

Date of Hearing: June 11, 2024

ASSEMBLY COMMITTEE ON HUMAN SERVICES

Alex Lee, Chair

SB 1281 (Menjivar) – As Amended May 16, 2024

**SENATE VOTE:** 38-0

**SUBJECT:** Advancing Equity and Access in the Self-Determination Program Act

**SUMMARY:** Creates statewide processes and procedures for the Self-Determination Program. Specifically, **this bill:**

- 1) Declares that it is the intent of the Legislature that the Department of Developmental Services (DDS) makes measurable improvements towards achieving equity in outreach and program promotion by race, ethnicity, and regional center for the Self-Determination Program.
- 2) Requires DDS, no later than January 1, 2026, to establish statewide standardized processes and procedures for the Self-Determination Program.
- 3) Requires DDS to ensure the standardized processes and procedures are consistently applied by each regional center and that they make measurable improvements towards achieving equitable enrollment by race, ethnicity, and regional center.
- 4) Requires DDS to approve any variation from the standardized processes and procedures by any regional center. Further, requires the standardized processes and procedures to include, but not be limited to, all of the following:
  - a) Enrollment;
  - b) Individual budgets;
  - c) Financial management services;
  - d) Access to self-directed and transition supports;
  - e) Spending plan; and,
  - f) Financial management service monthly spending report.
- 5) Requires any revised spending plans to be attached to a consumer's individualized program plan (IPP).
- 6) Requires regional centers to promptly send a copy of the spending plan and authorizations to the financial management services provider.
- 7) Clarifies that a regional center must review the spending plan only to verify goods and services are eligible for federal financial participation and are not used to fund goods or services available through generic agencies. Further, requires regional centers to ensure that participant choice of providers is respected.

- 8) Clarifies that after the spending plan is developed, the participant is responsible for assigning amounts only to the uniform budget categories developed by DDS. Further, permits the cost of services to be estimated, and, if needed, the spending plan may be adjusted by the participant when the actual cost is known.
- 9) Requires the spending plan to identify the type of provider that will provide each service.
- 10) Prohibits regional centers to require a provider name in the spending plan.
- 11) Prohibits goods and services purchased in the spending plan from being required to include, and are not limited to, the services utilized to develop the individual budget.
- 12) Prohibits a regional center from applying the purchase of service standards to services utilized through the Self-Determination Program spending plan.
- 13) Requires regional centers to ensure participants have a choice of financial management services providers for all budget sizes.
- 14) Requires individuals transitioning into the Self-Determination Program to have the option to receive transition services through participant-directed services.
- 15) Requires regional centers to include the full costs of the participant's financial management services provider in the participant's spending plan, and be clearly and individually identified in the monthly report sent to the participant.
- 16) Requires the financial management service provider to purchase services and goods in the spending plan or revised spending plan without additional review from the regional center.
- 17) Establishes that a financial management services provider serving as a sole employer is individually responsible for any fees, penalties, or fines resulting from its failure to comply with state and federal labor requirements.
- 18) Requires DDS to assess the availability, adequacy, and solvency of financial management services providers at each regional center, including the adequacy of fiscal management services for all sizes of spending plans. Requires the results of the assessment to be reported as part of the information being provided pursuant to these provisions.

**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 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)

- 3) Establishes the 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 IPP. (WIC § 4685.8)
- 4) Established the following definitions:
  - a) “Self-determination” is a voluntary delivery system consisting of a defined and comprehensive mix of services and supports, selected and directed by a participant through person-centered planning, in order to meet the objectives in their IPP. (WIC § 4685.8(c)(6))
  - b) “Independent facilitator” is a person, selected and directed by the participant, who is not otherwise providing services to the participant pursuant to their IPP and is not employed by a person providing services to the participant. Authorizes an independent facilitator to assist the participant in making informed decisions about the individual budget and in locating, accessing, and coordinating services and supports consistent with the participant’s IPP. Requires an independent facilitator to receive training in the principles of self-determination and the person-centered planning process. Specifies the cost of the independent facilitator, if any, shall be paid out of the participant’s individual budget. (WIC § 4685.8(c)(2))
  - c) “Individual budget” is the amount of regional center purchase of service funding available to the participant for the purchase of services and supports necessary to implement the IPP. Requires the individual budget to be determined using a fair, equitable, and transparent methodology. (WIC § 4685.8(c)(3))
  - d) “Spending plan” is the plan the participant develops to use their available individual budget funds to purchase goods, services, and supports necessary to implement their IPP. Specifies the spending plan must identify the cost of each good, service, and support that will be purchased with regional center funds, and that the total amount cannot exceed the amount of the individual budget. (WIC § 4685.8(c)(7))
  - e) “Financial management services” are services or functions that assist the participant to manage and direct the distribution of funds contained in the individual budget and ensure that the participant has the financial resources to implement their IPP throughout the year, as specified. (WIC § 4685.8(c)(1))
- 5) Provides that participation in the Self-Determination Program is fully voluntary. Specifies any regional center consumer who meets the all of following shall be eligible to participate in the Self-Determination Program:
  - a) The participant has a developmental disability, as defined, and is receiving regional center services;
  - b) The consumer does not live in a licensed long-term health care facility; and,
  - c) The participant agrees to the following terms and conditions:
    - i) The participant shall receive a program orientation prior to enrollment;

