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Assumptions, Resources, and Inputs to Case Management: Implications for California's Regional Center System

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Assumptions, Resources, and Inputs to Case Management:
Implications for California's Regional Center System

by

Jonathan Flint

A Thesis Quality Research Project
Submitted in Partial Fulfillment of the
Requirements for a Master's Degree

in

PUBLIC ADMINISTRATION

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THE PROBLEM STATEMENT

This project adds to knowledge of case management assumptions, resources, and inputs for California's Regional Center system by surveying members of the Service Access and Equity working group, formed by the Department of Developmental Services (DDS). It recommends development of a logic model to evaluate case management activities because their intended societal impacts are difficult to directly measure. Additionally, it adds to the debate on health equity and racial disparities in Medicaid long-term services and supports (LTSS). In 1969, passage of the Lanterman Developmental Disabilities Services Act (The Lanterman Act) led to the first and still only entitlement to community-based services that is granted to people with developmental and intellectual disabilities (I/DD) by a state. Twenty-one private, nonprofit Regional Centers have exclusive rights to provide case management and to purchase community-based services for eligible consumers within their catchment area. By contracting with DDS, Regional Centers receive reimbursement for case management operations, pass-through rates to purchase community-based services, and administer various grants, projects, and funds.

This project contributes to understanding whether and how knowledge gaps in Regional Center case management affect expenditures of home- and community-based services (HCBS). In addition, Vogel et al. (2019) lay out systemic LTSS and demographic challenges in California: a higher percentage of people require services and have autism; a growing unpaid caregiver and adult consumer population aging-in-place at home; a struggle with rising labor costs to recruit and retain qualified personnel, high cost of housing for community living, and non-compliance with Medicaid HCBS regulation that may restrict federal funding. Surveying working group members' knowledge of case management in home- and community-based services improves understanding of the disparities in service access for racial and non-English speaking consumers.

Neri (2022) asserts that despite California’s demographic majority-minority population, case management in the Regional Center system still caters to middle-class White families. In DDS reports written at the Legislature’s behest, Widaman and Blacher (2003a) analyzed 1990s purchase of service (POS) data and interviewed families receiving services (2003b). Notably, the focus group data raised questions about the POS statistical findings that independent variables (residence type and consumer age, characteristics, level of intellectual disability, and independent living skills) accounted for most disparities and that “client ethnicity had a rather small influence on service costs” (pg. xiii). Not long after this study, a four-part investigative series in the *L.A. Times* by Alan Zarembo (2011) put a spotlight on POS racial disparities, and Sen. Darrell Steinberg’s Select Committee on Autism and Related Disorders (2014) proposed 51 legislative measures to address the rising rates of autism diagnosis and need for new equity data. Lawmakers required that “DDS and Regional Centers work together to annually publish data on their websites relating to disparities in purchase of service (POS) dollars” (Topete, 2017, p. 1). Still, an analysis of children’s expenditure data by Public Counsel (2017) found disparities in the purchase of services between and within the 21 Regional Centers. Those in catchment areas with majority-minority populations were likely to have lower-than-average per capita authorizations. The study gave an example from a Regional Center where Hispanic children received 79% of their "fair share" of authorized services, and White children received 126% of their fair share. DDS distributed \$66M in grants between 2016 and 2022 to reduce racial disparities in the POS. Despite this, in a follow-up study, Public Counsel (2022) found POS racial disparities persisted at over 80% of Regional Centers. An exception was for Black and Hispanic children served by South Central Los Angeles Regional Center, where expenditures grew by 112% (\$72.1M) in five years and they eliminated POS disparities (but not for the consumers labeled “other ethnicities”).

Background on Community-based Services and Supports for People with Intellectual and Developmental Disabilities in California

Since the Legislature amended the Lanterman Act in 1977, each Californian meeting eligibility criteria is entitled to lifelong case-management services from the Regional Center responsible for their catchment area. Those criteria are: (a) having a developmental disability, which includes the diagnosis of autism, cerebral palsy, epilepsy, intellectual disability, and a fifth category of disabling conditions which have a similar developmental etiology that is not solely physical and (b) demonstrating significant impairment in at least three functional areas of daily life. Case managers are responsible for assessing need and writing the Individual Program Plan (IPP). The IPP is a legal contract between the individual, family, and Regional Center to purchase community-based services necessary for the "social, personal, physical or economic habilitation or rehabilitation of an individual with a developmental disability or toward the achievement and maintenance of an independent, productive and normal life" (WIC 4519.10). The Lanterman Act entitlement for people with developmental disabilities to receive community-based services was upheld by the California Supreme Court in *Association for Retarded Citizens v. California Department of Developmental Services et al.* 38 Cal. 3d 385 (1985).

Aday and Andersen defined health equity as the "just distribution of finite resources based on need" (1981, p. 192). Regional Centers seek just distribution by optimizing the finite types and number of community-based service providers, and separately, by identifying the needs of individuals and families to attain a self-sufficient and productive life. Factors impacting family demands include living arrangement, age, disability, language, cultural preferences, socio-economic status and the presence of unpaid natural supports, degree of physical impairment, and intellectual disability. A factor impacting the supply of community-based service providers is the California Code of Regulations Title 17 vendorization process, in which

entities create a program design and agree to provide certain types of HCBS waiver services to individuals referred by the Regional Center at a set hourly, daily, or monthly reimbursement rate. The Legislature sets the reimbursement rates to pay vendors' direct care workers at minimum wage (Developmental Services, 2023a). Lastly, Regional Center case managers (alternately referred to as social workers or service coordinators) seek just distribution through coordination with non-developmental disability-specific generic community-based services. Examples include service access in public education, Social Security, Medi-Cal, and Department of Rehabilitation.

Many primers on the origin of community-based services in California for people with intellectual and developmental disabilities begin with documentation by civil rights advocates of inhumane institutional care in the United States during the 1960s and 1970s (*Strengthening the Commitment... Reinvesting in the System: A Journey of Community Partnership*, 2019).

Prominent examples include Burton Blatt's *Christmas in Purgatory* (1974) photo expose in 1966 of working and living conditions at five state-run institutions, the litigation on behalf of family members residing at the Willowbrook State School described in *The Willowbrook Wars* (2005), and institutional care at state hospitals described by Dr. Gunnar Dybwad in a 1965 report *The Undeveloped Resource: A Plan for the Mentally Retarded of California* to the Legislature.

The deinstitutionalization movement harnessed liberal reformers' political interests in the pursuit of expanded economic and social opportunities and concerted legal efforts to protect civil rights.

Wolf Wolfensberger's *Principles of Normalization* (1972) gave philosophical firepower to the community living movement by articulating how, throughout history, depictions of people with disabilities conformed to stereotypes: a Holy Innocent, Eternal Child, Object of Pity, Object of Ridicule, Diseased Organism, Menace, Subhuman Organism, and Unspeakable Object of Dread. Wolfensberger concluded that when people are deprived of everyday productive lives in the

community, these depictions become a self-fulfilling and reinforcing social reality. Governor Edmond “Pat” Brown, in advocating for Assembly Bill 691 to establish a pilot program of two Regional Centers for developing services in the community, addressed the Legislature in 1965. He said, "Society's as well as the individual's interest can be served here. If [people with intellectual and developmental disabilities] can become more self-sufficient and productive, some may become taxpayers and more active participants in our society. In any event, they will require less expensive services from society than if they were totally dependent" (*Strengthening the Commitment... Reinvesting in the System: A Journey of Community Partnership*, 2019, pg. 5). Thus the Legislature sought to fulfill a moral imperative and deliver a fiscally responsible policy.

The Henry J. Kaiser Family Foundation (2015) describes distinct eras in long-term services and supports (LTSS), beginning with the institutional care era when the passage of the Social Security Act (SSA) of 1935 established the Old Age Assistance program and gave federal payments to low-income seniors living in their homes. Those residing in state-run poor houses were prohibited from receiving payments, leading to the creation of the private nursing home industry to capture funds. In 1950, an amendment to the SSA allowed nursing homes to receive direct payments for medical care if they obtained a state-issued license. In 1965, the creation of Medicaid (Medicare does not provide LTSS) required states with federal funding to provide institutional care, such as in a Developmental Center or nursing home, to dependent adults and medically fragile or developmentally disabled children. The era of federally funded community-based services began in 1974 when the SSA was amended to provide grants to states for homemaker services, protective services, transportation, adult day care, training for employment, nutrition assistance, and health support. In California, Gov. Ronald Reagan signed the Frank D. Lanterman Developmental Disabilities Services Act in 1969, creating the Regional Center

system. After becoming president in 1981, Reagan signed a bill adding section 1915(c) to the Social Security Act, creating the Home- and Community-Based Services (HCBS) waiver authority. According to the Centers for Medicare and Medicaid Services (2023), total spending on HCBS surpassed institutional care in 2013 (this political objective is known as Medicaid rebalancing). By 2020, total Medicaid expenditures for LTSS reached \$199.4 billion, \$124.6B of which were expended on HCBS compared to \$74.8B on institutional care. In California's FY23-24 adopted budget, total expenditures by DDS amounted to \$13.6 billion, representing \$5.4 billion in federal funding and an \$8.2 billion General Fund allocation (LAO, 2023).

