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Law and Policy Project (SIDDLAPP)

The Scope of the Lanterman Act Entitlement

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2019

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Table of Contents

I. Project Motivation and Overview

In 1969, California became the first state in the United States to grant individuals with intellectual and developmental disabilities (I/DD) the right to the services and supports they need to live more independent and normal lives. The Lanterman Act, now codified in the California Welfare and Institutions Code, declared that "[a]n array of services and supports should be established which is sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, and at each stage of life, and to support their integration into the mainstream life of the community."[1] To this day, California is the only state in which the right of individuals with I/DD to be supported in the least restrictive environment is construed as a civil right and an individual entitlement, not merely a right to "take a number and wait in line" until sufficient state resources become available.[2]

To effectuate the goals of the Lanterman Act, California divides responsibility between the Department of Developmental Services (DDS), a state agency, and a network of twenty-one private, nonprofit corporations called "regional centers" that are funded by DDS through annual contracts. Each regional center (RC) serves a different area of the state, providing services and supports to individuals with developmental disabilities in their local communities. DDS is responsible for monitoring the RCs and ensuring that they implement the Lanterman Act.

In the early years after the Act's passage, DDS (and in turn, the regional centers) were largely funded through the state's General Fund. Since the mid-1980s, however, a sizable portion of funding has been provided by the federal government. The Centers for Medicare and Medicaid Services (CMS) fund a significant portion of the residential, day, and family supports and services that regional center consumers receive.

As of this writing, California is not facing an imminent fiscal crisis and funding is relatively abundant. Given its relative prosperity at this historical juncture, the state is ideally positioned to shore up the service delivery system in a thoroughgoing fashion. Confronting each of the challenges that is threatening the system's long-term viability will help safeguard the Lanterman Act's beneficiaries from the effects of the next fiscal crisis if and when one materializes.

This report is part of a series issued by the Stanford Intellectual and Developmental Disabilities Law and Policy Project (SIDDLAPP), at the request of Disability Rights California (DRC) and the State Council on Developmental Disabilities (SCDD), to explore steps that the state might take to protect the Lanterman Act entitlement. The research was conducted from September, 2017 through June, 2019, by a team of researchers—including Stanford law students, research

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[1] CAL. WELF. & INST. CODE § 4501 (2017).

[2] *See* GRETCHEN ENGQUIST ET. AL., CTR. HEALTH CARE STRATEGIES, SYSTEMS OF CARE FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: A SURVEY OF STATES (Sept. 2012) (providing survey results of different states' systems of care for individuals with I/DD, such as states with population and/or income gaps and those states administering care via the HCBS Waiver) (last visited Feb. 14, 2019), http://www.chcs.org/media/IDD_State_Priorities_and_Barriers_Snapshot_082812.pdf.

fellows, and undergraduates—under the direction of Alison Morantz, Director of SIDDLAPP and the James and Nancy Kelso Professor of Law.

Research team members used several complementary approaches to investigate each issue considered. First, they analyzed primary and secondary materials produced by each branch of government at the state and federal levels, such as statutes, regulations, administrative hearing decisions, responses to Public Records Act requests, and judicial opinions. Second, they examined earlier reports on related issues released by nonprofit organizations, community task forces, the California State Controller's Office, The California State Auditor, legislative analysts, and consultants. Third, the team arranged in-person meetings with a variety of individuals with pertinent personal and/or professional expertise, including consumers of regional center services and their families, service providers, community activists, legislative staffers, and RC directors. Finally, the team sought to meet with various organizational entities that play leading roles in the development and analysis of state policy in the I/DD arena: DRC, SCDD, DDS, the Department of Health Care Services (DHCS), the Legislative Analyst's Office (LAO), Public Counsel, and the Association of Regional Center Agencies (ARCA). All of these individuals and organizations, with the exception of ARCA, accepted the team's invitation to discuss the issues examined in these reports.

The project team wishes to gratefully acknowledge the input and assistance of the numerous individuals and organizations who provided the information, insights, and knowledge on which these reports are based.

The purpose of this report, The Scope of the Lanterman Act Entitlement, is to analyze existing caselaw, administrative opinions, and other legal sources to develop a working definition of the scope of the Lanterman Act entitlement. The report begins by defining two overarching principles that that the Act encompasses, then proposes a doctrinal framework for resolving tensions between the two principles when they come into conflict.

SIDDLAPP encourages dissemination of its publications. Additional reports in this series are available for download at https://law.stanford.edu/siddlapp/.

II. Executive Summary

California's system for individuals with intellectual or developmental disabilities (I/DD) embodies a basic tension. On one hand, the key institutional actors must operate within a budget that is passed at the beginning of each fiscal year. On the other hand, the Lanterman Act—the landmark state law that created the I/DD system in its current form—is an open-ended entitlement. It requires regional centers (RCs) to provide each consumer with the services and supports (s)he requires to achieve the goals enumerated in his/her individual program plan (IPP). The core challenge of the I/DD system, then, is to fund a system of open-ended entitlements on a fixed budget.

The Lanterman Act itself provides little explicit direction on what principles limit the scope of the entitlement it provides. Nor has state case law provided much additional guidance. Most day-to-day decisions regarding the meaning of the Act are made by administrative hearing officers (HOs) from the Office of Administrative Hearings (OAH) operated by the state's Department of General Services, with little judicial input or oversight. For this reason, we look beyond those sources to define the contours of the Lanterman Act entitlement.

Drawing on state and federal law, we first argue that the Lanterman entitlement consists of two overarching principles. The first principle, which we call "needs-based individualization," embodies five subsidiary ideas: person-centered planning, community integration (and least restrictive environment), home preservation, consumer choice, and service continuity. The second principle, which we label "cost effectiveness," encompasses three concepts: demonstrable efficacy, budgetary prudence, and exhaustion of generic resources.

Building on the patterns we observe in the scant case law and publicly available OAH decisions, we propose a doctrinal framework that we believe accurately reflects the way in which most "hard" cases—i.e., those in which the principles of needs-based individualization and cost effectiveness conflict—have been resolved. We find that adjudicators (HOs and state court judges) begin with the presumption that each consumer is entitled to the services and supports that will enable him or her to meet the needs specified in the IPP. If a requested service or support is not cost effective, an adjudicator may still require its provision if there is no express statutory directive to the contrary, and if the consumer can demonstrate that it would otherwise be impossible to effectuate his/her right to needs-based individualization. If RCs' budgetary resources are insufficient to meet the needs of all consumers, DDS is obliged, at the RCs' request, to seek additional funding from the legislature.

Although we believe this doctrinal framework is well suited to the service delivery system that has been in place for the first five decades of the regional center system, California's new Self-Determination program will present new challenges and opportunities. The resolution of disputes in the Self-Determination context will likely require modifications to this framework that we hope to address in future research.

III. Introduction

California's I/DD system embodies a basic tension.[3] On one hand, the key institutional actors must operate within a budget that is enacted at the beginning of each fiscal year by the legislature and the governor.[4] On the other hand, the Lanterman Act—the landmark state law that created the I/DD system in its current form—is an open-ended entitlement. It obliges RCs to provide consumers with whatever services and supports are necessary to enable them to realize the goals enumerated in their IPPs. The core challenge of the I/DD system, then, is to fund a system of open-ended entitlements on a budget that is fixed at the start of each fiscal year.

The Lanterman Act itself provides little explicit guidance on what principles limit the scope of the entitlement it provides. The Act declares that "[t]he determination of which services and supports are necessary for each consumer . . . shall be made on the basis of the needs and preferences of the consumer . . . and shall include consideration of a range of service options proposed by individual program plan participants, the effectiveness of each option in meeting the goals stated in the individual program plan, and the cost-effectiveness of each option."[5] Yet it does not specify which of these factors—consumers' needs and preferences, the full range of available alternatives, each option's efficacy in meeting IPP goals, and each option's cost-effectiveness—should be decisive in cases where they are in tension. Nor has case law provided much additional guidance on these questions. Most day-to-day decisions regarding the meaning of the Act have been made by HOs rather than state court judges.

Our goal in this report is to flesh out the meaning of the Lanterman Act entitlement by not only examining the (scarce) case law that bears directly on its interpretation, but also referencing

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[3] CITYGATE ASSOCIATES, CORE STAFFING STUDY FINAL REPORT iii (1999) (identifying a "'Catch 22'" in the Lanterman Act's basic framework, whereby RCs were required to fulfill open-ended IPPs within the closed-end provision of appropriated funds); *see also* J.K. v. Office of Admin. Hearings, No. E034431, 2004 Cal. App. Unpub. LEXIS 10860, at *1 (Cal. Ct. App. Nov. 30, 2004) (noting "In a world of finite resources . . . translating any particular developmentally disabled person's needs and choices into a list of services to be provided is a messy job"); BOARD OF DIRECTORS, FRANK D. LANTERMAN REG'L CTR., TOWARD A SUSTAINABLE ENTITLEMENT FOR THE DEVELOPMENTAL SERVICES SYSTEM: A REGIONAL CENTER PERSPECTIVE 6 (2003), https://www.dds.ca.gov/Publications/HistoricPub/2003_SustainableEntitlementforDDSvcSys_RCPerspective.pdf (last visited Jan. 16, 2019) (identifying the fundamental tension of the Act as "how to provide all the services and supports mandated by an individually and broadly defined entitlement to all eligible consumers throughout the term of the contract and not exceed a set appropriation").

[4] *See*, PETER VOGEL ET. AL., STANFORD INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LAW AND POLICY PROJECT, A FISCAL PRIMER ON CALIFORNIA'S REGIONAL CENTER SYSTEM § IV.A. (2019) [hereinafter LANTERMAN PRIMER].

[5] CAL. WELF. & INST. CODE § 4512(b) (2017); *see also id.* § 4620.3 (2017) (noting "the department . . . shall develop best practices for the administrative management of regional centers"); *id.* § 4640.6 (2017) (noting "Contracts between the department and regional center shall . . . ensure maximum cost–effectiveness and to ensure that the service needs of consumers and families are met").

other sources that, although they are not binding on California courts, reasonably could be seen as persuasive.

First and foremost, we draw upon a relatively small number of opinions by Hearing Officers (HOs) employed by California's Office of Administrative Hearings (OAH). The Lanterman Act contains an administrative exhaustion requirement: disputes must first be heard by a HO before they may be appealed in state court.[6] Because very few OAH decisions are ever appealed, HOs generally have the final say in resolving disputes between consumers and regional centers. Although DDS is statutorily required to make all (redacted) fair hearing decisions available to the public, only a small percentage (about 8%) of the thousands of decisions issued by HOs are, in fact, readily available.[7] While we cannot be certain how representative these cases are of the entire corpus, we nevertheless draw upon their holdings and reasoning, as they shed some light on how the entitlement is understood by those adjudicators most often tasked with construing it.

Second, we occasionally reference federal statutes and case law that pertain to the rights of individuals with disabilities, such as the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and the landmark 1999 Supreme Court case *Olmstead v. L.C. ex rel Zimring*. Even though these doctrines apply in different contexts than those considered here and do not pertain directly to the construction of the Lanterman Act, some of their animating principles closely resemble those enshrined in California law. Exploring these parallels is often instructive.

Finally, we refer occasionally to the principles codified in the United Nations Convention on the Rights of Persons with Disabilities (CPRD). Here again, our goal is to contextualize and deepen our understanding of the Lanterman Act by comparing its core tenets to those embodied in other highly-regarded legal sources that address similar legal questions.

The analysis that follows consists of two parts. First, we argue that the text of the Lanterman Act and the way in which courts and HOs have interpreted it give rise to two general principles that we call "needs-based individualization" and "cost effectiveness." To probe the definitional contours of each principle, we enumerate its key nuances and summarize relevant (or arguably persuasive) legal sources that affect its interpretation. Second, drawing on the patterns we

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[6] *See* CAL. WELF. & INST. CODE § 4706(a); Gulbransen v. Far N. Reg'l Ctr., No. CIV S–11–1231 JAM DAD PS, 2011 U.S. Dist. WL 2462994, at *3 (E.D. Cal. June 17, 2011).

[7] *See* CAL. WELF. & INST. CODE § 4712.5(d) (noting "The department shall collect and maintain, or cause to be collected and maintained, redacted copies of all administrative hearing decisions issued under this division. Hearing decisions shall be categorized by the type of service or support that was the subject of the hearing and by the year of issuance. The department shall make copies of the decisions available to the public upon request . . . .") As discussed in a separate report, however, less than 8% of all OAH decisions are available online, *see also* CARLY HITE ET. AL., STANFORD INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LAW AND POLICY PROJECT, TRANSPARENCY AND ACCOUNTABILITY IN CALIFORNIA'S REGIONAL CENTER SYSTEM § IV.C.(1). (2019) (description of the small percentage of OAH opinions that are published online) [hereinafter LANTERMAN TRANSPARENCY & ACCOUNTABILITY REPORT].

observe in case law and publicly available OAH decisions, we propose a simple framework that we believe accurately reflects the way that “hard” cases—i.e., those in which the principles of needs-based individualization and cost effectiveness are in tension—have been resolved by most adjudicators.

We note, however, that our framework applies best to the traditional service delivery system that has been in place for the first five decades of the regional center system’s existence. The framework that will best facilitate the resolution of disputes under the (optional) Self-Determination program, which as of this writing is just entering a three-year phase-in period, awaits further doctrinal elaboration.

IV. The Principle of Needs-Based Individualization

The California Supreme Court held in 1985 that the Lanterman Act affords each Californian with I/DD the right to receive "on an individual basis [and] as an entitlement, services that enable him to live a more independent and productive life in the community."[8] We use "needs-based individualization" as an overarching term to capture the process whereby the scope of this entitlement is determined in individual cases. *Individualization* encapsulates the idea that the bundle of services and supports provided to each consumer must be tailored to his or her unique capabilities, goals, and preferences; the *needs-based* qualifier captures the notion that the needs and goals enumerated in the individual's IPP are the touchstone of the inquiry regarding which services and supports should be provided. *Needs-based individualization* can thus be understood as a process through which a customized bundle of services and supports is designed to meet each person's specific needs and preferences, as opposed to a one-size-fits-all approach in which each person receives an identical bundle or must select from a limited menu of options.

The concept of needs-based individualization is not unique to the Lanterman Act; three federal statutes mandate a similar approach to serving individuals with I/DD. For example, the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) declares: "[I]ndividuals with developmental disabilities and their families have competencies, capabilities, and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individuals."[9] Similarly under the ADA, the determination of a "reasonable accommodation" for a qualified individual with a disability necessitates "an individualized inquiry. . . to determine whether a specific modification for a particular person's disability would be reasonable under the circumstances as well as necessary for that person."[10] The structure of the IDEA is also closely analogous. The Individual Education Program (IEP), mandated under the IDEA, is central to the determination of which services and supports are needed to effectuate each student's entitlement

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[8] Ass'n for Retarded Citizens v. Dep't Developmental Servs., 38 Cal.3d 384, 392 (1985) [hereinafter *ARC v. DDS*].

[9] Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402 114 Stat. 1677 § 101(c)(2) (codified at 42 U.S.C. § 15001 (2019)).

