Date of Hearing: April 18, 2023

ASSEMBLY COMMITTEE ON HUMAN SERVICES
Corey A. Jackson, Chair
AB 1147 (Addis) – As Amended April 11, 2023

SUBJECT: Disability Equity and Accountability Act of 2023

SUMMARY: Deletes, revises, and adds requirements for the Department of Developmental Services (DDS) and the regional centers that coordinate services for the eligible population, to include process standardization, data and reporting requirements, and timelines for accessing services. Specifically, **this bill**:

1) On behalf of the Legislature finds and declares as follows:

    a) Recent reports and hearings by the California State Auditor, the Little Hoover Commission, and advocacy organizations have found that California's service system for the over 400,000 children and adults with intellectual or developmental disabilities (IDDs) through the Lanterman Developmental Disabilities Act (Lanterman Act), as overseen by DDS, which contracts with 21 regional centers, is failing in significant ways to deliver critical, adequate, and timely services to individuals and families. The result is that individuals and families, particularly those of color, are unable to access timely services and supports, resulting in barriers to their ability to live independent, productive, and integrated lives in their communities;

    b) California's developmental disability service system is plagued with racial, ethnic, and geographic disparities that can dramatically impact the essential services received by children and adults with developmental disabilities. Systemic inequities and discrimination within California's 21 regional centers broaden the gap between inclusive possibilities and segregated limitations. Data show Latinos are most negatively impacted by these disparities, but people who are clients of the lowest-performing regional centers are also significantly affected;

    c) California spends nearly $13 billion annually on the administration and delivery of developmental services, but lacks a transparent, common, integrated, and coordinated model for the delivery and measurement of services throughout the 21 regional centers, resulting in poor outcomes, poor satisfaction levels by consumers and families, and disparate levels of available services and performance expectations;

    d) The delivery of services through 21 separate private nonprofit regional centers with separate boards, funding, and delivery models was originally intended to ensure that the delivery of services could be more effectively delivered through nonstate entities. However, with the subsequent caseload and budget growth since the enactment of the Lanterman Act, local administration has become more disparate and less accountable. Boards of directors are untrained and are not providing the oversight needed of the regional centers. Stronger state oversight of regional centers by DDS is essential to ensure that services are equitably delivered, performance and outcomes are uniformly measured and reported, and the system is transparent and accountable to individuals and families;

e) DDS' system lacks a statewide automated technology system for the delivery of services to persons with IDDs and, as a result, the current program is constrained by disparate automation systems, inadequate documentation, the lack of open system architecture, insufficient data to support administration of the system, and the lack of data to support program improvements for improving the quality of life outcomes through new service delivery methods;

f) Statewide uniformity of service delivery practices and procedures is essential to an effective program and to support necessary oversight and research for ongoing program improvements;

g) DDS' technical infrastructure is over 40 years old. The lack of a statewide automation system does not meet current program needs and significantly contributes to the racial and geographic disparities in the delivery of services. California currently lacks clear and consistent service delivery outcomes for individuals with IDDs that sets high expectations for their quality of life, and must develop a system for measuring and quantifying the value of service delivery outcomes;

h) A previous effort to develop an IDD program technology system failed. As a result, DDS and regional centers maintain a patchwork of at least three case management and fiscal systems that are not integrated and six legacy case management automation systems that lack integration, have dissimilar data sources, and are technically outdated; and,

i) In the 2021-22 annual budget the Legislature appropriated $6 million to DDS for planning purposes related to the implementation of a uniform fiscal system and consumer electronic records management system. DDS has not developed a vision or scope for a proposed system development approach.

2) States legislative intent that enacting the bill to do all of the following:

a) Ensure that racial, ethnic, and geographic service disparities be systemically addressed and eliminated and that all people, regardless of their race or ethnicity or where they live, receive equitable access to services within the regional center system;

b) Ensure that all regional centers offer and provide a consistent and common set of services and that the services are delivered in a timely way;

c) Ensure that the delivery of all services and supports comply with federal law and guidance and are responsive to the needs and choices of beneficiaries receiving home- and community-based services, are person centered and strengths based, have high expectations for interdependence, self-direction, and competitive, integrated employment, provide support coordination to assist with a community-supported life, and achieve a more consistent and coordinated approach to the administration of policies and procedures across the state;

d) Provide DDS with new tools for holding regional centers and service providers accountable through the development of a standardized and coordinated set of performance measures and related standards that establish targets and standards above which a regional center may receive incentives for improved performance, and a separate set of standards that require corrective action;

   e) Improve regional center governance by establishing new standards and procedures for regional center governing boards to ensure they can more effectively represent the communities they serve by providing them with greater independence and protection from regional center retaliation; and,

   f) Require DDS to develop a written project charter for the planning and development of a uniform statewide automation system that serves as a foundation document for the system development, which includes project guiding principles, scope, strategies and approach, and project governance, in order to provide transparency to the Legislature and the public on the system development as has been used with other statewide system development.

