



NOVEMBER 2016

# More than 400,000 Californians with Developmental Disabilities Remain Outside the State Safety Net

*Haleigh Mager-Mardeusz and Gerald F. Kominski*

**SUMMARY:** An estimated 703,800 persons in California in 2015 had some type of developmental disability.<sup>1</sup> Since 1969, California has provided people with developmental disabilities access to specialized care if they meet certain programmatic criteria. However, not all Californians with developmental disabilities meet these criteria, leaving an estimated 423,800 of these individuals outside the state's safety net. Although the 2010 Affordable Care Act (ACA) expanded access to health insurance, including behavioral and habilitative services, it did not cover the wide range of benefits offered to those who meet the criteria for inclusion in California-specific developmentally disabled support services programs. Within the state program itself, racial and ethnic disparities in care expenditures persist. This policy note documents the services that remain out of reach for many Californians with developmental disabilities.

## BACKGROUND

People with developmental disabilities have unique health care needs, yet they remain one of the least studied groups in health services research.<sup>3</sup> Adults with disabilities under 65 are less likely to be privately insured compared to adults without disabilities in the same age group.<sup>3</sup>

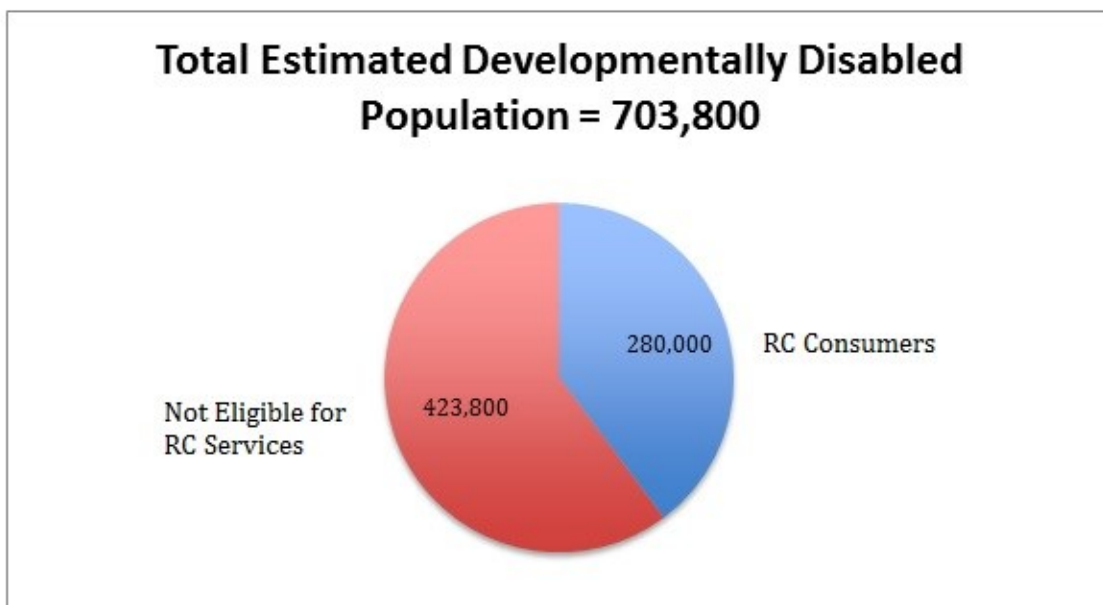
The 1969 Lanterman Developmental Disabilities Services Act (referred to herein as the Lanterman Act) established an entitlement to services for the developmentally disabled population in California.<sup>4</sup> These services, administered through Regional Centers (RCs), include supports necessary for individuals with developmental disabilities to live in the least restrictive environment possible and to maintain independence within the community. In California, adults with developmental disabilities who qualify for RC services are likely to have increased access to health insurance coverage, as caseworkers are responsible for coordinating services for consumers.

Roughly 280,000 consumers were served by RCs in 2015.<sup>5</sup> However, it is estimated that during that time, about

703,800 persons in California had some type of developmental disability.<sup>1</sup> It is speculated that the remaining 423,800 "high-functioning" individuals not eligible for RC services may have been uninsured at a higher rate when compared with consumers who qualified for RC services.

