

Disparities in Service Use and Expenditures for People With Intellectual and Developmental Disabilities in California in 2005 and 2013

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Abstract

This study examined service use and expenditures for people with intellectual and developmental disabilities (IDD) living at home and in the community in California in 2005 and 2013. The number of people assessed for IDD services increased, along with the percentage of individuals who did not receive any services between 2005 and 2013. Controlling for client needs, children age 3–21 were less likely than other age groups to receive any services using logistic regressions. All racial and ethnic minority groups were less likely to receive any services than were white populations. Females, younger people, and all racial and ethnic minority groups who received services had significantly lower expenditures, with wide geographic variations. The disparities by age, gender, race/ethnicity, and geography have persisted over time in California.

Key Words: *disparities; service use; expenditures; intellectual and developmental disabilities; California*

Home and community-based services (HCBS) have been important for enabling people with intellectual and developmental disabilities (IDD) to live at home and in residential settings, rather than in state institutions (Braddock et al., 2013a; Ticha, Hewitt, Nord, & Larson, 2013). The number of people with IDD living in Intermediate Care Facilities for Developmental Disabilities (ICF-DD) facilities has steadily declined, whereas HCBS has increased dramatically since the 1990s (Lakin, Scott, Larson, & Salmi, 2010). Although HCBS have expanded steadily, more than 349,511 people with IDD were on waiting lists for Medicaid HCBS waiver programs across the United States, with an average wait of 47 months for services in 2014 (Ng, Harrington, Musumeci, & Reaves, 2015). State Medicaid policies vary widely; many states have restrictive policies that limit access for people with IDD and other groups, and these policies result in persistent waiting lists and expenditure per capita variations (Braddock et al., 2013a, b; Ng, Stone, & Harrington, 2015; Ticha et al., 2013).

Even though the growth in access to HCBS is encouraging, a U.S. Surgeon General's conference identified a gap in services access for people with IDD compared to the national average (U.S. Public Health Services, 2002). A national survey found

that adults with IDD and another disability were more likely to report being in poor health compared to adults without a disability (Haverkamp & Scott, 2015). In addition, children with IDD have been found to have a higher level of health and functional impairments and need for services compared with other children (Boulet, Boyle, & Schieve, 2009).

A growing number of studies have identified disparities by race and ethnicity in preventive care, service use, and expenditures for people with IDD. A national survey showed that racial and ethnic minority groups with IDD, particularly Hispanic Americans, were disadvantaged in health care access, including dental services, general practitioner services, and flu shots. Although Black populations were more likely to have received cancer screenings, Hispanics were significantly less likely to have cancer screening (Scott & Haverkamp, 2014). Racial and ethnic disparities were found in less preventive health care for adults with IDD (Bershady, Hiersteiner, Fay, & Bradley, 2014), in lower use of primary care, outpatient care and other services and higher hospitalization for Black teenagers with muscular dystrophy (Ozturk et al., 2014), in mortality rates for individuals with Down syndrome (Flores, 2010),

and in mammogram use for Black women (Parish, Swaine, Son & Luken, 2013). Black and Hispanic children with IDD were found to receive lower quality health care than white children (Magana, Parish, Rose, Timberlake, & Swaine, 2012).

A study of all people in California with IDD, using 2005 data, found that 21% of people with IDD did not receive any services. People in younger age groups and all racial and ethnic minority groups were less likely to receive any services than were white people, and they also had significantly lower expenditures when they did receive services (Harrington & Kang, 2008; Kang & Harrington, 2008). This study is a follow-up to the 2005 study (Harrington & Kang, 2008).

The aim of this study was to examine disparities in race/ethnicity, age, and gender in (a) access to IDD service use and (b) expenditures per client in 2013 compared with 2005, while controlling for client need. All people with IDD living at home and in residential care settings were examined in California in 2005 and 2013, whereas those living in state institutions and intermediate care facilities were excluded. The hypothesis tested was that race and ethnicity, age, and gender disparities in access to service use and expenditures would be found in 2013 similar to the disparities found in 2005, when controlling for client need. Wide variations in service use and expenditures were also expected by geographical area.

California was selected for study for several reasons. First, the state has a large database of all people with IDD, which allowed for the examination of client need, client characteristics, service allocations, and expenditures. Second, data from a previous study in 2005 allowed for a comparison of health disparities in 2013. Third, California had the largest state IDD Medicaid waiver program (94,473 participants) and the second largest (to New York) total waiver spending (\$3 billion) in 2012, but it had low spending per capita compared to other states (Braddock et al., 2013b; Ng, Harrington, Muscumeci, & Reaves, 2015; Ticha et al., 2013). Although not a typical state in terms of IDD programs, California is a good state to examine disparities because its IDD services are state funded as an entitlement program available to all individuals with IDD, regardless of income (not just those on Medicaid). Therefore, client need for services should be the primary determining factor in access to IDD service use and expenditures.