[10] PGA Tour, Inc. v. Martin, 532 U.S. 661, 688 (2001) (holding that the Professional Golf Association violated the ADA by not allowing a professional golfer with a physical disability to use a golf cart during competition because the use of a cart was a reasonable modification that did not fundamentally alter the nature of the competition); *see also* U.S. DEP'T HOUS. URBAN DEV. & U.S. DEP'T JUSTICE, STATE AND LOCAL LAND USE LAWS AND PRACTICES AND THE APPLICATION OF THE FAIR HOUSING ACT 9 (Nov. 10, 2016) [hereinafter STATE AND LOCAL LAND USE LAWS], https://www.justice.gov/opa/file/912366/download (last visited Jan. 16, 2019) (noting "What constitutes a reasonable accommodation is a case-by-case determination based on an individualized assessment").

to a free and appropriate public education[11] in the least restrictive environment (LRE) amenable to his/her needs.[12] The IEP Team, which consists of the child, his/her parents, teachers, and school officials, convenes annually to create an IEP that "meet[s] the child's needs that result from the child's disability," including a "statement of any individual appropriate accommodations."[13] A recent Supreme Court case, *Endrew F. v. Douglas County School District*, underscores the centrality of needs-based individualization to the IEP process. The Court held that, because "[a] focus on the particular child [is] at the core of the IDEA," and because "[t]he instruction offered [must] be '*specially* designed' to meet a child's '*unique* needs' through an *individualized* education program,'" the IEP is "not a form document," but instead [is to be] "constructed only after careful consideration of the child's present levels of achievement, disability, and potential for growth."[14]

The principle of needs-based individualization takes on particular form and meaning, however, when understood in the specific context of the Lanterman Act. To explore in a more nuanced fashion how the principle applies to the RC system in California, we examine its relationship to five subsidiary concepts: (1) person-centered planning; (2) community integration/least restrictive environment; (3) home preservation; (4) consumer choice; and (5) service continuity. In the subsections that follow, we discuss each concept's application to the Lanterman Act and note its similarities with other areas of federal and international law.

A. Person-Centered Planning

In its earliest formulation, the Lanterman Act required treatment and services to be assessed through a medically-oriented patient record review process.[15] Under this system, RC physicians and nurses worked in consultation with counselors to develop treatment plans based largely on consumers' documented medical needs.[16] Consumers and their families played only a limited role in deciding how, when and by whom their needs would be met.

In the 1970s, however, the medical model began to give way to a more expansive and less paternalistic model that gave consumers an active role in defining and shaping their own lives. The first important change came in 1976, when the Legislature required the use of the Individual

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[11] 20 U.S.C. §1400(d)(1)(A) (2018); *see also* 20 U.S.C. § 1401(9) (2018).

[12] 20 U.S.C. § 1412(a)(5)(A) (2018).

[13] 20 U.S.C. §§ 1414(d)(1)(A)(i)(II)(aa), (d)(1)(A)(i)(VI)(aa) (2018).

[14] Endrew F. v. Douglas Cty. Sch. Dist., 137 S. Ct. 988, 999 (2017) (emphasis added).

[15] BUREAU MENTAL RETARDATION SERVS., CAL. DEP'T PUB. HEALTH, REGIONAL CENTERS FOR THE MENTALLY RETARDED 4-5 (June 1969) [hereinafter REGIONAL CENTERS 1969], https://www.dds.ca.gov/Publications/HistoricPub/1969_RCsfortheMR_First2Yrs.pdf (last visited Jan. 16, 2019).

[16] *Id.*

Planning Process (IPP) to create each consumer's program of services and supports. [17] Drafting the IPP requires the consumer, his/her family, and his/her case manager to collaboratively establish the consumer's life goals.[18] The IPP team then designs a flexible program of "individually tailored" services and supports to enable the consumer to pursue these goals in the LRE.[19]

In 1991, the Legislature further specified that the goals enumerated in the IPP should be "centered on the individual and the family of the individual with developmental disabilities and take[] into account the needs and preferences of the individual . . . to ensure that the provision of services . . . reflect[s] the preferences and choices of the consumer."[20]

Elaborating on the importance of person-centered planning, DDS's IPP Resource Manual explains that the IPP team should work to determine the consumer's "preferred future," with reference to his or her "life goals, capabilities and strengths, preferences, barriers and concerns, or problems."[21] The Resource Manual takes pains to distinguish person-centered planning from the medical model that it replaced, noting that "diagnosing the consumer and listing the deficits and needs that led to that diagnosis, and prescription of activities intended to remedy the condition described by the diagnosis, do *not* fill the requirement for providing a planning process that is centered on the person and family."[22]

During the Obama Administration, federal regulations similarly encouraged person-centered planning and urged its widespread adoption. The 2014 Final Settings Rule required that every HCBS Waiver recipient be provided with "necessary information and support to ensure that [(s)he] directs the [IPP] process to the maximum extent possible."[23] According to the Centers for Medicare and Medicaid Services (CMS), the goal of this process is to develop "person-centered service plans" that "reflect the services and supports that are important for the individual to meet

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[17] *See* CAL. WELF. & INST. CODE § 4646 (2017).

[18] *See* CAL. WELF. & INST. CODE §§ 4646.5(a)(2), (5) (2017).

[19] CAL. WELF. & INST. CODE § 4648(a)(2) (2018) (noting that least-restrictive environment ("LRE") refers to a concept found in both the Lanterman Act and the Americans with Disabilities Act ("ADA") that disabled persons receive treatment in the community whenever possible); *see also* DISABILITY RIGHTS CAL., *How to Stay Out Of an Institution, in* RIGHTS UNDER THE LANTERMAN ACT 9–2 (2013), https://www.disabilityrightsca.org/system/files/file-attachments/506301Ch09.pdf (last visited Jan. 16, 2019) (noting the antithesis of the LRE mandate is the former practice of providing services to persons with DD in segregated and isolated institutions).

[20] 1992 Cal. Legis. Serv. Ch. 1011 § 10.5 (S.B. 1383) (codified at CAL. WELF. & INST. CODE § 4646(a) (2019)).

[21] SERVS. & SUPPORTS SECTION, CAL. DEP'T DEVELOPMENTAL SERVS., PERSON-CENTERED PLANNING: BUILDING PARTNERSHIPS AND SUPPORTING CHOICES 1 (July 1, 2001), https://www.dds.ca.gov/Publications/docs/Person_Ctrd_Planning.pdf (last visited Jan. 16, 2019).

[22] *Id.* (emphasis added).

[23] 42 C.F.R. § 441.301(c)(1)(ii) (2018); *see also* CTRS. MEDICARE & MEDICAID SERVS., U.S. DEP'T HEALTH HUMAN SERVS., FACT SHEET: SUMMARY OF KEY PROVISIONS OF THE 1915(C) HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVERS FINAL RULE 2 (Jan. 10, 2014) [hereinafter FACT SHEET], https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf (last visited Jan. 16, 2019).

the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports."[24]

Two additional nuances, although not explicitly referenced in the Lanterman Act, seem consistent with the ideals articulated in the related statutory and regulatory materials we reviewed.

First, enabling consumers (and their families) to define their own needs, preferences and choices arguably should vest the consumer with the right to request an independent evaluation by an individual who is not employed by the RC. Under the IDEA, school districts are required to consider the results of an Independent Educational Evaluation (IEE), a report prepared "by a qualified examiner who is not employed by the public agency responsible for the education of the child in question,"[25] in determining which educational services to provide to a child.[26] Furthermore, if a parent disagrees with a school district's evaluation and requests that an IEE be conducted at public expense, the school district must either pay for the IEE or timely request a due process hearing to challenge its necessity.[27] Although the right to submit an independent evaluation for consideration in drafting an IPP is not referenced in the Lanterman Act, the rationale for authorizing it is arguably just as strong for RC consumers as it is for parents of school-aged children. In a separate report, we consider whether the right to an IEE might be used to further the goals of the Lanterman Act, so the IPP process is truly "individualized and provides a check on the judgments being made by [RC] officials" regarding the consumer's preferred life plan.[28]

Another concept not referenced in the Legislature's discussion of person-centered planning that nonetheless aids in its interpretation is Supported Decision Making (SDM), which "allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices."[29] As one prominent advocacy organization explains:

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[24] 42 C.F.R. § 441.301(c)(2) (2018).

[25] 34 C.F.R. §§ 300.502(a)(1), (a)(3)(i) (2018).

[26] *Id.* § 300.502(c) (noting "If the parent obtains an independent educational evaluation at private expense, the results…*must* be considered by the public agency in any decision made with respect to the provision of a [free appropriate public education] to the child") (emphasis added).

[27] *Id*. § 300.502(b)(2); *See also* Pajaro Valley United Sch. Dist. v. J.S., No. C 06-0380 PVT, 2006 U.S. Dist. WL 3734289 (N.D. Cal. Dec. 15, 2006) (holding that school district's failure to request a due process hearing in a timely manner can result in waiver of right to challenge parents' for an IEE).

[28] Cmty. Consol. Sch. Dist. No. 180, 27 IDELR 1004, 1006 (Ill. Feb. 18, 1998) *in* 27 INDIVIDUALS WITH DISABILITIES EDUCATION LAW REPORT 1004, 1006 (Ill. 1998); *see* LANTERMAN TRANSPARENCY & ACCOUNTABILITY REPORT, *supra* note 7, § VI.B.(4). (discussing how the right to an IEE could help protect the rights of Lanterman Act consumers).

[29] UC DAVIS MIND INST. CTR. EXCELLENCE DEVELOPMENTAL DISABILITIES, SUPPORTED DECISION-MAKING: FREQUENTLY ASKED QUESTIONS 1, https://www.ucdmc.ucdavis.edu/mindinstitute/centers/cedd/pdf/faq_about_supported_decision_making_ACLU.pdf (last visited Jan. 16, 2019) (responding to the question, "What is supported decision-making?").

> A person using SDM selects trusted advisors, such as friends, family members, or professionals, to serve as supporters. The supporters agree to help the person with a disability understand, consider and communicate decisions, giving the person with a disability the tools to make her own, informed, decisions.[30]

Although the SDM model is typically discussed as an alternative to conservatorship (guardianship) for adults with I/DD,[31] its underlying principles are more broadly applicable, and closely resemble those that animate person-centered planning. In fact, researchers at the University of California at Davis have described person-center planning as "a great example of a type of supported decision-making," in that "[f]or many people, the person-centered planning process will be one of the tools they use to support their decisions."[32]

In short, person-centered planning can be conceptualized as the process whereby needs-based individualization is put into practice with the consumer in the driver's seat. Person-centered planning requires that to the greatest extent possible, the *individual* be empowered to define his/her own needs and communicate his/her own life goals and preferences. This aspect of needs-based individualization differentiates it sharply from the medical model, in which the "professionals" (doctors, clinicians, social workers, etc.) play the primary role in deciding what is in the consumer's best interest.

B. Least Restrictive Environment (LRE) & Community Integration

The closely intertwined concepts of least restrictive environment (LRE) and community integration are also integral to the principle of needs-based individualization as defined here. The notion that individuals should live in the LRE appropriate to their needs and capabilities was revolutionary in an era when most individuals with I/DD, regardless of their diagnosis or the severity of their symptoms, spent their lives in segregated institutional settings. In 1975, just a few years after the passage of the (original) Lanterman Act, the DD Act declared that "treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty."[33] The 1977 amendments to the Lanterman Act reiterated these goals, declaring that Californians with I/DD have a right to treatment in "the least restrictive conditions necessary to achieve the purposes of the treatment, services, or supports."[34] As these statutes underscore, one cannot determine which environment is the "least restrictive"

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[30] *Id.*

[31] *See, e.g.*, *id.* at 2 (describing SDM as alternative to conservatorship under California law).

[32] *Id*. at 1 (responding to the question "How is SDM different form person-centered planning?").

[33] Developmentally Disabled Assistance and Bill of Rights Act, Pub. L. No. 94-103, 89 Stat. 486 (1975) (codified at 42 U.S.C. § 15009(a)(2) (2019)).

[34] Lanterman Developmental Disabilities Services Act, 1977 Cal. Legis. Serv. Ch. 1252 § 550 (A.B. 846) (codified at CAL. WELF. & INST. CODE § 4502(a) (2019)).

for any individual without a comprehensive understanding of that individual's treatment, services and supports. Here again, needs-based individualization is best understood as the *process* whereby the LRE is identified and selected.

Additional amendments to the Lanterman Act in 1992 broadened the idea of LRE by declaring that services and supports "shall be provided with the least restrictive *conditions* necessary to achieve the purposes of the [consumer's] treatment, services, or supports."[35] This amendment suggests that the LRE mandate encompasses not simply where consumers live, but also how and with whom they spend their time. The 1992 amendment further supports a broad understanding of LRE by declaring that the "intent of the Legislature" is for the IPP team to "take[] into account the needs and preferences of the individual and the family, where appropriate, as well as promoting community integration, independent, productive, and normal lives, and stable and healthy environments."[36] In this context, "community integration" is used not simply to denote the entitlement to LRE, but to convey a broader, more comprehensive vision in which each consumer has access to the full range of opportunities available to his/her non-disabled peers.

Class action litigation and statutory reforms since the 1980s also reflect this evolution from a narrow understanding of LRE to a broader "community integration" requirement. As discussed in a separate report, a primary focus of California's disability rights community in the 1980s and '90s was expediting the transition of individuals with I/DD from developmental centers (DCs), the highly restrictive state institutions in which most historically resided, into their communities.[37] The class action litigation of that era emphasized that the slow pace of deinstitutionalization deprived consumers of their right to LRE.[38] These lawsuits demanded not merely that consumers be removed from DCs, but also that this transition be accomplished through a rigorous process of needs-based individualization. For example, the Community Living Options Initiative, launched in 1994 as part of a settlement agreement in the landmark case *Coffelt v. California Department of Developmental Services,* required the IPP team to consider each consumer's preferred living arrangement and explore a range of suitable community-based options before deciding which arrangement was the most appropriate.[39] Similar measures were taken in the settlement of *Capitol People First v. DDS*.[40] As part of the latter settlement agreement, reached in 2009, DDS was required to ensure that RCs "discuss with

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[35] 1992 Cal. Legis. Serv. Ch. 1011 § 3 (S.B. 1383) (codified at CAL. WELF. & INST. CODE § 4502(a) (2019)) (emphasis added); *see also id.* § 15 (codified at CAL. WELF. & INST. CODE § 4648 (2019)).

[36] *Id.* § 10.5 (codified at CAL. WELF. & INST. CODE § 4646(a) (2019)).

[37] LANTERMAN PRIMER, *supra* note 4, § III.B.

[38] *See* Coffelt v. Cal. Dep't Developmental Servs., No. 916401, (Cal. App. Dep't Super. Ct. 1994).

[39] Settlement Agreement at 3, 33-34, Coffelt v. Cal. Dep't Developmental Servs., Cal. App. Dep't Super. Ct., (1994) (No. 916401).

[40] [Proposed] Settlement Agreement at 12-17, Capitol People First v. Cal. Dep't Developmental Servs., 155 Cal. App. 4th. 676 (2009) (No. 2002-038715), 2003 WL 25315367.

[each consumer and his/her family] whether a Community Living Option would meet the [consumer's] needs, preferences and life choices," and whether the consumer could take advantage of Community Placement Plans designed to ease the transition to community-based living.[41]

Developments in federal law since the 1990s reflect a parallel evolution. Although the DD Act does not grant consumers an affirmative entitlement to either community integration or needs-based individualization,[42] it implicitly recognizes that community integration requires needs-based individualization. The DD Act observes that, although "individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of . . . integration and inclusion in all facets of community life, [they] often require the provision of community services, individualized supports, and other forms of assistance."[43]

Moreover, in the landmark 1999 case *Olmstead v. L.C. ex rel Zimring*, the Supreme Court held that the ADA creates a (limited) entitlement to community integration.[44] In *Olmstead*, the Court held that the ADA did not impose a "standard of care" on states for whatever medical services they render, nor did it require them to "provide a certain level of benefits to individuals with disabilities."[45] Nevertheless, the Court held that "[s]tates must adhere to the ADA's nondiscrimination requirement with regard to the services they in fact provide."[46] Since *Olmstead* only entitles consumers to select the least restrictive setting from among the menu of options that the state chooses to offer, it is not as expansive as the Lanterman Act.[47] Indeed, critics have argued that states could "avoid *Olmstead*'s requirements by following its reminder

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[41] *Id.* at 12, 23; *see also* CAL. WELF. & INST. CODE §§ 4507, 7505 (2019) (restricting DC placement to instances when the person is a danger to him/herself or others, is committed through the criminal justice system, or is a prior DC resident who left the DC within the previous 12 months).