Gov. Brown and the reformers of the 1960s acted on the longstanding issue of services and supports for Californians with I/DD. But despite this extraordinary commitment 55 years ago, barriers to community living for people with intellectual and developmental disabilities persist and still pose social, medical, economic, and legal problems of extreme importance. That Californians face new questions, and not the shortcomings of institutional models of care, drives this project. Through what processes and by what means does California measure that a citizen affected by intellectual and developmental disabilities attains the highest degree of self-sufficiency and productivity? How should policymakers respond if expenditure data suggests that factors such as English proficiency, race and ethnicity, or catchment area influence the opportunities for full community participation exclusively available through the Regional Center's case management? Given limited public funds and the constraints on Regional Center service providers, how does society know what, whose, and how many needs are unmet by the present capacity and array of community-based service providers? These challenges and barriers demand our attention to re-envisioning the delivery of home- and community-based LTSS.

LITERATURE REVIEW

Health Equity in Medicaid Expenditures

Several studies since 2010 have evaluated disparities in utilization and of outcomes for Medicaid services. Polaha and Sunderji (2019) frame different ways to operationalize access as a health equity outcome measure, using the health equity framework developed by Aday and Andersen (1981). Barnett et al. (2018) found a dearth of research on the factors influencing Medicaid beneficiaries' satisfaction with and access to care. Their study used a national survey of Medicaid enrollees and found that the total supply of physicians and an increase in physicians participating in Medicaid per capita improved patient experience. They also found that higher spending per patient predicted satisfaction and access. The findings illustrated that entitlement programs are likely to face challenges with satisfaction where there is an insufficient supply of providers or lower expenditures on services. Smith (2010) examined the impact of shared doctor and patient race and gender on the utilization of health services. Their research found that racial and gender concordance between patients and primary care providers did not lead to an increased use of care services. However, it was associated with reduced likelihood of prescription drug use. Importantly, they introduced a theoretical framework (Figure 1) by Anderson (1995) to explain healthcare utilization that has evolved since the 1960s into what one can recognize as a logic

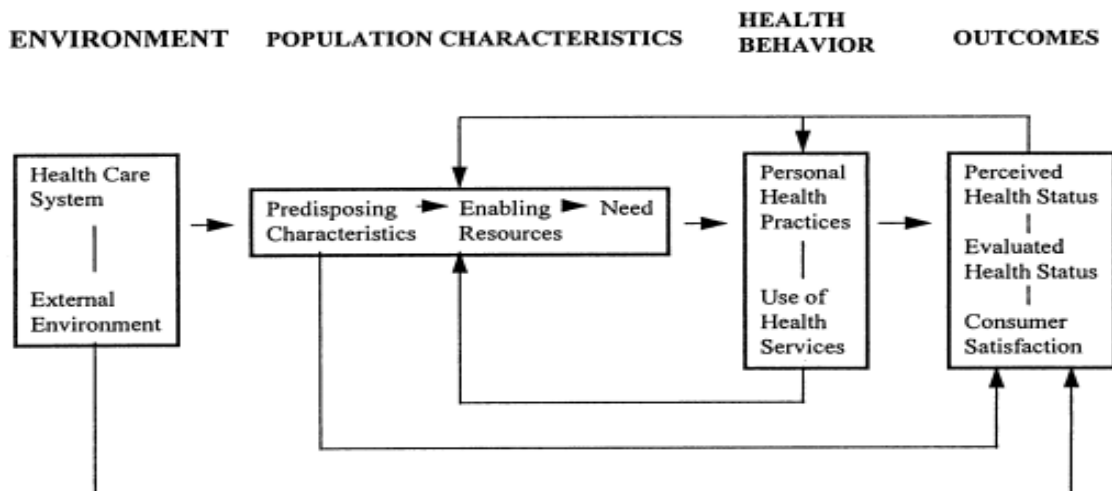


Figure 1. Theoretical Framework of Healthcare Utilization by Anderson (1995)

model today. Anderson writes that in the 1960s, increased utilization was a primary policy goal (which is true in the debate today about racial disparities in POS), and equity at that time meant “demographic and need variables account for most of the variance in utilization” (1995, 4). In addition, health policies should consider the degree of mutability (how difficult a factor is to change). Anderson suggests that personal health practices and enabling resources are key mutable variables within a target population that policymakers can address in health equity.

Holt (2019) examined racial disparities in patient healthcare experiences through an analysis of studies using survey data from the Clinician and Group Consumer Assessments of Healthcare Providers and Systems. He found positive experiences at safety-net clinics and federally qualified health centers were reported equally by patients of diverse racial and ethnic backgrounds. He also found evidence that race impacted patient experience in a study of family medicine clinics and suggested narrative protocols may help to contextualize the inconsistent satisfaction data. Martino et al. (2019) found through a survey data analysis of Medicaid beneficiary experiences that Asian and Hispanic beneficiaries tend to report worse outcomes than White beneficiaries. Black beneficiaries tend to report better experiences than Whites, which was consistent with past findings. The authors suggest that, due to a greater number of non-English language speakers in Asian and Hispanic populations compared with Black populations, one explanation is that language barriers may be an even more significant impediment for low-income beneficiaries than race. Horvitz-Lennon et al. (2015) examined differences in quality measurements for schizophrenia care by county in four states using Medicaid data. They found significant differences in county disparities in quality measurements for each racial group and state. The finding emphasizes the difficulty of addressing disparity in a Medicaid program that grants local control, as no county narrowed the initial gap over the period studied (2002 – 2008).

Gordon et al. (2020) contribute to understanding social factors that affect healthcare utilization, distinguishing between social determinants of health (SDoH), social risk factors, and social needs. SDoH include education, income, marital status, and neighborhood work and home environments, which affect individuals' access to and utilization of health care. Social risk factors refer to adverse individual effects caused by SDoH, including financial strain, low social support, low income, and low health literacy. Adverse health-related social needs include homelessness, social isolation, food or medical insecurity, and transportation barriers. The population studied included a cross-section of Kaiser Permanente members who varied in socio-economic status. The socio-economic diversity is important because the population studied was not limited to means-tested Medicaid enrollees but, like the Regional Center system, reflects the experiences of people with high and low SDoH risk factors accessing (and in some ways competing for) the same finite network of community-based service providers. Notably, the study survey instrument was limited to English-speaking people. The study found disparities, including a higher prevalence of social risks in Blacks, Latinos, and Filipinos relative to White and Chinese adults, and differences that seem to be mediated by levels of education and income.

How a Logic Model is Developed

The W.K. Kellogg Foundation (2004) developed the logic model to support grantees' philanthropic work in Latin America and the Caribbean. Since then, logic models have been adopted by organizations, including the Centers for Disease Control and Prevention (CDC), to model real-world relationships in programs in which there are barriers to testing variables in a controlled scientific manner, from patient completion of tuberculosis disease treatment to prevention of heart disease and stroke (Centers for Disease Control and Prevention, 2020). The

Foundation's grantees needed more user-friendly tools to communicate program direction, implementation, evaluation, and outcomes they sought to achieve. The CDC Division for Heart Disease and Stroke Prevention publishes an Evaluation Guide for Developing and Using a Logic Model (2017). It describes additional benefits as: engaging program stakeholders and improving staff expertise by creating a common reference point, incorporating findings from other research, and defining the actions expected to lead to the desired results while identifying likely obstacles in program operation from processes to outcomes. The evaluation guide explains a series of "if-then" statements that underpin the logic model as shown in Figure 2: "If we have _____ and _____, we can (do) _____ and _____, which will result in _____ and _____" (2017, 4).

LOGIC MODEL

IF... THEN

Assumptions:

- Certain resources are needed to operate your program.
- *If* you have access to them, *then* you can use them to accomplish your planned activities.
- *If* you accomplish your planned activities, *then*, you will, it is hoped, deliver the amount of product and/or service that you intended.
- *If* you accomplish your planned activities to the extent intended, *then* your participants will benefit in specific ways.
- *If* these benefits to participants are achieved, *then* certain changes in organizations, communities, or systems might occur under specified conditions.

The building blocks of a logic model are resources, inputs, activities, outputs, and outcomes as shown in Figure 2. In addition, assumptions, contextual factors, and impacts may also be included. These components illuminate the connection between a program's planned work and intended results (W.K. Kellogg Foundation, 2004). These are separated into processes and outcomes. The model includes resources and inputs, which must exist if program activity is to occur. These may be funding sources, staff availability, and pre-existing community partnerships. If the necessary resources and inputs are in place, certain program activities can occur, as well as defined events intended to produce desired outcomes. If the program activities are done, then specific outputs are produced, which are the direct and tangible work products resulting from activities. In a logic model, if the program outputs are present, then short-term, intermediate, and long-term outcomes are expected to show

Figure 2. Evaluation Guide for Developing and Using a Logic Model (2017)

measurable improvement over an identified time frame. The insight of the logic model is that the presence of program outputs generates observable outcomes that a programmatic activity cannot directly address. Such is the case with Regional Center case management, in which outputs are work products that may or may not produce the intended observable outcomes on a short-term, intermediate, and long-term basis. The Evaluation Guide for Developing and Using a Logic Model (2017) describes short-term outcomes as the immediate effects that often focus on the knowledge and attitudes of the participants in the program activity. An intermediate outcome typically refers to effects requiring multiple years of program outputs that result in behavioral, normative, and policy change. Long-term outcomes are the furthest longitudinal measurable results of the program, which can be attributable to program processes.

Assumptions, contextual factors, and impacts are external to logic model program processes and outcomes. Still, they are often included because failing to identify these components can lead to unforeseen obstacles that lessen program success. Communicating assumptions about the reasons for proposing solutions and the program's approach helps all stakeholders recognize unwritten rules and expectations that an organization assumes all participants hold. Similarly, contextual factors such as each participant's educational level and English fluency are often outside the program's control. Still, they can profoundly influence a logic model's processes and outcomes. For a focus on equity, a firm grasp of the contextual factors affecting case management for family and individual consumers of the Regional Center is essential. Finally, the desired impacts of a logic model are crucial to achieving a shared program vision and the ultimate justification for the program's existence to address a problem or need.