- ii) The participant shall utilize the program services and supports only when generic services and supports are not available;
  - iii) The participant shall only purchase services and supports necessary to implement their IPP;
  - iv) The participant shall manage program services and supports within their individual budget;
  - v) The participant shall utilize the services of an Financial Management Services provider of their own choosing and who is rendered by a regional center;
  - vi) The participant may utilize the services of an independent facilitator of their choosing, or their regional center service coordinator, and,
  - vii) If eligible, with the assistance of the regional center, if needed, timely apply for Medi-Cal in order to maximize federal funding. (WIC § 4685.8(d))
- 6) Requires each regional center to implement the Self-Determination Program as a term of its contract. (WIC § 4685.8(r))
  - 7) Requires each regional center to review the spending plan to verify that goods and services eligible for federal financial participation are not used to fund goods or services available through generic agencies. (WIC § 4685.8(r)(6))
  - 8) Requires a regional center to pay the full costs of the participant’s financial management services provider. (WIC § 4685.8(u))

**FISCAL EFFECT:** According to the Senate Committee on Appropriations on May 16, 2024, “Unknown, ongoing General Fund costs, for DDS to establish statewide standardized processes and procedures and to assess financial management providers in the [Self-Determination Program].”

**COMMENTS:**

**Background:** *Lanterman Developmental Disabilities Act* originally became statute in 1969. The Lanterman Act provides entitlement to services and supports for individuals three years of age 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 18 years of age, and is expected to be lifelong. There are no income-related eligibility criteria. Direct responsibility for implementation of the Lanterman 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. Geographically, regional centers' spending also varies. 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 The Centers for Medicare & 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 (HCBS) 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, and then a second set of participants again one year later were selected. The 2020-21 Annual Budget included \$4.4 million in 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.

*Self-Determination Program in Practice.* Under the Self-Determination Program, each participant has an individual budget for how much they can spend in a 12-month period. Participants then establish a spending plan to budget for the actual costs of services and supports within their budget. Each regional center vendors with Financial Management Services providers issue payment for Self-Determination Program services. Financial Management Services

providers assist participants in managing their individual budgets, handling financial transactions, and ensuring compliance with Self-Determination Program guidelines.

There are three Financial Management Services models that offer different levels of support:

**Bill Payer Model:** the Self-Determination Program participant does not hire any staff directly, and instead purchases goods or services listed in their IPP from a business, and the Financial Management Services provider issues payment.

**Co-Employer Model:** the Self-Determination Program participant shares some of the employer roles and responsibilities with the Financial Management Services provider. While the Financial Management Services provider is the employer of record and pays for insurance and liability, the participant has the ability to hire and terminate service providers, with input from the financial management services provider.

**Sole Employer Model:** the Self-Determination Program participant is considered the direct employer of service providers. The participant hires providers directly and pays for workers compensation and liability insurance either through homeowners' or renters' insurance or through their Self-Determination Program spending plan. The Financial Management Services provider assists the participant to abide by applicable employment laws.

*Self-Determination Program Challenges.* Proponents of this bill report challenges in accessing the Self-Determination Program including racial inequities, administrative burdens, and lack of knowledge about the program. While program enrollment has steadily increased since the full rollout, the enrollment broken down into racial and ethnic demographics has not been proportionate to the overall number of regional center consumers.