[42] *See, e.g.*, Pennhurst State School and Hospital v. Halderman, 451 U.S. 1 (1981) (holding that DDABRA did not provide disabled individuals with the affirmative right to appropriate treatment in the least restrictive environment possible).

[43] Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402 114 Stat. 1677 § 101(c)(1) (codified at 42 U.S.C. § 15001 (2019)); *see also* 42 U.S.C. § 15002(16) (2019) (noting "The term 'individualized supports' means supports that enable an individual with a developmental disability to . . . be integrated and included in all facets of community life; are designed to . . . prevent placement into a more restrictive living arrangement than is necessary; and enable such individual to live, learn, work, and enjoy life in the community").

[44] Olmstead v. L.C. *ex rel.* Zimring, 527 U.S. 581, 593-94 (1999).

[45] *Id.* at 603 n.14.

[46] *Id.*

[47] *Compare* 28 C.F.R. § 35.130(d) (2018) (noting "[P]ublic entities must administer services, programs and activities in the most integrated setting possible"), *with* CAL. WELF. & INST. CODE § 4502(b) (2017) (positing an affirmative entitlement to treatment and services in the least restrictive environment).

that Title II does not require states to provide any particular level of care in the first place."[48] Yet at least in a state like California, which provides services and supports to residents with I/DD in a wide range of settings, *Olmstead*'s community integration mandate carries considerable force.

Subsequent interpretation of *Olmstead* by federal agencies highlights the integral role of needs-based individualization in ensuring that the law's requirements are met. [49] For example, the Department of Justice's guidelines require states to "identify individuals' needs and the services and supports necessary for them to succeed in an integrated setting,"[50] and a settlement agreement reached between the Department of Justice and North Carolina in 2012 requires that the state's provision of services and supports "be flexible and individualized to meet the needs of each individual."[51]

Additionally, the Final Settings Rule, adopted by CMS in 2014 and scheduled to take effect in 2022, is particularly far-reaching in its articulation of what criteria must be met for a setting to qualify as "community based" for federal reimbursement purposes. [52] The Rule specifies, among other things, that a community-based setting must be "integrated in and support[] full access . . .

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[48] DEBBIE JARET, PROT. & ADVOCACY, INC., IS THERE A PROFESSIONAL JUDGMENT STANDARD IN OLMSTEAD V. L.C. AND E.W. 10-11 n.45 (2001) (noting the majority of cases citing *Olmstead* held that the case stood "for the proposition that the ADA does not mandate the creation of new programs"); *see also* Black v. Dep't of Mental Health, 83 Cal. App. 4th 739, 754 (Cal. Ct. App. Sept. 11, 2000); *see also* Shoshana Fishman, *Olmstead v. Zimring: Unnecessary Institutionalization Constitutes Discrimination Under the Americans with Disabilities Act*, 3 J. HEALTH CARE L. & POL'Y 430, 438 (2000); *see also* Carol Beatty, *Implementing Olmstead by Outlawing Waiting Lists*, 49 TULSA L. REV. 713, 719 (2014); *see also* Mary C. Cerreto, *Olmstead: The Brown v. Board of Education for Disability Rights: Promises, Limits and Issues*, 3 LOY. J. PUB. INT. L. 47, 56-57 (Fall 2001) [hereinafter OLMSTEAD]; *but see* Mark C. Weber, *Home and Community-Based Services, Olmstead and Positive Rights: a Preliminary Discussion*, 39 WAKE FOREST L. REV. 269, 271 (Spring 2004).

[49] *See also* OLMSTEAD, *supra* note 48, at 75; *see also* ANDREW POWER ET AL., ACTIVE CITIZENSHIP AND DISABILITY 104-05 (2013) [hereinafter ACTIVE CITIZENSHIP AND DISABILITY].

[50] CIVIL RIGHTS DIV., U.S. DEP'T OF JUSTICE, STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND OLMSTEAD V. L.C., https://www.ada.gov/olmstead/q&a_olmstead.htm (last visited Jan. 16, 2019); *see also* STATE AND LOCAL LAND USE LAWS, *supra* note 10, at 11; CAL. OLMSTEAD ADVISORY COMM., CAL. HEALTH AND HUMAN SERVS. AGENCY, POLICY STATEMENT (2005) [hereinafter POLICY STATEMENT], https://www.chhs.ca.gov/wp-content/uploads/2017/06/Committees/Olmstead-Advisory/Document-Archive/OlmsteadAdvisoryCommitteePolicyStatement.pdf (last visited Jan. 16, 2019).

[51] Settlement Agreement at 8, U.S. v. North Carolina (E.D.N.C. 2012) (No. 5:12-cv-557); *see also* ADA Interim Settlement Fact Sheet, Steward v. Perry (W.D. Tex. Aug. 5, 2013) (No. 5:10-CV-1025-OG) (emphasis added), https://www.ada.gov/Olmstead/documents/steward-settlement.pdf (last visited Jan. 16, 2019); Statement of Interest of the U.S. at 7, M.R. et. al., v. Dreyfus (W.D. Wash. Jan. 26, 2011) (No. 210-cv-02052-TSZ).

[52] *See supra* Section IV.A; *see also* CTR. MEDICAID & CHIP SERVS., U.S. DEP'T HEALTH & HUMAN SERVS., CMS INFO. BULL., EXTENSION OF TRANSITION PERIOD FOR COMPLIANCE WITH HOME AND COMMUNITY-BASED SETTINGS CRITERIA (May 9, 2017), https://www.medicaid.gov/federal-policy-guidance/downloads/cib050917.pdf (last visited Jan. 16, 2019) (noting that community-based settings criteria would not be enforced until March 17, 2022).

to the greater community, including opportunities to seek employment and work in competitive *integrated settings*, engage in community life . . . [and] *receive services in the community*."[53]

The close connection between needs-based individualization, LRE and community integration is not limited to laws that concern the rights of disabled adults. The IDEA likewise grants school-age individuals with I/DD the right "[t]o the maximum extent appropriate . . . [to be] educated with children who are not disabled,"[54] and specifies that the decision of whether to educate a child in the general educational setting is an "individualized, fact specific inquiry."[55]

Finally, although the U.S. is not a signatory,[56] the United Nations Convention on the Rights of Persons with Disabilities echoes very similar themes. The CPRD declares that "State Parties . . . shall . . . ensur[e] that . . . [p]ersons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community."[57]

In short, the mandate to provide LRE in both residential and educational settings requires key decision makers to determine the individual's entitlement through a process of needs-based individualization. Over time, however, the relatively narrow doctrinal focus on LRE has given way to a broader and most holistic vision of full community integration and inclusion.

C. Home Preservation

Another important facet of needs-based individualization is home preservation, the idea that a consumer should live at home so long as the state can feasibly support such an arrangement and doing so is consistent with the needs and preferences of the consumer and his/her family.

One of the first articulations of this principle came in 1977, when the legislature declared that the state "places a high priority on providing opportunities for children with developmental disabilities to live with their families, when living at home is the preferred objective in the child's individual program."[58] In 1992 the legislature expanded on this point by requiring that the IPP Team "consider every possible way to assist families in maintaining their children at

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[53] 42 C.F.R. § 441.530(a)(1)(i)-(ii) (2019) (emphasis added).

[54] 20 U.S.C. § 1412(a)(5)(A) (2019).

[55] *See* Sacramento Sch. Dist. Bd. Educ. v. Rachel H., 14 F. 3d 1398, 1402 (9th Cir. 1994) (quoting Daniel R.R. v. State Bd. Of Educ., 874 F. 2d 1036, 1048 (5th Cir. 1989)).

[56] *See* UNITED NATIONS GEN. ASSEMBLY, CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2016) [hereinafter CRPD], http://www.un.org/disabilities/documents/COP/cosp9_infographic.pdf (last visited Jan. 16, 2019).

[57] *Id.* § Art. 19.

[58] 1977 Cal. Legis. Serv. Ch. 1252 § 550 (codified at CAL. WELF. & INST. CODE § 4685 (2019)).

home, when living at home [is] in the best interest of the child, before considering out-of-home placement alternatives."[59]

Federal and international law recognize very similar rights for minor children. The DD Act, for example, declares that "it is the policy of the United States that all programs, projects, and activities funded under this title . . . shall be provided in a manner consistent with the goal of providing families of children with disabilities with the support the families need to raise their children at home."[60] The CPRD, meanwhile, requires that "State parties . . . ensure that a child . . . not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine . . . that such separation is necessary for the best interests of the child."[61]

Importantly since middle-aged and elderly consumers constitute a growing proportion of the I/DD population[62], the value of home preservation is not limited to school-age children. State regulations specify that regional center consumers of all ages and their families have the right to "participate in decisions affecting their own lives" including "where and with whom they live."[63] At least one OAH decision has held that adult consumers living with their parents are entitled to the same protections as minors,[64] a doctrinal nuance that is of considerable practical importance given that about 60% of all adult consumers in California live with a parent or guardian.[65] Adults receiving Supported Living Services (SLS) in their own homes likewise have the right to modify their services and supports, including changing their SLS vendor and direct service staff, without having to move elsewhere.[66] Finally, state legislative reforms enacted in 2014 clarified the right of adult consumers to receive independent living services regardless of whether they reside in the family home or an independent living arrangement.[67]

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[59] 1992 Cal. Legis. Serv. Ch. 1011 § 21 (S.B. 1383) (codified at CAL. WELF. & INST. CODE §§ 4685(c)(1)-(2) (2019)).

[60] Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402 114 Stat. 1677 § 202(c) (codified at 42 U.S.C. § 15001(c) (2019)); *see also id.* § 102(12)(A) (codified at 42 U.S.C. § 15002(12)(A) (2019) (definition and scope of family support services)).

[61] CPRD, *supra* note 56, at § Art. 9.1.

[62] CAL. DEP'T DEVELOPMENTAL SERVS., FACT BOOK: 14TH ED. 10 (2017) [hereinafter 14TH DDS FACT BOOK], http://www.dds.ca.gov/FactsStats/docs/factBook_14th.pdf (last visited Jan. 17, 2019).

[63] CAL. WELF. & INST. CODE § 4501 (2019).

[64] *See* Claimant v. Harbor Regional Center, No. 2015020092, at 5 (OAH July 31, 2015), https://www.documents.dgs.ca.gov/oah/dds_decisions/2015020092.pdf (last visited Jan. 16, 2019) (finding that, because "the services to be provided to any consumer of regional center services must be individually suited to meet the unique needs of the individual consumer in question," and because the consumer required transportation in order to preserve his home living arrangement, the RC was required to fund transportation between the divorced parents of an adult consumer).

[65] 14TH DDS FACT BOOK, *supra* note 62, at 13-14 (documenting the growth in the percentage of adult consumers who lived at home with a parent between 2006 and 2016—from 50.6% to 59.9%).

[66] *See* CAL. WELF. & INST. CODE § 4689(a)(2) (2019); *see also* CAL. CODE REGS. tit. 17, § 58620 (2019).

[67] 2014 Cal. Legis. Serv. Ch. 402 § 3 (S.B. 1093) (codified at CAL. WELF. & INST. CODE § 4688.05 (2019)).

Recent changes to federal law similarly suggest that adults with I/DD who do not reside with their families nevertheless enjoy a (limited) right to home preservation. Noting the disruption that can result from a discontinuation of services in a home rented or owned by a residential services provider, CMS's Final Settings Rule (scheduled to take effect in 2022) contains special guidance applicable to "residents of provider-owned or controlled residential settings":

> The unit or dwelling [must be] a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual [must have], at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the state, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.[68]

Although compliance with this rule will not guarantee individuals with I/DD the right to remain in their homes indefinitely, it entitles them to at least the same rights in this regard that other citizens enjoy.

In short, the home preservation principle can be understood as the application of needs-based individualization to residential housing choices. By protecting each consumer's capacity to continue living with family members or in his/her preferred domestic setting, it protects each consumer's right to treat his or her residence as not just a place to sleep and receive services, but as a home.

D. Consumer Choice

The concept of "consumer choice" is another vital underpinning of needs-based individualization. It signifies the idea that to the greatest extent possible, consumers should be empowered to make their own choices on issues that affect their lives. The Legislature captured the close relationship between consumer choice and needs-based individualization in its 1992 amendments to the Lanterman Act:

> [Consumers] should be empowered to make choices in all life areas . . . [They] should participate in decisions affecting their own lives, including, but not limited to, where and with whom they live, their relationships with people in their community, the way in which they spend their time, including education, employment, and leisure, the pursuit of their own personal future, and program

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[68] 42 C.F.R. § 441.710(a)(1)(vi)(A) (2018).

> planning and implementation. . . . [A]ll public or private agencies receiving state funds for the purpose of serving persons with developmental disabilities, including, but not limited to, regional centers, shall respect the choices made by consumers or, where appropriate, their parents, legal guardian, or conservator. Those public or private agencies shall provide consumers with opportunities to exercise decision-making skills in any aspect of day-to-day living and shall provide consumers with relevant information in an understandable form to aid the consumer in making his or her choice.[69]

In at least one instance, California courts have held that the principle of consumer choice overrides the principle of community integration. In *In Re Borgogna*, Harbor Regional Center sought a writ of habeas corpus ordering release of a consumer from a DC into the community.[70] The consumer, who had lived in the DC for 25 years, expressed a preference to remain there.[71] The trial court reasoned that, although the Legislature intended to integrate persons with I/DD into their communities, it had also articulated a desire to "maximiz[e] the personal liberty and dignity of [consumers] by, among other things, permitting [them] as much freedom of choice as [was] consonant with [their] disability."[72] The court held that when these two principles conflict, "the [consumer's] choice [is] the first consideration if he is competent to choose."[73] The decision was upheld on appeal.[74] It should be noted, however, that the *In Re Borgogna* decision is almost four decades old and preceded many watershed events[75]—such as the passage of the ADA in 1990,[76] the landmark *Olmstead* decision of 1999,[77] and the issuance of the Final Settings Rule of 2014[78]—that stress the importance of community integration and LRE, so its precedential value is uncertain.[79]

The consumer choice principle is also enshrined in many federal laws that bear on the rights of individuals with I/DD. The regulations that apply to Medicaid's HCBS Waiver, for example,

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[69] 1992 Cal. Legis. Serv. Ch. 1011 §§ 2.5, 3.5 (S.B. 1383) (codified at CAL. WELF. & INST. CODE §§ 4501, 4502.1 (2019)); *see also id.* § 9 (codified at CAL. WELF. & INST. CODE § 4640.7(a) (2019)) (RCs maximizing consumer opportunity and choice) (emphasis added); *see also id.* § 15 (codified at CAL. WELF. & INST. CODE § 4648(a)(1) (1992)); *see also id.* § 26 (codified at CAL. WELF. & INST. CODE § 4750 (2019)).

[70] *In Re* Borgogna, 121 Cal. App. 3d 937, 937 (Cal. Ct. App. 1981).

[71] *Id*. at 941.

[72] *Id*. at 947.

[73] *Id*.

[74] *Id*. at 949.

[75] *Id*. at 937.

[76] Pub. L. No. 101-335, 104 Stat. 327 (1990) (codified as amended in scattered sections of 42 and 47 U.S.C.).

[77] *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. at 581.

[78] *See supra* Section IV.A.