The Use of Logic Models

LaForett and De Marco (2020) studied disproportionate school suspension and expulsion rates. They developed a logic model to support educator activities that reduce racial disparities and improve educational outcomes. Gase et al. (2017) evaluated Health in All Policies (HiAP) using a logic model formed through analysis and interviews with stakeholders in three states, including California's 2010 Health in All Policies Task Force. They found a broadly defined logic model valuable to practitioners because of the inherent difficulty in attributing specific impacts from one body of diverse practices that unfold within ongoing health and equity-focused efforts. Similarly, Andermann et al. (2016) wrote that a logic model helps identify multiple potential pathways connected to improving whole population health outcomes. Complex health challenges require that the public understand how a program will be implemented and evaluated in real-time, because it is not feasible to prove that an activity at the individual level will produce a benefit relative to doing nothing when the desired impact is at a population level (consider the challenges of convincing the public to adopt new health measures during the pandemic).

Nerlinger et al. (2021) worked with three healthcare sites to develop a logic model for evaluating a medical-legal partnership in which physicians can refer patients to receive legal services through an interdisciplinary team, a growing trend between health systems and community-based organizations to address health disparities. One aspect of interest is how knowledge of the logic model components affects individual actors in future interactions and improves recognition of health inequities.

Cheadle et al. (2016) developed a logic model to show how implementing 22 policy, system, environment, and infrastructure changes promoted healthy eating, active living, and reduced tobacco use and exposure in King County, WA. They found a positive relationship between a sector dyad and beneficial health outcomes. A sector dyad is a partnership between an

engaged staff champion with organizational readiness and a consultant or staff member from a backbone organization that provides subject matter expertise, funding, and technical assistance to facilitate organizational change. Rollins et al. (2019) discuss the methodological value of participatory evaluation frameworks using a health equity lens to address disparities. They share lessons learned, including the need for continuous communication and mutually beneficial partnerships among stakeholders. They saw a logic model as an overarching blueprint that engaged partners and facilitated collaboration. Keller and Bauerle (2009) posit that logic models can be tactical and strategic, as they define specific activities within a simplified and easily communicated vision. The authors caution users to incorporate feedback loops in their logic models to ensure that the system's dynamic behavior can become data that continually informs the development and revisions to the model. Lastly, Kashinath et al. (2015) contributed an implementation checklist based on the acronym ROLE (Relationships, Observation, Learning, and Evaluation) to build consistency across activities and outcomes and communicate discrete linear relationships in the logic model. The checklist is derived from four ROLE components with sub-domains linking the activities and outcomes. The authors note that logic models can fulfill data reporting requirements for program funders.

METHODOLOGY

Research Design

The interpretive group of research methods generates observable outcomes in the social sciences when the researcher desires to recognize their connection to the phenomena under investigation by analytically disclosing the meaning-making practices of human subjects (Labaree, 2023). A robust body of academic research on California's Regional Center system is

contained in graduate theses and doctoral dissertations written since 2000. Most use a survey or interview instrument. The research topics investigated include racial disparities in expenditures (Neri, 2022; Rivera, 2016), disaster planning (Cook, 2022), employment (Smith, 2014; Quigley, 2014; Smith, 2012; Wahl, 2012; Arenales, 2011), stakeholder perspectives on service satisfaction (Reyna, 2020; Montiel, 2014; Drummer Taylor, 2006; Morrett, 2004), and program evaluation (Woods, 2015; Harney, 2011; John, 2011; Pompa-Craven, 2000). The current research builds on the knowledge of racial disparities in expenditures and stakeholder perspectives on service satisfaction, seeking to introduce into the literature the use of the logic model developed by the W.K. Kellogg Foundation (2004). A logic model is a systematic and visual way to share a common understanding of relationships among a) resources or inputs, b) the activities of a program, and c) the intended results or impacts. It is the best way to address the research question because of a recent Public Counsel (2022) report that calls into question the accuracy of Regional Center case management data and, thus, valid analysis. Public Counsel noted demographic anomalies such as the “other ethnicity” category increasing across the population by 66% over five years for children (0-2) and by 52% for children (3-21), which stands in direct contrast to related census data and “calls into question the credibility of the Regional Centers general consumer demographic information” (pg. 24). Understanding the barriers to collecting consumer data is essential for reliable quantitative analysis. This qualitative exploratory research uses a survey instrument to collect data about Regional Center consumer case management. The survey data collection met the criteria for Institutional Review Board (IRB) exclusion at San Jose State University, which ensures that ethical standards are upheld for academic research that involves human subjects.

Survey Population

Participants in this research are Department of Developmental Services Access and Equity Workgroup members. DDS updated the list of 35 working group members on January 8, 2021. This convenience sample of state-wide professional stakeholders includes family members, individuals with I/DD, and members representing service providers, Regional Centers, University Centers for Excellence in Developmental Disabilities (UCEDD), State Council on Developmental Disabilities (SCDD), and Disability Rights California (DRC). Members were presumed to have direct knowledge of assumptions, inputs, and resources for Regional Center case management. In January 2024, the author contacted one Service Access and Equity Workgroup member and received a list of active members. The author then compared the active list with the published Department of Developmental Services (2024a) member list and reviewed public recordings of Zoom meetings from 2020 – 2022 to determine who attended at least one meeting. Of the 35 members, two were on the original list but were not present on Zoom or considered active by the member contacted. The researcher did not pursue contacting these members or three members who had retired. The remaining 30 members were separated into two groups: one group of 13 members who both DDS and the member listed (but were not visible on one of the Zoom recordings) and a group of 17 who participated in the recording. The researcher obtained missing contact information by Googling the member's name and organization affiliation. Only one member did not have a public email. However, the member had a LinkedIn profile and responded to direct messages. By Googling the member's name and email address, the researcher obtained an additional contact phone number or LinkedIn profile for 20 members.

Data Collection and Survey Instrument

On February 13, 2024, an introductory request to complete the Google Forms survey was sent via email to the 30 members identified as eligible participants. The researcher received eleven responses by March 18. Participants were informed that their participation was voluntary, they were assured of confidentiality, and they were told that the survey met the criteria for IRB exclusion at SJSU. The researcher incentivized respondents by donating \$20 to Public Counsel for each response, with a maximum of \$200 donated for the first ten responses. The survey “Assumptions, Inputs, and Resources of Service Coordination in the Regional Center System” sought insight into the member’s professional knowledge and experiences of case management, using three of the seven logic model components to determine the usefulness of further development. The POS study focus groups and interviews by Widaman and Blacher (2003b) and *L.A. Times* journalist Alan Zarembo (2011) with family members indicated that knowledge of assumptions in the Lanterman Act, access to resources, and the input of expectations about an individual’s need for community-based services impacts the total purchase of service. Thus, it is essential to disassemble the logic model and understand how people involved in IPP planning team decision-making formed their expectations for service delivery and to what extent this process deviated from the principles created by the Legislature in the passage and subsequent amendments to the Lanterman Act. Public Counsel (2017) indicates the Goldilocks Principle might explain why the Regional Center system did not generate satisfactory results for either White or Hispanic children because expenditures were in excess (for White children) or deficient (for Hispanic children). This study explores whether a logic model would provide a “just right” amount of purchase of service through the lens that stakeholders holding differing assumptions, resources, or inputs would explain too high or too low POS expenditures.

The survey posed statements from the Lanterman Act about expectations for service delivery (assumptions in a logic model) and asked members whether they agreed or disagreed that IPP planning team members demonstrated knowledge of the expectation. The phrasing was revised several times prior to collecting responses based on feedback to improve the readability and accuracy. However, one respondent indicated that this part was confusing at first. Other respondents added criteria such as service quality measurements, comprehensive assessments, person-centered planning, and compliance to consider in future research. Next, respondents were asked to agree or disagree with proposed relationships between resources in the logic model, identified as access to caregiving, expectations of community participation, time to advocate, and fluency in the Regional Center case management process. Lastly, respondents were asked to agree or disagree with the planning team's knowledge of inputs to the logic model that were defined as federal Medicaid grants and state General Funds, the DDS funding formula for Regional Centers, service coordinator caseload ratios, vendorization requirements, Regional Center Board of Director approved purchase of service policies, and eligibility for generic services including Medi-Cal, public education, Social Security, and Department of Rehabilitation job training. The proposed logic model is shown in Figure 3. The researcher collected demographic data, including name, ethnicity, and the year of first interaction with the Regional Center. This data is essential because of differing philosophical and systems change approaches in developmental services over the past 50 years. All questions were optional, so respondents could skip questions or sections that were not applicable, and several did. Three people who worked for a Regional Center or were family members responded that they experience significant stress in their daily lives. Thus, researchers must approach contacts with empathy in the developmental disabilities field and adjust when respondents are overwhelmed.