**Developmental Disability:** The federal definition of this term includes individuals with mental and/or physical impairment, with the onset of disability occurring before the age 22 and significant limitations present in three or more areas of major life activities, including self-care, self-direction, learning, expressive or receptive language, mobility, economic self-sufficiency, and the capacity for independent living.<sup>2</sup> California uses a more narrow definition for entitlement services, requiring the onset of disability to have occurred before the age of 18, and further requiring the disability to be a specific qualifying condition. Among these conditions are cerebral palsy, epilepsy, autism, and mental retardation or "conditions requiring services similar to those required for persons with mental retardation."<sup>2</sup>

### Exhibit 1: Estimated Number of Californians with Developmental Disabilities Eligible/Ineligible for RC Services, 2015



In 2010, the ACA was passed, although major coverage provisions were not implemented until 2014, providing uninsured Californians with disabilities access to care, including behavioral and habilitative care and protection from discrimination based on a preexisting condition. Access to care came through both the insurance exchanges established by the state and expanded coverage to Medi-Cal for Californians with incomes below 139 percent of the Federal Poverty Level (FPL). In addition, Medi-Cal permits individuals with developmental disabilities whose income (or whose parents' or spouse's income) is above this threshold to qualify for the program if they meet additional criteria and have an "Aged, Blind, and Disabled — Medically Needy"<sup>6</sup> waiver request submitted to the county by an RC caseworker or a relevant institution, or through institutional deeming.<sup>7</sup>

## Impact of ACA on California's Uninsured Individuals with Disabilities

Data from the American Community Survey (ACS) showed that in 2013, 17 percent of noninstitutionalized persons ages 21-64 across the U.S. who had disabilities were uninsured.<sup>8</sup> In California, 17.3 percent of this population were uninsured. After ACA implementation in 2014, the uninsured rate for this population dropped to 13.3 percent across the U.S. and 11.5 percent in California.<sup>9</sup> An estimated 712,400 persons within this population nationally gained health insurance coverage under the ACA; approximately 112,100 of these individuals resided in California. Further, ACS data revealed that this increase was due primarily to the Medicaid expansion: enrollment in Medicaid for this population increased from 36.5 percent in 2013 to 39.2 percent in 2014, with approximately 593,100 persons within this group gaining Medicaid coverage. Similarly, in California, Medi-Cal enrollment rates for this population increased from 41.4 percent in 2013<sup>8</sup> to 46.3 percent in 2014,<sup>9</sup> with an estimated 92,600 persons in this group gaining Medi-Cal coverage.

### Exhibit 2: Source of Insurance Coverage for Individuals with Disabilities in California, 2013 and 2014

Year	Medi-Cal	Purchased Private Coverage	Employer/Union Coverage
2013 <sup>8</sup>	41.4%	8.2%	31.8%
2014 <sup>9</sup>	46.3%	9.1%	32.4%

Uninsured rates for the developmentally disabled population are potentially lower in California than in states where no previous protections akin to the Lanterman Act exist for the developmentally disabled.

### Likely Impact of ACA on Uninsured Individuals with Developmental Disabilities

While insurance trends for individuals with disabilities are known, the developmentally disabled are not broken out in current research, so little data exist for examining insurance rates for this population. However, it is reasonable to hypothesize that insurance trends for individuals with developmental disabilities track or even exceed those of the general population with disabilities.

Specifically, California's ACA-mandated Medi-Cal expansion is likely to have significantly increased coverage for California's uninsured developmentally disabled population. Adults with disabilities are historically more likely to enroll in public programs such as Medicare and Medicaid.<sup>3</sup> The National Health Interview Survey reported that between 2001 and 2005, about 25 percent (or approximately 2,216,500)<sup>10</sup> of adults ages 18-64 with a complex activity limitation were enrolled in Medicaid.<sup>3</sup>

Many adults in California with developmental disabilities also qualify for Supplemental Security Income (SSI).<sup>11</sup> In 1993, a study of SSI beneficiaries with disabilities indicated that nearly 30 percent of these beneficiaries had

been diagnosed with intellectual disabilities.<sup>12</sup> SSI recipients in California with developmental disabilities are also usually eligible for Medi-Cal.<sup>13</sup> Between 2001 and 2005, 41 percent of those with cognitive difficulties (or about 711,760 individuals) were enrolled in Medicaid, and roughly 38.2 percent of those with self-care limitations (or an estimated 971,044) had Medicaid coverage.<sup>3</sup>

### **Impact of the ACA on Access to Care for Californians with Developmental Disabilities**

The ACA has greatly improved access to health services for all Californians and includes important provisions for individuals with developmental disabilities. The biggest change in benefits can be seen for individuals with developmental disabilities who do not qualify for RC services. Behavioral health and habilitative services are included in California's essential health benefits (EHB) benchmark plan.<sup>14</sup> Individuals eligible for Medi-Cal also have access to dental services under the ACA. The law also added provisions to Medicaid for long-term services and supports, which serve as a crucial part of the safety net for the developmentally disabled.