Conceptual Framework

The Institutes of Medicine and others (IOM, Smedley, Stith, & Nelson, 2002) defined disparities as “racial and ethnic differences in the quality of care that are not due to access factors or clinical needs, preferences, and appropriateness of intervention.” Racial and ethnic disparities for non-IDD populations have been identified across a range of illnesses and health care services that can result in serious negative consequences to health and welfare (IOM et al., 2002). Williams and Mohammed (2013) developed a framework for understanding racial and ethnic disparities in health outcomes. Worse health outcomes for racial and ethnic groups have been found in higher age-adjusted mortality rates, earlier onset of diseases, higher prevalence rates of disease (morbidity), poorer overall health status, higher behavioral risk factors, higher disability rates, poorer mental health, and other outcomes (IOM et al., 2002; Williams, 2012; Williams & Mohammed, 2013;). According to their framework, the first major pathway that adversely affects health outcomes is institutional racism that reduces access to housing, neighborhood and educational quality, employment opportunities, and other societal resources. Second, cultural racism is also a factor that may occur at both societal and individual levels, which Williams and Mohammed (2013) described as “creating a hostile environment and discrimination.” These factors may increase individual stress, reduce socioeconomic opportunities, and reduce knowledge and resources, as well as access to health care services.

In this study, we examined disparities in IDD service use and expenditures. We used the operational framework by Duan, Meng, Lu, Chen, and Alegria (2008), which defined factors that are “allowable” and those that are “nonallowable” that would identify disparities in service use and expenditures at the level of the service system. Allowable factors are those that cause justifiable differences in use and expenditures defined as clinical need and preferences (although data on client preferences were not available). Nonallowable factors were considered client characteristics (age, gender, and race/ethnicity), insurance coverage, and geographical service areas. Differences in use and expenditures due to nonallowable factors are defined as “health care disparities” (Duan et al., 2008).

Allowable Factors

Client need factors, such as physical, developmental, and mental disabilities, are expected to account for differences in health care use and expenditures and they are considered allowable factors (Anderson, 1995; Duan et al., 2008). People with IDD may have limitations in a number of areas: capacity for independent living, economic self-sufficiency, learning, mobility, receptive and expressive language, self-care, and self-direction. Intellectual disability (Benedict, 2006; Bongiorno, 1996; Freedman & Chassler, 2004; Lakin et al., 2008; Lawer, Brusilovskiy, Salzer, & Mandell, 2009; Pruchno & McMullen, 2004), cerebral palsy, and epilepsy are expected to increase the use and expenditures for services. People with autism (Blanchard, Gurka, & Blackman 2006; Harrington & Kang, 2008), with a dual diagnosis of developmental and psychiatric disabilities (Harrington & Kang, 2008), and with a range of special behavior disorders may require more services (Freedman & Chassler 2004; Harrington & Kang, 2008; Pruchno & McMullen, 2004).

Nonallowable Factors

Client characteristics in this study may affect use and expenditures, but they are considered to be nonallowable and defined as health disparities. Gender may affect the use and expenditures of services. Male children have a higher incidence of emotional, developmental and behavioral health problems (Blanchard et al., 2006) and may use more services or have higher expenditures than females may have (Harrington & Kang, 2008). In addition, males with IDD have a greater risk of dying from disease at a younger age than do females (Patja, Molsa, & Livanainen, 2001). When controlling for client need, gender differences would not be expected.

As the IDD population ages, people may experience age-related disorders that require more assistance (Hogg, Lucchino, Wang, Janicki, & Working Group, 200; Janicki, Dalton, Henderson, & Davidson, 1999). Age has been found to be a potential predictor of IDD service use and expenditures, with older age groups receiving more services (Harrington & Kang, 2008). Because regional centers in California are expected to use school services first, school-age children (3–22 years) with IDD may receive some services at school. Younger people with IDD who live with

their families may need less support than older people who are living alone.

As discussed previously, race and ethnicity have been found to be predictors of disparities in health care service use and expenditures in a number of areas. Mental health services, for example, are less frequently received by many racial/ethnic minorities (McCallion, Janicki, & Grant-Griffin, 1997; Cauce et al., 2002) compared to white populations. Studies of African American adults with developmental disabilities indicate that they are more likely to have unmet needs for services (Pruchno & McMullen, 2004) and used fewer professional services than white adults (McCallion et al., 1997). Another study revealed that African American adolescents used more mental health services whereas Asian and Mexican Americans used less compared to white adolescents in one study (Bui & Takeuchi, 1992). Evidence suggests that Asians and Hispanics have lower rates of mental health service use in general (McCallion et al., 1997). When controlling for need, differences identified in use and expenditures by race and ethnicity will be considered to be disparities (Harrington & Kang, 2008; Scott & Haverkamp, 2014).

Income and health insurance may be important factors in the use of and unmet need for services. One study found that where clients had health insurance and community clinics, there were still health disparities in access for African Americans, but not for Latinos, compared to white clients (Alegria et al., 2012). On the other hand, Benedict (2006) found that children in families with higher incomes have an advantage in obtaining services and in identifying unmet needs. Higher-income families may have greater education and knowledge and may be better able to obtain services or to advocate for their service needs.

In this study, Medicaid eligibility was used as a proxy for low income because family income was not available. In California, some state funds are available to provide services but Medicaid funds (which are a combination of state money and federal matching money) are a preferred payment source by the state because matching funds are received. Those who are Medicaid eligible may receive more access to services than those who are not eligible, as was found in 2005 (Harrington & Kang, 2008).

Geographical Areas

California established a comprehensive system for providing services to people with IDD, using regional centers as the administrative unit. Regional centers are nonprofit organizations to assess clients, plan, coordinate, and provide contract services to meet the needs of people with IDD (California Department of Developmental Services, 2015a). Each of the 21 regional centers has a specific geographic service area and receives state funds for clients, although allocation amounts vary. Every regional center has a board of directors who determines how services are organized and delivered to eligible clients (i.e., local autonomy), which may result in variability in services and expenditures, as well as the number and types of clients they serve (Harrington & Kang, 2008) and other factors. Disparities in use and expenditure patterns are expected across regional centers (i.e., geographic areas).