3) Provides that DDS must require all of the following of regional centers:

   a) The use, when reporting data by race and ethnicity, of consistent classifications of race and ethnicity, based on categories current in use by the United States Census Bureau;

   b) Confirmation of the race and ethnicity identification of each consumer at the time of the annual review of the consumer's individual program plan (IPP);

   c) When reporting by residence types, separate presentation of data for those in independent living services and those in supported living services; and,

   d) Consistent standards and requirements for regional center internet websites, using the same placement and language for all information required by these provisions, including that data be posted in a machine-readable format

4) Requires, as part of DDS' planning process for the planning and development of a uniform statewide data automation system, the department, in consultation with stakeholders to develop, by March 1, 2024, a project charter that shall be approved by the Secretary of the California Health and Human Services Agency and the Department of Technology. The charter development process shall include the participation and input of program consumers and families, researchers and quality and outcome evaluators, regional centers, and service providers.

5) Requires the project charter described in 4) to include all of the following:

   a) An impact statement on the primary entities and individuals impacted by the system development;

   b) Project guiding principles that are foundational to the project approach to be used throughout the planning, development, implementation, and maintenance of the system;

   c) Project scope that addresses business problems required to be solved by the system, including all of the following:

   i) Worker effectiveness and accountability that are constrained by the lack of timely, adequate, and accurate data, the lack of uniformity, and the current system's limited functionality;

   ii) Service delivery that is constrained by the lack of timely, adequate, accurate, and accessible data, the lack of clear understandable communication of information, lack of uniformity, and the system's limited functionality;

   iii) Current system maintainability that is constrained by disparate systems, inadequate documentation, the lack of open system architecture, and business changes;

   iv) Disparate systems, complex business rules, the number of locations and variability of local system delivery, and changes in the way of doing business; and,

   v) Limited access of researchers and program evaluators to the set of person-level data that they need to assess program effectiveness.

d) Program goals, which must include all of the following:

   i) Maximizing the performance and the business processes for the delivery of IDD system services to consumers at the regional centers;

   ii) Improving data quality, privacy, confidentiality, and integration of all data sources at an individual level;

   iii) Enabling data-driven decisionmaking and performance measures for the effective administration of the program;

   iv) Improving the business processes administered by DDS to support regional center service delivery; and,

   v) Supporting access to individual-level data to support program evaluation and other research.

e) Technology goals that recognize that a statewide system solution not only meets requirements, but also ensures effective transition, while minimizing disruption to existing services;

f) Project strategies and approaches for development and implementation;

g) Project governance; and,

h) Technology that can readily be enhanced and modernized for the expected system life. In selecting the new system, consideration will be given to the extent to which the candidate systems employ open architectures and standards and the future ability of the selected system to provide enhancements that will improve long-term effectiveness of program management of the statewide service delivery system.

6) Requires, by March 1, 2024, DDS to submit a report to the policy and budget subcommittees of the Legislature describing the extent to which the requirements of this section have not been met, including the surveying of all consumers, including those with no purchase of services, and providing specific steps and the schedule by which these requirements will be met.

7) To provide uniformity, consistency, and cost-effectiveness in the delivery of services by regional centers throughout the state, requires the department, by January 1, 2025, to establish a common set of services and supports, including supported living services, that every regional center in the state must make available to consumers in negotiating, developing, or amending the IPP as required by existing law; and requires the common set of services and supports to be prominently posted on each regional center's internet website.

8) Requires DDS to develop the common set of services and supports in consultation with the Association of Regional Center Agencies, consumers and their families, advocacy organizations, and service providers.

9) Requires, in each contract with a regional center, DDS to require the common set of services and supports developed pursuant to this section to be available to consumers in the development of an IPP. Clarifies that by enacting 7) – 9), it is the intent of the Legislature the provisions not be construed to control or interfere with the discretion of the individual program planning team to determine the needs and services appropriate for each person with a developmental disability who is entitled to services.

10) Enacts the following reforms regarding membership of each regional center's governing board:

    a) Specifies that members of the governing board may not serve more than a six-year term, and may return to the board for a subsequent term after five years. The members of each regional center governing board nominating committee must comprise current board members and members of the community, and should be representative of the community served in the regional center's catchment area;

    b) The board nominating committee must solicit interests and nominations from the broader community through outreach. The committee must interview candidates for the board and make recommendations to the governing board for election. During the meeting at which the board elects new members, a candidate may be nominated by a board member with a second by another board member for the open positions. A regional center executive director must be prohibited from any involvement in the recruitment or election of governing board members.

11) Revises the training program that DDS is required to provide to board members to require that the training is be developed with community input, including persons served and family members. Ongoing support by DDS must include surveying board members about their ability to meaningfully participate in, and understand the subjects and votes at, board meetings. If board members report that they are unable to meaningfully participate, DDS must work with the regional center and the board member to ensure adequate and appropriate accommodations are provided.

12) Requires DDS to establish guidelines for governing boards to measure executive director performance, including with respect to issues of equity and diversity.