[79] *See supra* note 48 and accompanying text.

require that states utilize a person-centered planning process in which the individual with I/DD is provided with "necessary information and support to ensure that [she] directs the process to the maximum extent possible."[80] The DD Act, moreover, declares:

> [I]ndividuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination . . . [they] and their families are the primary decisionmakers regarding the services and supports [they] and their families receive, including regarding choosing where [they] live from available options, and play decision-making roles in policies and programs that affect [their] lives . . . . in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences.[81]

Likewise, observers in California and across the nation have understood the Supreme Court's *Olmstead* ruling as promoting the robust protection of consumer choice.[82]

The Final Settings Rule, discussed earlier, expands on *Olmstead* by defining a community-based residence as one that is "*selected by the individual* from among setting options[;] [o]ptimizes but does not regiment *individual initiative*, *autonomy*, and *independence* in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact[;] [and] [f]acilitates *individual choice* regarding services and supports, and who provides them."[83] It further specifies that in provider-owned or provider-controlled residential settings, residents with I/DD must be able to control access to their bedrooms, furnishings and decorations, schedules and activities, food access, visitors, and the selection of their roommates.[84] The CPRD touches on very similar themes.[85]

In short, since the Lanterman Act's passage, state and federal law have placed increasing emphasis on the primacy of consumer choice not only in the way that the IPP process is conducted, but also in the selection of the bundle of services and supports will best enable individuals with I/DD pursue their life goals.

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[80] 42 C.F.R. § 441.301(c)(1)(ii) (2019); *see also* FACT SHEET, *supra* note 23, at 2-3 (noting "[The Settings Rule] specifies that service planning for participants in Medicaid HCBS programs . . . must be developed through a person-centered planning process that addresses health and long-term services and supports needs in a manner that reflects individual preferences and goals").

[81] Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402 114 Stat. 1677 § 101(c)(1) (codified at 42 U.S.C. § 15001 (2019)); *see also id.* § 102 (codified at 42 U.S.C. § 15002(16)) (2019) (defining "individualized supports"); and *id.* § 15002(27) (defining "self-determination activities").

[82] *See, e.g.*, POLICY STATEMENT, *supra* note 50, at 1; *see also* OLMSTEAD, *supra* note 48, at 47, 75; *see also* ACTIVE CITIZENSHIP AND DISABILITY, *supra* note 49, at 104-05.

[83] 42 C.F.R. § 441.530(a)(1) (2019) (emphases added).

[84] *Id.*

[85] CPRD, *supra* note 56, at § Art. 19.

E. Service Continuity

We use the term "service continuity" to capture the idea that a RC cannot terminate an effective service, support, or relationship without providing the consumer with a valid rationale and sufficient time to transition to an alternative provider. Maintaining continuity of services is particularly vital when the consumer has become accustomed to or reliant upon services being delivered in a particular way, and for individuals with some forms of developmental disabilities (such as autism), abrupt transitions may be particularly challenging.[86] Although service continuity is not explicitly mentioned in the Lanterman Act, the statute stresses the importance of "ensur[ing] that no gaps occur in communication or provision of services or supports," and mandate a variety of specific measures to minimize disruptions that can arise from discontinuities in the provision of care.[87]

In a wide variety of contexts, state laws and regulations include concrete measures to enhance service continuity. For example, regional centers must provide the emergency and crisis intervention services necessary to enable consumers to stay in the "living arrangement of their choice," and "if dislocation cannot be avoided, every effort shall be made to return the person to his or her living arrangement of choice, with all necessary supports, as soon as possible."[88] In cases where a consumer must be relocated from a licensed residential care facility, regional centers are further obliged to take "any additional measures necessary to meet the consumer's health and safety needs until the relocation has been accomplished" within the statutorily specified time frame.[89] If advocates for consumers aged 0-3 challenge a RC's determination regarding early intervention services through a request for fair hearing, the services in question must be maintained during the "pendency of mediation and/or due process hearing procedures."[90] In many contexts in which a regional center is considering a termination of community-based day program services, services may not be terminated if a consumer timely files a fair hearing request.[91] Additionally, in most cases, a vendor who wishes to exclude a consumer from a community-based day program because the "the vendor determines that the consumer is a threat to the health and safety of other individuals in the program" must meet with

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[86] *See, e.g.*, Kara Hume, *Transition Time: Helping Individuals on the Autism Spectrum Move Successfully from One Activity to Another*, 13(2) THE REPORTER 6, 6 (2008) (summarizing research on the fact that many individuals on autism spectrum have difficulty with transitions and changes in routine, and suggesting strategies to make transitions as successful as possible).

[87] CAL. WELF. & INST. CODE § 4501 (2017).

[88] *Id.* § 4648(a)(10).

[89] CAL. CODE REGS. tit. 17, § 56016(g) (2019).

[90] *Id.* § 52172(g).

[91] *Id.* §§ 56718(a), (e).

the consumer, his/her representative, and his/her program coordinator within three working days to "discuss the basis of the exclusion and any program changes that may be required."[92]

More broadly, the due process protections embedded in the fair hearing process help ensure that consumers do not experience abrupt or unexpected changes in services.[93] For example, Section 4710(a) of the Lanterman Act specifies that in most circumstances, consumers must be notified by certified mail at least 30 days prior to either the agency "mak[ing] a decision without the mutual consent of the service recipient or authorized representative to reduce, terminate, or change services" in the consumer's IPP or the recipient becoming "no longer eligible for agency services."[94] Additional regulations provide that if a consumer requests a fair hearing "postmarked or received by a service agency no later than 10 days after receipt of the notice of the proposed action . . . current services shall continue" during the appeal procedure.[95]

Several cases adjudicated by OAH reinforce the notion that service continuity is an important tenet of needs-based individualization. In *Francine F. v. SDRC*, for example, the HO required San Diego Regional Center to fund supplemental staffing for a consumer's day program even

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[92] *Id.* § 56718(g).

[93] As of this writing, there is some uncertainty regarding the rights available to fee-for-service (FFS) consumers who appeal a denial or change in behavioral health therapy (BHT) services. Unlike consumers on Medi-Cal managed care plans (MCP), who can appeal a denial or change in BHT services directly with their MCP, *see* CAL. HEALTH & HUMAN SERVS. AGENCY, CAL. DEP'T HEALTH CARE SERVS., ALL PLAN LETTER 14-011, INTERIM POLICY FOR THE PROVISION OF BEHAVIORAL HEALTH TREATMENT COVERAGE FOR CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER (Sept. 15, 2014), https://www.dhcs.ca.gov/services/medi-cal/Documents/APL_14-011_and Attachments.pdf (last visited Mar. 13, 2019), FFS consumers receiving BHT through an RC's administration evidently must appeal to the Medi-Cal state hearing process, *see* CAL. HEALTH & HUMAN SERVS. AGENCY, CAL. DEP'T HEALTH CARE SERVS., BEHAVIORAL HEALTH TREATMENT: FREQUENTLY ASKED QUESTIONS FOR FEE-FOR-SERVICE BENEFICIARIES 2 (Dec. 2018) (on file with authors) [hereinafter BHT FAQ]; *see also Behavioral Health Treatment*, CAL. DEP'T HEALTH CARE SERVS., https://www.dhcs.ca.gov/services/medi-cal/pages/behavioralhealthtreatment.aspx (last visited Mar. 15, 2019) (noting "Children with fee-for-service Medi-Cal will receive BHT services from their local Regional Center"). However, it is uncertain how closely the rights provided to consumers requesting fair hearings under Medi-Cal correspond to the rights available to consumers requesting fair hearings under the Lanterman Act, *see* Letter from Brian Capra, Senior Staff Attorney, Pub. Counsel, to Sec'y Diana Dooley and Dirs. Nancy Bargmann, Will Lightbourne, and Jennifer Kent (July 19, 2018) (on file with authors); *see also* BHT FAQ, *supra* note 93, at 2 (noting, in response to the question "What are my rights if I do not agree with a denial or change of my services?" only that "If you do not agree with a denial or change of services, you can: Ask for a State Hearing if you have FFS Medi-Cal").

[94] CAL. WELF. & INST. CODE § 4710(a) (2017). Note that under *id.* § 4710(f), "the advance notice specified in subdivision (a) shall not be required when a reduction, termination, or change in services is determined to be necessary for the health and safety of the recipient. However, adequate notice shall be given within 10 days after the service agency acition."

[95] *Id.* §§ 4701(n), 4715(a) (noting "services shall continue as provided in Section 4715," which ensures that "services…shall be continued during the appeal procedure up to and including the 10th day" after "[r]eceipt by the service agency, following an informal meeting, of the withdrawal of the fair hearing request…[r]eceipt by the service agency, following mediation, of the withdrawal of the fair hearing request, [or r]eceipt by the recipient of the final decision of the hearing officer or single state agency").

though “it [would] significantly increase…the monthly expense to the Regional Center.”[96] In reaching this decision, the Hearing Officer reasoned that, because change “involve[d] significant dislocation in [a consumer’s] life,” it should be ordered “only when it [could] be demonstrated to be reasonably beneficial to the claimant.”[97] Turning to the facts of the case, the HO found that because there was “insufficient evidence to support a finding that claimant’s acknowledged needs can and will be met in the [RC-proposed alternative] program,” and because “the Lanterman Act clearly contemplate[d] that the services to be provided to each client be selected on an individual basis,”[98] the RC was required to fund the supplemental staffing. Similarly, in *Jon v. Regional Center of the East Bay (RCEB)*, the HO cited the importance of service continuity in requiring Regional Center of the East Bay to fund a consumer’s after-school program. The HO explained that the consumer had “extraordinary treatment needs” that necessitated “continuity and consistency to help him adjust” to programmatic changes. [99] The HO accordingly held that the RCEB must fund the program for at least one more year.[100]

A pair of OAH opinions from the early 1990s appear to qualify the importance of service continuity by suggesting it sometimes can be overridden by cost concerns, even if doing so threatens the principle of needs-based individualization. In each case, a HO rejected a consumer’s challenge to the discontinuation of an indisputably beneficial service because continuing to provide it would force the RC to exceed a fixed cap it had imposed on the quantity of the service available to each consumer.[101] Importantly, however, both cases were appealed to state court by Protection & Advocacy, Inc. (PAI), the precursor to DRC, on the ground that their holdings violated the Lanterman Act, and at least one was settled in the consumer’s favor.[102]

In short, the capacity to maintain stability and continuity in one’s daily activities is an important facet of needs-based individualization whose importance is recognized, at least implicitly, in

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[96] Francine F. v. San Diego Reg’l Ctr., No. 2004080502, at 2 (OAH Jan. 18, 2005), https://www.documents.dgs.ca.gov/oah/dds_decisions/2004080502.084.pdf (last visited Jan. 16, 2019).

[97] *Id*. at 4.

[98] *Id*. at 4, 6.

[99] Jon v. Reg’l Ctr. of the E. Bay, No. DDS1-456 2, at 4 (OAH Apr. 13, 1990).

[100] *Id*. at 4.

[101] *See* Douglas Holt v. Reg’l Ctr. of the E. Bay, No. 665007-8 (OAH Apr. 22, 1991) (upholding RC’s termination of claimant’s secondary day program under RC’s POS guidelines limiting consumers to one day program); *see also* Jason Goldberg v. Developmental Disabilities Ctr., No. 608130 (OAH July 1, 1990) (upholding RC’s denial of 16 hours per day of respite care on ground that RC had discretion to enforce across-the-board policy limiting nursing services to 32 hours per month).

[102] DRC found archived historical records indicating that *Holt v. Reg’l Ctr. of the E. Bay* was settled in the consumer’s favor. Although DRC could not locate historical records on the *Goldberg* case, it seems likely that the case also settled in the consumer’s favor, since the superior court never issued an opinion in the case and a contemporaneous *L.A. Times* article stated that the court ordered the regional center to provide the requested service, 16 hours of daily respite care, before the hearing, *see* Jerry Hicks, *Jason’s Battle for Life*, L.A. TIMES (Nov. 16, 1989), http://articles.latimes.com/1989-11-16/local/me-2255_1_orange-county-center (last visited Jan. 22, 2019).

state and federal regulations as well as in several OAH opinions. Although it is not always possible to guarantee continuity of services, the needs-based individualization principle requires RCs to make every effort to do so, especially when disruptions will negatively affect the consumer's quality of life.

V. The Principle of Cost Effectiveness

The needs-based individualization principle does not account for the fact that in some situations, a range of different "bundles" of services and supports could enable a consumer to meet the goals specified in his or her IPP. The cost of these different bundles can vary widely, and which one is selected can affect, at least in the aggregate, the capacity of each RC to stay within its budget. As one hearing officer posed the problem, "[t]he regional centers' obligations to other consumers are not controlling in the individual decision-making process, but a fair reading of the law is that a regional center is not required to meet a consumer's every possible need or desire, in part because it is obligated to meet the needs of many other disabled persons and their families."[103] An important question, then, is which limiting principles RCs can justifiably apply so as to effectuate the goals of the Lanterman Act without exceeding their budgetary constraints.

The Lanterman Act itself alludes obliquely to the existence of a limiting principle in its declaration that it is the "intent of the Legislature" that the "provision of services to consumers and their families" should "reflect the cost-effective use of public resources."[104]

In the remainder of this section, we look to the text of the Act itself, and to its interpretation in judicial and administrative proceedings, to better understand the nature and scope of this limiting principle, which we refer to as "cost effectiveness." We discuss, in turn, three subsidiary concepts that we believe the cost effectiveness principle comprises: (1) demonstrable efficacy, (2) budgetary prudence, and (3) exhaustion of generic resources.

A. Demonstrable Efficacy

In the words of California's Assembly Office of Research, the Lanterman Act is a "results oriented body of law."[105] In practice, this means that the state is not obligated to fund any services "that are unable to demonstrate their effectiveness in delivering the results specified in law."[106] We use the term *demonstrable efficacy* to signify the idea that the state only funds expenditures for services that are shown to be successful in helping consumers meet their goals, thereby shielding the state from wasteful expenditures and shielding consumers from ineffective or unscrupulous providers. The demonstrable efficacy requirement was first articulated in the 1977 amendments to the Lanterman Act, which specified that "the mere existence or the delivery

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[103] Claimant v. Harbor Reg'l Ctr., No. 2015020092, at 5 (OAH July 31, 2015), https://www.documents.dgs.ca.gov/oah/dds_decisions/2015020092.pdf (last visited Jan. 16, 2019).

[104] CAL. WELF. & INST. CODE § 4646(a) (2018).

[105] ASSEMBLY OFFICE RES., KEEPING THE PROMISE OF THE LANTERMAN ACT, REPORT 1: QUALITY SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES 20 (1984); *see also id.* at 22, 39 (Stating that Lanterman Act does not "establish or guarantee an unqualified 'right to service'" and instead arguing that consumers "are entitled to specified service accomplishments").

[106] *Id.* at 22.

of services is, in itself, insufficient evidence of program effectiveness. . . . [A]gencies serving developmentally disabled persons shall produce evidence that their services have resulted in more independent, productive, and normal lives for the persons served."[107]

In 1992, the Legislature strengthened the demonstrable efficacy requirement in two important regards. First, it clarified that the IPP process "shall include consideration of a range of service options proposed by individual program plan participants [and] the effectiveness of each option in meeting the goals stated in the individual program plan."[108] Second, it specified that in order to be considered efficacious, services and supports must further the goal of "enabl[ing] developmentally disabled persons to approximate the pattern of everyday living available to nondisabled people of the same age."[109] The IPP team was further instructed to systematically assess whether the services provided were achieving their intended goals by drafting "a statement of specific, time-limited objectives for implementing the person's goals and addressing his or her needs," and then ascertaining in subsequent IPP reviews whether these "objectives have been fulfilled within the times specified."[110]

In 2009, in the midst of the Great Recession, the Legislature passed two more amendments designed to prevent the purchase of services that failed the demonstrable efficacy requirement. First, the Legislature mandated that RCs "[o]nly purchase ABA [applied behavioral analysis] services or intensive behavioral intervention services [used in the treatment of autism and other developmental disabilities] that reflect evidence-based practices."[111] Second, the Legislature declared that RCs could "not purchase experimental treatments, therapeutic services, or devices that have not been clinically determined or scientifically proven to be effective or safe or for which risks and complications are unknown."[112]

The demonstrable efficacy requirement is a mixed blessing for consumers. Although in some circumstances it may protect them from being subjected to risky or harmful treatments with no clinical validity, it may also may prevent them from accessing cutting-edge services or supports

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[107] 1977 Cal. Legis. Serv. Ch. 1252 § 550 (codified at CAL. WELF. & INST. CODE § 4501 (2019)).