Logic Model Selected Components for Regional Center Case Management

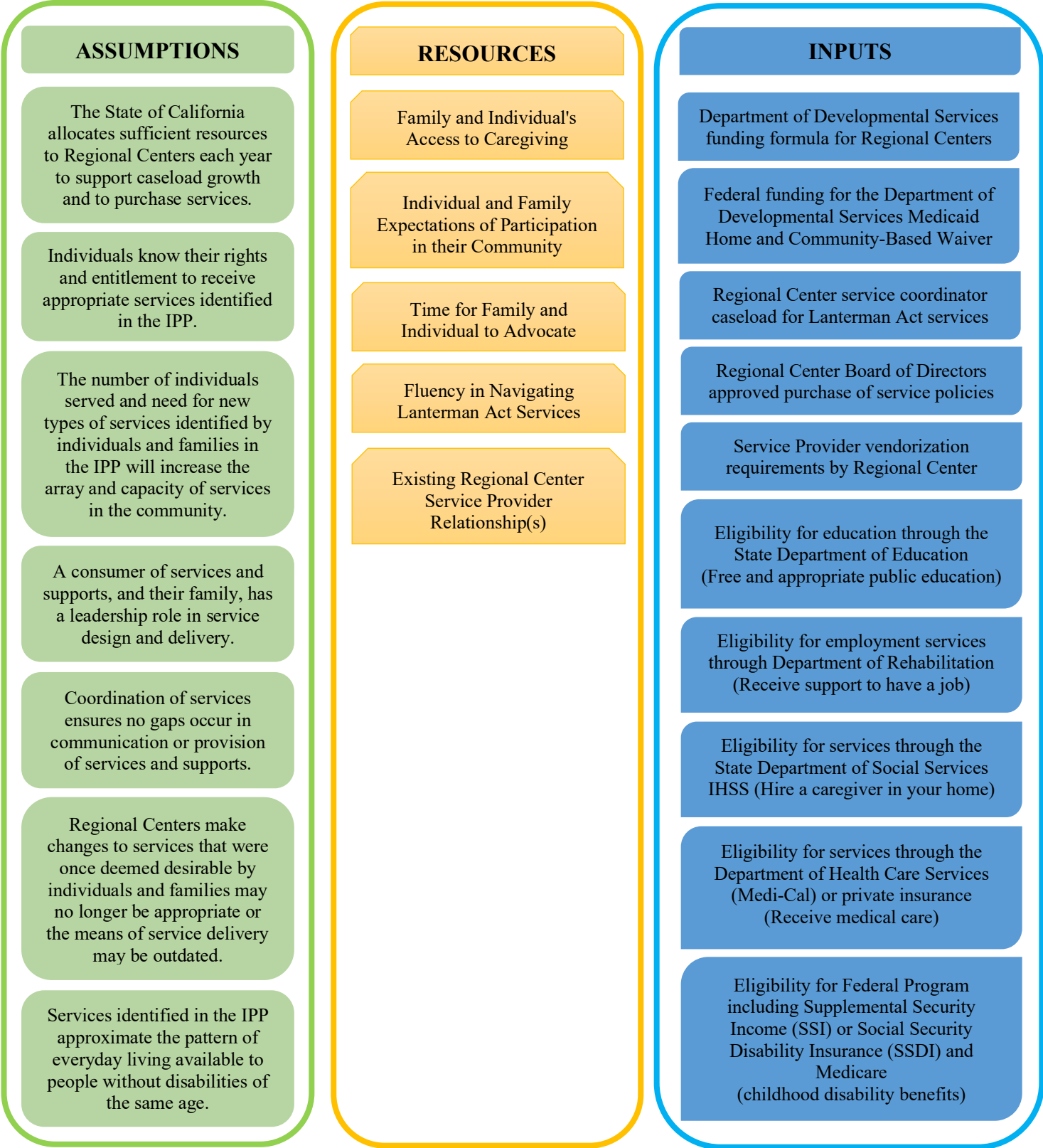


Figure 3. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system

RESULTS

Demographic Characteristics of Respondents

The researcher collected 11 out of 30 possible responses from members of the DDS Service Access and Equity working group. Six responses came from members affiliated with a state-wide federally mandated organization (UCEDD, SCDD, and DRC) working on behalf of people with developmental disabilities. Fewer than five responses were submitted by family members, individuals with a developmental disability, direct service providers, or local non-profit advocacy organizations. Regional Center employees did not provide survey responses and are not represented in the data. However, all members working for Regional Centers in 2021 were employed by their agency in 2024, while over 25% of direct service providers had retired or changed agencies, and between 15 – 20% of family members were inactive or UCEDD, DRC, or SCDD or employees that had changed jobs. The researcher received five responses from working group members who identified as White or Caucasian and five surveys from Hispanic or Latino and Multiracial or Biracial members; one respondent did not identify an ethnicity.

To better understand respondents' baseline range of experience with case management, they were asked about the number of Regional Centers with which they have interacted in the case management process. Shown in Figure 4, five respondents selected the option of between two and five Regional Centers. In general, non-White respondents reported interacting with a greater number of Regional Centers over their lifetime than White respondents.

With how many Regional Centers have you interacted in your lifetime with the service coordination process?

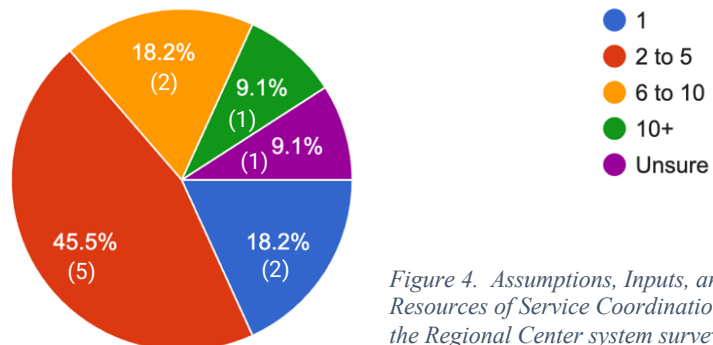


Figure 4. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

Respondents were also asked about the first decade in which they interacted with the Regional Center are shown in Figures 6. The typical White respondent began in the 1990s, while the typical non-White respondent first interacted in the 2000s.

This result reinforces a 1996 minority-majority demographic transition shown in Figure 5 from the 10th Edition of the Fact Book by the Department of Developmental Services (2008).

The growth in non-White consumers reflected advocacy and new public awareness of Regional Center community-based services for non-White children with developmental disabilities. Between 1996 and 2006, the number of non-White consumers nearly doubled from 73,544 to 127,320 while White consumers increased by 21,000. It is important to note that for the ~80%

of non-White consumers who have entered the Regional Center after 1996, their lived experience of service provision reflects state budget crises following the dot.com crash in 2001 and the Great Recession in 2008, when cuts to services and provider reimbursements were enacted. Thus, their experience and knowledge baselines differ in important ways from White consumers, who were the primary consumer and dominant service provider population before 1996.

Ethnicity	Number of Persons	Percentage of Total
White	66,873	47.6%
Hispanic	35,996	25.6%
Black	14,876	10.6%
Asian	6,222	4.4%
Filipino	2,204	1.6%
Native American	572	0.4%
Pacific Islander	229	0.2%
Other	13,445	9.6%
Total	140,417	100.0%

Ethnicity	Number of Persons	Percentage of Total
White	87,726	40.8%
Hispanic	70,517	32.8%
Black	21,235	9.9%
Asian	12,544	5.8%
Filipino	4,418	2.1%
Native American	833	0.4%
Pacific Islander	486	0.2%
Other	17,287	8.0%
Total	215,046	100.0%

Figure 5. Department of Developmental Services Fact Book Tenth Edition pg. 5, comparing consumer population by ethnicity in 1996 (top) and 2006 (bottom)

In which decade did you first interact with the Regional Center system?

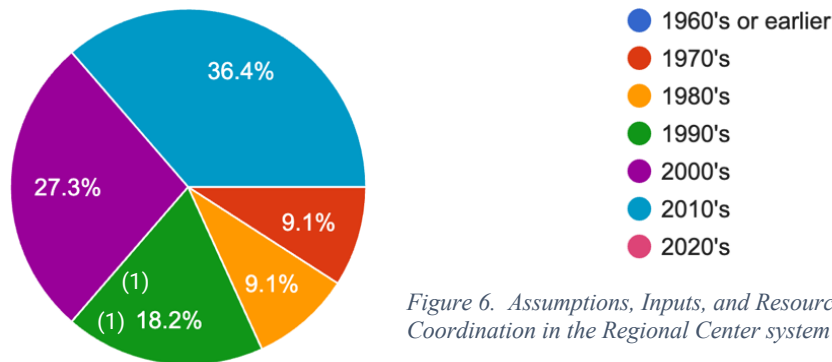


Figure 6. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

Themes in the Results: Assumptions

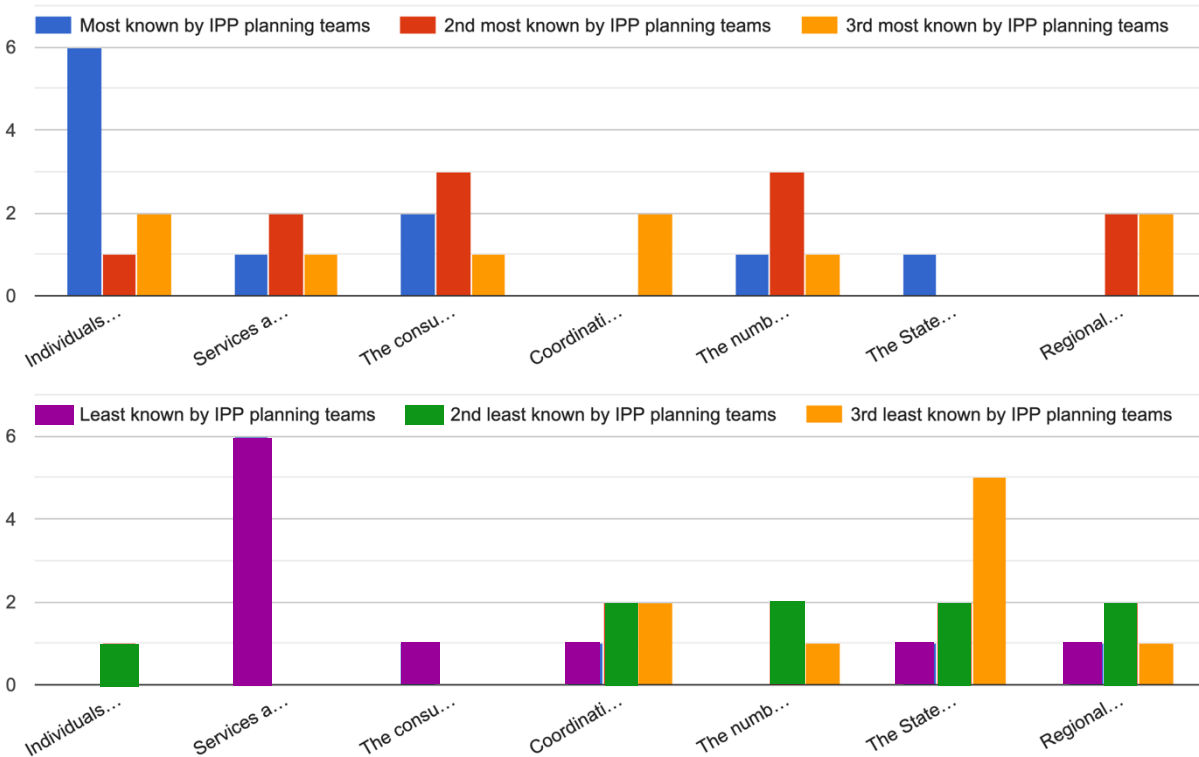
Knowledge of the Legislature's Intent for Lanterman Act services