13) Requires DDS to establish, and each board must adopt, an anti-retaliation policy for board members that requires department approval for any reduction in services for consumer board members or the family member of family board members.

14) Requires DDS to establish and adopt a grievance procedure whereby a governing board member who has concerns, complaints, or questions may contact a specific executive at the department.

15) Requires a conflict of interest policy for board members to do the following (in addition to requirements of existing law):

    a) Prohibit a regional center employee from accepting a gift or gifts from a service provider, consumer, or consumer's family member valued over $10 per year; and,

    b) Establish a policy prohibiting regional center senior staff from hiring relatives at the center or any ancillary foundation and organization. The policy must be included in the regional center contract and must be included in training of the governing board.

16) Requires that notwithstanding any other law, the evaluation of regional center performance must be implemented using a common set of performance measures specified in the bill, which must be administered by DDS.

17) Provides, notwithstanding any exemption, that a regional center with which DDS maintains a contract must be subject to the California Public Records Act.

18) Defines "request for assistance" for purposes or eligibility for initial intake and assessment for services in a regional center, to include any initial contact or inquiry from an individual, or a person acting on their behalf, on the nature of services or supports available or provided by the regional center, and the individual's eligibility to receive them.

19) Requires the standardized information packet required under existing law to be provided to any person seeking services from a regional center, to also including the following:

    a) Information about appeals procedures; and,

    b) Information on the Self-Determination Program, including the eligibility requirements.

20) Requires, if assessment is needed, the regional center to require the assessment to be completed within 60 days following initial intake. Assessment must be commenced as soon as possible, and in no event more than 30 days following initial intake when any delay would expose the client to unnecessary risk to their health and safety or to significant further delay in mental or physical development, or the client would be at imminent risk of placement in a more restrictive environment.

21) States legislative intent that an IPP must be developed consistent with the federal Affordable Care Act (ACA) and the regulations and federal guidance adopted pursuant to the ACA requiring that community-based long-term services and supports be person-centered and self-directed. Further, states legislative intent to ensure that goals in any plan allow for innovation

and nontraditional service delivery and not be limited by the lack of easily identified services or supports.

22) Requires an IPP, including all assessments to be developed through a process of individualized needs determination and person-centered service planning developed pursuant to, and consistent with the ACA, federal regulation implementing the ACA, and federal guidance issued by the Centers for Medicare and Medicaid Services (CMS) on June 6, 2014, requiring community-based, long-term services and supports to be person-centered, strengths-based, and self-directed. Further, requires that the individual must lead the service planning process to the greatest extent possible.

23) Requires an initial assessment agreement to be completed and provided to the consumer within 30 days of an intake unless there is good cause for the regional center to exceed the 30-day time period, but in no event can the assessment be completed any later than 60 days from the intake. If the assessment is not completed within the 30- or 60-day time period, as applicable, the regional center must provide the consumer with an adequate notice of action, and must notify DDS of the reason for not meeting the deadline. At the time of intake, the regional center must inform the consumer and, if appropriate, the consumer’s parents, legal guardian or conservator, or authorized representative, of the services available through the state council and the protection and advocacy agency designated by the Governor pursuant to federal law, and shall provide the address and telephone numbers of those agencies.

24) Requires, as part of the initial IPP meeting and each annual review required by law, the consumer or, if appropriate, their parents, legal guardian, conservator, or authorized representative, to be provided by the service coordinator oral and written information about the Self-Determination Program. The information must include each of the provisions as specified. Each IPP must include a provision stating that the consumer or authorized representative was informed about the availability of the Self-Determination Program. If the consumer chooses not to participate in the program, the IPP must include an explanation of the reason or reasons for that decision, or, if the consumer is ineligible for the program, the reason or reasons for that ineligibility.

25) Requires, if the consumer is interested in participating in the program or wants additional information or assistance, the service coordinator, within five days of expressing the interest, to provide the consumer a date for the Self-Determination Program orientation, training resources, dates of local volunteer Self-Determination Program advisory committee meetings, and other information to assist the consumer in participating in the program.

26) Requires, at the conclusion of an IPP meeting, an authorized representative of the regional center to provide to the consumer, in written or electronic format, a summary page written in plain language. The identified services and supports specified in an IPP referred to a provider must begin on the date specified in the plan. In the event the services or supports are not started by the provider within 45 days of the specified start date, a referral must be made within 14 days to another provider for delivery of the specified services and supports.

27) Allows the individualized family service planning team for infants and toddlers eligible and the IPP team to determine that a service provided by a generic agency identified in the individualized family service plan or IPP is not available, and, therefore, will be funded by the regional center.

28) Requires, for all active cases, IPPs to be reviewed and modified by the planning team, in response to the person's achievement or changing needs, and no less often than once every 12 months, rather than once every three years, as required by existing law.

29) Requires the department to require each regional center to use, for all new and modified IPPs, the training materials and the standard format plan prepared by DDS pursuant to the bill's requirements by no later than March 1, 2024.

