

American Journal on Intellectual and Developmental Disabilities

Improving Uptake in Regional Center Services: Using Program Data to Identify Predictors of Under-Utilization and Non-Utilization

--Manuscript Draft--

Manuscript Number:	AJIDD-D-24-00067R1
Article Type:	Research Report
Keywords:	home and community services; California regional centers; secondary data analysis; regression analyses; service utilization disparities
Corresponding Author:	Robin Dodds, PhD California State University Los Angeles: Cal State LA Los Angeles, CA UNITED STATES
First Author:	Robin Dodds, PhD
Order of Authors:	Robin Dodds, PhD
	Soma Roy
	Hilary Wu
	Amanda Belden
	Cameron Hafer
	Christina Toapanta
Manuscript Region of Origin:	UNITED STATES
Abstract:	Racial/ethnic disparities in expenditures have long plagued the California regional center system. The regional center at the center of this study has removed such disparities. However, they continue to experience service under-utilization and non-utilization. Regression models were used to investigate what characteristics are predictors of total amount utilized and predict the odds of a client using any of their allocated funds. Findings show that clients who are male, under 3, don't speak English, and live in care facilities use less of their allocation. School-aged clients had lower odds of utilizing any of their allocated funds. Implications for practice include using care-coordination models in residential settings, improving training opportunities for families, and hiring cultural brokers.

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Abstract

Racial/ethnic disparities in expenditures have long plagued the California regional center system. The regional center at the center of this study has removed such disparities. However, they continue to experience service under-utilization and non-utilization. Regression models were used to investigate what characteristics are predictors of total amount utilized and predict the odds of a client using any of their allocated funds. Findings show that clients who are male, under 3, don't speak English, and live in care facilities use less of their allocation. School-aged clients had lower odds of utilizing any of their allocated funds. Implications for practice include using care-coordination models in residential settings, improving training opportunities for families, and hiring cultural brokers.

Keywords: home and community services, California regional centers, secondary data analysis, regression analyses, service utilization disparities

(word count: 5144)

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Improving Uptake in Regional Center Services: Using Program Data to Identify Predictors of Under-Utilization and Non-Utilization

In 1964, California Governor Edmund Brown signed Assembly Bill 691, which authorized the development of two “pilot” regional centers for individuals with intellectual disabilities ("Association of Regional Center Agencies [ARCA]," n.d., "History of the System"). These centers aimed to assist individuals and families with additional support to fulfill unmet service needs and provide assessments and diagnostic services. These two pilot centers were deemed successful after the 1968 California Assembly analyzed the effectiveness of the programs and thus recommended expanding regional center locations throughout the state of California. Shortly after, in 1969, California Assemblyman Frank D. Lanterman introduced Assembly Bill 225, a bill that would authorize the expansion of the regional center network throughout California.

In 1969, California Governor Ronald Reagan signed the Lanterman Act into law (ARCA, n.d.). The Lanterman Act is a California law that promises services and related supports to individuals with developmental disabilities and their families across the lifespan. The Lanterman Act outlines the rights of individuals with developmental disabilities and how regional centers provide and fulfill these services. The California Department of Developmental Services defines a developmental disability as “a disability that originates before an individual attains 18 years of age, continues, or can be expected to continue indefinitely, and constitutes a substantial disability for that individual” (California Department of Developmental Services [CDDS], 2023)

Under the umbrella term of developmental disability (DD), the following conditions are included, cerebral palsy, epilepsy, autism and intellectual disability. Additionally, other disabling

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

conditions related to intellectual disability or those that require similar services and supports to those with intellectual disability but are not solely physical in nature (CDDS, 2023).

There are now 21 regional centers in California, which serve over 275,000 individuals and their families ("Lanterman Overview," n.d.). Each regional center provides a variety of services through approved vendors, such as: assessments and diagnosis, service planning, assistance in finding and utilizing community resources, advocacy for the protection of legal, service, and civil rights, early intervention for infants and their families, and family support and training (Lanterman, n.d.).

Service Expenditures

The California Department of Developmental Services (CDDS) allocates federal and state funds to regional centers across the state. There has been a history of disparities in expenditures, as whites have overwhelmingly received the most expenditures compared to all racial minority groups (Alpert Reyes, 2022; Public Counsel, 2022). Seven regional centers currently show spending disparities exceeding \$5,000, favoring White children over Hispanic children. Further, disparities between English speaking and Spanish speaking families have worsened across thirteen regional centers (Public Counsel, 2022).

The [REDACTED] Regional Center ([REDACTED]) has implemented an expenditure model designed to reduce these gaps, doubling its expenditures from \$64,64,991 to \$136,771,935 and allocating additional funds for racial minority groups (Public Counsel, 2022). The resulting mean expenditures were greater than or about equal compared to Whites. It is important to note that [REDACTED] serves a majority minority catchment area in [REDACTED], with 71% of their clientele in 2021-22 identifying as Hispanic and 21% as Black/African American, and 60% of clients being English-speakers and 40% Spanish-Speakers

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

([REDACTED], 2023). While this is an outstanding accomplishment, [REDACTED] continues to struggle with service utilization. During the 2020-2021 fiscal year, [REDACTED] paid approximately \$228 million for services, which was a 320% increase from the fiscal years 2016-2017, illustrating their ongoing efforts in supporting families ([REDACTED], 2022). However, they indicated that \$177 million (43%) was unutilized. In the following fiscal year, [REDACTED] authorized \$662 million in services and paid out over \$392 million, indicating that \$230 million (37%) of purchase of service were non-utilized ([REDACTED], 2023).