[108] 1992 Cal. Legis. Serv. Ch. 1011 § 4.5 (S.B. 1383) (codified at CAL. WELF. & INST. CODE § 4512(b) (2019)); *see also id.* § 10.5 (codified at CAL. WELF. & INST. CODE § 4646(a) (2019)) ("It if further the intent of the Legislature to ensure that the provision of services to consumers and their families be effective in meeting the goals stated in the individual program plan").

[109] *Id.*

[110] 1992 Cal. Legis. Serv. Ch. 1011 § 11 (S.B. 1383) (codified at CAL. WELF. & INST. CODE § 4646.5(a)(2), (a)(8) (2019)); *see* also *Id.* § 15 (codified at CAL. WELF. & INST. CODE § 4648(a)(7) (2019)) (noting "No service or support provided by any agency or individual shall be continued unless . . . reasonable progress toward objectives have been made").

[111] 2009-10 Cal. Legis. Serv., 4th Exec. Sess. Ch. 9 § 19 (A.B. 9) (codified at CAL. WELF. & INST. CODE § 4686.2(b)(1) (2019)) (emphasis added).

[112] *Id.* § 10 (codified at CAL. WELF. & INST. CODE § 4648(a)(16) (2019)) (emphasis added).

whose efficacy, although real, has not yet been empirically proven. It is nevertheless clear that the requirement has shaped legislative and judicial understandings of how cost effectiveness should be evaluated.

B. Budgetary Prudence

The original Lanterman Act was intended both to help individuals with I/DD reach their full potential *and* to conserve state funds. The expectation was that supporting consumers in their own homes or in licensed community care facilities would be less costly than funding their care in DCs. The second important tenet of the cost effectiveness principle, then, is the idea that RCs should select, from among the services and supports that will enable the consumer to achieve the goals specified in his or her IPP, those that help to conserve state funds. We refer to this mandate as the "budgetary prudence" principle.

In the years following the passage of the original Lanterman Act, the Legislature amended the Act with clear concern for budgetary prudence. In 1977, language was added to ensure that the exodus of consumers from DCs did not burden the state's budget. Section 4682 provides:

> Under no circumstances shall the rate of state payment to any provider of out-of-home care exceed the average amount charged to private clients residing in the same facility, nor shall the monthly rate of state payment to any such facility, with the exception of a licensed acute care or emergency hospital, exceed the average monthly cost of services for all persons with developmental disabilities who reside in state hospitals.[113]

At face value, this provision prohibits the cost of community care facilities (such as group homes) from exceeding the average cost of DCs, and also bans operators of these facilities from charging the state more than they charge private-pay clients.

After the 1980s, the Legislature articulated the budgetary prudence principle with increasing specificity. In 1992, for example, the Legislature mandated that the IPP team consider not only "the effectiveness of each [service]" option in meeting the goals stated in the individual program plan," but also "the cost-effectiveness of each option."[114] More than a decade later, during the Great Recession, the Legislature took further steps to ensure that RCs made every effort to reduce costs, specifying that consumers must receive services from "the least costly available provider of comparable service" so long as "use the least costly provider [does not] result in the

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[113] 1977 Cal. Legis. Serv. Ch. 4552 § 550 (codified at CAL. WELF. & INST. CODE § 4682 (2019)).

[114] 1992 Cal. Legis. Serv. Ch. 1011 § 4.5 (S.B. 1383) (emphasis added) (codified at CAL. WELF. & INST. CODE § 4512(b) (2019)); *see also Id.* § 10.5 (codified at CAL. WELF. & INST. CODE § 4646 (2019)) ("[T]he provision of services to consumers and their families [must] be effective in meeting the goals stated in the individual program plan.").

consumer moving from an existing provider of services or supports to more restrictive or less integrated services or supports."[115]

Importantly, however, the budgetary prudence requirement is not synonymous with cost minimization. State regulations implicitly draw this distinction by defining the term "cost effective" not as securing a service at the lowest possible cost, but rather as "obtaining the optimum results for the expenditure."[116] The California Court of Appeal explicitly distinguished the two concepts in a 2004 decision, opining that "[c]ost-effectiveness is not the same thing as cost [under the Lanterman Act]. Thus, this does not mean the cheapest service always has to be used. If one service costs twice as much as another but is three times as effective (assuming some suitable measure of effectiveness), all else being equal, it is to be preferred."[117]

In short, the budgetary prudence requirement has evolved somewhat since the Act's passage. The original Act did not impose clear limits on the acceptable level of expenditure in individual cases. Over time, however, the Legislature has increasingly urged RCs to take cost into account during the IPP process. Although budgetary prudence does not imply that the RC must always select the least costly option, it does require the IPP team to exercise reasonable restraint and prudence by prioritizing those choices that are not only consistent with needs-based individualization, but also help to conserve the state's limited budgetary resources.

C. Exhaustion of Generic Resources

The third and final component of the cost effectiveness principle is the idea that consumers must access all "generic" resources—i.e., those available from school districts, private insurers, and agencies tasked with serving the general public[118]—before receiving purchase of service (POS) funds from their RCs. Although we refer to this principle as generic resource exhaustion, it is essentially synonymous with the idea that the state should be the "payor of last resort." [119]

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[115] 2009 Cal. Legis. Serv., 4th Ex. Sess. Ch. 9 § 10 (A.B. 9) (codified at CAL. WELF. & INST. CODE § 4648(a)(6)(D) (2019)).

[116] CAL. CODE REGS. tit. 17, § 58501(a)(6) (2019).

[117] J.K. v. Office of Admin. Hearings, No. E034431, 2004 WL 2713269, at *11 n.6 (Cal. Ct. App. 4th Nov. 30, 2004).

[118] "Generic agency" means any agency which has a legal responsibility to serve all members of the general public and which is receiving public funds for providing such services," *see* CAL. WELF. & INST. CODE § 4659.7 (2019). An example of a generic agency is the California Department of Health Care Services ("DHCS"), which provides the generic resource of Medi-Cal.

[119] *See, e.g.*, J.K. v. Office of Admin. Hearings, 2004 WL 2713269, at *11 (noting that consumers' entitlement to choose their own services is subject to "the state's role as the payor of last resort").

The mandate to exhaust generic resources has been a feature of the Lanterman Act since its inception.[120] A 1969 study of the first two pilot RCs, for example, described their primary role as helping individuals with I/DD identify, access, and exhaust generic resources.[121]

Amendments to the Act passed in 1977 made the generic resource exhaustion requirement explicit, stating that "services shall, inasmuch as feasible, be provided by appropriate generic agencies . . . In no case, shall regional center funds be used to supplant funds budgeted by any agency which has a responsibility to provide prevention services to the general public."[122]

Confronting a financial crisis in the 1980s, the Legislature reemphasized RCs' duty to exhaust generic resources:

> [Regional Centers must] identify and pursue all possible sources of funding for developmentally disabled persons receiving regional center services. These sources shall include, but not be limited to [g]overnmental or other entities or programs required to provide or pay the cost of providing services, including Medi-Cal, Medicare, the Civilian Health and Medical Program for Uniform Services, school districts, and federal supplemental security income and the state supplementary program [and p]rivate entities, to the maximum extent they are liable for the cost of services, aid, insurance, or medical assistance to the client.[123]

The budgetary effects of the Great Recession spurred further revisions to the generic resource exhaustion mandate. In 2008, the Legislature required RCs to establish an internal process to ensure "[u]tilization of generic services and supports when appropriate."[124] The following year, the Legislature instructed RCs "not [to] purchase any service that would otherwise be available from Medi-Cal, Medicare, the Civilian Health and Medical Program for Uniform Services, In-Home Support Services, 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."[125] In anticipation of potential disputes over whether generic resources had in fact been exhausted, the Legislature created an interagency dispute resolution process, including an appeals provision that elevated disputes to the director of the Office of Administrative Hearings.[126]

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[120] CAL. WELF. & INST. CODE § 4659 (2017).

[121] REGIONAL CENTERS 1969, *supra* note 15, at 2.

[122] 1977 Cal. Legis. Serv. Ch .1252 § 550 (codified at CAL. WELF. & INST. CODE § 4644(a) (2019)).

[123] 1984 Cal. Legis. Serv. Ch. 1137 § 3 (codified at CAL. WELF. & INST. CODE § 4659(a) (2019)).

[124] 2008 Cal. Legis. Serv. Ch. 758 § 21.5 (codified at CAL. WELF. & INST. CODE § 4646.4(a)(2) (2019)).

[125] 2009 Cal. Legis. Serv., 4th Ex. Sess. Ch. 9 § 15 (A.B. 9) (codified at CAL. WELF. & INST. CODE § 4659(c) (2019); *see also id.* (codified at CAL. WELF. & INST. CODE § 4659(d)(1) (2019)) (applying same restrictions to medical and dental services).

[126] *See* 2009 Cal. Legis. Serv. Ch. 84 § 1 (A.B. 140) (codified at CAL. WELF. & INST. CODE §§ 4659.5-59.24 (2019)).

State regulations go to great lengths, however, to ensure the generic resource exhaustion requirement does not jeopardize consumers' capacity to obtain the services and supports to which they are entitled under the Lanterman Act. First, the regulations place the onus on regional center staff to "assist persons with developmental disabilities and their families in securing those services and supports which maximize opportunities and choices for living, working, learning, and recreating in the community,"[127] including engaging in "advocacy to assist persons in security income maintenance, educational services and other benefits to which they are entitled."[128] Service coordinators' responsibilities include "securing, through purchasing or by obtaining from generic agencies or other resources, services and supports specified in the person's individual program plan."[129] In addition, the regulations specify that as the payers of last resort, RCs must "ensure that no gaps occur in communication or provision of services and supports."[130] In effect, then, regional centers' role in implementing the generic resource exhaustion mandate is two-fold: they must assist consumers in identifying and accessing generic resources, and they must "gap fund" any shortfalls in services and supports,[131] unless and until generic resources are fully in place.

In short, the generic resource exhaustion mandate complements the demonstrable efficacy and budgetary prudence requirements in an important way. By formalizing the state's role as the payor of last resort, it places the onus on RCs to ensure that the state does not fund services or supports to individuals with I/DD that other public or private entities would otherwise provide.

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[127] CAL. WELF. & INST. CODE § 4640.7(a) (2017).

[128] *Id.* § 4685(c)(1).

[129] *Id.* § 4647(a); *see also id.* § 4640.7(b) (noting that "each consumer shall have a designated service coordinator who is responsible for providing or ensuring that needed services and supports are available to the consumer").

[130] *Id.* § 4501.

[131] RCs' "gap funding" role was weakened by 2009 budget cuts and the addition of CAL. WELF. & INST. CODE § 4659(d)(1) (adding additional restrictions on RC purchasing of medical or dental services"). These restrictions reportedly had a negative effect on equity because as a practical matter, cultural or socioeconomic factors made it very difficult for some families to pursue an appeal with the generic agency as a condition of receiving RC funding, *see* EVELYN ABOUHASSAN, DISABILITY RIGHTS CAL., ASSEMBLY BUDGET SUBCOMMITTEE #1: HEALTH AND HUMAN SERVICES 8 (Mar. 1, 2017) (stating "[t]he unintended consequence is that low-income families that use Medi-Cal do not have the time, resources or skills to appeal an adverse Medi-Cal decision and thus forego the service").

VI. Reconciling Doctrinal Tensions: A Proposed Framework

The needs-based individualization principle and the cost effectiveness principle provide useful guidance on how the Lanterman Act entitlement should be construed. The difficult question, however, is which principle should prevail when they are in tension. This question is particularly urgent in light of the core challenge of the I/DD system, mentioned at the outset, of funding an open-ended entitlement system on a fixed budget.

In this section, we propose a doctrinal framework for reconciling these two principles when they conflict. We propose that courts begin with the presumption that consumers are only entitled to appropriate services and supports that are "cost-effective" in the sense described above, meaning that they are demonstrably efficacious, promote budgetary prudence, and exhaust generic resources. However, this presumption is not ironclad. If the consumer can demonstrate that withholding a service or support that fails the cost effectiveness principle would violate needs-based individualization, the RC must provide it absent a clear statutory directive to the contrary. If regional centers' budgetary resources are insufficient to accomplish these goals, DDS is required, at regional centers' behest, to request additional legislative appropriations.

We believe this doctrinal framework accords well with the reasoning and holdings of most cases and publicly-available OAH opinions on the meaning of the Lanterman Act.[132] First and foremost, it is consistent with the holding of *ARC v. DDS*, the landmark 1985 case that upheld consumers' rights to needs-based individualization. In response to budget cuts in fiscal year 1982–83,[133] DDS instructed RCs to eliminate particular categories of services that it deemed nonessential.[134] The ARC and other I/DD advocacy organizations challenged DDS's action, which it alleged was undertaken without regard for consumers' individual needs as specified in their IEPs.[135] The California Supreme Court held, in effect, that the principle of needs-based individualization overrode DDS's desire not to exceed its budget.[136] As the court explained:

> The Act defines a basic right and a corresponding basic obligation: the right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services . . . By requiring the regional centers in effect to cut back on services by category without regard to

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[132] As noted in another report, despite the legislative mandate that OAH opinions be publicly available, only a small fraction are available online, *see* LANTERMAN TRANSPARENCY & ACCOUNTABILITY REPORT, *supra* note 7, at § IV.C.(1).

[133] LANTERMAN PRIMER, *supra* note 4, § IV.B. Figure 5.

[134] Ass'n for Retarded Citizens v. Dep't of Developmental Servs., 38 Cal. 3d 384, 390–1 (1985).

[135] *Id.* at 391-92.

[136] *Id.* at 393–95.

> the individual client's IPP, the [funding cuts] would have vitiated the IPP procedure, and with it the rights and obligations the Act defines.[137]

The court went on to explain that although RCs had "'wide discretion' in determining how to implement the IPP," "they [had] no discretion at all in determining whether to implement it: they must do so."[138] Thus, DDS's authority was "basically limited to promoting the [budgetary] cost-effectiveness of the operations of the regional centers."[139] The court held that "so long as funds remain, the right [to such services] must be implemented in full."[140] Only if the Legislature were to eliminate a particular service, or withhold necessary funding, could DDS deny a consumer services specified in his/her IPP.[141] In other words, consumers' entitlement to needs-based individualization cannot be infringed upon by DDS without an express legislative directive to that effect. In the case of a budgetary shortfall, the court instructed DDS to seek "relief from the Legislature, which could . . . resolve[] the crisis by appropriating more funds or reducing the entitlement by amending the Lanterman Act," not by "administratively altering the Act to give developmentally disabled persons [some]thing less than [what] the Legislature provided."[142]

In the subsections that follow, we show that numerous lower-court cases and HO opinions are consistent with the doctrinal framework we propose. To guide our analysis, we consider, in turn, conflicts between needs-based individualization and each of the three key tenets of cost-effectiveness: demonstrable efficacy, budgetary prudence, and generic resource exhaustion.

A. Reconciling Needs-Based Individualization and Demonstrable Efficacy

In considering conflicts between needs-based individualization and demonstrable efficacy, HOs generally focus the factual inquiry on whether depriving the consumer of the service or support in question would preclude him/her from achieving the goals specified in his/her IPP. If the consumer can prove that the answer is yes—for example, by showing that a particular service is

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[137] *Id.* at 391-92; *see also* CAL. WELF. & INST. CODE § 4501 (2017) (noting "The State of California accepts a responsibility for persons with developmental disabilities . . . [to provide a]n array of services and supports . . . which is sufficiently complete to meet the needs and choices of each person with developmental disabilities"); *see also* Williams v. Cal., 764 F.3d 1002, 1004-5 (9th Cir. 2014) (emphasis added) (explaining that the Lanterman Act establishes a system whereby "regional centers are responsible for locating developmentally disabled persons, assessing their needs, and—*on an individual basis*—selecting and providing services to meet such needs"); *see also* Marvin R. v. N.L.A. Reg'l Ctr., No. N-9512031, at 6 (OAH Jan. 11, 1996) (ordering a RC to provide 40 hours of independent living services listed in the claimant's IPP because, "in order to preserve the sanctity of the IPP process, the [RC] [was] mandated to assure that each individual client's program plan [was] carried out").