30) Provides that if any services or supports that require an assessment are requested by a consumer at any time after an IPP is in place, and for as long as the individual remains eligible for services, the assessment must be completed, at no cost to the consumer, within 30 days from the date of request.

31) Provides that if the assessment recommends services or supports, the services or supports shall be authorized by the regional center within seven days and the consumer must be referred to a provider within seven days from the date of the authorization. If the services or supports are not commenced by the provider within 45 days of the referral, a referral must be made to another provider within seven days for the specified services and supports.

32) Provides that a consumer is entitled to an adequate notice of action and the appeal procedures specified in the law if the regional center does not comply with the deadlines specified in 30) and 31).

33) Requires service coordinators to be accessible to consumers and their representative by telephone and other electronic means, and respond to consumer inquiries within two business days of the inquiry.

34) Requires regional centers to ensure that every consumer has a service coordinator and provide written notice of any temporary change in the assigned service coordinator.

35) Requires regional centers to advise consumers of 37) -39) before prohibiting from purchasing of any service that would otherwise be available from Medi-Cal, Medicare, the Civilian Health and Medical Program for Uniform Services, In-Home Support Supportive Services (IHSS), California Children's Services, private insurance, or a health care service plan when a consumer or a family meets the criteria of this coverage.

36) Removes the existing requirement that regional centers must not purchase any service that would otherwise be available from Medi-Cal, Medicare, the Civilian Health and Medical Program for Uniform Services, IHSS, California Children's Services, private insurance, or a health care service plan when a consumer or a family meets the criteria of this coverage but chooses not to pursue that coverage, and replaces it with 37).

37) Permits a regional center to request a consumer or family member to pursue a service or source of funding from specified entities, if the request is documented with specificity in the IPP or individualized family plan and the plan contains detailed instructions for the consumer or family pursuing the service. Further, the IPP or individualized family plan must also specify the ways in which the regional center will initially assist the consumer or family to apply for and pursue the service or source of funding and specify that it will provide additional assistance when requested by the consumer or family.

38) Requires the regional center to purchase the service when either of the following occurs:

   a) The entity denies the service; or,

   b) The entity does not provide the requested service within 45 days from the date of the request, or 15 days after the statutory or regulatory time limit, if any, for the entity to make an initial decision, whichever is shorter.

39) Prohibits a consumer, or their family, to be required to appeal an entity's denial of the requested service for the regional center a verification that an administrative appeal is being pursued to purchase that service pursuant to this subdivision. The regional center may file an appeal on behalf of the consumer, but the appeal cannot delay the payment of the requested service by the regional center as specified in 36) b) above.

40) Specifies this bill does not prohibit a consumer or their family, where appropriate, from filing a formal appeal of an entity's denial of the service at issue, or a regional center from seeking reimbursement from the entity it believes is responsible for providing the service and from requesting assistance with filing the appeal or from utilizing assistance from other advocacy organizations.

41) Requires DDS, to provide uniformity, consistency, and cost-effectiveness, to reduce barriers, and to increase the number of service providers throughout the state, to comprehensively review the current processes for vendorizing providers for the delivery of services and supports to regional center consumers and revise those processes to streamline the process and create a uniform statewide vendorization process. Further, requires DDS to develop the revised processes, in consultation with the Association of Regional Center Agencies, consumers and their families, advocacy organizations, and service providers.

42) States legislative intent to ensure that a service provider vendored in one regional center is automatically, without additional requirements, eligible to provide services in all regional centers; and 35) - 41) cannot be construed to control or interfere with the discretion of the individual program planning team to determine the needs and services appropriate for each person with a developmental disability who is entitled to services in this bill.

43) Requires DDS, no later than March 1, 2024, and on March 1 annually thereafter, to submit a report to the Legislature and post on its internet website the following data, statewide and for each regional center, broken down by qualifying disability category, race or ethnicity, and age categories 0–21 years of age, 22–64 years of age, and 65 years of age and over:

   a) The number of consumers for whom health and safety waivers have been requested;

   b) The number of consumers for whom health and safety waivers have been granted;

   c) The number of days elapsed between the date on which the department received the health and safety waiver request worksheet from the service provider and the date the service provider was notified of the outcome; and,

   d) The percentage of health and safety waiver requests that are due to behavioral challenges.

44) Requires DDS to post on its internet website brief summaries, with any individual identifying information redacted, of the health and safety risks and challenges, and the service changes that are necessary to protect the health and safety, of the affected consumer or consumers, contained in each health and safety waiver request worksheet received by DDS.

45) Requires each regional center, as a part of implementing the Self-Determination Program to ensure that each individual plan includes the information required in 24).

46) Deletes the current initial regional center complaint process.

47) Requires any complaint made pursuant to Welfare and Institutions Code Section (WIC) 4731 to be made to the director of DDS. Further, requires the director within 30 days of receiving a complaint, to issue a written administrative decision and send a copy of the decision to the complainant, the director of the regional center or state-operated facility, and the service provider, if applicable.