Theoretical Framework

The Andersen Model for Service Utilization is a theoretical model that helps explain the relationship between individual and contextual factors on service use (Andersen, 1995). This model suggests variables that impact the utilization of health services, and in their absence, individuals are less likely to use them. Within this framework, service use may be predicted and explained by predisposing characteristics and enabling resources. Predisposing characteristics include the language, age, gender, and race of the individual. Enabling components include where a person resides, the proximity to and availability of services, social support, and socioeconomic status. These characteristics influence whether an individual utilizes services and their overall satisfaction with provided services.

Factors Affecting Service Patterns

Predisposing Factors

Research has identified several reasons why caregivers and families decide not to utilize resources and services offered to them. In a focus group study by Stahmer et al. (2019), culturally and linguistically diverse (CLD) caregivers voiced concerns about transportation,

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

scheduling, and language match as barriers to engaging with services and service providers.

Caregivers shared that services are generally available during work hours, and they cannot utilize these services due to economic constraints to take time off their jobs and to fear of termination.

Meyer-Dyer et al. (2014) reported similar findings but found another significant barrier to engagement with services and service providers was caregiver immigration status. Further, in their ethnographic study, Angell et al. (2014) completed parent interviews asking Latino parents the reasons for discontinuing their child's allotment of services. Parents shared difficulties integrating services into their family's lifestyle due to the provider's attendance requirements.

Caregivers shared that they wanted a break because they were exhausted, stressed, or wanted to spend time with their other children.

In addition to culture, the primary language used in the home has been shown to impact service utilization, especially in heritage language speakers (Harrington & Kang, 2016; Wodehouse & McGill, 2009). Heritage language speakers are individuals who grew up in or currently live in a non-English speaking home but are bilingual in English and their heritage language (Valdes, 2000). Many service agencies have a paucity of qualified bilingual providers (Stahmer et al., 2019), and even when service coordinators provide interpretation to help bridge this gap, caregivers may find the presence of the interpreter to be overwhelming and have difficulty scheduling the interpreter to align with the caregiver and service provider's existing schedule (Zuckerman et al., 2014, as cited by Gulsrud et al., 2021).

Family support services such as respite, transportation, family-focused education and training, and having reliable direct support professionals have been identified as critical services to support the health and wellbeing of families with loved ones with DD and may allow individuals to remain in the family home and community instead of being housed in a care

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

facility (Williamson et al., 2016). Saboktka et al. (2019) studied families with children with medical technology dependency (MTD) and their utilization of respite services. The quantitative findings from the study illustrated that 59% of families received no respite care at all. Interviews with home care coordinators revealed that barriers to utilization were staffing or availability of beds in respite facilities. Additionally, care coordinators stated that some families are reluctant to utilize respite outside the home. These commonalities lead to a troubling pattern, as children with MTD whose families do not receive any respite hours are more likely to become hospitalized. These hospitalizations are likely due to families' last efforts to obtain help with caregiving or their child's health condition worsening, requiring medical intervention.

In our dataset, client age, sex at birth, race/ethnicity, and home primary language were existing variables available for all clients. Location of residence data, immigration status and household income variables were not available.

Enabling Factors

Service delays are a significant obstacle to service utilization. Lack of available providers and long waitlists lead to caregivers being unable to use services they are eligible for, such as behavior therapy and respite care (Moodie-Dyer et al., 2014, Wodehouse & McGill, 2009). Yingling et al. (2018) used time-lag measures to determine the time from diagnosis to the receipt of therapeutic services for young children with autism. They found an average of 1,041 days between the date of diagnosis and the date of the initial therapy session. According to an evaluation of early childhood services in California, the division of disability supports and services occurs across two disparate systems, the Department of Developmental Services and the Department of Education. This division increases the likelihood of assessment and service delays for young children. As toddlers age out of early intervention (birth to <3) services which are

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

provided through the regional center to preschool services (3 to 5) which are provided by the school district, they frequently experience a gap in service due to poor communication and coordination between the two agencies (Anderson et al., 2018; Chang et al., 2023). Additionally, caregivers of children and young adults with autism in a focus group study reported dissatisfaction with their family member's service providers and disappointment with gaps in allocated services, such as employment support, social skills training, extended school day activities, funds for sensory equipment, and community education (Moodie-Dyer et al., 2014).

While higher income has been observed to serve as a mediator for increased service satisfaction, the opposite pattern has been seen for lower-income families (Moodie-Dyer et al., 2014; Pickard & Ingersoll, 2016). Parents with lower incomes may be more likely to face barriers in accessing services and be left needing more information about their child's disability. Whereas, higher income parents, who often engage in higher levels of advocacy for supports and services for their child with a disability, have expressed disappointment with their quality as compared to private providers (Pickard & Ingersoll, 2016) While family income and insurance type are factors of interest for service utilization research, these variables were not available in our dataset. However, aggregate census data indicates that the regional center catchment area includes predominantly low-income, racially and culturally diverse areas (██████████, 2022).