Service Use

The state-funded regional centers can authorize a variety of services, including day programs, out-of-home services, support services, transportation, respite services, and other services. People with IDD can receive services in a variety of settings, including the home of a parent, family member or guardian; independent living; and supportive living setting (homes that client own or lease with personal attendants, housemates, or alone). Clients may also live and receive services in residential (community) care settings, which include foster homes, family homes, group homes, or residential care facilities for children, adults, and the elderly. This study examined whether people received any service, including residential care.

Service Expenditures

This study examined total state-funded expenditures made from the regional centers for purchased services. As noted previously, regional centers are required by the state to use all other resources or generic resources first before using regional center funds. Generic services are those provided by public programs, such as those provided by school districts; but this study could not examine generic service expenditures because of lack of data (Harrington & Kang, 2008).

Methods

This study conducted a secondary analysis of public data to examine factors associated with use and expenditures for people with IDD living at home or in residential settings in California in 2005 and 2013. No client identifiers were used, and the study was exempt from Human Subjects review.

Data

The study examined all people age 3 and over with IDD assessed and covered by the California regional centers for the fiscal years July 1, 2004, through June 30, 2005, and July 1, 2012, to June 30, 2013. Three secondary databases were used for this analysis. The first dataset was the client master file (CMF), which contains demographic information on all persons served by the California regional centers. The database included a unique client identifier, gender, age, race/ethnicity, and regional center. This information was used to match the information to client assessment data and all identifying information was removed before the files were given to the investigators. Information on regional center (geographic location) was included, along with whether or not an individual was on Medicaid (called Medi-Cal in California).

The second dataset used for the analysis was the IDD Client Development Evaluation Report (CDER) file. The client evaluation report was based on the assessment by professionals in the regional centers for cognitive and physical disabilities, health behaviors (e.g. severe behavioral problems), and other conditions. It included detailed annual data on each client's: physical abilities, language, vision, cognitive functioning, psychological status, social functioning, behavioral problems, medical conditions, special conditions, special aids, care needs, and medical conditions. The client need variables were the same in both time periods except that "severe behavioral problems" and "transferring" items were not available in 2013. In addition, the variable "does not understand spoken words" was changed to "does not use words to communicate" on the assessment forms in 2013 and labeled as "communication problems." The client assessments are generally completed every year, but can sometimes occur every 3 years by one of the 21 regional centers in the state. The most recent client assessment data were used for the study.

The third dataset used was the IDD Purchase of Service file, which had client identifiers for service use and cost data. It included the program code, budget category, authorization number, and expenditures by month, regional center identifier, subcodes and services codes, and vendor IDD number and type. Each record comprised 12 months (fiscal year base) of information for each period.

Data Analysis

The data analysis consisted of three parts. First, descriptive statistics were examined for all of the people assessed by the regional centers, although descriptive statistics for 2005 expenditures were not available. Second, logistic regression analyses were conducted using SAS Version 9.4 to examine the factors that predicted whether or not people with IDD received any services during 2005 and in 2013. Finally, ordinary least-squares analyses examined predictors of total annual expenditures per client during the same period.

The predictive factors were divided into the following two categories: (a) allowable factors of client need; and (b) nonallowable factors (age, gender, race/ethnicity, Medicaid eligibility status, and geographical areas). Finally, for the expenditure analysis, we also identified the people who received services in residential settings because those are the most costly services that are provided.

The regressions were conducted separately by categories of variables to compare the effects of each category. In all regressions, client need was entered into the model first because these variables should account for most of the variation in service use and expenditures. Nonallowable factors were entered second.

In the expenditures analysis, some clients were outliers. The expenditures per client were truncated (winsorized) by setting a ceiling on the highest value at the 99.9th percentile for 138 people to eliminate outliers in 2005 and 164 people in 2013. Ordinary Least Squares (OLS) regression analyses were conducted using Statistical Analysis System (SAS) Version 9.3 to examine the factors that predicted the annual expenditures per client. Regression analyses were conducted separately for regional centers, but tables were not shown. Finally, a dummy variable for residential service expenditures was used as independent variable (Yes = 1) because these services are more expensive; and a separate regression analysis was conducted.

Because the study had such a large dataset, we used a 0.001 level for the significance test.

Findings

Descriptive Analysis of Use

Table 1 shows the descriptive statistics for each of the independent variables in the study for those who received services. Of the total 175,595 people with IDD, 21.2% (37,259) received no reported services in 2005. In 2013, of the 226,426 people with IDD, 54,002 (23.8 %) received no services. Although the population with IDD increased by 29% in 2013, the number of people not receiving services increased by 45% over the previous period. In both time periods, a higher percentage of men did not receive services compared to women. A higher percentage of people who did not receive services were 21 or younger and people who were in racial and ethnic minority groups. A separate descriptive analysis of access to residential services found a significantly lower use of residential services for men, children, and all minorities groups than for females, older age groups, and white populations (no table shown) (using a chi-square statistical test for each group separately).