Ten of the survey questions asked respondents to rank their familiarity with statements from the Lanterman Act related to the Legislature's intent for Regional Center services. The order of statements was shuffled to improve validity. Assumptions were included because the W.K. Kellogg Foundation (2004) emphasizes that "we must understand the principles on which a program is based, a notion not included in evaluation until recently" (pg. 10). In two areas, the responses suggest there is disagreement that IPP planning teams usually demonstrate knowledge. While there are too few responses to show statistically significant relationships, differences between ethnicities shown in Figure 7 for statements E, F, and G may warrant further research.

IPP Planning Team Assumptions in the Logic Model: Knowledge of the Legislature's Intent for Lanterman Act Services			
<i>Survey Question: Please indicate the degree to which you agree or disagree based on your professional experience of IPP planning teams (circle of support, family member, service provider or regional center employee) that members demonstrated knowledge of the Legislature's intent for Lanterman Act services:</i>	Mean of (5) White Respondents	Mean of (5) Non-White Respondents	Mean of all Respondents (11)
A. Individuals are entitled to receive appropriate services identified in the IPP.	4 (Agree)	3.8 (Agree)	4 (Agree)
B. Services are identified in the IPP to approximate the pattern of everyday living available to people without disabilities of the same age.	2.4 (Disagree)	2 (Disagree)	2.4 (Disagree)
C. The consumer of services and supports, and their family, has a leadership role in service design and delivery.	2.8 (Neutral)	2.6 (Neutral)	2.9 (Neutral)
D. The coordination of services by the Regional Center ensures no gaps occur in communication or provision of services and support.	2.2 (Disagree)	2.4 (Disagree)	2.5 (Disagree)
E. The number of individuals served and need for new types of services identified by individuals and families in their IPP affects the array and capacity of services in the community.	2.8 (Neutral)	3.2 (Neutral)	3 (Neutral)
F. The State of California allocates sufficient resources to Regional Centers each year to support caseload growth and to purchase services identified through the IPP process.	2.4 (Disagree)	2.8 (Neutral)	2.6 (Neutral)
G. Regional Centers make changes to services that were once deemed desirable by individuals and families that may no longer be appropriate or the means of service delivery may be outdated.	3 (Neutral)	3.4 (Neutral)	3.2 (Neutral)

Figure 7. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

A consensus among respondents was that IPP planning teams are most familiar with the entitlement to receive appropriate services identified in the IPP and most unfamiliar with the Lanterman Act’s intent that services approximate the pattern of everyday living available to people without disabilities of the same age, shown in Figure 8. This finding is important in the logic model because Regional Center service coordinators could ask IPP planning teams to use assumptions and assess their baseline knowledge of Lanterman Act services. Widaman and Blacher (2003a) identified differences in the IPP planning team’s knowledge but omitted it as a bias variable because no information was available from DDS. Therefore, a new measure of the IPP planning team’s assumptions is valuable to understanding disparities in POS expenditures.



- A. Individuals are entitled to receive appropriate services identified in the IPP.
- B. Services are identified in the IPP to approximate the pattern of everyday living available to people without disabilities of the same age.
- C. The consumer of services and supports and their family, has a leadership role in service design and delivery.
- D. The coordination of services by the Regional Center ensures no gaps occur in communication or provision of services and support.
- E. The number of individuals served and need for new types of services identified by individuals and families in their IPP affects the array and capacity of services in the community.
- F. The State of California allocates sufficient resources to Regional Centers each year to support caseload growth and to purchase services identified through the IPP process.
- G. Regional Centers make changes to services that were once deemed desirable by individuals and families that may no longer be appropriate or the means of service delivery may be outdated.

Figure 8. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

About half of the respondents commented on additional knowledge of the Legislature’s intent for Lanterman Act services that IPP planning teams should demonstrate. Two respondents indicated the need for IPP planning teams to evaluate service outcomes or improve compliance activities:

“DDS (and many others) confuse staff turnover and training with measuring service quality. Reducing staff turnover and providing relevant training could improve quality, but those aren't measuring the quality of the services delivered. Until quality measures for services are developed, it is impossible to collect relevant data.”

To give context to the comments, the Legislature added WIC 4571 – 4572 [Quality Assessments] to the Lanterman Act in 2009, requiring the Department of Developmental Services (2019) to identify an improved, unified quality assessment system. DDS selected the National Core Indicators (NCI) assessment, which takes a national perspective on home- and community-based services to help make state-to-state comparisons and create a benchmark for state service system performance (National Core Indicators, 2024). DDS also added Personal Outcomes to the annual Client Developmental Evaluation Report (CDER) and published highlights in the 18th Edition of the Fact Book (Department of Developmental Services, 2022). In addition, Regional Centers receive annual funding through Community Placement Plan (CPP) and Community Resource Development Plan (CRDP) grants to ensure individuals with I/DD live in the least restrictive setting and to increase the capacity of community-based services (Department of Developmental Services, 2023b). This comment is an important assumption to consider for inclusion in the logic model because while these mechanisms exist to comply with Lanterman Act requirements that the types of services available to families and individuals change based on needs, IPP planning teams are unaware of their existence or intent. This lack of knowledge may then affect components of the logic model such as fluency in navigating services (resource) and may impact an input like Regional Center vendorization requirements for new service providers.

Lastly, three respondents remarked that IPP planning teams need to demonstrate familiarity with person-centered thinking or planning and trauma-informed comprehensive assessments:

“Individual, person-centered planning where services are found to match a person's needs, not a person placed into available slots or services.”

“Regional centers tell us they use person-centered thinking to make decisions and to plan, but this is inaccurate.”

“I found a lack of services based upon comprehensive assessments for trauma-related issues and restorative justice components...”

These comments reflect systems change efforts in the philosophy of HCBS delivery for people with intellectual and developmental disabilities (I/DD). Different eras since the modern deinstitutionalization movement left their mark like tree rings in the promulgation of regulations, and changes to the Lanterman Act tended to lag adoption after their introduction by at least a decade. Wolf Wolfensberger published *Principles of Normalization* in 1972, but references to “normal lives” only appear in the Lanterman Act beginning in the 1990s. The philosophical assumptions that IPP planning teams hold related to person-centered practices, which date back to the 1990s when systems change advocates like John O’Brien, Judith Snow, and Beth Mount introduced new planning team tools, first appears in the Lanterman Act in Section 4685.7 for the Self-Directed Services Program in 2005. In a word search of the Lanterman Developmental Disabilities Services Act and Related Laws (2024b), 28 of 33 mentions of “person-centered” occurred in sections introduced after 2020, largely because of changes to adopt new federal regulation contained with the HCBS Final Rule (Department of Developmental Services, 2024c). If the pattern continues, it will be another decade until social determinants of health (like trauma) appear in the Lanterman Act, as one respondent suggested. The only mention of trauma today is in Section 4503, the right to refuse behavioral modification techniques that cause pain or trauma.

Second Theme: Resources

Family and Individual's Expectations for Lanterman Act Services

The following survey section asked respondents to disagree or agree (using a scale of 1 to 5) with the component relationships between resources identified in the logic model. This section was structured to explore the dynamic relationship between resource components, seeking to understand how the racial disparities in the purchase of service reflect underlying expectations of community participation and access provided by higher expenditure Lanterman Act services. A consumer's total purchase of services does not simply rise incrementally to an optimized service level but is driven by expenditures for service types. Residential-type services are more costly by several multiples than services for children or adults living in the family home and contribute significantly to racial disparities in overall POS. Widaman and Blacher (2003a) pointed out that "one is confronting parent/guardian preferences for services or preferences to forego certain services... Still, these preferences regarding services may be particularly powerful influences on the pattern of services a consumer receives" (pg. 9). For instance, DDS consumer data from FY19-20 shows average expenditures of \$65,000 for 28,869 individuals receiving residential services and \$16,700 for the remaining 296,575 individuals not receiving residential services (Department of Developmental Services, 2022). While DDS did not report consumer ethnicity by residence type, Regional Centers are required to do so. San Andreas Regional Center (2024) reports that of 1,669 adult consumers receiving residential service, 58% (971) are White, yet White adult consumers are 37% (3,099) of the 8,322 adult consumer population receiving case management from SARC. Thus, in absolute dollar amounts, the racial disparity creates a larger total dollar systemic investment in the service types most utilized by White adult consumers, even as compared to less expensive services utilized by more non-White consumers.