Another enabling factor of interest in this study is living situation. People with DD are most likely to live with family across their lifespan, while some live independently with or without specific professional supports (Larson et al., 2017). A small number of individuals with DD live in care facilities including but not limited to, group homes, psychiatric centers and nursing facilities due to a lack of available family caretakers or specialized care needs (Larson et

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

al., 2015)). Around the clock professional care and monitoring may sound wholly beneficial to the individual, however quality of support and services may vary between and within these residential settings. While it is clear that residential care often is very costly (Fujiara et al., 2018), and we know that people with DD are less likely to receive preventative health care such as cancer screenings and annual vaccines when they live in the family home (Bershinsky et al., 2012), and that coordination between mental and physical health providers is often lacking for this population (Stone et al., 2024), it is unknown whether clients living in care facilities are more or less likely to utilize their regional center services.

Statement of the Problem

The purpose of this study was to identify specific client factors associated with service uptake based on the Anderson model to better understand which [REDACTED] clients are not utilizing or underusing their allocated services and supports.

Methods

Data Source

The [REDACTED] Regional Center is a non-profit organization that allocates and provides resources for evaluation, diagnosis, treatment, advocacy and support for people diagnosed with developmental disabilities. The data analyzed for this project were provided by [REDACTED] for the service period July 1, 2021 to July 20, 2023. The dataset contained information on 20,184 unique clients – including both client and service characteristics for each client who was authorized any type of services during that period of time. Each row of the dataset was a service authorized to a client by [REDACTED]. This meant that a client could appear in multiple rows of the dataset. Also, a client and service combination could appear in multiple

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

rows of a dataset if the same service was authorized multiple times in that reporting time period to a client, perhaps with the same or different vendors or service providers, each time.

Client level variables

For each client, data were available on variables such as status (e.g. active, inactive, closed), sex (binary), age (in years), whether client has been diagnosed with cerebral palsy, epilepsy, autism, intellectual disability, category 5 (conditions similar to intellectual disability), or other developmental disabilities; also recorded was each client's race/ethnicity (e.g. Black/African American, Hispanic), primary language spoken (e.g. English, Spanish), living arrangement (e.g. living with parent/relative/legal guardian, independent supported living), and types of services the client was approved for.

Service-vendor level variables

Data were also available on each service that a client was authorized for; the type of service, as well as the vendor, start and end dates, amount (\$) allocated, and how much of the allocated amount was utilized by the client for that service. It should be noted that during the June 2021 – July 2023 reporting period, it was possible for a client to have been approved for the same service multiple times, and that each of those times could possibly have different vendors or service providers; these were recorded as separate incidences in the dataset.

Data Analysis

Andersen's Model of Service Utilization (1995) and Harrington and Kang (2008) indicate that several client characteristics and service characteristics are at play when it comes to utilization of allocated funds. The primary research question that this study explored using several of variables suggested by these researchers was the following:

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Primary research question (PRQ): For clients who utilize some or all of their total allocated funds for all services and vendors combined, what client characteristics are significant predictors of total amount utilized across all services?

A secondary research question investigated was:

Secondary research question (SRQ): Across the service-vendor authorizations, what client and service characteristics are significant predictors of whether allocated funds are utilized at all?

To investigate what client characteristics are significant predictors of total amount utilized across all services (PRQ), a weighted least squares (WLS) regression model was used. WLS regression analysis was used instead of ordinary least squares because total amount used displayed heteroscedasticity (James et al. 2021). Prior to the analysis, the dataset was collapsed to create one row for each client, and the total amounts allocated and utilized across all service-vendor assignments, as well as the total number of authorizations was calculated for each client. Only data for the 13,639 active clients whose amounts authorized, and amounts used were non-zero, and amount used did not exceed amount authorized during the reporting period, were used for the WLS regression analysis. On average, these 13,639 active clients used 72.1% of their allocated amount, with a standard deviation to 28.3%. The objective for the PRQ is to understand the sizable variation in utilization (28.3%). For the PRQ, the choice was made to use the total amount utilized as the dependent variable instead of the proportion or percentage of allocated amount utilized to keep the interpretation of the findings straightforward. The model, however, does still address the percentage utilized by using the total amount allocated as one of the predictors.

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

It should be noted that the following client-level variables were modified or created prior to analysis due to reasons such as very high number of levels and very small observed cell counts.

- Race/Ethnicity: the levels were collapsed to Asian, Black/African American, Hispanic, White, and Other; Filipino and Polynesian were combined with Asian, while Native American was combined with Other.
- Age group: the lowest age group was split into under 3, 3 to < 5, 5 to < 22, and 22+ years, to isolate the 3 to < 5 years as the age group where autism diagnoses are most prevalent.
- Primary language: grouped as English or Other (includes Spanish).
- Living arrangement: collapsed into three levels (living with parents/guardians/relatives, living in an independent living or foster home facility, or living in a care facility – which includes living in a rehabilitation center, etc.) from the original 37 levels.
- Consumer status: collapsed into three levels (Active, Inactive, or Closed) from original 11 levels; duplicates removed.