48) Requires DDS, on a quarterly basis, to compile the number of complaints filed, by each regional center and state-operated facility, the subject matter of each complaint, and a summary of each decision and post the compilation on its internet website at the end of each quarter. Copies of any decision included in the compilation to be made available within 10 days, with all individually identifiable information redacted, to any person upon request.

EXISTING LAW:

1) Establishes the Lanterman Developmental Disabilities Act (Lanterman 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. (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) Provides the Director of DDS the authority to issue directives to regional centers when necessary to protect a consumer's health, safety, welfare, or when needed to ensure that regional centers comply with the Act or other state or federal law. (WIC 4639.6)

4) Establishes an IPP as the process to ensure that services and supports are customized to meet the needs of consumers who are served by regional centers for the purpose of alleviating a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with a developmental disability, or toward the achievement and maintenance of independent, productive, and normal lives. (WIC 4512(b))

5) Requires decisions concerning the consumer's goals, objectives, and services and supports included in their IPP to be made by agreement between the regional center representative and the consumer or, when appropriate, the consumer's parents, legal guardian, conservator, or authorized representative, at the program plan meeting. (WIC 4646(d))

6) Requires the IPP planning processes to include:

   a) A statement of the individual's goals and objectives, a schedule of the type and nature of services to be provided and other information and considerations, as specified;

   b) Review and modification, as necessary, by the regional center's planning team no less frequently than every three years; and,

   c) Statewide training and review of the IPP plan creation, as specified. (WIC 4646.5)

7) Provides the dispute process when a regional center believes that a generic agency is legally obligated to fund or provide services described in an IPP for children under age six. (WIC 4659.5)

8) Makes all information and records obtained in the course of providing services under the Lanterman Act, to either voluntary or involuntary recipients of services confidential. (WIC 5328(a))

9) Provides that the people have the right of access to information concerning the conduct of the people's business and, therefore, the writings of public officials and agencies are be open to public scrutiny. Specifies that any law or rule that limits the public right of access shall be adopted with findings demonstrating the interest protected by the limitation. (California Constitution, art. I, Section 3)

FISCAL EFFECT: Unknown, this bill has not been analyzed by a fiscal committee.

COMMENTS: This bill is seeking major reforms that will impact delivery of developmental services. These reforms impact IPPs, timeliness for access to services and programs, standardizing services in all regional centers, governance and oversight of regional centers by DDS, and new data reporting for increased transparency.

Background*: Lanterman Developmental Disabilities Act* originally was passed in 1969. The Lanterman 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 life-long. There are no income-related eligibility criteria. As of December 2022, DDS serves about 330,000 Lanterman-eligible individuals and another 2,900 children ages three and four who are provisionally eligible.

Recent and ongoing oversight discussions: California State Auditor and the Little Hoover Commission. In June 2022, the California State Auditor found a number of deficiencies in the developmental disabilities system that negatively impact services, particularly for people of color. The audit of three regional centers, which collectively serve more than 65,000 consumers, found that they have neither sufficient staff nor funding. The audit found regional centers struggles with a number of issues due to inaction from DDS. The key findings include: regional centers have insufficient staffing because DDS has not ensured adequate funding was received, regional centers are not monitoring vendors appropriately, DDS and regional centers are failing to monitor access to convenient services, and DDS does not provide adequate oversight on consumer complaints with regional centers. The State Auditor made the following recommendations to DDS:

- Work with regional centers as necessary to update the core staffing formula so that it aligns with actual regional center staffing costs.
- Provide vendor monitoring training so that regional centers understand the statutory requirements for vendor monitoring.
- Establish standards for measuring how convenient it is for consumers to access services.
- Ensure that regional centers provide statutorily required information to consumers about how to file a consumer rights complaint.
- Issue guidance to regional centers and develop best practices to ensure that regional centers complete complaint investigations within statutory deadlines."

The Little Hoover Commission held a series of public meetings in the fall of 2022 to discuss the disparities plaguing California's Developmental Disabilities System and is scheduled to release a study in spring 2023. At one of the public meetings in the fall of 2022, comments from regional centers, DDS, and advocates were made discussing problems and possible steps forward. DDS' director, in their written testimony posted on The Little Hoover's Website, committed to:

- Develop a Strategic Plan;
- Host meetings with regional center representatives to hear directly from individuals and families;
- Direct regional centers to develop community engagement plans;
- Work with ARCA to develop and implement standardized intake standards;
- Work with community partners to identify and implement assessment tools and process used in determining early start eligibility;
- Work with ARCA to establish a streamlined and standardized vendorization process; and,
- Continue to build capacity for data fluency, prioritize data integrity, usefulness and transparency.

The study will "assess the extent of current disparities in service access within the state, identify the underlying causes of these disparities and the current state efforts to address them, and consider how state government can improve the consistency and timeliness of service delivery for the individuals and their families who rely on the state's developmental services programs."

Regional center governance and structure. 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. 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.