[138] Ass'n for Retarded Citizens, 38 Cal.3d at 390.

[139] *Id.* at 389.

[140] *Id.* at 393.

[141] *Id.* at 395.

[142] *Id.*

clinically effective, or necessary to the particular consumer's health or well-being—HOs may overlook deficiencies in the demonstration of efficacy.

One highly publicized case that affirms this principle, *Benito R. v. East Los Angeles Regional Center*, unfolded in the wake of the 2009 amendments, discussed earlier, that banned RCs from purchasing therapeutic services that had not been "clinically determined or scientifically proven to be effective."[143] ELARC used the passage of these amendments as its basis for terminating a popular autism therapy called DIR/Floortime,[144] even though it had been funding this type of therapy for over a decade.[145] The RC argued that since there were no peer-reviewed journal articles supporting the treatment's efficacy, it was experimental and therefore outside the scope of services that a RC could lawfully provide.[146] Several affected consumers brought suit in Los Angeles Superior Court, arguing that DIR/Floortime had been proven to be "clinically effective," and therefore did not meet the statutory definition of "experimental."[147] In June of 2010, the court approved a final settlement agreement and enjoined the RC from continuing to withhold the treatment.[148]

In 2016, a HO ordered the Regional Center of the East Bay to provide additional staffing to facilitate a cannabis oil treatment, an experimental medical procedure that had been prescribed by the consumer's neurologist and also was called for in his IPP.[149] Because the consumer's ICF refused to allow him to receive the treatment on its premises, the consumer sought RC funding for his transportation to, and support at, an off-site treatment facility.[150] Since it was undisputed that the cannabis treatment was experimental, the request at least arguably violated the

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[143] *See supra* Section VI.A.

[144] *See* Benito R. v. E.L.A. Reg'l Ctr., No. BC429819 2010 Cal. Super. Ct. WL 283468, at 2 (Cal. App. Dep't Super. Ct. Jan. 14, 2010) (complaint for injunctive and declaratory relief) (noting "Defendants [ELARC] now…deny these children access to DIR treatment services based on a misapplication of the so called 'Trailer Bill'…[e]ffective August 1, 2009"); *see also What is Floortime?*, INTERDISCIPLINARY COUNCIL DEVELOPMENTAL LEARNING, http://www.icdl.com/floortime (last visited Mar. 27, 2019).

[145] *Court Orders Reinstatement of Treatment for Children with Autism*, PUB. COUNSEL (June 22, 2010), http://www.publiccounsel.org/press_releases?id=0005 (last visited Mar. 27, 2019).

[146] Alan Zarembo, *Preliminary settlement reached in autism lawsuit*, L.A. TIMES, June 18, 2010, https://www.latimes.com/archives/la-xpm-2010-jun-18-la-me-0618-autism-treatment-20100617-story.html. (last visited Mar. 27, 2019).

[147] Alan Zarembo, *Families of autistic kids sue over therapy's elimination*, L.A. TIMES, Jan. 14, 2010, https://latimesblogs.latimes.com/lanow/2010/01/families-of-autistic-children-in-la-county-sue-over-elimination-of-therapy.html. (last visited Mar. 27, 2019).

[148] *See* Benito R. v. E.L.A. Reg'l Ctr., 2010 WL 283468 (proposed settlement agreement and order for final injunction); *see also* Alan Zarembo, *State funding reinstated for autism treatment*, L.A. TIMES, Sept. 13, 2010, https://latimesblogs.latimes.com/lanow/2010/09/autism-treatment-austic-children-lawsuit-settlement.html (last visited Mar. 27, 2019); *see also Children with Autism Regain Important Therapy Through Class Action Lawsuit*, PUB. COUNSEL, http://www.publiccounsel.org/stories?id=0024 (last visited Mar. 27, 2019).

[149] Claimant v. Reg'l Ctr. of the E. Bay, No. 2016030502, at 2 (OAH May 5, 2016).

[150] *Id.*

demonstrable efficacy requirement.[151] Nevertheless, the HO held that because the treatment was "necessary for [the consumer's] well-being," his RC must fund 70 hours of one-on-one aide.[152]

OAH adjudication of several RC denials of requests for vision therapy displays a similar pattern. Consumers who could not persuade the HO that the requested therapy was efficacious, or that withholding it would violate needs-based individualization, lost their appeals. For example, in a consolidated case concerning identical twins with autism, OAH upheld a decision by Alta California Regional Center (ACRC) to deny vision therapy services because the claimants failed to prove that vision therapy was "clinically determined or scientifically proven" to treat their autism.[153] Although the consumers did present a supporting optometrist's letter and several articles on vision therapy, many of the articles were not specific to autism, and they presented no expert testimony to counter ACRC's claim that vision therapy services were not evidence-based.[154] In another case involving Kern Regional Center, the HO similarly denied the claimant's request for vision therapy services because although she presented a letter from her treating optometrist recommending vision therapy and describing her progress, the articles she presented were incomplete, and she presented no expert testimony to explain why the therapy was warranted in her case despite its experimental nature.[155] Yet in three later appeals that also involved Kern Regional Center, the HO overturned the RC's denial of the claimants' requests for vision therapy in reliance on testimony from the claimants' respective optometrists delineating the causal connection between each claimant's particular constellation of impairments and his/her need for the therapy.[156]

These decisions underscore that in order to prevail in a dispute with a RC, a consumer must present evidence showing the likely efficacy of a requested service or support in ameliorating his/her specific developmental disability or impairment(s). Expert testimony that lays out in a highly particularized fashion why the form of treatment requested will address the claimant's unique limitations or challenges can be especially helpful. If a consumer can show that a requested service is the only option consistent with needs-based individualization, some HOs may be willing to authorize it even if it does not entirely comport with the demonstrable efficacy requirement.

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[151] 2009–10 Cal. Legis. Serv., 4th Exec. Sess. Ch. 9 § 10 (A.B. 9) (codified at CAL. WELF. & INST. CODE § 4648(a)(16) (2019)).

[152] Claimant v. Reg'l Ctr. of the E. Bay, at 3.

[153] Claimant 1 v. Alta Cal. Reg'l Ctr. & Claimant 2 v. Alta Cal. Reg'l Ctr., No. 2014050009, 2014050012, at 9 (OAH June 27, 2014).

[154] *Id.*

[155] B.I. v. Kern Reg'l Ctr., No. 2013010953, at 2 (OAH May 28, 2013).

[156] *See* Claimant v. Kern Reg'l Ctr., No. 2015030191 (OAH June 10, 2015); *see also* Claimant v. Kern Reg'l Ctr., No. 2015031097 (OAH July 20, 2015); *see also* Claimant v. Kern Reg'l Ctr., No. 2015041093 (OAH Sept. 17, 2015).

B. Reconciling Needs-Based Individualization and Budgetary Frugality

In this subsection, we consider situations in which a consumer's requested service or support, although consistent with needs-based individualization, appears to violate the budgetary prudence requirement. First, as background, we catalogue the Legislature's frequent inclusion of provisions allowing for individual exceptions in cases where it has categorically limited or eliminated certain services in response to fiscal crises. Secondly, we examine cases in which consumers sought exceptions to legislatively-mandated cost restrictions. Third, we consider situations in which consumers have sought exceptions to across-the-board spending restrictions imposed by DDS. Finally, we discuss cases in which consumers have challenged blanket spending cuts or restrictions imposed by RCs.

(1) Legislative Exceptions to Budgetary Frugality

In response to periodic fiscal crises (in 1983, 1991, 2002, and 2008), the Legislature has repeatedly trimmed "around the edges" of the Lanterman Act entitlement by reducing regional centers' operational budgets, freezing or reducing provider rates, and capping or eliminating certain service categories. In so doing, however, the Legislature has tried to avoid making categorical cuts, and even when such cuts could not be avoided, it has usually permitted exceptions to be made in cases of extraordinary need.

In response to a multi-billion-dollar budgetary shortfall in 1991–92, for example, Senate Bill 1045 authorized DDS to "temporarily adopt, amend, or suspend regulations as necessary to allow regional centers to implement their cost reduction plans," but specifically prohibited any actions that would "authorize categorical reductions in services."[157] Also in 1992, Senate Bill 485 made an unallocated cut to DDS' budget of $31.5 million[158] and realized cost savings (primarily) through reductions in RCs' OPS budgets[159] and a reduction in the required frequency of IPP meetings from annually to triennially.[160] Though consumers reportedly experienced less access

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[157] 1991 Cal. Legis. Serv. Ch. 93 § 2 (S.B. 1045) (codified at CAL. WELF. & INST. CODE § 4646(g) (2019)).

[158] 1992 Cal. Legis. Serv. Ch. 722 § 27 (S.B. 485) (codified at CAL. WELF. & INST. CODE § 4791 (2019)).

[159] According to DDS, RCs achieved reductions by increasing service coordinator-to-consumer ratios, lowering the qualifications for entry-level service coordinators, laying off or furloughing personnel, suspending salary increases, making fewer investments in staff training, consolidating or closing offices, and initiating other cost-cutting measures such as temporary office closures, reduced work weeks, and hiring freezes, *see* CAL. DEP'T DEVELOPMENTAL SERVS., CONTROLLING REGIONAL CENTER COSTS 36-37 (2007) [hereinafter CONTROLLING REGIONAL CENTER COSTS], http://www.dds.ca.gov/Publications/docs/ControllingRCCosts2007.pdf (last visited Jan. 16, 2019).

[160] 1991 Cal. Legis. Serv. Ch. 93 § 1 (S.B. 1045) (codified at CAL. WELF. & INST. CODE § 4646(e) (2019)).

to case managers, longer response times, and less careful monitoring of service delivery as a result,[161] their core entitlement to needs-based individualization was left intact.

The next round of cuts came in 2002–2004. Facing a new fiscal crisis, the Legislature considered a variety of reform proposals, such as establishing waiting lists for services; authorizing DDS to deny, modify, reduce, or terminate services to any consumer; and eliminating "non-core" services, such as respite and non-medical therapies.[162] The Legislature chose, instead, to reduce costs by modifying the eligibility standards and the intake process,[163] encouraging the movement of consumers from DCs into community-based residences,[164] freezing the development of new programs,[165] and increasing service coordinator caseloads.[166] To justify this approach, the Legislature explained that "even when the state faces an unprecedented fiscal crisis, the services and supports set forth in the [Lanterman Act] shall continue to be provided to individuals with developmental disabilities in accordance with [*ARCv. DDS*]."[167] Facing continued deficits in 2004, the Legislature considered authorizing DDS to promulgate statewide POS standards that would have established categorical limits, including outright prohibitions, on certain POS expenditures.[168] DRC vigorously opposed the proposal on the grounds that it "would compromise the integrity of the Lanterman Act by negating the Act's core right of each person with a developmental disability to individualized service determinations allowing him or her to receive the supports needed to be integrated into the mainstream of community life."[169]

Ultimately, the Legislature opted not to enact the POS service standards, and instead to create a new program called the Family Cost Participation Program (FCPP). Under FCPP, families

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[161] *Oversight Hearing of the S. Budget Subcomm: # 3 on Health, Human Servs. and Labor*, 1992 Leg. (1992) (statement of Dir. Dennis Amundson, Dir. Cal. Dep't Developmental Servs.), http://www.dds.ca.gov/Publications/HistoricPub/1992_TestimonyOversightHearingSenateBudget.pdf (last visited Jan. 16, 2019).

[162] CONTROLLING REGIONAL CENTER COSTS, *supra* note 159, at 44.

[163] For the first time, the Legislature explicitly defined "substantial disability," moving the determination from a subjective assessment to an objective one in which consumers needed to demonstrate a minimum of three significant functional limitations among seven enumerated major life activities," *see* 2003 Cal. Legis. Serv. Ch. 230 § 46 (A.B. 1762) (codified at CAL. WELF. & INST. CODE § 4512(l) (2019)); *see also* 2002 Cal. Legis. Serv. Ch. 1161 § 32 (A.B. 442) (codified at CAL. WELF. & INST. CODE § 4643(a) (2019)) (lengthening initial eligibility assessment period from 60 to 120 days).

[164] 2002 Cal. Legis. Serv. Ch. 1161 § 28 (A.B. 442) (codified at CAL. WELF. & INST. CODE § 4418.25 (2019)).

[165] 2002 Cal. Legis. Serv. Ch. 1161 § 34 (A.B. 442) (codified at CAL. WELF. & INST. CODE § 4781.5(b) (2019)).

[166] *See* 2003 Cal. Legis. Serv. Ch. 230 § 49 (A.B. 1762) (codified at CAL. WELF. & INST. CODE §§ 4640.6(c)(3)–(4) (2019)).

[167] 2002 Cal. Legis. Serv. Ch. 1161 § 30.5 (A.B. 442) (codified at CAL. WELF. & INST. CODE § 4631.5(a)(2) (2019)).

[168] *See* Memorandum from Prot. & Advocacy, Inc. to Interested Persons 4–8 (Apr. 14, 2004) (on file with authors).

[169] *Id.* at 1.

whose incomes are greater than 400% of the federal poverty level (FPL) and whose children do not receive Medi-Cal are required to share the cost of certain services (respite, day care, and camp) purchased by RCs.[170] Since the establishment of the FCPP program, IPP teams may no longer include these three services in the IPPs of minor consumers whose families meet these criteria unless the families agree to pay their share of the costs. This arrangement is arguably in keeping with Lanterman's original goal of sharing responsibility between the state and families.

Importantly, the amendment includes an exception for cases of demonstrated hardship,[171] and the enacted version is far narrower than many of the versions that were originally proposed. Moreover, the FCPP is limited in scope to a few services, and the financial burden it imposes is, by design, concentrated on families with the greatest means to share costs with the state.[172]

During and immediately after the Great Recession, the Legislature once again sought to impose massive budgetary cuts, this time totaling approximately $1 billion.[173] Rather than adopt broad programmatic cuts, the Legislature enacted a series of cuts from 2008–2013 that included reductions in OPS funding,[174] a uniform holiday schedule for service providers,[175] and limited access to certain services and supports.[176] These cutbacks were the most serious ones that have been undertaken to date. With one exception,[177] however, the Legislature specified that these service cutbacks could be overridden if a consumer's goals and needs necessitated that (s)he receive otherwise unavailable services or supports.[178] For example, although the Legislature

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[170] 2004 Cal. Legis. Serv. Ch. 228 § 9 (S.B. 1103) (codified at CAL. WELF. & INST. CODE § 4783(a)(1) (2019)).

[171] *Id.* (codified at CAL. WELF. & INST. CODE § 4783(g)(5) (2019)).

[172] *Id.* (codified at Cal. WELF. & INST. CODE § 4783(c) (2019)).

[173] FRANK D. LANTERMAN REG'L CTR., STRENGTHENING THE COMMITMENT . . . REINVESTING IN THE SYSTEM: A JOURNEY OF COMMUNITY PARTNERSHIP 33-34 (2016), https://lanterman.org/uploads/info_resources_general/Lanterman-50thHistory-r6(Blue)(web)_final.pdf (last visited Jan. 16, 2019) (totaling $344 million in FY 2009–10, $251.2 million in FY 2010–11, $339.8 million in FY 2011–12, and $100 million in FY 2012–13).