Owing to the nested nature of the data where the service-vendor assignments are nested within clients, a multilevel logistic regression model (Agresti, 2012) was used to predict the odds of a client using any of their allocated funds at all for a service-vendor assignment (SRQ). While a logistic regression model is able to classify observations into categories, a multilevel model accounts for the dependency of service-vendor assignments within each client. Recall that each row of the original data spreadsheet received from [REDACTED] was identified by an authorization ID – indicating each service-vendor authorization for a client, such that in some instances a client with multiple service-vendor assignments took up multiple rows of the spreadsheet. To

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

investigate SRQ, the outcome variable was an indicator of whether the client used any of the allocated amount for each service-vendor assignment; this outcome variable was created from the data provided. For this analysis, the following variable modifications to service-level characteristics are to be noted as well.

- Type of service: original 70 levels were combined into five categories – Medical services; Mental health and behavioral services; Residential and supportive services; Respite, transportation, goods and services; and, Therapies/evaluation/wellness.
- Service length: calculated from start to end date for each service-vendor assignment.
- Service received by: client, caregiver, or both – this was created by looking at the type of service.

The statistical programming *R* (version 4.4.0) was used to carry out the analysis. The function *glmer* was used to carry out the multilevel logistic regression, while the *lm* was used to carry out the least squares regression.

Results

Descriptive analysis

Tables 1 and 2 shows descriptive statistics on these potential client-level and service-level predictors of utilization. The dataset contained information on 20,184 unique clients. Table 1 shows the characteristics of these clients; the total for Table 1 may in the case of some variables be less than 20,184 due to missing data values. With regard to the variable “Client status” in Table 1, it should be noted that “Closed” implies that the client status was considered closed at the end of the two-year period but may have been active at the beginning of that period.

There were 120,048 authorizations of service-vender combinations to clients in the July 1, 2021, to July 20, 2023 service period. Table 2 shows the frequency of assignments of various

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

services, whether the services were considered to be for the client, caregiver, or both, typical values for amount of time the service was authorized for, amount allocated and utilized for the various service-vendor assignments, as well as how often none of the amount allocated for a service-vendor authorization was utilized. It appears from Table 2 that for this regional center services that fall under therapies, evaluation, and wellness and are targeted for the client primarily form the majority; there is substantial variability in service lengths and amounts allocated and used. Also notable is that the percentage of cases where none of allocation is used is very low (0.4%).

Inferential analyses

To investigate what client characteristics could be predictors of amount utilized (PRQ), for active clients who do utilize at least some portion of their allocated funds, a weighted least squares regression analysis was carried out. Table 3 shows coefficient estimates and corresponding confidence intervals and p-values for that resulted. For the 13,639 clients for whom complete data were available, the analysis found sex assigned at birth, race/ethnicity, age group, primary language, living arrangement, diagnoses of developmental disabilities, number of services, and total amount authorized over all the services and vendors to be statistically significant predictors of total amount utilized over all the services and vendors. For instance, as per the estimates in Table 3, clients 22+ years of age used on average \$2,271 more than clients aged under 3 years of age, [95% CI: (\$2121.86 – \$2,420.58)], all else being the same. Notably, clients who tend to use statistically significantly lower amounts of their allocated funds are males, of other race/ethnicity, aged under 3 years, don't speak English, live in care facilities, and have been diagnosed with one or more developmental disability.

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Keeping in mind that the percentage of cases where none of allocation was used was very low (0.4%), the multilevel logistic regression analysis, to investigate the SRQ, provided no evidence of sex assigned at birth, race/ethnicity, or being diagnosed with a developmental disability as being significant predictors of utilizing funds for service-vendor assignments. The estimated odds ratio from this model and corresponding 95% confidence intervals as well as p-values for the variables are shown in Table 4. An odds ratio of 1.0 indicates that the odds of “success” are the same for the two groups being compared. Among predictors that were found to be significant predictors are age group, primary language, living arrangement, client status, type of service, and whom the service was targeted at. In particular, those in the age group 5 to under 22 years were found to have statistically significantly lower odds of utilizing their allocated funds for any service-vendor assignments, compared to those aged less than 3 years [95% CI: (0.09 – 0.86)]. Similarly, those reporting English (vs. other) as their primary language, living with a parent/relative/guardian (vs. in a care facility), and with closed or inactive status (vs. active) had statistically significantly lower odds of utilizing their allocated funds. Also, funds had statistically significantly odds of being utilized for residential and support services (vs. mental health and behavioral services) and when services were for the caregiver (vs. for the client).