Regression Analyses of Service Use

Client need. Table 2 shows the logistic regressions for people with IDD age 3 and over who received any services in the home and community in California in 2005 and in 2013. Table 2 Regression 1 indicates that need variables accounted for only 7.6% of the total variation in receiving services (the Max-rescaled R-square) in 2013 and about 6.1% in 2005. In 2015, people with intellectual disabilities at more severe levels (formerly termed profound, severe, or moderate mental retardation [MR]); autism; epilepsy; medical problems; dual diagnosis; special behavioral; special health care needs; behavioral modifying drugs, bladder and bowel problems; hearing problems; vision problems; and who needed help in bathing and toileting had higher odds of receiving services. People with wheelchairs and those who needed help with eating had lower odds of receiving services. The factors predicting services use were similar in 2005, except for the item that was for “communication problems” because the measure changed on the assessment forms.

Table 1
Individuals With Intellectual and Developmental Disabilities (Age 3 and Older) in California Who Received and Did Not Receive Services in 2005 and in 2013

Variable	2013						2005					
	Total			Received Services			Total			Received Services		
	N	%		Yes	No	%	N	%		Yes	No	%
Total	226,426	100.0		172,424	54,002	23.8	175,595	100.0		138,336	37,259	21.2
Allowable Factors: Client Need												
Profound MR	8,482	3.7		7,413	1,069	12.6	9,321	5.3		8,237	1,084	11.6
Severe MR	14,044	6.2		12,216	1,828	13.0	14,639	8.3		12,881	1,758	12.0
Moderate MR	33,206	14.7		27,460	5,746	17.3	31,287	17.8		25,891	5,396	17.2
Mild/no retard/MR unspecified	170,694	75.4		125,335	45,359	26.6	120,348	68.5		91,327	29,021	24.1
Cerebral palsy	34,222	15.1		27,325	6,897	20.2	32,942	18.8		26,736	6,206	18.8
Autism	62,278	27.5		46,256	16,022	25.7	27,626	15.7		21,975	5,651	20.5
Epilepsy	37,221	16.4		30,887	6,334	17.0	35,545	20.2		29,702	5,843	16.4
Average number of medical problems	0.51			0.57	0.30		0.39			0.42	0.28	
Dual diagnosis	25,895	11.4		21,967	3,928	15.2	25,182	14.3		20,984	4,198	16.7
Special behavior	15,761	7.0		14,302	1,459	9.3	15,619	8.9		13,855	1,764	11.3
Wheelchair	21,276	9.4		17,048	4,228	19.9	24,813	14.1		20,448	4,365	17.6
Does not understand spoken words	NA	NA		NA	NA	NA	5,698	3.2		4,557	1,141	20.0
Does not use words to communicate	33,522	14.8		27,352	6,170	18.4	NA	NA		NA	NA	NA
Severe behavioral problems	NA	NA		NA	NA	NA	11,165	6.4		9,551	1,614	14.5
Special health care needs	50,144	22.1		42,427	7,717	15.4	40,682	85.5		34,977	5,705	14.0
Behavior-modifying drugs	40,726	18.0		35,691	5,035	12.4	28,749	16.4		25,255	3,494	12.2
Bladder/ Bowel problem	64,290	28.4		51,409	12,881	20.0	57,651	32.8		46,836	10,815	18.8
Hearing problem	14,969	6.6		12,309	2,660	17.8	12,902	7.3		10,834	2,068	16.0
Vision problem	19,367	8.6		16,258	3,109	16.1	17,615	10.0		15,061	2,554	14.5
Bathing	124,824	55.1		98,311	26,513	21.2	103,135	58.7		83,228	19,907	19.3
Dressing	103,169	45.6		80,991	22,178	21.5	103,446	58.9		82,087	21,359	20.6
Transferring	NA	NA		NA	NA	NA	33,315	19.0		26,878	6,437	19.3
Toileting	52,780	23.3		42,261	10,519	19.9	74,296	42.3		60,336	13,960	18.8
Eating	26,535	11.7		20,840	5,695	21.5	84,222	48.0		67,058	17,164	20.4

(Table 1 continued)

Table 1
 Continued

Variable	2013						2005					
	Total			Received Services			Total			Received Services		
	N	%	%	Yes	No	%	N	%	%	Yes	No	%
Nonallowable Factors												
Male	143,587	63.4	75.4	108,201	35,386	24.6	105,679	60.2	82,784	22,895	78.3	21.7
Female	82,839	36.6	77.5	64,223	18,616	22.5	69,916	39.8	55,552	14,364	79.5	20.5
Age Group												
3-13	69,899	30.9	69.9	48,843	21,056	30.1	56,519	32.2	41,013	15,506	72.6	27.4
14-21	45,863	20.3	59.6	27,330	18,533	40.4	34,127	19.4	22,065	12,062	64.7	35.3
22-31	42,207	18.6	81.6	34,436	7,771	18.4	28,490	16.2	24,143	4,347	84.7	15.3
32-41	23,641	10.4	87.6	20,700	2,941	12.4	21,966	12.5	19,722	2,244	89.8	10.2
42-51	20,533	9.1	91.2	18,730	1,803	8.8	19,515	11.1	17,894	1,621	91.7	8.3
52-61	15,938	7.0	92.6	14,763	1,175	7.4	10,286	5.9	9,402	884	91.4	8.6
62+	8,345	3.7	91.3	7,622	723	8.7	4,692	2.7	4,097	595	87.3	12.7
Race												
White	82,870	36.6	82.0	67,922	14,948	18.0	75,873	43.2	63,839	12,034	84.1	15.9
Asian/PI	20,686	9.1	74.9	15,503	5,183	25.1	14,350	8.2	10,978	3,372	76.5	23.5
African Am.	22,460	9.9	77.9	17,500	4,960	22.1	19,194	10.9	14,698	4,496	76.6	23.4
Hispanic	80,402	35.5	70.4	56,638	23,764	29.6	55,103	31.4	40,456	14,647	73.4	26.6
Other	20,008	8.8	74.3	14,861	5,147	25.7	11,075	6.3	8,365	2,710	75.5	24.5
Medicaid	183,049	80.8	79.4	145,314	37,735	20.6	135,145	77.0	110,138	25,007	81.5	18.5

Note. Levels of intellectual disability are included in their former descriptive terms; AAIDD uses terms referring to levels of severity.