[174] *See* CAL. WELF. & INST. CODE § 4791 (2017) (RCs permitted to temporarily modify personnel and staff training requirements, as well as progress reporting requirements, for providers, including community–based day programs and in–home respite agencies); *see also* CAL. WELF. & INST. CODE § 4640.6(i)-(j) (2017) (service coordinator caseload ratios suspended from Feb. 1, 2009 – June 30, 2010, and again from July 1, 2010 – June 30, 2013).

[175] *See* 2009 Cal. Legis. Serv. 4th Ex. Session Ch. 9 § 26 (A.B. 9) (codified at CAL. WELF. & INST. CODE § 4692(a) (2019)).

[176] *See id.* § 10 (A.B. 9) (codified at CAL. WELF. & INST. CODE § 4648(a)(15) (2019); *see also id.* § 12 (codified at CAL. WELF. & INST. CODE § 4648.35 (2019)); *see also id.* § 13 (codified at CAL. WELF. & INST. CODE § 4648.5(a) (2019)); *see also id.* § 17 (codified at CAL. WELF. & INST. CODE § 4685(c)(3)(B) (2019)); *see also id.* § 19 (codified at CAL. WELF. & INST. CODE § 4686.2 (2009)); *see also id.* § 20 (codified at CAL. WELF. & INST. CODE § 4686.5 (2019)).

[177] The Legislature did not provide any exception to the prohibition against paying for experimental treatments.

[178] *See supra* note 176 and accompanying text.

required consumers to use the “least costly available provider of a comparable service,”[179] it also emphasized that “[t]he consumer shall *not* be required to use the least costly provider if it will result in the consumer moving from an existing provider of services or supports to more restrictive or less integrated services or supports.”[180] During this round of cutbacks, the only instance in which no provision was made for exceptions was the ban on experimental treatments.

In short, the history of legislative cutbacks since the passage of the Lanterman Act is broadly consistent with our proposed doctrinal framework. The Legislature’s decisions regarding which services to cut in response to acute budgetary pressure evinces a clear intent to preserve the core principle of needs-based individualization. In most cases, the Legislature has resisted categorical cuts in POS expenditures, and sought instead to reduce operational costs. In situations where POS expenditures have been trimmed, the Legislature has nearly always allowed exceptions to be made for consumers whose needs are particularly acute or compelling.

(2) Administrative and Judicial Exceptions to Budgetary Frugality

Since the inception of the Lanterman Act, the three state entities with decision-making authority over the allocation of resources—the Legislature, DDS, and RCs—have sought to stay within a fixed budget by minimizing costs. Whether by statute, regulation, or agency rule, each entity has periodically imposed restrictions on certain types of expenditures, such as specifying which consumers can receive them or how much money may be spent. Although such restrictions are intended to further the goal of budgetary prudence, their enforcement arguably violates the Lanterman Act, at least in certain cases, by infringing on the principle of needs-based individualization. Examining how courts and HOs have resolved such conflicts provides useful insight into the rules of decision that have animated judicial and administrative adjudication of Lanterman Act disputes.

i. ***Challenges to Statutory Spending Cuts***

The first group of cases, pertaining to legislatively-imposed restrictions on spending, concerns Section 4682 of the Lanterman Act, which we also discuss in a separate report.[181] The plain language of the statute declares that the cost of out-of-home (facility-based) care may not exceed the average monthly cost of supporting consumers in DCs. It does not provide for any individual exceptions. Yet HOs have sometimes found that in exceptional cases, needs-based individualization justifies waiver of the cost-equivalency requirement.

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[179] 2009 Cal. Legis. Serv. 4th Ex. Sess. Ch. 9 § 10 (A.B. 9) (codified at CAL. WELF. & INST. CODE § 4648(a)(6)(D) (2019)).

[180] *Id.* (emphasis added); *see also* 2010 Cal. Legis. Serv. Ch. 717 § 137 (S.B. 853) (codified at CAL. WELF. & INST. CODE § 4791(b)(2) (2019)).

[181] LANTERMAN PRIMER, *supra* note 4, § IV.B.

The first case, *Amy N. Headley v. NBRC*, was decided in 1990. The claimant, who had suffered significant brain damage, challenged North Bay Regional Center's denial of funding for her out-of-home placement and treatment at the Centre for Neuro Skills. The HO held that because the costs for maintaining the claimant at that facility "far exceed[ed] rates" under the section 4682 cap, the RC was not required to fund the placement.[182]

A more recent challenge to the same provision, *Samantha S. & DDS v. ELARC*, was decided in 2011. The claimant contested East Los Angeles Regional Center's denial of funding for an assessment at the Kennedy Krieger Institute (KKI) Neurobehavioral Unit in Baltimore, Maryland. She was aging out of her current placement and her RC had struggled to find an acceptable placement because her severe developmental and emotional issues put her at high risk of victimization. KKI was identified as a suitable placement, but it cost approximately $1.23 million per year, compared to an average annual cost of $307,000 at a DC. The HO held that legislative cost caps such as section 4682 were invalid in cases where they conflicted with needs-based individualization. Finding that KKI was the "undisputed" sole appropriate treatment option, the HO opined further that:

> [the notion] that costs must dictate the determination of placement of a consumer in the proper and appropriate setting is unsupported by statue or regulation . . . [and] defeats the intent of the Legislature to ensure that the provision of service and supports by the regional center system is centered on the individual with developmental disabilities.[183]

Although the case was ultimately resolved on narrower grounds—namely, that section 4682 did not even apply because DDS rather than ELARC was in charge of the service determination—the opinion buttresses the idea that even an express, statutory cost cap will not necessarily be treated as binding if a consumer can prove that the requested service or support is the *only* one that satisfies the principle of needs-based individualization.

ii. ***Challenges to Blanket Spending Cuts Imposed by DDS***

The second cluster of judicial and administrative decisions concern uniform cost caps or restrictions imposed by DDS. The first and most important case in this group is, of course, *ARC v. DDS*, decided by the California Supreme Court in 1985. As discussed earlier, the court held that DDS's attempt to apply across-the-board limits on POS expenditures violated the Lanterman Act.

Two more recent cases shed additional light on how conflicts between DDS-imposed cost-cutting measures and needs-based individualization are to be resolved. In *Harbor Regional*

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[182] Shawn M. v. Reg'l Ctr. of Orange Cty., No. 5A CV 00-929 GLT, at 5 (S.D. Cal. Jan. 11, 2001) (holding that section 4682 did not violate the *Olmstead* integration mandate because it was a "nondiscriminatory means of allocating limited funds among the state's population of disabled persons").

[183] Samantha S. v. E.L.A. Reg'l Ctr., No. 2011110426, at 18 (OAH Dec. 20, 2011).

Center v. Office of Administrative Hearings, a California Court of Appeal upheld the HO's determination that an exception to DDS's standard rate for in-home care was necessary to meet the needs of Hannah, a child with a rare degenerative disease. Hannah's mother had challenged the RC's refusal to increase the rate paid to her in-home care providers because of rate cap imposed on this form of care.[184] The court agreed with the HO that Hannah was "a severely disabled child with extraordinary needs that [could] be attended to at home only through the unique program [her mother] has devised, and only by a select few who [were] willing to commit to, and [were] able to bond with, Hannah."[185] The court went on to explain that, although "the rate-setting provisions of the Lanterman Act [were] designed to let DDS set rates for the general population of persons receiving services under the Act,"[186] OAH had "the power to order deviations from DDS established pay rates on an individual basis when warranted by unusual circumstances."[187] Relying on this authority, the court held that exceeding the cost caps

> [was] the only way that Hannah [could] receive the services she needs and to which she [was] legally entitled, and [was] fully in line with the high priority the Act places on keeping disabled children at home, and its mandate to be flexible and creative and consider every possible way of doing so.[188]

Importantly, in upholding the HO's decision, the appellate court relied not only on the general principle of needs-based individualization, but also on the value of home preservation.[189]

Similarly in *J.K. v. OAH*, a California appellate court overruled a superior court decision upholding Inland Regional Center's narrow interpretation of DDS Regulation 58613,[190] which limits the provision of SLS to consumers living in their own homes. [191] The RC had refused to provide the claimant with SLS because it did not consider leased space in her parents' home to be a Regulation 58613-compliant living situation. Although the superior court agreed, the court of appeal reversed, opining that the RC's and superior court's interpretations of the regulation were unduly narrow in light of "the substantial evidence that J.K. needed the proposed services."[192]

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[184] Harbor Reg'l Ctr.v. Office of Admin. Hearings, 210 Cal. App. 4th 293, 315 (Ct. App. 2012).

[185] *Id.* at 312.

[186] *Id.* at 313.

[187] *Id*. at 315.

[188] *Id*. at 313.

[189] *See also* Clemente v. Amundson, 60 Cal. App. 4th 1094, 1106-07 (Ct. App. 1998) (holding that neither the parental day care co-payment requirement, nor the mandate to utilize alternative funding sources, authorized DDS and RCs to impose parental co-payment for respite care because doing so would be contrary to "the remedial purpose of the Lanterman Act to provide at state expense a broad spectrum of treatment, habilitation and supports to enable developmentally disabled individuals to live in the least restrictive environment possible").

[190] CAL. CODE REGS. tit. 17, § 58613 (2019).

[191] J.K. v. Office of Admin. Hearings, No. E034431, 2004 WL 2713269, at *8 (Cal. Ct. App. Nov. 30, 2004).

[192] *Id*. at *11.

Numerous other OAH decisions have relied on similar reasoning to grant exceptions to cost-cutting restrictions imposed by DDS. For example, a cluster of HO decisions have used principles of needs-based individualization to justify non-enforcement of Regulation 58617, which mandates that the annual cost of supportive living services not exceed the total cost of care in a licensed residential facility.[193] In *Russell v. RCEB*, the HO held that to interpret the regulation as an "absolute bar to funding of claimant's SLP" would violate the Lanterman Act, because the Act "contemplate[d] that services for each client will be selected and provided on an individual basis."[194] The high cost of the proposed supportive living plan, which all parties agreed would meet the claimant's needs and goals, was held an insufficient ground on which to base a denial.[195] The holdings and reasoning of several other OAH opinions—*Claimant v. Tri-Counties Regional Center,*[196] *Marvin R. v. North Los Angeles Regional Center,*[197] *and Randy M. v. North Bay Regional Center*[198]—are closely analogous. Although California courts have never ruled on the question, DRC has further argued that the regulation is invalid on its face.[199]

iii. *Challenges to Blanket Spending Cuts Imposed by Regional Centers*

The final and largest cluster of decisions addressing the tension between budgetary prudence and needs-based individualization involves challenges to cost-saving restrictions or policies imposed by RCs. Although a few such cases have been appealed to state appellate courts, most ended in a decision by a HO.

In *Williams v. Macomber*, the parents of a child with disabilities challenged the RC's policy of refusing day-care services to children with working parents. The court of appeal first explained that the RC's "denial of the requested services on the basis of a general policy against providing day-care services to clients with working parents [could not] be reconciled with the requirements of the Lanterman Act . . . that . . . services . . . provided each client . . . be selected on an individual basis."[200] Citing evidence that the family "had been forced to consider an out-of-home

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[193] CAL. CODE REGS. tit. 17, § 58617 (2019).

[194] Russell v. Reg'l Ctr. of the E. Bay, No. N2000070115, at *10 (OAH Oct. 20, 2000).

[195] *Id.*

[196] Claimant v. Tri-Ctys. Regional Center, No. L-1997120340 (OAH Jan. 28, 1998).

[197] Marvin R. v. N.L.A. Cty. Reg'l Ctr., No. N-9512031 (OAH Jan. 11, 1996).

[198] Randy M. v. Reg'l Ctr.of the E. Bay, No. N 20000020377 (OAH Mar. 28, 2000) (requiring that RCEB fund proposed SLS plan, despite plan's cost exceeding average cost of SLS services, because RCs were required to be "flexibl[e] in fashioning individualized support plans," and consumer's needs demanded higher expenditures).

[199] ANAHID HOONANIAN & ELLEN GOLDBLATT, PROT. & ADVOCACY, INC., PROTECTION & ADVOCACY INC.'S COMMENTS ON PROPOSED AMENDMENTS TO THE SUPPORTED LIVING REGULATIONS 7-10 (Aug. 28, 2005) (arguing that the regulation contravenes the Lanterman Act, and also violates the ADA as interpreted in the *Olmstead* decision) (on file with author).

[200] Williams v. Macomber, 226 Cal. App. 3d 225, 231-232 (Ct. App. 1990).

placement for [the child] because of the denial of day-care services,"[201] the court found that "by failing to determine whether day-care services were necessary to permit appellant to remain with her family," the RC had violated the principle of home preservation.[202] Holding that enforcement of an "inflexible policy denying [day care] services [was] contrary to the Act,"[203] the court remanded the case for further consideration of "[t]he extent to which day-care services [were] necessary to enable [the] child to remain at home."[204]

Similarly, in *Clemente v. Amundson*, an appellate court struck down a general RC policy that required families receiving respite care for children under 13 years of age to provide a $3 copayment for each hour of respite care they received.[205] Finding that neither a parental day care co-payment requirement, nor the mandate to utilize alternative funding sources, authorized RCs to impose parental co-payments for respite care, the court invalidated the policy as contrary to "the remedial purpose of the Lanterman Act to provide at state expense a broad spectrum of treatment, habilitation and supports to enable developmentally disabled individuals to live in the least restrictive environment possible."[206]

To be sure, not all state court decisions have prioritized the consumer's right to needs-based individualization over the RC's right to implement across-the-board cost-cutting measures. In *Nadina J. v. DDS*, for example, a consumer challenged Regional Center of the East Bay's denial of 24-hour nursing care because it conflicted with the RC's policy that the total monthly cost of services provided to a consumer not exceed the average cost of supporting the consumer in a DC, regardless of the level of individual need. In an opinion issued in 1980, a superior court judge upheld the HO's rejection of the claimant's challenge, reasoning that the RC's policy was a "reasonable means for achieving an equitable allocation of RCEB's limited financial resources among all of its clients."[207] Importantly, however, the superior court opinion seems to conflict with the reasoning and holding of *ARC v. DDS*, decided five years later, and therefore may no longer be good law.

The patterns observed in OAH decisions are very similar. By and large, these cases hold that the budgetary prudence requirement can be overridden if it conflicts with needs-based individualization. For example, in *Luis R v. Kearn Regional Center*, a HO explained that the RC could not limit service access "on the basis of an inflexible internal guideline," and required the

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[201] *Id.* at 233.

[202] *Id.*

[203] *Id.*

[204] *Id.* at 234.

[205] Clemente v. Amundson, 60 Cal. App. 4th 1094, 1100 (Ct. App. 1998).

[206] *Id.* at 1106.

[207] Nadina J. Riggsbee v. Cal. Dep't of Developmental Servs., No. 5276301, at 4 (Cal. App. Dep't Super. Ct. Feb. 27, 1980).

RC to fund sixty-five hours of ABA "to meet [the consumer's] unique developmental needs.[208] Likewise in *Francine F. v. San Diego Regional Center*, the HO required the RC to fund supplemental staffing for a consumer's day program even though doing so "[would] significantly increase. . . the monthly expense to the Regional Center."[209] The HO explained that, because there was "insufficient evidence to support a finding that claimant's acknowledged needs can and will be met in the [RC-proposed alternative] program," and because "the Lanterman Act clearly contemplates that the services to be provided to each client be selected on an individual basis," the RC had to fund services that exceeded the scope of its general POS policies. [210]

A particularly large cluster of OAH opinions that consider across-the-board restrictions on transportation funding have held that RCs must make exceptions if the transport is required to implement goals specified in the IPP. In *Jeffrey Z. v. San Diego Regional Center*, for example, the HO required the RC to fund the costs of transporting the consumer to his horseback riding and swimming activities notwithstanding the RC's general policy against funding transportation to social activities. The HO explained that enforcement of the policy in the claimant's circumstances would violate his right to individualized planning.[211] In *Timothy H. v. Regional Center of the East Bay,* parents successfully challenged the RC's refusal to transport their minor son to an extended day program. The HO explained that, because regression in the consumer's behavior would threaten his ability to remain at home, "[his] need for consistency of programming [was] to be treated with paramount importance."[212] In *Claimant v. San Gabriel/Pomona Regional Center*, a consumer at "significant risk of injury" without adapted transportation challenged the RC's refusal to fund a vehicle conversion. In ruling in the claimant's favor, the HO explained that because "polic[ies] established . . . to generally govern the provision of services may not take precedence over the established individual needs of the consumer," and because an inquiry rooted in needs-based individualization suggested the vehicle conversion was warranted, the RC must cover its cost.[213] Finally, in *Christopher C. v. San Diego Regional Center,* a minor consumer challenged the RC's decision, in accordance with its general policy, to deny transportation funding because he was not accompanied by an adult at all times.