Discussion

Client characteristics were shown in this study of regional center data to be significant predictors of whether individuals utilized their allocated services. Overall, the study demonstrated the importance of using the Andersen Model of service utilization for examining the effects of predisposing and enabling factors on service use for people with disabilities who are clients of [REDACTED]. However, different client characteristics were associated with not using

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

any of the allocated service than using a lower portion of the allocation. While being school age (5 to <22 years), living with family and speaking English were associated with a greater likelihood of a client not using any of their allocated service funds, those who were likely to use a lower proportion of their allocated funds were male, in early intervention (under 3 years), didn't speak English, lived in a care facility, and had been diagnosed with one or more developmental disability. It is worth reiterating that those regional center clients not utilizing any of their allocated funds is a tiny proportion (0.4%) of their total clientele, whereas those clients underutilizing their approved services are a considerably large constituency. In fact, on average, clients in this dataset utilized only approximately 57% of the funds they were allocated, meaning that a significant amount of supports, services and funds for enrichment are being "left on the table," likely affecting the health, well-being and social integration of people with disabilities and their families served by the regional center.

The findings related to underutilization showed that clients under 3 years of age, those not from an English-speaking household, those living in a care facility, and those having one or more diagnosed disability use a significantly lower portion of their allocated funding for supports and services. These findings align well with the Anderson model and previous literature on service use for people with developmental disabilities. Consistent with Stahmer (2019), caregivers of young children in early intervention, birth to three services in this dataset were likely to utilize a lower proportion of their allocated services and supports. This may be related to the nature of these services being provided in the home or other natural setting and during traditional work hours, meaning that the caregiver could be required to forego work opportunities and be present as these services depend on providers teaching caregivers to implement routines-based strategies (Cole et al., 2011). Therefore, parents may need to shift their focus from other

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

children in the home or give up an otherwise restful moment in order to utilize these services. Services provided in semi-clinical settings such as playgroups may allow caregivers to take a much-needed break and spend quality time with the nondisabled siblings, encouraging caregivers to utilize a greater portion of their child's service allotment, benefitting the child's development and limiting future special education needs (Cole et al., 2011; ECTA Center, 2023).

Clients from non-English backgrounds have also been consistently shown to underutilize services due to a lack of availability of bilingual service providers (Gulsrud et al., 2021). The [REDACTED] catchment area has experienced a dramatic demographic shift over the past 30 years, with an expanding number of Hispanic/Latino (including many Spanish-speaking immigrants) households, outnumbering the Black residents in 2000 and continuing to grow (Sides, 2023). Therefore, it is possible that the regional center providers no longer align culturally and linguistically with the current clientele. This misalignment may cause a delay in access to Spanish-speaking providers with waitlists, affecting a client's educational, adaptive, physical and emotional health long-term. An evidence-based solution to this provider gap may be the employment of cultural brokers (Blinded for Review). Cultural brokers are professionals from a community who understand the cultural beliefs and speak the language of the client while also having strong knowledge of the disability supports and healthcare systems. These professionals can provide interpretation during service provision, but also information and navigational support for people with disabilities and their families (Blinded for Review). Use of cultural brokers to augment services can increase access to culturally and linguistically appropriate care and support clients in utilizing more of their allocated services until an adequate number of bilingual providers can be identified or cultivated.

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Interestingly, in our sample non-White clients of the RC utilized more of their services than their white counterparts. This finding is unique as RCs have long been criticized for the disparities in funding between White and non-White clients (Alpert Reyes, 2022; Public Counsel, 2022). Further, as the motivation for this study by SCLARC was to extend their lauded achievement in removing allocation disparities between White and non-White clients to improve their service uptake, this finding is notable (Public Counsel, 2022). This indicates that although many services and supports are not being used, this is not likely a result of a racial or ethnic disparity, which may mean that less complex solutions may be required.

Another factor that impacted overall service uptake was a client's place of residence. Individuals living in care facilities, which included group homes, specialized nursing facilities, psychiatric care facilities amongst other short and long-term care environments, were shown to use significantly less of their service allocation. This finding highlights the need for comprehensive care coordination for people with developmental disabilities in care facilities to ensure that health and rehabilitative care service appointments are prioritized. Care coordination is an organizational strategy for healthcare and rehabilitation services between the target individual and at least one other person involved in a patient's care to facilitate the appropriate delivery of allocated and preventative services (Ruiz et al., 2020). While residents in care facilities generally have a staff person who acts as a care manager, due to the high levels of support required for such residents and frequent staff turnover, this strategy often falls short, putting residents with DD and special healthcare needs at risk of costly and traumatic acute mental and physical health crises (Ruiz et al., 2020; Friedman, 2020). A healthcare provision system for people with DD that includes integrated care coordination may better support clients in a care facility to utilize more of their allocated services and engage in greater preventative care

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

to support their health and well-being and reduce emergency care needs (Redfern et al., 2015). Such a system would provide integrated psychological and medical services to adults with DD using the medical home model, frequently provided to children with DD in children's hospitals across the country (Aguayo, et al., 2024).