DDS highlighted provisions added to contracts with regional centers in written testimony to The Little Hoover Committee. The following are recent changes and are the most pertinent to this bill:

- Added language requiring regional centers to review and provide, at minimum, annual training to all board members regarding the board's approved Whistleblower Policy and Conflict of Interest Policy;

- Added language requiring that either a board-approved policy or bylaws must describe: the roles and responsibilities of the board in setting policy and overall governance and the executive director in day-to-day operations; and the selection, training and monitoring of facilitators who will support board members to ensure maximum understanding and participation in carrying out their roles and responsibilities; and,

- Added language requiring regional centers to report: caseload ratio data by October 10th, and, monthly, specified information for whom the Director of DDS is conservator and conservatorship responsibilities have been delegated to the regional center.

Because regional centers are private nonprofits, DDS has limited ability, but not none, to take corrective action. If DDS finds that a regional center is not complying with its contractual obligations, DDS may issue a letter of noncompliance and establish a corrective action plan for the regional center. If the regional center cannot comply with the corrective action plan, DDS has the power to terminate the regional center's contract. In accordance with specific provisions of the Lanterman Act, DDS can directly operate a regional center for 120 days while it contracts with a new Board to operate the regional center.

When there is a complaint that a regional center, developmental center, or a provider has violated or improperly withheld a right, current law allows the consumer or any representative acting on their behalf to file a complaint with the regional center's director. The regional center's director must investigate and provide a written response within 20 working days. A complainant can then appeal within 25 more working days to DDS and DDS then has 45 days to respond. There is no appeal process after it has reached the DDS level.

The State Auditor found that each regional center they examined exceeded this required timeline and DDS has not taken action to remedy this problem as of June 2022. Two out of the three regional centers examined also failed to notify consumers of their rights to file complaints.

This bill makes a number of changes to regional center governance and operations in an effort, according to proponents of this measure, to increase transparency and accountability as well as encourage equity gaps to shrink disparities. This bill revises the standards and procedures for regional center governance such as more limits on board members' terms of service, a more open board nominating process, and more standardized training for board members to be conducted by DDS instead of the regional center. This bill also requires that complaints are made to DDS and a decision must be issued within 30 days instead of the current 45 days. DDS would also have to post, on a quarterly basis, all complaints received on their internet website with redacted personal information.

Regional center services. The 21 regional centers serve approximately 370,000 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 centers services vary at each location. One location might offer one program and the next might offer what they consider an alternative or nothing comparable. Geographically, regional centers' spending also varies. For continuity of care, it makes it difficult for eligible consumers to move from one regional center to another. It is unclear why the services vary so widely.

This bill requires DDS to establish a uniform set of services for all regional centers to provide uniformity, consistency and cost-effective delivery of services.

Vendorization process. Service providers must be vendored by a regional center before they can provide and be reimbursed for services. DDS and regional centers use the term "vendorization" to describe the entire approval process involved in preparing to provide services to regional center consumers. Typically, this process also often involves obtaining licenses or approvals from other state and local agencies prior to becoming a vendor, but starts at the regional center.

According to DDS, vendorization is the process for identification, selection, and utilization of service providers based on the qualifications and other requirements necessary in order to provide the services. The vendorization process allows regional centers to verify, prior to the provision of services to consumers, that an applicant meets all of the requirements and standards specified in regulations. Applicants who meet the specified requirements and standards are assigned a service code and a unique vendor identification number.

Service providers are vendored by the regional center in whose catchment area the service is located, known as the vendoring regional center. The vendoring regional center is responsible for ensuring that the applicant meets licensing and Title 17 requirements for vendorization, determining the appropriate vendor category for the service to be provided, and approving or disapproving vendorization based upon their review of the documentation submitted by the applicant.

Once a potential service provider has obtained all necessary licenses, submitted a complete application and all necessary documentation to the vendoring regional center, the regional center has 45 days to approve or disapprove vendorization.

DDS reported at The Little Hoover Commission public meetings that stakeholders have expressed frustration with the difference in how services are provided between regional centers. DDS also reported the department has already undertaken standardization efforts.

This bill will require DDS and stakeholders to review the current vendorization process and create streamlined uniform processes for all regional centers. Further, the bill states legislative intent that if approved by one regional center, then the vendor should be considered approved by all other regional centers.

Payer of Last Resort. Under the Lanterman Act, regional centers are considered the "payer of last resort," meaning, individuals and families must first exhaust all other "generic resources" available to them as outlined in existing law above, including funds from state and federal programs and private insurance before regional centers will purchase a requested service. Regional centers are tasked with coordinating services which may be service providers or vendors or within the regional center or might be with other public entities such as school districts and transportation agencies, and from other state and federal programs. Further, enacted as a cost saving measure during the Great Recession, in order to get services paid for by the regional center, consumers must prove denial and provide proof that an administrative appeal was being pursued. Because of these rules, consumers report significant hurdles to accessing services in a timely manner.

This bill significantly revises the current requirements around payer of last resort and purchasing of generic services by only permitting a regional center to request the consumer seek services through state and federal programs or private insurance if it is documented in the IPP with detailed instruction on pursuing the service. Further, this bill would require that the regional center would have to provide the services if this request was denied or if the entity does not provide the requested service within 45 days from the date of the request, or 15 days after the statutory or regulatory time limit.