Significantly, under the ACA, insurers are no longer allowed to deny coverage or to rescind it based on preexisting conditions, an issue that significantly affected the ability of individuals with disabilities to find affordable coverage prior to passage of the ACA.

Other benefits that may be particularly important for the developmentally disabled population include a ban on lifetime and annual limits and new standardized EHBs, which include rehabilitative services and devices. Furthermore, Senate Bill 946, passed in 2011, compels insurers to cover autism-specific services as outlined in the ACA's behavioral health requirements.<sup>15</sup>

*Continued on next page...*

### Exhibit 3: Services Provided Under California's RC Program vs. Affordable Care Act

Service Type	Eligible for Regional Center (RC) N= 280,000		Not Eligible for Regional Center Est. N= 423,800	
	Pre ACA	Post ACA	Pre-ACA	Post-ACA
<b>Residential Services</b>	✓	✓	X	X
<b>Adult Day Program<sup>16</sup></b>	✓	✓	X	X
<b>Supported Living &amp; Related Services</b>	✓	✓	Must have Medi-Cal and be approved by caseworker	Must have Medi-Cal and be approved by caseworker
<b>Behavioral and Habilitative Services</b>	✓	✓	X	✓
<b>Transportation</b>	✓	✓	X	X
<b>Medical Care &amp; Services</b>	✓	✓	Subject to income level and categorical eligibility	✓
<b>Dental Services</b>	✓	✓	X	Must have Medi-Cal
<b>Supported Employment Program</b>	✓	✓	Subject to fiscal status of the Department of Rehabilitation	Subject to fiscal status of the Department of Rehabilitation
<b>Work Activity Program</b>	✓	✓	X	X
<b>Day Care</b>	✓	✓	X	X
<b>Social/Recreational Activities</b>	✓	✓	X	X
<b>Nonmedical Therapy Services</b>	✓	✓	X	Behavioral health and habilitative services
<b>Camps</b>	✓	✓	X	X
<b>Environmental &amp; Vehicle Modification</b>	✓	✓	X	X
<b>Mobility Training</b>	✓	✓	X	X
<b>Other Services</b>	✓	✓	X	X
<b>Services Provided Under HCBS Waiver<sup>17</sup></b> *Some RC consumers may not qualify for HCBS waiver services if their personal incomes are too high or their needs do not match those required for intermediate care facilities.	✓	✓	In-home supportive services if eligible for Medi-Cal and approved by social worker	In-home supportive services if eligible for Medi-Cal and approved by caseworker; behavioral health and habilitative services

The ACA does not provide the extensive services mandated under California's Lanterman Act (Exhibit 3). Given that the mandate of the ACA is to provide medical coverage first, this is not surprising. However, the question for policymakers is whether the 423,800 Californians with developmental disabilities who lack access to more extensive care are being adequately served.

#### Disparities in Regional Center Expenditures

Recent data on racial and ethnic disparities within the RC program suggest room for consideration of best practices regarding who is accepted into the program and how these individuals are served.

Because of research showing major ethnic disparities in RC Purchase of Service (POS) expenditures,<sup>18</sup> RCs are now required to report their POS expenditure data by ethnicity.<sup>19</sup> We conducted an analysis of RC POS expenditures for each of the 21 RCs for fiscal years 2011-12 and 2013-14 (Exhibit 4).

**Exhibit 4: Percent of Aggregated RC Program Expenditures by Race/Ethnicity, FY 2011-12 and 2013-14**

Ethnicity	Fiscal Year 2011-12			Fiscal Year 2013-14		
	Percent of Consumers	Percent of Expenditures	Per Capita Spending	Percent of Consumers	Percent of Expenditures	Per Capita Spending
<b>White</b>	34%	50%	\$16,486	33%	49%	\$17,449
<b>Native American</b>	0.003%	0.004%	\$14,402	0.004%	0.004%	\$13,271
<b>African-American</b>	9%	10%	\$12,443	9%	10%	\$13,568
<b>Asian and Pacific Islander</b>	8%	8%	\$10,147	-	-	-
<b>Asian</b>	-	-	-	6%	5%	\$10,425
<b>Filipino</b>	-	-	-	2%	2%	\$10,905
<b>Polynesian</b>	-	-	-	0.002%	0.002%	\$9,945
<b>Latino</b>	37%	24%	\$7,475	37%	25%	\$8,083

Notes: These proportions do not sum to 100% because the published data also contain an "Other Ethnicity" category.