Interestingly, our analysis showed that to whom the service was provided impacted whether or not the service was utilized. We found that services and supports that supported the client directly (i.e. physical therapy, psychiatry) were more likely to be used than those that were for the caregiver only (i.e. respite, reimbursements) or for both the client and their caregiver (i.e. travel expenses to appointments, parent behavioral training). This means that many of the services and supports that are beneficial to the caregiver and family for overall well-being and economic stability are not being accessed consistently. As caregivers of people with DD are frequently confronted with elevated stress and depressive symptoms placing them at greater risk of preventable health conditions such as heart disease and diabetes (Jenaro et al., 2020; Fraser et al., 2021), these services and supports should be streamlined so that they are easily accessible and simple to use. As people with DD may rely on family to provide high levels of care and informal support across their lifespans, it is imperative that their families maintain healthy habits such as quality sleep, exercise, stress mediation and financial solvency so they can continue to provide for their loved ones and plan for the future (Jenaro et al., 2020; Lee & Burke, 2020).

Limitations & Future Directions

Because this was a secondary data analysis, variables of interest were not available in the [REDACTED] dataset, including household income and severity of disability, meaning that we were unable to assess how these would fit in our model. **Future research should consider incorporating these variables as they** could provide a more comprehensive understanding of how

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

socioeconomic factors, and the degree of disability are related to service utilization. As focus groups are a fundamental part of qualitative research that provide insights into the experiences and perspectives of participants, future researchers should incorporate focus groups into their studies to better understand the motivations and barriers behind service use. By prioritizing the voices of non-English speaking and non-White participants researchers can ensure the research captures the experiences and needs within those communities most impacted by service disparities.

Another limitation that cannot be overstated is the COVID-19 pandemic's impact on early identification of children with disabilities and availability of services during this period of time. Whether the regional center has experienced longer waiting lists for intake assessments and service providers for young children is beyond the scope of this study, but the pandemic may still be influencing this population due to such downstream effects. Further, it is not known whether regional center clients may have decided not to return to services as they reopened during the period of collection in our 2021-23 data. Longitudinal studies exploring datasets of service utilization prior to the pandemic may better explain the differences in utilization patterns before and after COVID-19.

Implications for practice include improving transition practices from early intervention to school-age services. For example, retaining service coordinators across the transition could improve continuity of care and support for families, while advocacy training offered in English and Spanish could prepare families to make informed choices in accessing services for their child across the lifespan.

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

References

- Agresti, A. (2012). *Categorical data analysis (Vol. 3)*. John Wiley & Sons.
- Aguayo, P., Lin, A. G., Stevens, P. T., Carbone, P. S., Bilder, D. A., & Rapaport, M. H. (2024). A patient-centered multidisciplinary medical HOME for persons with intellectual and developmental disabilities. *Focus*, 22(2), 170–174.
<https://doi.org/10.1176/appi.focus.20230036>
- Alpert Reyes, E. (2022, May 25). Disabled children unserved; racial disparities in California regional centers, report finds. *The Los Angeles Times*.
<https://www.latimes.com/california/story/2022-05-25/disabled-children-unserved-racial-disparities-california-regional-centers-report-finds>
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1), 1-10.
<https://www.jstor.org/stable/2137284>
- Anderson, R., Petek, S., Kuhn, J., & Newton, M. C. (2018). *Evaluating California's system for serving infants and toddlers with special needs*. Legislative Analyst's Office.
- Angell, A.M., Frank G., & Solomon O. (2016). Latino families' experiences with autism services: Disparities, capabilities, and occupational justice. *OTJR: Occupational Therapy Journal of Research*, 36(4), 195-203. <https://doi.org/10.1177/1539449216666062>
- Association of Regional Center Agencies (ARCA). (n.d.). *History of the System*. Retrieved from <https://arcanet.org/your-regional-center/history-of-the-system>
- Bershadsky, J., Taub, S., Engler, J., Moseley, C. R., Lakin, K. C., Stancliffe, R. J., ... & Bradley, V. (2012). Place of residence and preventive health care for intellectual and

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

developmental disabilities services recipients in 20 states. *Public Health Reports*, 127(5), 475-485. <https://doi.org/10.1177/003335491212700503>

California Department of Developmental Services. (2018, February). *Consumer Guide to the Lanterman Act*. Retrieved from https://www.dds.ca.gov/wp-content/uploads/2021/03/Consumer_Guide_To_The_Lanterman_Act.pdf

California Department of Developmental Services. (2019, March 12). *Disparities: Background Process for Developing Disparity Measures (Publication No. 20190329)*. Retrieved from https://www.dds.ca.gov/wp-content/uploads/2019/03/Disparities_BgProcessDevelopingDisparityMeasures_20190329.pdf

California Department of Developmental Services. (2023, 29 April). *Regional Center Eligibility & Services*. Retrieved from <https://www.dds.ca.gov/general/eligibility/>

California State Senate. (2017, March 14). *Hearing Background Paper*. Retrieved from https://shum.senate.ca.gov/sites/shum.senate.ca.gov/files/03-14-2017_heraing_background_paper_final.pdf

Blinded for Review

Cole, P., Oser, C., & Walsh, S. (2011). Building on the foundations of Part C legislation. *Zero Three*, 3, 52-59.