Table 2
 Logistic Regression: Factors Predicting Service Use for Individuals With Intellectual and Developmental Disabilities in California in 2005 and 2013

Independent Variables	Model	2013 (N = 226,426)				2005 (N = 175,595)			
		1		2		1		2	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Allowable Factors:									
Client Need									
Profound MR ¹		1.641***	(1.525–1.766)	0.847***	(0.783–0.916)	1.864***	(1.734–2.004)	0.938	(0.868–1.014)
Severe MR		1.784***	(1.690–1.883)	1.096**	(1.034–1.161)	1.962***	(1.858–2.071)	1.194***	(1.127–1.265)
Moderate MR		1.537***	(1.489–1.586)	1.159***	(1.120–1.199)	1.455***	(1.407–1.504)	1.127***	(1.088–1.167)
Cerebral Palsy		0.996	(0.961–1.032)	0.972	(0.936–1.009)	0.977	(0.941–1.015)	0.970	(0.932–1.009)
Autism		1.160***	(1.132–1.188)	1.725***	(1.680–1.772)	1.329***	(1.284–1.377)	1.679***	(1.618–1.742)
Epilepsy		1.275***	(1.235–1.316)	1.115***	(1.078–1.153)	1.203***	(1.164–1.244)	1.093***	(1.056–1.132)
No. of medical problems		1.154***	(1.140–1.167)	1.068***	(1.055–1.081)	1.093***	(1.076–1.111)	1.014	(0.997–1.031)
Dual diagnosis		1.292***	(1.243–1.344)	1.193***	(1.146–1.243)	1.147***	(1.104–1.192)	1.110***	(1.066–1.155)
Special behavior		2.461***	(2.324–2.605)	1.675***	(1.578–1.778)	1.840***	(1.745–1.941)	1.391***	(1.315–1.471)
Wheelchair		0.623***	(0.592–0.655)	0.670***	(0.635–0.707)	0.911***	(0.870–0.955)	0.860***	(0.819–0.902)
Communication problems		1.077***	(1.036–1.119)	1.119***	(1.075–1.166)	0.679***	(0.631–0.730)	0.898**	(0.832–0.968)
Severe Behavioral problems		NA		NA		1.399***	(1.322–1.480)	1.507***	(1.423–1.596)
Special health care needs		1.530***	(1.480–1.582)	1.211***	(1.170–1.255)	1.587***	(1.529–1.648)	1.208***	(1.161–1.256)
Behavioral modifying drugs		1.921***	(1.858–1.987)	1.531***	(1.478–1.587)	1.678***	(1.611–1.747)	1.378***	(1.321–1.438)
Bladder/Bowel problem		1.110***	(1.069–1.153)	1.213***	(1.166–1.263)	1.056**	(1.019–1.093)	1.202***	(1.159–1.247)
Hearing problem		1.147***	(1.096–1.200)	1.014	(0.967–1.063)	1.234***	(1.174–1.298)	1.094***	(1.039–1.153)
Vision problem		1.241***	(1.190–1.294)	1.070**	(1.024–1.119)	1.295***	(1.236–1.355)	1.107***	(1.055–1.161)
Bathing		1.238***	(1.200–1.277)	1.459***	(1.412–1.507)	1.227***	(1.185–1.271)	1.374***	(1.325–1.424)
Dressing		0.994	(0.962–1.027)	1.170***	(1.131–1.211)	0.797***	(0.769–0.826)	1.101***	(1.061–1.144)

(Table 2 continued)

Table 2
Continued

Independent Variables	Model	2013 (N = 226,426)				2005 (N = 175,595)			
		1		2		1		2	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Transferring		NA	NA	NA	NA	0.900***	(0.868-0.934)	0.983	(0.946-1.021)
Toileting		1.124***	(1.077-1.173)	1.197***	(1.145-1.251)	1.209***	(1.165-1.256)	1.303***	(1.254-1.354)
Eating		0.846***	(0.811-0.883)	0.963	(0.921-1.007)	0.911***	(0.882-0.941)	1.095***	(1.060-1.132)
Nonallowable Factors									
Gender ²	Male			1.014	(0.992-1.037)			0.996	(0.971-1.022)
Age ³	3-13			0.230***	(0.211-0.250)			0.380***	(0.345-0.417)
	14-21			0.182***	(0.168-0.198)			0.352***	(0.321-0.386)
	22-31			0.579***	(0.533-0.629)			1.147	(1.043-1.262)
	32-41			0.887**	(0.812-0.968)			1.700***	(1.540-1.877)
	42-51			1.183***	(1.079-1.297)			1.992***	(1.798-2.206)
	52-61			1.341***	(1.215-1.479)			1.760***	(1.573-1.968)
Race ⁴	Asian/PI			0.838***	(0.806-0.871)			0.731***	(0.698-0.765)
	African Amer.			0.884***	(0.851-0.920)			0.728***	(0.698-0.759)
	Hispanic			0.701***	(0.683-0.720)			0.686***	(0.666-0.707)
	Other			0.905***	(0.871-0.941)			0.772***	(0.734-0.812)
Medicaid (Medi-Cal)				1.812***	(1.768-1.857)			1.370***	(1.332-1.409)
Generalized R-square		0.0505		0.1196		0.0393		0.0977	
Max-rescaled R-square		0.0757		0.1794		0.061		0.1516	

Note. Levels of intellectual disability are included in their former descriptive terms; AAIDD uses terms referring to levels of severity. Comparison Groups. ¹Mild or no retardation/unspecified; ²Females; ³Age: 62 and Older; ⁴Race: White. *p-value < 0.05, **p-value < 0.01, ***p-value < 0.001.