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[208] Luis R. v. Kern Reg'l Ctr., No. 2012060529, at 6 (OAH Aug. 3, 2012).

[209] Francine F. v. San Diego Reg'l Ctr., No. L 2004080502, at 2 (OAH Jan. 18, 2005).

[210] *Id*. at 6; *see also* Spann v. Westside Reg'l Ctr., No. DDS1-1219, at 4 (OAH Feb. 10, 1994) (holding that RC could not deny service without first "consider[ing] the [consumer's] and the family's needs and circumstances, including the loss of child support and the mother's limited income"); *See also* Jon v. Reg'l Ctr.of the E. Bay, No. DDS1-456, at 4-5 (OAH Apr. 13, 1990) (finding that claimant's "extraordinary treatment needs" necessitated the funding of after-school program, despite general POS policy to the contrary); Christian F. v. E.L.A. Reg'l Ctr., No. 2012050975, at 3 (OAH Aug. 23, 2012) (granting exception to RC's policy that in-home respite only be used "when there [was] no out of home respite arrangement available" because consumer's unique needs required in-home respite in order to effectuate his entitlement to Home Preservation).

[211] Jeffrey Z. v. San Diego Reg'l Ctr., No. DDS1-156, at 3 (OAH Aug. 26, 1988).

[212] Timothy H. v. Reg'l Ctr. of the E. Bay, No. DDS1-673, at 3-4 (OAH Nov. 18, 1991).

[213] Claimant v. San Gabriel/Pomona Reg'l Ctr., No. 2014110364, at 5 (OAH Dec. 23, 2014).

The HO granted an exception because the RC's general policy erroneously presumed, "without considering the individual needs of each client," that no child could be transported safely on his or her own.[214] Since the RC's presumption was not supported by "competent evidence" in the consumer's case, its enforcement violated his right to individualized planning.[215]

When HOs have upheld a RC's enforcement of blanket cost-saving measures, they have generally done so on the ground that the consumer failed to prove that granting an exception was necessary to accomplish needs-based individualization. For example, in *Jordan M-P v. East Los Angeles Regional Center*, the HO found that although "services to be provided to any consumer of a regional center must be individually suited to meet the unique needs of the individual consumer in question," the RC's reliance on a blanket policy of denying in-home respite care did not violate needs-based individualization because the consumer failed to demonstrate that out-of-home respite services could not meet her needs.[216] In another case involving a dispute over respite hours, *Claimant v. Valley Mountain Regional Center*, the HO found that although RCs could not "deny a request for services based upon the application of an inflexible policy denying such services," the RC's formulaic POS guideline, which used an eight-factor Family Respite Needs Assessment to calculate the number of in-home respite hours for which each consumer qualified, was sufficiently detailed to satisfy needs-based individualization.[217] Finally, in *Frederick N., v. Regional Center of Orange County*, the HO denied a consumer's request that the RC fund a supported employment program at Goodwill because he did not indicate that work was available on his preferred terms, or that other day programs could not meet his needs.[218]

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[214] Christopher Collins v. San Diego Reg'l Ctr., No. DDS1-125, at 3-4 (OAH July 14, 1988).

[215] *Id.* at 3; *see also* Claimant v. Alta Cal. Reg'l Ctr., No. 2017080081 (OAH Nov. 22, 2017) (holding that RC had to reimburse parents for the cost of a van necessary to transport consumer even though they did not receive pre-approval from the RC to purchase the van, as per RC policy); *see also* Robert H. and Reg'l Ctr. of Orange Cty., No. 2011110920 (OAH Feb. 16, 2012) (holding that RC must fund cost of van conversion because RCs "cannot deny requested services and supports on the basis of a general policy not to provide such services and supports" as that "is inconsistent with the Lanterman Act's stated purpose to provide services…on an individual basis"); *see also* Claimant v. Golden Gate Reg'l Ctr., No. 2015050210 (OAH June 30, 2015) (holding that RC could not cap its funding of a consumer's van conversion at the "arbitrary" amount of $19,000, "even [if] [it] . . . had legitimate budgetary and fiscal reasons for doing so," although it was not "required to bear the full monetary brunt of the parents' decision to purchase a top-of-the-line minivan that require[d] the most expensive van conversion"); *See also* Claimant v. Harbor Reg'l Ctr., No. 2015020092 (OAH July 31, 2015) (requiring that HRC fund transportation for consumer because family had demonstrated that the requested option was the only means of meeting the consumer's unique needs); *See also* Samantha Blake v. San Diego Reg'l Ctr., No. DDS1-129 (OAH July 14, 1988) (holding that SDRC's policy of denying transportation services to unaccompanied minor children was invalid as applied to minor consumer who did not need accompaniment because cost-effectiveness did not always mean "least expensive or its equivalent," but instead that "services and supports [were] expected to be effective in meeting goals").

[216] Jordan M.-P. v. E.L.A. Reg'l Ctr., No. 2013040107, at 4, 6 (OAH May 23, 2013).

[217] Claimant v. Valley Mountain Reg'l Ctr., No. 2013100839, at 2-3, 9 (OAH Dec. 3, 2013).

[218] Frederick N., v. Reg'l Ctr. of Orange Cty., No. 2013080175, at 5-6 (OAH Oct. 3, 2013).

In short, our review of legislative enactments, court opinions, and administrative hearings suggests that conflicts between needs-based individualization and budgetary prudence have been resolved in a fairly consistent fashion by all three branches of government. In response to budget shortfalls that necessitated cutbacks in I/DD spending, the Legislature has repeatedly sought to cut systemic costs in ways that do not interfere with the core entitlement of the Lanterman Act, and has usually allowed exceptions to be made in cases of extraordinary need. Meanwhile, in situations where claimants have challenged blanket caps or restrictions on spending, state courts and HOs have usually been willing to grant exceptions where doing so was the only way to meet the goals specified in a consumer's IPP. Express statutory spending restrictions that do not provide for any exceptions are both rare and difficult for courts (and HOs) to disregard. Yet even here, at least one HO declined to enforce a legislatively-imposed restriction because as applied to a particular consumer, it violated the principle of needs-based individualization.

C. Reconciling Needs-Based Individualization and Generic Resource Exhaustion

Consumers have occasionally challenged a RC's denial of services in circumstances where the consumer declined to access a generic resource that, at least on its face, could provide an equivalent service or support. Review of these cases suggests that the operative question is whether the claimant, before requesting an exception, could prove that the generic resource was insufficient (in quality and/or quantity) to satisfy his/her right to needs-based individualization.

In *Claimant v. San Andreas Regional Center,* for example, the father of a boy with I/DD challenged the RC's reduction in respite hours from 150 to 24 hours per month.[219] Despite the child's demonstrated need for extensive respite care, the HO upheld the reduction in services because the father had repeatedly failed to follow through on his agreement to apply for IHSS.[220] Although the father expressed concern that IHSS could not fund a provider capable of handling his son's unique and severe self-destructive behaviors, he provided no evidence to support this claim.[221] The HO held that the father could not ask the RC to grant an exception without first demonstrating that the generic resource in question (IHSS) could not meet his son's needs.[222]

Where consumers have proven that the generic resource is insufficient or inadequate, HOs have often granted exceptions. In *Claimant v. Tri-Counties Regional Center*, for example, parents challenged the RC's refusal to fund extra speech and language therapy for their child.[223] The RC had based the denial "on the grounds that such services would supplant the budget of a

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[219] Claimant vs. San Andreas Reg'l Ctr., No. 2015030573 (OAH Sept. 11, 2015).

[220] *Id.* at 5.

[221] *Id.*

[222] *Id.*

[223] Claimant v. Tri-Ctys. Reg'l Ctr., No. DD7-0287-441, at 1 (OAH Mar. 10, 1987).

legally responsible agency [the school district]."[224] The HO held that the RC's withdrawal of supplemental therapy "was improper because the school district "provided services at a lower level than specified in the Act, and those services [were] insufficient to foster the developmental potential of the claimant."[225] In *Monica P. v. KRC*, a consumer similarly challenged the RC's denial of her request for mental health services because the same type of service was available through a generic resource. The HO held that because the "Lanterman Act requires funding decisions to focus on individual needs and on services and supports designed to meet specific needs," and because the consumer had shown that the mental health services available through the generic resource were ineffective, the RC had to continue providing the service in the form that had proven to be beneficial to the consumer.[226] Finally, in *Jon v. Regional Center of the East Bay,*[227] the HO required the RC to continue funding a consumer's extended day program despite the availability of IHSS funding. Because the claimant had a "need for extraordinary structure and training" and his day program was facing imminent risk of closure, the HO held that replacing the extended day program with IHSS would have a "serious detrimental impact" and would "likely cause regression in his skills and functioning."[228] In light of these unique circumstances, the HO ordered the RC to continue funding the program for one more year so that the claimant would have "time to adjust" to a new day program.[229]

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[224] *Id.*

[225] *Id*.

[226] Monica P. v. Kern Reg'l Ctr., No. 2013090421, at 4-6 (OAH Nov. 14, 2013).

[227] Jon v. Reg'l Ctr. of the E. Bay, No. DDS1- 456 (OAH Apr. 13, 1990).

[228] *Id.* at 2, 4.

[229] *Id.* at 4.

VII. Defining the Lanterman Act Entitlement in the Self-Determination Program

The term "self-determination" is often used synonymously, or nearly so, with the "consumer choice" principle described above as a key component of needs-based individualization.[230] In California, however, "self-determination" has recently taken on a more specialized meaning. In 2013, the Legislature passed the Self-Determination Program, which gives consumers (or their legal representatives) control over their individual budgets, including the discretion to decide for themselves which services and supports to purchase and from whom, as long as they are consistent with the Final Settings Rule.[231]

On October 1, 2018, the initial three-year transitional phase of the program started, with 2,500 randomly selected consumers being offered an opportunity to participate.[232] As of this writing, it is expected that after a three-year phase-in period, all RC consumers will have the option of joining the program.[233]

The doctrinal framework proposed here is likely to be less useful, or at least would apply very differently, to self-determined consumers. On one hand, the Self-Determination Program gives the consumer choice principle greater weight than it receives under the traditional system. This shift in decision-making power potentially could alter the way in which the needs-based individualization principle is understood. On the other hand, the three tenets of the cost effectiveness principle discussed above–demonstrable efficacy, budgetary prudence, and exhaustion of generic resources–could be construed differently or play somewhat different doctrinal roles in the Self-Determination context.

In short, the rollout of the new Self-Determination Program is poised to present new doctrinal challenges that the framework proposed here does not adequately address. Although consideration of such complexities is beyond the scope of this report, we hope to address them in future work.

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[230] *See, e.g.*, POLICY STATEMENT, *supra* note 50.

[231] *See* CAL. WELF. & INST. CODE § 4685.8 (2017) (creating a statewide Self-Determination Program that provides "participants and their families, within an individual budget, increased flexibility and choice, and greater control over decisions, resources and needed and desired services and supports to implement their IPP").

[232] *Self-Determination Program – Implementation Updates*, CAL. DEPT' DEVELOPMENTAL. SERVS., https://www.dds.ca.gov/SDP/SDPUpdates.cfm (last visited Jan. 16, 2019).

[233] *Self-Determination Program – Frequently Asked Questions*, CAL. DEPT' DEVELOPMENTAL. SERVS., https://www.dds.ca.gov/SDP/faq.cfm (last visited Jan. 16, 2019).

VIII. Conclusion

Our goal in this report was twofold. First, we suggested that the various goals, requirements, and entitlements that the Lanterman Act encompasses can be usefully grouped into two overarching principles, which we label "needs-based individualization" and "cost effectiveness." We defined needs-based individualization as the process whereby services and supports are tailored to the needs and aspirations of each individual. We suggested that this principle encompasses five subsidiary concepts: person-centered planning; community integration (including the entitlement to live, learn and work in the least restrictive environment); home preservation; consumer choice; and continuity of services. We then introduced the cost effectiveness principle, which helps the state meet the needs of all consumers on a fixed budget. This principle includes three key tenets: demonstrable efficacy, budgetary prudence, and exhaustion of generic resources.

After defining these two overarching principles, we proposed a doctrinal framework for resolving conflicts between them. We concluded that courts should begin with the presumption that consumers are entitled only to services and supports that are consistent with needs-based individualization and also are cost effective. However, if a consumer can persuade the factfinder that withholding a particular service or support would violate the principle of needs-based individualization, then absent a clear statutory directive to the contrary, the RC must provide it regardless of its cost effectiveness.[234] If a RC's budget is insufficient to fulfill this mandate, then DDS is obliged, at the RC's request, to ask the legislature for additional funding. Our detailed examination of state court and OAH opinions suggests that this framework accords well with the way judges and HOs have resolved most of the cases available for our review.

It is worth reiterating, however, that the OAH fair hearing process is opaque and case law on the interpretation of the Lanterman Act is very thin. Not only is an extremely small percentage of decisions issued by HOs made publicly available,[235] but hardly any decisions issued by HOs are ever appealed to state court. It is hard to know what to make of the latter fact. It is possible that the parties are generally in agreement with the opinions rendered by HOs. Yet it could also be that few complainants can afford to appeal adverse decisions. Unlike many other laws intended to protect the rights of individuals with I/DD, such as the ADA[236] and the IDEA,[237] the fair hearing process created by the Lanterman Act contains no fee shifting provision.[238] Consumers

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[234] These latter two concepts, which we discuss here in reference to RCs, are reminiscent of the holding in *ARC v. DDS,* which held that the principle of needs-based individualization trumped DDS's desire to stay within its fixed budget.

[235] *See supra* note 7 and accompanying text.

[236] 42 U.S.C. § 12205 (2018).

[237] 34 C.F.R. 300.517 (2018).

[238] DISABILITY RIGHTS CAL., DISAGREEMENTS WITH REGIONAL CENTERS AND DEVELOPMENT CENTERS IN RIGHTS UNDER THE LANTERMAN ACT 25 (Dec. 1, 2012), https://www.disabilityrightsca.org/system/files/file-

who avail themselves of the fair hearing process generally must cover their own attorney's fees and costs, even if they successfully challenge OAH decisions in state court.[239] In a separate report, we suggest that adding a fee-shifting provision in the Lanterman Act's appeals process would improve access to justice among RC consumers, particularly those in underserved communities.[240]

In closing, we note the irony in the fact that we are releasing this report at very moment that DDS is launching a statewide Self-Determination program. This new service delivery model represents a marked departure from the traditional system discussed here, and likely will require significant modifications to the doctrinal framework we propose. Yet regardless of which service delivery system eventually predominates, the core tension between needs-based individualization and cost effectiveness is likely to persist. In our view, helping adjudicators strike the appropriate balance between these two competing principles is the best way to safeguard the rights and improve the lives of the Lanterman Act's intended beneficiaries.

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attachments/506301Ch12.pdf (last visited Jan. 16, 2019) (noting that to date, no one has asked "the court to award lawyer's fees for an appeal of an administrative hearing in a regional center matter").

[239] *Id.*

[240] *See* LANTERMAN TRANSPARENCY & ACCOUNTABILITY REPORT, *supra* note 7, § VI.B.(5).

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Issued July 1, 2019

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