In the respective parts of the logic model component relationships, White and non-White respondents agreed that resources increased access to paid and natural caregiving. Caregiving was presented twice because, as the quote attributed to Roman playwright Titus Maccius Plautus goes, “You must spend money to make money,” it is true that, “You must have caregiving to get more caregiving.” The construction reflects the researcher’s observation that poorly resourced caregiving situations will paradoxically worsen significantly (to the point of neglect or death) because the level of care gradually diminishes and becomes more isolated, which further reduces opportunities for attracting new resources. On the other hand, well-resourced caregivers will be actively involved in their communities in ways that attract additional caregiving resources to fulfill greater amounts of need. In part, this is due to a greater need for caregiving resources than there are available, so well-resourced caregiving situations will tend to attract resources, even if the need is objectively greater elsewhere. In this respect, a caregiving situation equilibrium is difficult to maintain and tends to be in an expansionary or contractionary phase.

IPP Planning Team Resources in the Logic Model: The Family and Individual's Expectations for Lanterman Act Services			
<i>Survey Question: Demonstrating the Strength of Relationships between the Resource Components in the Logic Model</i>	Mean of (5) White Respondents	Mean of (5) Non-White Respondents	Mean of all Respondents (11)
Do you agree or disagree that the family and individual's access to paid and natural caregiving will have a positive relationship to the individual and their family's expectations of community participation?	4.2 (Agree)	3.8 (Agree)	4.1 (Agree)
Do you agree or disagree that the individual and their family's expectations of their community participation will have a positive relationship to the amount of time that the individual and their family is willing and able to advocate in the Regional Center service coordination process?	4.2 (Agree)	4.2 (Agree)	4.2 (Agree)
Do you agree or disagree that the amount of time that the individual and their family is willing and able to advocate will have a positive relationship to the fluency with which they navigate the Regional Center service coordination process?	4 (Agree)	4.2 (Agree)	4.1 (Agree)
Do you agree or disagree that the fluency with which individuals and families navigate the Regional Center service coordination process will have a positive relationship to their access to paid and natural caregiving?	4.4 (Agree)	4.4 (Agree)	4.4 (Agree)
Do you agree or disagree that existing Regional Center service provider supports will have a positive relationship to the fluency with which individuals and families navigate the Regional Center service coordination process, the amount of time that the individual and their family is willing and able to advocate, and their access to paid and natural caregiving?	2.6 (Disagree)	3.8 (Agree)	3.4 (Neutral)

Figure 9. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

The most disagreement among respondents was whether existing direct service provider supports would have a positive relationship to all the logic model resource components, including fluency in the Regional Center service coordination process, time to advocate, and access to caregiving. As shown above, in Figure 9, White respondents sharply disagreed that existing service provider relationships play their proposed role enhancing resource components. However, non-White respondents indicated that existing service provider relationships did have a positive relationship with the resource components. Figure 10 shows the response distribution.

Do you agree or disagree that existing Regional Center service provider supports will have a positive relationship to the fluency with which individuals and families navigate the Regional Center service coordination process, the amount of time that the individual and their family is willing and able to advocate, and their access to paid and natural caregiving?

11 responses

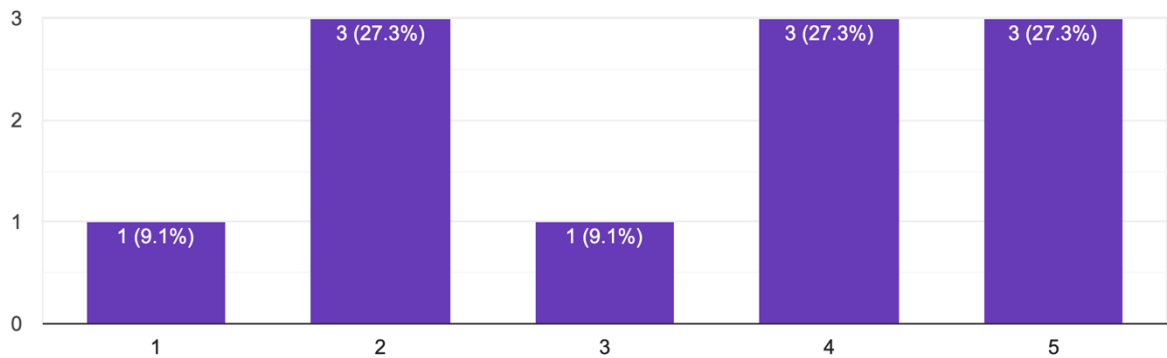


Figure 10. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

In addition to identifying their level of agreement with the statements on the component resource relationships, about half of the respondents provided comments. Respondent indicated in different ways the need for an accessible, equitable, and reliable case management system:

“Fluency, knowledge, time & resources needed to be applied to other systems needed by the person eligible for services and supports (ie Medi-Cal, IHSS, housing, education, accessible transportation, health care, behavioral health services, food security) that are outside of the regional center system and generally outside the knowledge or monitoring/coordination of the regional center service coordinator.”

“I think a family’s advocacy skills and persistence affects the services they get and response from their service coordinator (given SC large caseloads).”

“...high turnover at the case management level results in a fractured, disjointed, and dysfunctional case management system.”

“DDS's 1984 software program can barely process the purchase of services...”

“Actual person-centered philosophy -- believing that participants are capable of having a voice.”

“SCs often act like if a RC client gets a support or service, the SC's personal budget will be impacted negatively (ie they will get in trouble for approving or offering appropriate supports)”

“Education and accessibility are key in the regional centers ability to provide effective services”

Giardino & De Jesus (2024) define case management as a process in which a professional helps a client develop a plan that coordinates the support services needed to optimize their health and psychosocial goals and outcomes. The respondents indicate the integral role of Regional Centers in case management required to provide Lanterman Act services. California Welfare and Institutions Code, Division 4.5 Services for the Developmentally Disabled, Article 2. Regional Center Responsibilities (1977) specifies: service coordinator-to-consumer caseloads ranging from 25 – 62 individuals; the responsibility of Regional Centers to maintain specialized expertise; process billing and payments; standardize information for prospective consumers and families; assessment and intake processes including the Early Intervention Program; development and implementation of the IPP and utilization of generic resources; monitoring, and quality assurance by the Regional Center; requirements for service access and equity; and the cost-effectiveness of services. When the Legislature carved out 21 equal catchment areas in 1969, there were 20 million Californians. Today, the same geographic boundaries contain families and individuals with I/DD varying from 5,000 at Redwood Coast Regional Center to 50,000 consumers at Inland Regional Center (Department of Developmental Services, 2024d). Scaling oversight procedures to organizations of different sizes presents unique challenges to harmonize across California the family and individual expectations for Lanterman Act services.

Third Theme: Inputs

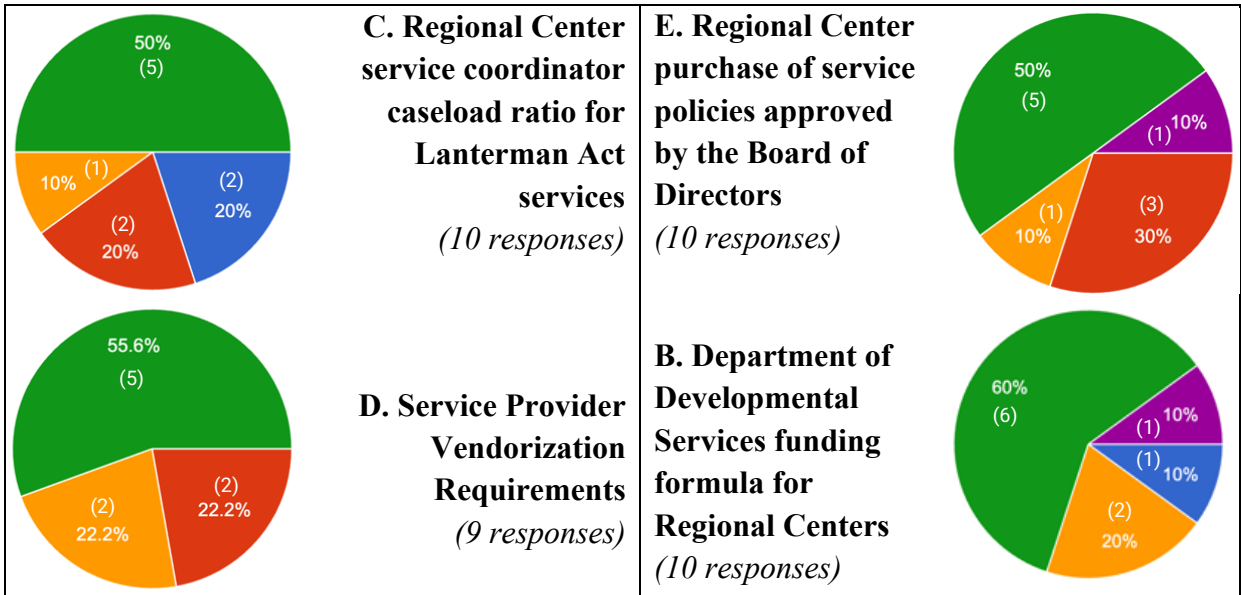
Federal, State, and Regional Center Contexts in the Lanterman Act Services

The last survey section asked respondents to agree or disagree with nine statements describing the IPP planning team's awareness of proposed inputs to the logic model. They were reported to be less aware of Regional Center practices and policies than they were of the roles held by other agencies in providing services. For example, no respondent disagreed that most IPP planning team members know their right to a free and appropriate public education (FAPE). Since the logic model proposed that fluency in navigating Regional Center service coordination is a crucial resource, this section indicates that key process areas may have gaps in knowledge. However, non-White respondents tend to indicate greater agreement with knowledge of generic services, while White respondents had greater knowledge of Regional Center processes. The responses are shown in Figures 11 and 12.