"Asian & Pacific Islander" and "Asian" appear as separate categories because the data were aggregated for FY 2011-12 and disaggregated for 2013-14.

The biggest disparities in POS spending can be seen between white and Latino consumers. Whites made up 34 percent of consumers in FY 2011-12 and 33 percent in 2013-14, but they accounted for 50 percent and 49 percent of expenditures, respectively, in those years. Latinos represented 37 percent of consumers in both FY 2011-12 and 2013-14, but they accounted for only 24 percent and 25 percent of spending, respectively. Per capita spending on white consumers was about \$16,486 in FY 2011-12 and \$17,449 in FY 2013-14, but for Latino consumers it was estimated to be only \$7,475 in FY 2011-12 and \$8,083 in FY 2013-14.

## Recommendations

California is the only state in the nation to have an entitlement to care for the developmentally disabled. This legislation was complemented by passage of the ACA, but many California residents with developmental disabilities still do not have access to social services. Further, language, culture, and bias may create obstacles to care, and even access, for those eligible for RC services. Among our recommendations:

- Little to no data exist specifically on the developmentally disabled population that would enable policymakers to track their progress in gaining access to insurance and care. Some data sources, such as the California Health Interview Survey (CHIS), are now including questions on developmental disabili-

ties. However, other data sets — including state exchanges and Medicaid programs and national surveys such as the National Health Interview Survey and the American Community Survey — still need to incorporate this area into their data collection.

- Access to the RC program is based on the severity of an individual's disability as gauged by caseworkers. Developmental disability advocates say that parents and caregivers of persons with developmental disabilities have often been either turned away or misinformed by RCs of their assessment rights under the Lanterman Act. A review of the intake and assessment process, criteria for determining eligibility, and a more transparent appeal process should be considered by the California Department of Developmental Services.
- As with the ACA, greater investigation into and provision to remediate limited English proficiency and cultural biases may help RCs promote greater equity in expenditures for all eligible consumers.

While the ACA has helped to fill in health insurance gaps for individuals with developmental disabilities in California, more work is needed to ensure that this population has access to essential services.

### **Author Information**

Haleigh Mager-Mardeusz is a graduate student in the UCLA Fielding School of Public Health MPH Program in Health Policy and Management. Gerald F. Kominski, PhD, is a professor in the UCLA Fielding School of Public Health's Department of Health Policy and Management and director of the UCLA Center for Health Policy Research.

### **Funder Information**

This policy note was developed with funding from United Cerebral Palsy of Los Angeles, Ventura and Santa Barbara counties.

### **Suggested Citation**

Mager-Mardeusz H, Kominski GF. 2016. *More Than 400,000 Californians with Developmental Disabilities Remain Outside the State Safety Net*. Los Angeles, CA: UCLA Center for Health Policy Research.

**Find this publication online:** <http://healthpolicy.ucla.edu/publications/search/pages/detail.aspx?PubID=1592>

### **Endnotes**

<sup>1</sup>This figure is based on methods used by the State Council on Developmental Disabilities. The 2015 California population estimate was multiplied by the Gollay and Associate national prevalence estimate of 1.8 percent.

<sup>2</sup>California State Council on Developmental Disabilities. 2010. *About Developmental Disabilities*. Available at: <http://www.sccd.ca.gov/aboutdevelopmentaldisabilities.htm>