Nonallowable factors. No gender difference was found in access. As expected, people who were age 3–21 had lower odds of receiving services than those 62 and older, controlling for the need (Table 2, Regression 2) in both periods. People age 42–61 had higher odds of receiving services than the comparison group age 62 and over in 2013. In 2005, people age 32–41 also had higher odds of receiving services. In both time periods, people in each of four minority groups (Asians/Pacific Islanders, African Americans, Hispanics, and other races) had lower odds than did white populations of receiving services, controlling for need. People with IDD who were on Medicaid had higher odds of receiving services than those who were not on Medicaid. The nonallowable variables accounted for 10.3% more of the total Max-rescaled R-square variation beyond the need variables in 2013, which was similar to the variation (9.1 %) in 2005.

Geographical variations. The variations in service use were wide across regional center service areas. The range in use varied from 2.6 times higher in East Los Angeles to 0.77 times higher in the East Bay compared to the Inland regional center, which had the lowest use (no table shown).

Descriptive Analysis of Expenditures

Table 3 shows the average expenditures for people with IDD aged 3 and older who received services in 2013 (descriptive data were not available for 2005). The average expenditures were \$18,318 per year compared to \$13,323 in 2005 (table not shown). The expenditures were higher for those who had greater client needs, such as IDD at a more severe level. People who were younger had lower average expenditures, and those who were Asian/Pacific Islander, Hispanic, and other groups had lower expenditures. Those who were eligible for Medicaid and who used residential care services had high average expenditures.

Regression Analyses of Expenditures

Table 4 shows the OLS regression analyses of total expenditures per user, where the results are in thousands. Three models are shown for (a) client need factors; (b) nonallowable factors, and (c) residential care service use.

Client need. People with intellectual disability at more severe levels (formerly termed profound, severe, or moderate mental retardation); autism; epilepsy; medical problems; dual diagnosis; special

behavior; special health care needs; use of behavioral modifying drugs; and other conditions were positive predictors of expenditures. For example, people with profound MR had expenditures of \$15,300 and those with special behavior had expenditures of \$16,170, controlling for other need characteristics. Negative predictors of expenditures were people in wheelchairs and those who needed help with dressing, toileting and eating in 2013. The results in 2013 were similar to those in 2005, except for a couple of measures. The need variables accounted for 15% of the variance in total expenditures per client in 2013 compared to 18% in 2005 (Table 4 Regression 1).

Nonallowable factors. After accounting for need, men had more expenditures than women per year in both periods. Children age 3–21 had less expenditures per year compared to those 62 and over in both time periods (Table 4, Regression 2). People 62 and older had the highest expenditures in 2013 and 2005. People in each of the four minority groups (Asians/Pacific Islanders (–\$2,530), African Americans (–\$2,120), Hispanics (–\$4,480) and other races (–\$1,560) had lower total expenditures per year than white populations, controlling for need in 2013. These expenditure differences were higher in 2013 than in the 2005 period. People with IDD who were on Medicaid had higher expenditures (\$1,630) per year than those who were not on Medicaid. The nonallowable factors accounted for 3.8% more of the total variance beyond the need variables.

A dummy variable for those people who received any type of residential service showed an overall expenditure of \$28,530 per year, in additional cost per client in 2013 (Table 4 Regression 3). When residential services were included in the model, minorities in all groups continued to have significantly lower expenditures than white populations. Younger ages also had lower expenditures. This dummy variable increased the estimates to a total variance to 31.4% because these services are so costly. The relationships were similar in 2005.

Geographical variations in service expenditures were high across regional centers. Controlling for need and nonallowable factors, the range in expenditures were \$13,580 higher per client in Golden Gate regional center than the comparison center (Inland Regional Center) and San Diego regional center had expenditures of \$680 per client less than Inland (no table shown).

Table 3
Total Expenditures: Individuals With Intellectual and Developmental Disabilities (Age 3 and Older) Who Received Services in California in 2013