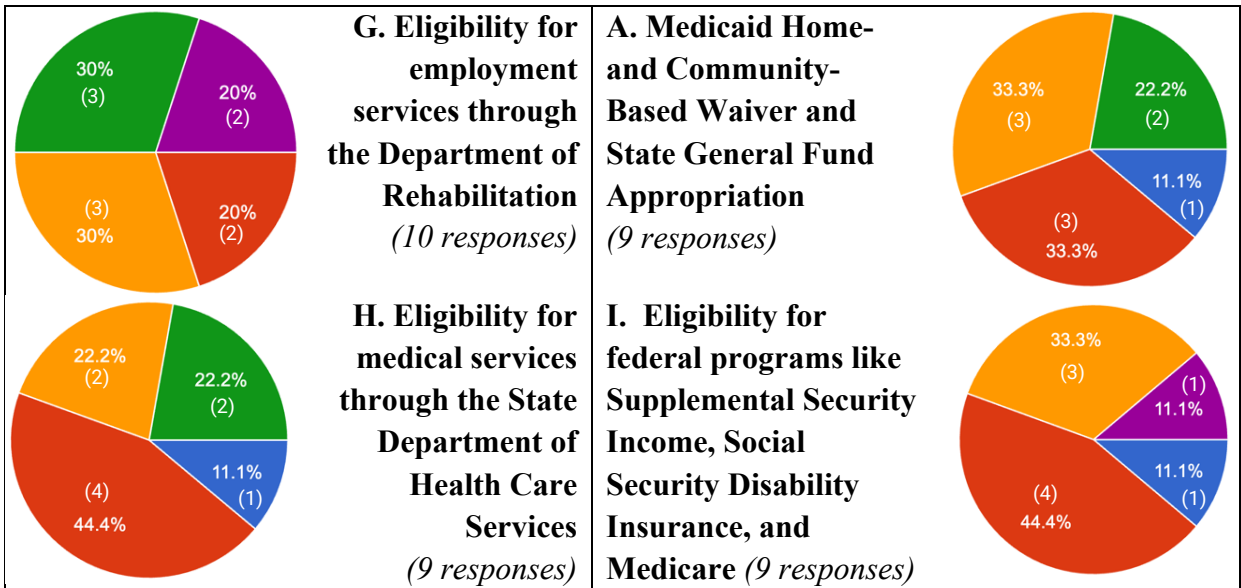
IPP Planning Team Inputs of the Logic Model: Knowledge of Regional Center Service Coordination for Lanterman Act Services			
<i>Survey Question: Please indicate the degree to which you agree or disagree that all parties involved in Regional Center service coordination are aware of each input affecting planning team outcomes:</i>	Mean of (5) White Respondents	Mean of (4) Non-White Respondents	Mean of all Respondents (10)
A. Medicaid Home and Community-Based Waiver (HCBS) and State General Fund Appropriation	2.6 (Neutral)	2 (Disagree)	2.5 (Neutral)
B. Department of Developmental Services funding formula for Regional Centers	2.2 (Disagree)	2 (Disagree)	2.4 (Disagree)
C. Regional Center service coordinator caseload ratio for Lanterman Act services	3 (Neutral)	2.8 (Neutral)	3.1 (Neutral)
D. Service Provider Vendorization Requirements	2.5 (Disagree)	2.5 (Neutral)	2.7 (Neutral)
E. Regional Center purchase of service policies approved by the Board of Directors	2.6 (Neutral)	2.3 (Disagree)	2.6 (Neutral)
F. Eligibility for education services through the State Department of Education (Free and appropriate public education)	3.8 (Agree)	3.8 (Agree)	3.7 (Agree)
G. Eligibility for employment services through the Department of Rehabilitation (Receive support to have a job, Employment)	3 (Neutral)	3.5 (Agree)	3.3 (Neutral)
H. Eligibility for medical services through the State Department of Health Care Services (Medi-Cal)	2.8 (Neutral)	4 (Agree)	3.4 (Neutral)
I. Eligibility for federal programs including Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and Medicare (childhood disability benefits)	2.8 (Neutral)	4 (Agree)	3.4 (Neutral)

Figure 11. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

Please indicate the degree to which you agree or disagree that all parties involved in Regional Center service coordination are aware of each input affecting planning team outcomes:



● Strongly agree
 ● Agree
 ● Neutral
 ● Disagree
 ● Strongly disagree



F. Eligibility for education services through the State Department of Education (Free appropriate public education)
(10 responses)

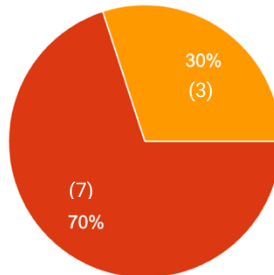


Figure 12. Assumptions, Inputs, and Resources of Service Coordination in the Regional Center system survey data

DISCUSSION

Regional Center Case Management and Health Equity

This survey adds to the literature on health equity and introduces a new framework for case management in Medicaid HCBS, which now mainly focuses on quantitative expenditure data or consumer satisfaction analysis. While important, without understanding whether and to what extent gaps in consumer knowledge exist, such analysis does not provide a full scope of mechanisms or levers to policymakers who are responsible for monitoring and responding to the disparities that arise in Medicaid expenditures. Such was the case in the 2003 Purchase of Service studies, and a decade later, the Legislature and Department of Developmental Services awarded tens of millions of dollars to reduce racial disparities in the purchase of Regional Center services with limited methods of program evaluation. Meanwhile, many racial disparities in expenditures grow unabated as new challenges arise with delivering services to consumers noted as “other ethnicity.” The Lanterman Act requires that Regional Center case management account for community participation barriers in a way that is unique among Medicaid-funded programs, but which is gaining widespread acceptance in the broader understanding of social determinants of health; Neri (2022) found the same SDoH that influence health outcomes also affect the racial gap in POS expenditures for people with I/DD. Few Medicaid HCBS waiver programs fully account for consumers' unmet needs and goals in health, education, employment, relationships, natural, unpaid supports, and a safe home environment because other vulnerable populations lack the entitlement protection that exists for people with developmental disabilities in California. Expectations of community participation and access are significantly impacted by the differing access to resources described in the logic model. The components are visually represented by a well-known illustration of equality, equity, and justice, shown in Figure 13.

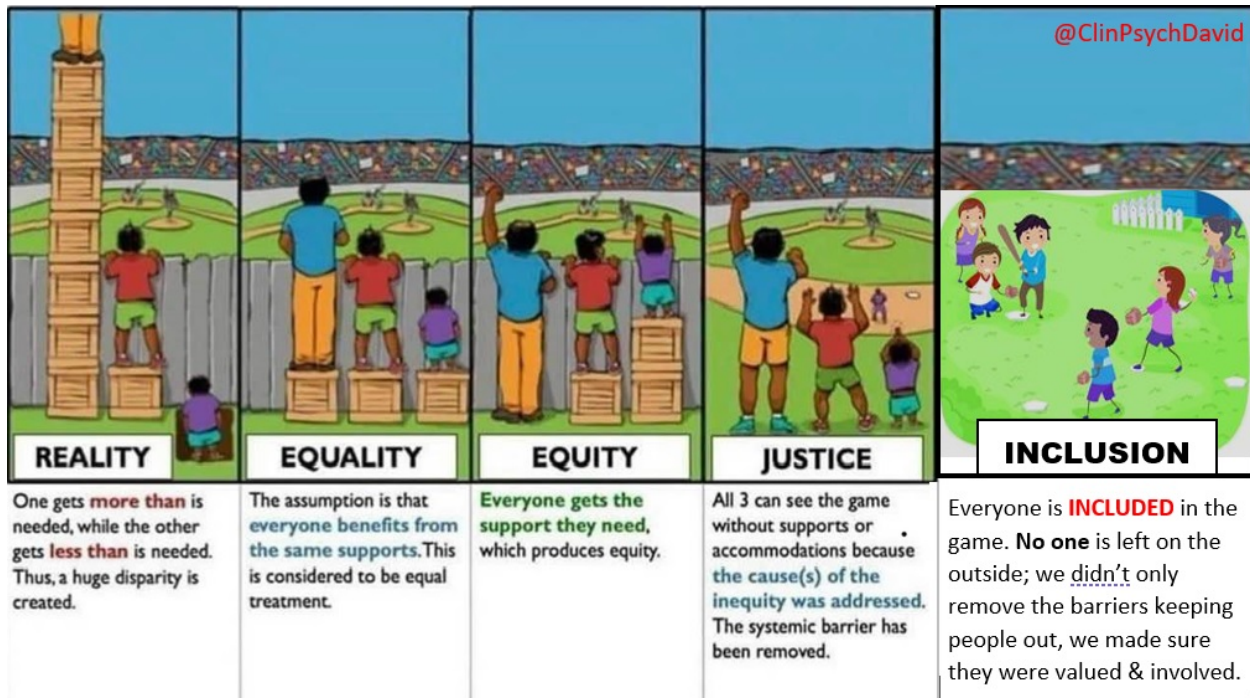


Figure 13. (David Murphy [[@ClinPsychDavid](#)], 2021)

Focusing on the fence analogy depicted as distinct vertical planks, consider them as interlocking social and economic barriers to long-term services and supports for people with and without disabilities and as structural barriers in education, healthcare, and employment that limit Californians from attaining their full potential through community participation. The responses from members of the DDS Service Access and Equity working group suggest that IPP planning team members do not have essential knowledge about home- and community-based services, rendering their baseline experience with Regional Center case management one of frustration from dealing with hidden structural barriers. Given the procedural complexity of navigating Regional Center case management, what is the likelihood that vulnerable populations will navigate to an optimal expenditure of services for employment, education, and basic needs outside of the Regional Center? The problem of equity is, therefore, not inherent only to those with developmental and intellectual disabilities but also to how legislative policy choices for all Californians impact their experience of barriers to community participation.