Blinded for Review

Early Childhood Technical Assistance Center. (2023, May 1). *Part C of IDEA*. ECTA Center. <https://ectacenter.org/partc/partc.asp>

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

- Fraser, L. K., Murtagh, F. E., Aldridge, J., Sheldon, T., Gilbody, S., & Hewitt, C. (2021). Health of mothers of children with a life-limiting condition: A comparative cohort study. *Archives of Disease in Childhood*, *106*(10), 987-993.
- Friedman, C. (2020) The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. *Inclusion*, *9*(1), 63–73.
<https://doi.org/10.1352/2326-6988-9.1.63>
- Fujiura, G. T., Li, H., & Magaña, S. (2018). Health services use and costs for Americans with intellectual and developmental disabilities: a national analysis. *Intellectual and Developmental Disabilities*, *56*(2), 101-118. <https://doi.org/10.1352/1934-9556-56.2.101>
- Gulsrud, A., Lee, H. S., Hassrick, E. M., Iadarola, S., Pellecchia, M., ... & Stahmer, A. C. (2021). It's who you know: Caregiver social networks predict service use among under-resourced children with autism. *Research in Autism Spectrum Disorders*, *88*, 101843.
<https://doi.org/10.1016/j.rasd.2021.101843>
- Harrington, C., & Kang, T. (2016). Disparities in service use and expenditures for people with intellectual and developmental disabilities in California in 2005 and 2013. *Intellectual and Developmental Disabilities*. <https://doi.org/10.1352/1934-9556-54.1.1>
- James, G., Witten, D., Hastie, T., & Tibshirani, R. (2013). *An introduction to statistical learning: with applications in R* (Vol. 112, p. 18). New York: Springer.
- Jenaro, C., Flores, N., Gutiérrez-Bermejo, B., Vega, V., Pérez, C., & Cruz, M. (2020). Parental stress and family quality of life: Surveying family members of persons with intellectual disabilities. *International journal of environmental research and public health*, *17*(23), 9007. <https://doi.org/10.3390/ijerph17239007>

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Lanterman. (n.d.). *Lanterman Overview*. Retrieved from

https://lanterman.org/lanterman_overview

Larson, S., Eschenbacher, H., Anderson, L., Pettingell, S., Hewitt, A., Sowers, M., ... & Agosta, J. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2015. residential information systems project report. *Institute on Community Integration*.

Moodie-Dyer, A., Joyce, H.D., Anderson-Butcher, D. & Hoffman, J. (2014). Parent–caregiver experiences with the autism spectrum disorder service delivery system. *Journal of Family Social Work*, 17(4), 344-362. <https://doi.org/10.1080/10522158.2014.903581>

Pickard, K. E., & Ingersoll, B. R. (2016). Quality versus quantity: The role of socioeconomic status on parent-reported service knowledge, service use, unmet service needs, and barriers to service use. *Autism*, 20(1), 106-115.

Public Counsel. (2022, May). *2022 Disparity Report: California Developmental Services Regional Centers*. Retrieved from https://publiccounsel.org/wp-content/uploads/2022/05/2022-Disparity-Report_Californiai-developmental-services_regional-centers.pdf

Redfern, H., Burton, J., Lonne, B., & Seiffert, H. (2015). Social work and complex care systems: The case of people hospitalised with a disability. *Australian Social Work*, 69(1), 27–38. <https://doi.org/10.1080/0312407X.2015.1035295>

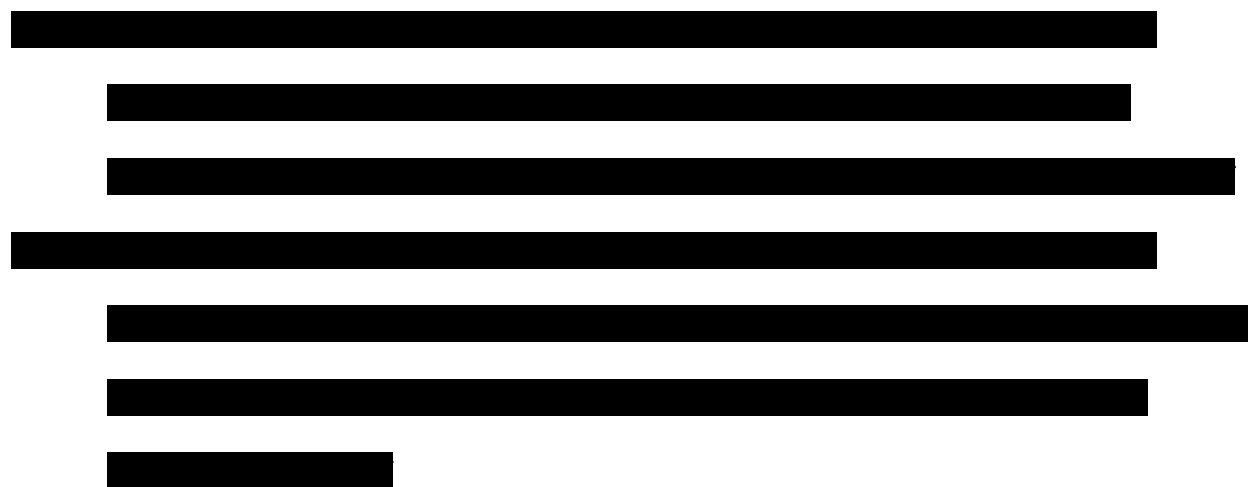
IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Ruiz, S., Giuriceo, K., Caldwell, J., Snyder, L. P., & Putnam, M. (2020). Care Coordination Models Improve Quality of Care for Adults Aging with Intellectual and Developmental Disabilities. *Journal of Disability Policy Studies*, 30(4), 191-201.