		<i>N</i>	Col%	Mean
	Total	172,424	100.0	18,318
Allowable Factors: Client Need				
Profound MR	Yes	7,413	4.3	34,551
Severe MR	Yes	12,216	7.1	27,473
Moderate MR	Yes	27,460	15.9	22,417
Mild/noRetard /Unspecified MR	Yes	125,335	72.7	15,567
Cerebral palsy	Yes	27,325	15.8	20,698
Autism	Yes	46,256	26.8	15,622
Epilepsy	Yes	30,887	17.9	24,197
Average No. medical problems	Continuous			18,318
Dual diagnosis	Yes	21,967	12.7	31,976
Special behavior	Yes	14,302	8.3	39,499
Wheelchair	Yes	17,048	9.9	21,634
Communication problems	Yes	27,352	15.9	22,011
Severe behavioral problems	NA			
Special health care needs	Yes	42,427	24.6	24,133
Behavior-modifying drugs	Yes	35,691	20.7	32,695
Bladder/ Bowel problem	Yes	51,409	29.8	19,052
Hearing problem	Yes	12,309	7.1	23,228
Vision problem	Yes	16,258	9.4	23,480
Bathing	Yes	98,311	57.0	19,079
Dressing	Yes	80,991	47.0	18,421
Transferring	NA			
Toileting	Yes	42,261	24.5	18,487
Eating	Yes	20,840	12.1	17,477
Nonallowable Factors				
Gender	Male	108,201	62.8	18,232
	Female	64,223	37.2	18,464
Age Group	3–13	48,843	28.3	9,182
	14–21	27,330	15.9	10,177
	22–31	34,436	20.0	21,574
	32–41	20,700	12.0	24,510
	42–51	18,730	10.9	27,124
	52–61	14,763	8.6	29,603
	62+	7,622	4.4	31,031
Race	White	67,922	39.4	23,508
	Asian/PI	15,503	9.0	15,615
	African Am.	17,500	10.1	19,265
	Hispanic	56,638	32.8	13,217
	Other	14,861	8.6	15,742
Medicaid (Medi-Cal)	Yes	145,314	84.3	19,510
Received Residential Care Services	Yes	26,960	15.6	48,844

Note. Levels of intellectual disability are included in their former descriptive terms; AAIDD uses terms referring to levels of severity.

Table 4
 OLS Regression for Total Expenditures in \$1,000 for Individuals with Intellectual and Developmental Disabilities Age 3 and Over in California, 2005 and 2013
 (Data Winsorized at the 99.9 percentile)

Indep. Variables	2013 (N = 172,424)			2005 (N = 138,336)			
	Model	1	2	3	1	2	3†
Intercept		8.51***	16.09***	7.86***	5.84***	9.34***	8.94***
Allowable Factors: Client Need							
Profound MR ¹		15.30***	8.01***	5.60***	9.37***	1.87***	1.56***
Severe MR		8.74***	3.32***	0.44	8.04***	2.70***	1.18***
Moderate MR		5.05***	2.03***	0.15	4.54***	1.77***	0.54***
Cerebral Palsy		0.76***	-0.02	0.58**	0.23	-0.21	0.35
Autism		2.10***	6.21***	6.08***	2.40***	4.93***	4.66***
Epilepsy		2.58***	1.47***	1.08***	1.76***	0.94***	0.79***
No. of medical problems		1.00***	0.49***	0.17***	1.39***	0.86***	0.80***
Dual diagnosis		7.18***	6.44***	4.34***	4.94***	4.53***	2.93***
Special behavior		16.17***	13.81***	9.48***	10.17***	8.00***	5.73***
Wheelchair		-1.95***	-2.13***	-0.22	0.13	-0.96***	1.01***
Communication problems		1.56***	1.92***	1.35***	-2.64***	0.10	-0.36
Severe behavioral problems		NA	NA	NA	4.60***	5.61***	4.99***
Special health care needs		2.99***	0.98***	1.53***	2.84***	0.87***	1.07***
Behavioral modifying drugs		11.48***	8.84***	4.49***	9.30***	7.16***	3.92***
Bladder/Bowel problem		0.60**	1.93***	1.60***	-1.16***	0.91***	0.67***
Hearing problem		1.52***	0.49*	0.89***	1.26***	0.38	0.55***
Vision problem		1.14***	-0.08	-0.16	1.23***	0.22	-0.03
Bathing		2.25***	4.32***	3.26***	1.92***	3.23***	1.75***
Dressing		-1.02***	1.47***	2.28***	-1.82***	1.00***	1.15***
Transferring		NA	NA	NA	-1.68***	-0.66***	-0.47***
Toileting		-1.04***	0.16	0.02	-0.11	1.09***	1.15***
Eating		-2.94***	-0.94***	-0.17	-0.07	1.82***	1.43***

(Table 4 continued)

Table 4
Continued

Indep. Variables	Model	2013 (N = 172,424)			2005 (N = 138,336)		
		1	2	3	1	2	3 [†]
Nonallowable Factors							
Gender ²	Male		1.44***	1.01***		0.78***	0.38***
Age ³	3-13		-17.40***	-8.38***		-13.90***	-5.57***
	14-21		-15.75***	-7.64***		-9.50***	-2.97***
Race ⁴	22-31		-4.24***	2.26***		-0.42	4.95***
	32-41		-2.76***	2.97***		0.53	4.70***
Race ⁴	42-51		-2.29***	1.65***		0.42	3.27***
	52-61		-0.84*	1.27***		0.29	1.92***
Race ⁴	Asian/Pacific Island		-2.53***	-1.53***		-2.32***	-1.63***
	African American		-2.10***	-1.56***		-1.08***	-0.60***
Race ⁴	Hispanic		-4.48***	-2.82***		-3.19***	-1.52***
	Other		-1.56***	-0.92***		-1.21***	-0.75***
Medicaid (Medi-Cal)			1.63***	0.67***		1.25***	0.33**
Received Residential Care Services			28.53***				20.58***
R-square		0.1505	0.1983	0.3138	0.1802	0.2504	0.3951

Note. OLS = Ordinary Least Squares. Levels of intellectual disability are included in their former descriptive terms; AAIDD uses terms referring to levels of severity. Comparison Groups. ¹Mild or no retardation/unspecified; ²Females; ³Age: 62 and Older; ⁴Race: White. [†]Included provider variables not shown.