Applying a Logic Model in Regional Center Case Management

A logic model shows promise for improving the IPP planning team’s knowledge of the Lanterman Act and the appropriateness of home- and community-based services to reduce barriers to community participation. A more in-depth project is needed to determine how this knowledge would then reduce racial disparities in the purchase of services through Regional Center case management. However, the agreement with this logic model can be helpful in framing the recommendations from three significant reports issued by Public Counsel, Disability Rights California, and Disability Voices United since 2022, as shown in Figures 14 and 15. The framework allows policymakers to understand how adopting a specific recommendation may not lead to the desired outcome because components are interrelated and affected by each other.

Report Name / Theme	<i>Recommendations for Logic Model Outcomes</i>	
	Long-Term Services and Supports (Outputs & Outcomes)	Barrier-Free Community and Experience of Belonging (Impacts)
Public Counsel (2022) <i>Examining Racial and Ethnic Inequity Among Children Served Under California’s Developmental Services System: Where Things Currently Stand</i>	1. Repeal the stringent 2009 law that requires families to apply for and appeal denials of services through other agencies before the regional center will consider funding services	/
Disability Rights California (2023) <i>From Navigation to Transformation: Addressing Inequities in California’s Regional Center System Through Community-Led Solutions</i>	2. Interrogating the racially disproportionate impact of how “gatekeeping” laws and purchase of service guidelines are implemented	1. Use the Governor’s call to embed equity throughout government to not just consider equity in DD program design and implementation, but to center it. 2. Reimagine what it means to partner with the community, and redistribute power to those most impacted.
Disability Voices United (2022) <i>A Matter of Race and Place: Racial and Geographic Disparities Within California’s Regional Centers Serving Adults with Developmental Disabilities</i>	3. Require DDS to provide more oversight of regional centers with higher racial and geographic disparities. 4. Monitor whether underserved communities are actually accessing recently restored and new services, which were put in place to reduce disparities. 5. Consider disparities in the context of the future of the developmental disabilities system	3. In advance of the implementation of the federal Settings Rule in 2023, urge regional centers to encourage the use of more integrated, empowering, and less expensive housing options

Figure 14. Applying the logic model framework to policy recommendations for Lanterman Act services

Report Name / Theme	Recommendations for Logic Model Processes			
	Legislative Action (Assumptions)	Expectations of Community Participation (Resources)	Generic Services and Regional Centers (Inputs)	Case Management (Activities)
Public Counsel (2022) <i>Examining Racial and Ethnic Inequity Among Children Served Under California's Developmental Services System: Where Things Currently Stand</i>	1. Appoint a legislative taskforce to explore replacing DDS' current funding formula with a new model that targets underfunded and unserved populations within each regional center. 2. Amend the law to require additional data reporting that will enable the public to have access to the same data that DDS is using to assess for improvement under its disparity measures.	1. Convene a joint legislative oversight hearing on regional center funding disparities to thoroughly examine the issue. 2. Repeal restrictive parent/caregiver participation requirements for behavioral health treatment services enacted in 2009 which now conflict with Medicaid law	1. Restore respite and other critical family support services to Early Start families that were cut during the 2009 budget crisis because they were "nonrequired." 2. Require regional centers to comply with the data reporting obligations and other public disclosures requirements by tying compliance to their performance contracts with DDS.	1. Require DDS to investigate and remedy defects in the regional centers' collection of demographic information and to ensure that a uniform system for gathering demographic information is established and implemented statewide going forward. 2. Require regional centers, as part of their contractual obligations with DDS, to review all cases where consumers are receiving no purchase of services, to classify the reasons for why this is occurring, and to report these findings to the public.
Disability Rights California (2023) <i>From Navigation to Transformation: Addressing Inequities in California's Regional Center System Through Community-Led Solutions</i>	3. Making regional centers subject to the California Public Records Act.	/	3. Performance-based funding holds tremendous potential for driving regional centers to take greater responsibility for advancing equity.	3. Reexamining the broad amount of discretion regional centers have to interpret and implement the Lanterman Act and striking a better balance between state and local control.
Disability Voices United (2022) <i>A Matter of Race and Place: Racial and Geographic Disparities Within California's Regional Centers Serving Adults with Developmental Disabilities</i>	4. Require more data reporting and increased public access to data to improve transparency	3. Increase DDS oversight and accountability over regional center interactions with underserved individuals and families to ensure they are culturally humble.	4. Require DDS to provide strategic direction to guide the use of service access and equity grants.	4. Ensure whole-person case management by regional centers. 5. Make the statewide system more consistent across regional centers

Figure 15. Applying the logic model framework to policy recommendations for Lanterman Act services cont.

In addition, the logic model structure helps frame Neri's (2022) analysis of 2016 - 2020 Service Access and Equity grant proposals and reports, which included 59 proposals and 17 reports available from DDS (Neri excluded 77 funded projects that were less than two years in length).

“The discernment of eight themes [in the grant reports]: trusting relationships; experiencing barriers; engagement with the system; increase; collaboration and partnerships; outreach and advocacy; training, education, and information; and empowerment... and six main themes [in the grant proposals]: stakeholder engagement and collaboration; training, education, and workshops; outreach and advocacy; addressing barriers; underutilization of services; and family support/support services and empowerment” (pg. 111-112).

This finding can also be formulated as "**If we have** *trusting relationships, training, education, and information*; **we can** *collaborate, build partnerships, and increase engagement with the system*; **which will result in** *more family [and individuals] support services while experiencing fewer barriers and more stakeholder empowerment, outreach and advocacy.*” The survey with working group members goes into great depth to explore the first statement to unveil some of the essential assumptions, inputs, and resources. However, it shows the complexity that underlies the simplified but valuable presentation of the relationship between Lanterman Act services and the desired impact. Further research is needed to determine how existing service provider relationships contribute to case management and how to disseminate knowledge of the funding mechanisms for Regional Centers. It is also relevant to investigate why most IPP planning teams may not know that Lanterman Act services are intended to approximate the pattern of everyday living available to people without disabilities of the same age and that coordination of services by the Regional Center is intended to ensure no gaps occur in services and supports.

LIMITATIONS

This survey was limited to the 30 members of the DDS Service Access and Equity working group, of which only 11 responded, not all of whom answered every question. The researcher made every effort to contact each member individually but did not receive any response from approximately half of the members after the third attempt. The researcher was unable to obtain input from Regional Center employees, who are essential members of IPP planning teams. It is vital to find more effective ways of engaging Regional Center employees in research about case management. As a result of these factors, the sample size needs to be increased for statistically significant analysis and generalizable findings.

Another limitation is the survey was shortened to grow the total number of respondents, so the activities, outputs, and outcomes of the logic model were not evaluated. Due to time and resource constraints, the researcher focused on assumptions, resources, and inputs to present the concept of developing a complete logic model for case management in future research.

CONCLUSION

Implications for California's Regional Center System

The provision of Lanterman Act services through the Regional Center system has reached a pivotal moment for Californians who receive or are seeking case management services. As one respondent shared, “The whole system may be on the verge of collapse, but it does seem to limp along every year (until it won't).” One may ask if the *L.A. Times* article by Rebecca Ellis (2024) “*Adults with autism faced ‘torture’ at this L.A. group home*” investigating the care of adults with profound autism at a community care facility is a single broken link in the chain of long-term services and supports. Or does it represent an extreme but statistical inevitability of Californians

who rely on the fragmented, fraying, worn, cracking, and potholed infrastructure of Medicaid-funded community-based services? The Lanterman Act envisions a bridge benefiting (directly or indirectly) all Californians, riveted by the strength of thousands of interdependent community-based service providers that uplift each family and individual with I/DD over societal barriers because of their self-evident potential to lead productive lives. The Lanterman Act is a promise made to all Californians to elevate the most vulnerable persons in a human moral and fiscal engineering achievement of liberalism. But to most Californians, the critical infrastructure's invisibility today blocks from public view the growing crowds of families throttled at the start of the bridge's approach to rise over societal barriers. It is a policy failure shared by multiple state departments responsible for providing services and for which the common denominator is California's Executive Branch. So, families and individuals with I/DD wait today for their turn to cross over in and contribute to a community where they belong. Meanwhile, they shield loved ones from asking about their peers who didn't make it and were swept away by an unyielding current of wider social, political, and economic inequity. The Regional Center system, as the operators of the Lanterman Act bridge, cannot be held responsible for flaws in its structural design but they can be held accountable for obscuring the tremendous toll of Californian's squandered potential caused by a lack of urgency and reimagination since 1969. In the same *L.A. Times* article, two of the three working mothers, Linda Carter and Laura Topete, left their respective jobs at a military base and as a nurse to remove their sons from abusive community-based services and made a one-way trip back across the Lanterman Act bridge. As staff writer Rebecca Ellis (2024) concludes in her article, Laura and Gregorio Topete are still seeking safe passage across the bridge and belonging in the community to no avail: "For months, she's been looking for another home. But she keeps being told there's nothing available."

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