer bill, established a self-directed services option statewide, contingent upon approval of a federal waiver. A waiver was never obtained, and it has not been implemented.

AB 1762 (Committee on Budget), Chapter 230, Statutes of 2003, a budget trailer bill, added two more regional centers to the self-determination pilot program.

AB 430 (Cardenas), Chapter 171, Statutes of 2001, a budget trailer bill, extended the local self-determination pilot programs for two additional years.

SB 1038 (Thompson), Chapter 1043, Statutes of 1998, created a three-year pilot project for local self-determination programs.

REGISTERED SUPPORT / OPPOSITION:

Support

Disability Voices United (DVU) (Sponsor)
Educate. Advocate.

Opposition

None on file.

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