As an effort to increase service access and equity, and reduce disparities, the 2021-22 Budget provided money to establish the following:

- An Office of the Self-Determination Program Ombudsperson within the DDS to provide information and assist regional center consumers and their families in understanding their rights under the Self-Determination Program;
- Participant Choice Specialists to provide timely transition to program participation and access to regional center staff; and,
- Enhanced Transition Support Services for individuals and their families who need greater assistance in transitioning to the Self-Determination Program.

University of California, Los Angeles, Tarjan Center for Excellence in Developmental Disabilities collected survey data for 7 months and prepared an evaluation in June of 2023 regarding participant experience in the Self-Determination Program with the State Council on Developmental Disabilities, University of Southern California's University Center for Excellence in Developmental Disabilities, and Disability Rights California. The data included 244 consumers, 314 parents/caregivers, 20 independent facilitators, and 14 other respondents (e.g., siblings, conservators) regarding their experiences with the Self-Determination Program in California. Participants in the survey reported satisfaction with the program concept and overall endorsed the program; however, the survey also revealed inequities and difficulty accessing the program. The inequities reported included racial, socioeconomic, and regional centers. The

evaluation made seven recommendations to better facilitate the goals of the Self-Determination Program for current and future participants:

- Improve access to information about the Self-Determination Program;
- Streamline the enrollment process;
- Streamline the individualized budgeting process;
- Reduce administrative burden on Self-Determination Program participants;
- Improve compensation and capacity of independent facilitators;
- Leverage Self-Determination Program as a model to improve workforce recruitment, hiring, and retention; and,
- Create a more equitable system and mitigate disparities.

**Author’s Statement:** According to the Author, “The Self-Determination Program (SDP) in California is designed to help individuals with developmental disabilities access tailored supportive services to reach self-reliance. When Californians with developmental disabilities can tailor their supportive services to meet their specific needs, programs are far more effective than those that are prescribed by default. These person-centered plans are integral for participants to achieve greater independence, employment, and improved health outcomes. SDP participants have reported positive growth in areas such as self-awareness, responsibility, mental health, community integration, independence, employment, and quality of life.

“In 2023, the State Council on Developmental Disabilities submitted a statutorily required report with findings and recommendations to the legislature. The report found that despite participants favoring SDP, there were many administrative burdens and hurdles that came along with the program. Additionally, there were reported concerns about inequities in the program, such as racial disparities and disparities in how the SDP is being implemented across regional centers in California.

“[This bill] will build upon the program's success by eliminating racial inequities in enrolling and receiving services so all Californians who qualify for the SDP can realize its benefits and achieve their self-determined goals.”

**Equity Implications:** The Legislative Analyst Office’s 2023-24 Budget report on DDS reports that “white consumers comprise a plurality of [Self-Determination Program] participants (45 percent), despite making up only 30 percent of all DDS consumers. By comparison, Latino consumers comprise only 23 percent of [Self-Determination Program] participants, but 40 percent of all DDS consumers.”

Additionally, participants have reported that they wish the Self-Determination Program was less complicated and that they had more support while navigating the program. According to the June 2023 Self-Determination Program evaluation, “Most prominently, participants thought the Self-Determination Program could be improved by reducing complexity and administrative burden on the participant. Individuals and families perceived the enrollment process and ongoing navigation of the program as time-consuming, labor-intensive, and demanding. This was seen as



an issue of inequity, as some individuals may not have the time or capacity to manage such requirements.”

The evaluation pointed to administration burdens amplifying the existing disparity in access and supports in the Self-Determination Program among underserved communities. Research shows that administrative burdens disproportionately impact affect communities of color, who often face barriers when interacting with governmental agencies and any related costs associated with these interactions.

Under this bill, the Self-Determination Program remains administered by each regional center, but under direction from DDS to standardize processes. The Self-Determination Program may increase equity and consistent application can begin to resolve the disparities reported above while more equitably distributing the administrative burdens onto DDS and regional centers and away from the individuals navigating the Self-Determination Program.

#### **RELATED AND PRIOR LEGISLATION:**

***SB 1463 (Niello) of the current legislative session***, would require 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. *SB 1463 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) (Co-Sponsor)  
Integrated Community Collaborative (Co-Sponsor)  
Association of Regional Center Agencies  
Autism Support Community  
California Independent Facilitator Association  
Council of Autism Service Providers (CASP)  
Disability Rights California  
Educate. Advocate.  
SCDD

**Opposition**

None on file.

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