Individual Program Plan. IPPs are guiding services provided to people with developmental disabilities and are outlined in a person-centered IPP, which is developed by a series of planning discussions and interactions with the IPP team—including, among other individuals, the consumer, their legally authorized representative, and one or more regional center representatives—and is based on the consumer's needs and choices. The team helps determines a "preferred future" by identifying a preferred place to live, favorite people with whom to socialize, and preferred types of daily activities, including preferred jobs.

The Lanterman Act requires that the IPP promote community integration and maximize opportunities for each consumer to develop relationships, be part of community life, increase control over their life, and acquire increasingly positive roles in the community. The IPP must give the highest preference to those services and supports that allow minors to live with their families and adults to live as independently as possible in the community.

The recommendations set forth in each IPP are the foundation for each individual's care as it guides services received, eligibility for services, and can help assist in the quality of life for that individual. Each regional center operates independently as described above. As such, the development of each IPP varies in forms and specific processes used; however, the general guiding steps are similar and are as follows: Once an individual or their representative contacts a regional center there is an initial basic intake and then the family will wait up to 60 days for an assessment. Preceding the diagnosis and eligibility determination, an IPP meeting will take place to determine services needed and desired. The IPP can take multiple meetings or discussions until a plan is settled on. Federal law dictates that this plan is to be renewed annually, and should be determined by the guiding rules stated above. However, families can request an IPP meeting at any time.

In November 2021, a coalition of disability rights advocates released a report titled, *Unfair Hearings: How People with Intellectual & Developmental Disabilities Lack Access to Justice in California* and the report found that 90% of all survey respondents reported at least one problem with the IPP process, with the most common complaint being that no one authorized to make a decision on behalf of the regional center attended their IPP; the informal dispute resolution process does not encourage swift and equitable solution to disagreements; belief that the fair hearing system magnifies systemic inequalities and is inaccessible, opaque, and biased; 72% of fair hearings are withdrawn, likely showing that many individuals and families give up because of the complexities of the process and the inability to hire a lawyer; and people served win, or partially win, fewer than 5% of cases filed.

This bill would standardize the IPP format among all regional centers. This bill also would require assessments to be done within 30 days of the request, or 60 days within good cause, and services must be authorized within seven days of service recommendation. If the regional center will not meet this timeline, then they must provide notice to the consumer and DDS. Further, this bill would require the regional center to make a referral within seven days.

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 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 total funds ($3.1 million General Fund) ongoing to support 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 ethnicity demographics are not proportionate.

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

- An Office of the Self-Determination Program Ombudsperson within the department 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.

The Legislative Analyst Office (LAO)'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."

This bill builds upon past the Self-Determination Program efforts by requiring regional centers to inform individuals about the Self-Determination Program during request for assistance and then again during the IPP meetings. This bill will also require documentation from coordinators indicating if the individual is interested and if they are not interested, a reason for not wanting to participate. Furthermore, the regional center must provide information within five days of a consumer requesting information about the Self-Determination Program.

Ongoing racial disparities in developmental services. There is a longstanding documentation about disparities in the amount of spending on services amongst racial/ethnic groups. According to DDS, within the regional center system, 24% of individuals served speak a language other than English and 72% of all consumers served by DDS are non-white; however, studies consistently find that communities of color are less likely to receive regional center services, and receive lower than average per capita purchase of service compared to White individuals. Several DDS initiatives are currently underway; these initiatives have the goal of improving language access, in addition to reducing disparities within the developmental services system more broadly.

Beginning in 2011-12, state law required all regional centers to annually publish data on the amount spent on services for consumers disaggregated by the race/ethnicity of these consumers. These data consistently have shown large disparities in the average amounts spent among these groups. In particular, spending for Hispanic/Latino consumers is about half that for White consumers on average. Since 2016-17, the state has invested $11 million annually for equity grants. In 2021-22, DDS was required to contract with a research entity to evaluate the effectiveness of the plan; this research has not been published yet. The existing and available data has not shown much change. In some instances, it has even gotten worse. The Inland Empire Regional Center reported that in "Fiscal year 2021/2022 data shows that disparity gaps increased across all clients regardless of ethnicity, age, or diagnosis."

In the same 2023-23 budget report by the LAO, the LAO points out that one possible reason the ongoing $11 million per budget year might not be moving the needle is because there is not an understanding of what is causing the disparities. The LAO writes, "Although the Administration has pointed to some factors which explain a share of the overall disparities (most notably, that Latino/Hispanic consumers are more likely than white consumers to live with their parents and thus consume fewer residential services), to date, no attempt has been made to *document* comprehensively the drivers of disparities and to quantify their likely effects."

This bill adds more reporting-specific requirements. Under this bill, DDS must submit an annual report with statewide and regional center data, broken down by qualifying disability category, race or ethnicity, and age categories with the number of consumers for whom health and safety waivers have been requested, and granted. As well as the number of days elapsed between the date on which DDS received the health and safety waiver request worksheet from the service provider and the date the service provider was notified of the outcome.