Discussion

Overall, the study findings show persistent disparities in access to services and expenditures for people with IDD. Surprisingly, only 76% of people with IDD received any paid services from the state regional center program in 2013, which was lower than the 79% in 2005. As shown in 2005, logistic regressions showed that client needs predicted 6.1% of the variance in access to services and 7.5% of the variance in 2013.

The nonallowable factors predicted more than two times as much variation in access to services as client need predicted in both time periods, showing disparities in service use. After needs were taken into account, younger clients (3–21) had significantly lower odds of receiving services than those age 62 and older and lower expenditures than people age 62 and older in both time periods. Some children may be receiving services through the school system while others may be cared for by their parents and families. Nevertheless, age disparities in access to services warrant more study to understand these differences and whether children and the aged are being given adequate services and sufficient funds to provide for their needs.

The lower access to services by all minority groups is striking, after controlling for need, age, and Medicaid status. Asians and Pacific Islanders, African Americans, Hispanics, and other races had significantly lower odds (9% to 29% lower) of receiving any services than did white populations. This pattern was similar to the findings in 2005. For those people in minority groups who received services, their expenditures were significantly lower than those of white populations, controlling for need and other factors in both time periods. When a dummy variable for residential care services (out-of-home living) was included in the model, minorities continued to have lower expenditures.

These findings on racial/ethnic disparities are consistent with the findings from other studies of IDD, mental health, and long-term care (Alegria et al., 2012; Bui and Takeuchi, 1992; Cauce et al., 2002; McCallion et al., 1997; Pruchno & McMullen, 2004; Scott & Haverkamp, 2014). Disparities in access to services by minorities may reflect institutional racism (e.g., housing, neighborhood, and educational quality, and other resources differences) and cultural discrimination

(Williams, 2012; Williams & Mohammad, 2013). The individual or family's familiarity and comfort with navigating the service system, understanding rights to services, the availability of services, and knowledge of how to access services may be factors. People from minority groups may be less able or willing to question and challenge professional judgments and to ask for arbitration of disagreements regarding service allocations. Language other than English may also be an important barrier to services. A lack of match between client and provider race/ethnicity could be another factor.

Clients living in some regional center areas had higher odds of receiving services and expenditures compared to other centers, after controlling for differences in client need and predisposing/enabling factors. Regional center staff assessment and case management procedures or cultural competence, along with regional center staff and provider discrimination, could be other factors. Clearly there is a need for comprehensive efforts to remove barriers of language, geography, and cultural familiarity, as well as provider stereotyping and discrimination (IOM et al., 2002). Without a strong state and regional center effort to activate and empower clients and families to reduce disparities, changes are not likely to occur. Some models have been developed to address disparities, such the strategies developed by Chen, Mullins, Novak, and Thomas (2015).

Some variation may be related to differences in regional center budget allocations, administrative decision-making practices, and management policies, as well as differences in staff expertise, commitment, and experience. Regional center funding allocations do not take into account client need and disparities in access (California Department of Developmental Services, 2015b). Making adjustments to funding allocations based on client need and to address disparities may improve the equity in access across regional centers.

The overall funding levels for regional centers may account for some of the lack of services to some clients and the patterns of inequity in access shown in this study. In 2013, California ranked 42th among states in its per capita spending on HCBS services for people with IDD services (Braddock et al., 2013b; Ticha et al., 2013). Although there are no formal written waiting lists for the IDD waiver in California, there have been informal reports of waits for appropriate services and problems with the

allocation of waiver services (Ng, Harrington, Musumeci, and Reaves, 2015). Thus, limited funds and availability of HCBS are probably important contributors to disparities in access to services and expenditures. Ensuring adequate IDD funding for HCBS to eliminate disparities could have potential savings and benefits, such as reducing hospitalization and other medical care costs (Cook, Liu, Lessios, Loder, & McGuire, 2015)

This study had several limitations, including the cross-sectional study design that does not permit the identification of causal effect. One important limitation was the lack of available information on generic service use, which California should attempt to collect. The lack of information on family preferences, family characteristics (e.g., number of children and marital status), social supports, and family income, health insurance, and primary care providers limited the analysis. Decisions about services are related to family situations, including the characteristics of parents and the family, extent of help from children and role demand and family relationships, and social supports (Pruchno & Patrick, 1999). The state should consider adding this information to its client databases to allow for a more comprehensive analysis of access to IDD services. Moreover, the lack of information on regional center case management, policies, and practices did not allow for inclusion of these factors in the model. Finally, the quality of services is obviously important and not captured in current state data sets.

Controlling for client needs, disparities in access to services were found that predicted whether people received services and the amount of expenditures per client, and that these disparities did not improve over the study period. Although findings from this study cannot be used to generalize to other states, the analysis of disparities in IDD services within and across states is an important issue to study. Because other states may also have disparities in IDD services, new research is needed within states. The findings show the need for California to conduct a comprehensive evaluation of the reasons for disparities and to develop and implement a specific plan to address them. Policy makers also need to consider improvements in policies, practices, and fund allocations that would improve equity in access to regional center services at home and in the community.

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Received 8/12/2015, accepted 10/20/2015.

The data analysis for 2005 was supported by the National Institute on Disability and Rehabilitation Research grant no. H133G050358. The data analysis for 2015 was supported by Disability Rights California and Skadden, Arps, Slate, Meagher & Flom LLP Law Firm in Los Angeles, California, and funding from National Institute on Disability, Independent Living and Rehabilitation Research grant no. 905026.

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