- <sup>3</sup>Altman B, Bernstein A. 2008. *Disability and Health in the United States, 2001–2005* (pp. 47-51). National Center for Health Statistics (NCHS).
- <sup>4</sup> Frank D. Lanterman Regional Center. (n.d.) The Lanterman Developmental Disabilities Services Act. Available at: [http://lanterman.org/lanterman\\_act#.WCZX9NxrX6E](http://lanterman.org/lanterman_act#.WCZX9NxrX6E)
- <sup>5</sup> Brown EG, Dooley DS, Rogers SJ. 2015. *Department of Developmental Services: Governor's Budget Highlights*. State of California. Available at: <http://www.dds.ca.gov/Budget/docs/budgetHighlights15.pdf>
- <sup>6</sup> Disability Benefits 101. 2016. *Medi-Cal: The Details*. Berkeley, CA: World Institute on Disability. Available at: [https://ca.db101.org/ca/programs/health\\_coverage/medi\\_cal/program2.htm](https://ca.db101.org/ca/programs/health_coverage/medi_cal/program2.htm)
- <sup>7</sup> Disability Rights California. 2012. *Rights Under the Lanterman Act: The Medi-Cal Developmental Disability Waiver*. Available at: <http://www.disabilityrightsca.org/pubs/506301Ch13.pdf>
- <sup>8</sup> Erickson W, Lee C, von Schrader S. 2015. *Disability Statistics from the 2013 American Community Survey*. Ithaca, NY: Yang Tan Institute, Cornell University. Available at: [www.disabilitystatistics.org](http://www.disabilitystatistics.org)
- <sup>9</sup> Erickson W, Lee C, von Schrader S. 2015. *Disability Statistics from the 2014 American Community Survey*. Ithaca, NY: Cornell University Yang Tan Institute. Available at: [www.disabilitystatistics.org](http://www.disabilitystatistics.org)
- <sup>10</sup> This number was estimated from the figures provided in Altman B & Bernstein A, 2008 (see note 3).
- <sup>11</sup> Harbor Regional Center. (n.d.) *Making It Happen: Supplemental Security Income (SSI) Benefits for Adults*. San Bernardino, CA: Harbor Developmental Disabilities Foundation. Available at: [http://www.harborrc.org/files/uploads/SSI\\_Benefits\\_for\\_Adults.pdf](http://www.harborrc.org/files/uploads/SSI_Benefits_for_Adults.pdf)
- <sup>12</sup> Kochhar S, Scott G. 1995. Disability Patterns Among SSI Recipients. *Social Security Bulletin* 58: 3-14.
- <sup>13</sup> Social Security Administration. 2016. *Continued Medicaid Eligibility (Section 1619(B))*. Available at: <https://www.ssa.gov/disabilityresearch/wi/1619b.htm>
- <sup>14</sup> Centers for Medicare & Medicaid Services. 2015. *California EHB Benchmark Plan*. Available at: <https://www.cms.gov/CCIIO/Resources/Data-Resources/Downloads/california-ehb-benchmark-plan.pdf>
- <sup>15</sup> Tri-Counties Regional Center. 2016. *Budget Watch*. Available at: <http://www.tri-counties.org/index.php/budget-watch-cat/404-governor-brown-signs-sb-946>



<sup>16</sup> Adult day programs also include:

- Adult developmental centers
- Other look-alike programs
- Independent living programs
- Activity centers
- Social recreation programs

<sup>17</sup> HCBS services include:

- Homemaker
- Home Health Aide Services
- Respite Care
- Habilitation:
  - ◊ Residential habilitation for children services
  - ◊ Day habilitation
  - ◊ Prevocational services
  - ◊ Supported employment services
- Environmental Accessibility Adaptations
- Skilled Nursing
- Transportation
- Specialized Medical Equipment / Supplies
- Chore Services
- Personal Emergency Response System (PERS)
- Family Training
- Adult Residential Care:
  - ◊ Adult Foster Care
  - ◊ Assisted Living
  - ◊ Supported Living Services
- Vehicle Adaptations
- Communication Aides
- Crisis Intervention:
  - ◊ Crisis Intervention Facility Services
  - ◊ Mobile Crisis Intervention
- Nutritional Consultation
- Behavior Intervention Services
- Specialized Therapeutic Services
- Transition / Set-Up Expenses
- Habilitation

<sup>18</sup> Harrington C, Kang T. 2008. Disparities in Service Utilization and Expenditures for Individuals with Developmental Disabilities. *Disability and Health Journal* 1(4): 184-95. <http://doi.org/10.1016/j.dhjo.2008.05.004>

<sup>19</sup> Frank D. Lanterman Regional Center. (n.d.) *Disparity Data on Purchased Services*. Available at: [http://lanterman.org/uploads/transparency/Documents%20Channel/Reports/DisparityData/disparity\\_20150108103452.pdf](http://lanterman.org/uploads/transparency/Documents%20Channel/Reports/DisparityData/disparity_20150108103452.pdf)