Author's Statement: According to the Author, "Regional centers play a critical role in California's developmental disability system by providing assessments, determining eligibility, and coordinating the services for those with intellectual and developmental disabilities. Despite California's network of centers that serve nearly 400,000 individuals, numerous issues plague the system, including a lack of transparency, accountability, and disparities in the services provided. Not only has this undermined confidence in California's developmental disability system, but it has failed to serve the Californians that need these services most. [This bill], the Disability Equity & Accountability Act, enacts several reforms to help ensure that all people, regardless of their race or ethnicity or where they live, receive equitable access to services within the regional center system and that all regional centers offer and provide a consistent and common set of services and that the services are delivered in a timely way. It is time that we provide accountability, transparency, and fairness to Californians with disabilities and their families."

Equity Implications: Individuals living with developmental disabilities rely on services from regional centers to live independently and effectively integrate into the community. As outlined above, regional centers are severely underperforming for years which is having an adverse effect on the population who relies on these services. While some of the issues can be traced back to cost saving measures implemented during the Great Recession, the impact has been profound on the community. There is clear inequity between different race and ethnicities as well geographically that is not improving despite grants issued over the last seven years. Regional centers have a duty to offer equitable services and close the gap.

Although unclear the best way to achieve equity, the spending data shows a clear inequity on services provided. For almost a decade, heightened attention has been given to disparities in regional center spending and service provision; data from DDS indicate that, statewide, per capita spending for services for a Latino consumer was $12,152 in 2021 compared to $28,143 for a White consumer. In 2015, statewide data showed that Latino consumers utilize services for which they are authorized at a lower rate (76.6%) than White consumers (82.7%).

Policy Considerations: This bill makes a number of sweeping changes and reforms to the developmental services system through DDS and the regional centers by trying to address transparency and oversight, close the equity gap, improve overall timeliness of access, and consistency of services. Over the past few years and after multiple calls for oversight, DDS began implementing changes to address issues raised at oversight hearings as described above.

Many of the changes, but not all, DDS is currently undergoing is noted above. The changes include undergoing initiatives to standardize data collection, IPP forms and processes, and vendorization. These efforts are ongoing and in some cases in the middle of policy changes using technological systems and data collection. This bill might cause some of these efforts to halt and in some cases, force projects to begin at phase 1 despite similar desired objectives from DDS and stakeholders. Should this measure move forward, the author should continue to work with this committee, interested stakeholders, and DDS to determine how to best combine the efforts of this bill with current ongoing efforts so the laudable goals of this bill are not inadvertently and unnecessarily slowed down. It is in the best interest of the consumers of developmental services for all interested parties to work on a reform that can implemented quickly, efficiently, and with the best results.

Double referral: This bill pass out of the Assembly Judiciary Committee on April 11, 2023, with an 11-0 vote.

RELATED AND PRIOR LEGISLATION:

AB 649 (Wilson) of the current legislative session, would permit regional centers to purchase services that would otherwise be available from other specified means when a consumer or a consumer's representative chooses not to pursue coverage despite eligibility. *AB 649 is pending before this Committee and is set to be heard on April 18, 2023.*

AB 1957 (Wilson), Chapter 314, Statutes of 2022, added additional data points to the set of data that DDS and regional centers must report. These additional data mostly relate to services that were cut during the pandemic and recently restored, including social recreation, camping, educational services, and nonmedical therapies such as art, dance, and music. AB 1957 also added untimely translations of an IPP in a threshold language to be included in the set of data.

AB 1 X2 (Thurmond), Chapter 3, Statutes of 2016, authorized the Service Access and Equity grant program through which $11 million in ongoing General Fund resources for DDS was provided to assist regional centers in reducing purchase of service disparities.

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

AB 1244 (Chesbro) of 2011, would have created a self-determination program to provide individuals with a single, capitated funding allocation they may use to purchase services that support goals identified in their IPP. *AB 1244 failed passage in the Senate Human Services Committee.*

AB 9 X4 (Evans), Chapter 9, Statutes of 2009, 4th Extraordinary Session, created an option for the individual choice budget, which allowed for the purchase of otherwise suspended services but required savings of $35.1 million. *AB 9 X4 has not been implemented.*

AB 131 (Committee on Budget), Chapter 80 Statutes of 2005, 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.

SB 1038 (Thompson), Chapter 1043, Statutes of 1998, authorized the creation of pilot projects for self-determination at three regional centers. Two other regional centers also created independent self-determination pilots under an alternative service delivery model, bringing to five the number of regional centers engaged in the pilot.

REGISTERED SUPPORT / OPPOSITION:

Support

Disability Voices United (UNREG) (Sponsor)
Autism Support Community
Disability Rights California
Down Syndrome Association of Santa Barbara County
Integrated Community Collaborative
Parents Helping Parents
Pragnya
326 Private Citizens

Opposition

None on file

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