<https://doi.org/10.1177/1044207319835195>

Sobotka, S. A., Lynch, E., Quinn, M. T., Awadalla, S. S., Agrawal, R. K., & Peek, M. E. (2019) Unmet respite needs of children with medical technology dependence. *Clinical Pediatrics*, 58, 11-12.

Sides, J. (2003). *L.A. city limits: African American Los Angeles from the Great Depression to the present*. University of California Press.



Stahmer, A. C., Vejnaska, S., Iadarola, S., Straiton, D., Reinos Segovia, F., Luelmo, P., ... & Kasari, C. (2019). Caregiver voices: Cross-cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities*, 6, 752–773.

<https://doi.org/10.1007/s40615-019-00575-y>

Stone, E. M., Jopson, A. D., German, D., McCourt, A. D., & McGinty, E. E. (2024). Interagency coordination to manage co-occurring intellectual and developmental disabilities and

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

mental health conditions. *Psychiatric Services*, 0(0).

<https://doi.org/10.1176/appi.ps.20230451>

Valdés, G. (2005). Bilingualism, heritage language learners, and SLA research: Opportunities lost or seized? *The Modern Language Journal*, 89(3), 410–426.

<http://www.jstor.org/stable/3588667>

Williamson, H.J., Perkins, E.A., Acosta, A., Fitzgerald, M., Agrawal, J. & Massey, O.T. (2016). Family caregivers of individuals with intellectual and developmental disabilities: Experiences with Medicaid Managed Care long-term services and supports in the United States. *Journal of Policy and Practice in Intellectual Disabilities*, 13: 287-296.

<https://doi.org/10.1111/jppi.12198>

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful? *Journal of Intellectual Disability Research*, 53(7), 644-653.

<https://doi.org/10.1111/j.1365-2788.2009.01163.x>

Yingling, M. E., Hock, R. M., & Bell, B. A. (2018). Time-lag between diagnosis of autism spectrum disorder and onset of publicly-funded early intensive behavioral intervention: Do race–ethnicity and neighborhood matter? *Journal of Autism and Developmental Disorders*, 48, 561-571. <https://doi.org/10.1007/s10803-017-3354-3>

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Table 1: Descriptive statistics on potential client-level predictors of utilization

<i>Client characteristics</i>	<i>Categories or levels</i>	<i>n (%)</i>
Sex	Female	6,885 (34.1%)
	Male	13,299 (65.9)
Age	Under 3 years	3,479 (17.2%)
	3 to less than 5 years	3,203 (15.9)
	5 to less than 22 years	6,617 (32.8)
	22+ years	5,858 (29.0)
Race/Ethnicity	Asian	178 (0.9%)
	Black/African American	4,302 (21.3)
	Hispanic	14,016 (69.4)
	White	476 (2.4)
	Other	1,212 (6.0)
Client status	Active	14,708 (72.9%)
	Closed	5,046 (25.0)
	Inactive	423 (2.1)
Primary Language	English	12,402 (61.4%)
	Other	7,782 (38.6)
Diagnosed with Autism	Yes	6,368 (31.5%)
	No	13,816 (68.5)
Diagnosed with Epilepsy	Yes	1,592 (7.9%)
	No	18,592 (92.1)
Diagnosed with Cerebral Palsy	Yes	1,380 (6.8%)
	No	18,804 (93.2)
Diagnosed with Intellectual disability	Yes	7,368 (36.5%)
	No	12,816 (63.5)
Diagnosed with Category 5	Yes	2,632 (13.0%)
	No	17,552 (87.0)
Other developmental disability	Yes	6,125 (30.3%)
	No	14,059 (69.6)
Living arrangement	Parent/Relative/Guardian	16,555 (82.0%)
	Independent or Foster living	2,186 (10.8)
	Care facility	1,443 (7.1)

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Table 2: Descriptive statistics on potential service-level predictors of utilization, across the 120,048 service-vendor authorizations

<i>Service characteristics</i>	<i>Categories or levels</i>	<i>n (%)</i>
Type of service	Medical services	19,657 (16.4%)
	Mental Health and Behavioral services	8,991 (7.5)
	Residential and Supportive services	20,823 (17.3)
	Respite, Transportation, Goods, and Services	16,151 (13.5)
	Therapies/Evaluation/Wellness	54,426 (45.3)
Service received by	Client	72,159 (60.1%)
	Caregiver	7,030 (5.9)
	Both	40,859 (34.0)
Service length	Mean:	97.9 days
	Median:	7.0 days
	Standard deviation:	137.8 days
Total amount allocated	Mean:	\$4,969.00
	Median:	\$399.00
	Standard deviation:	\$13,174.82
Amount utilized	Mean:	\$2,849.90
	Median:	\$172.50
	Standard deviation:	\$10,647.61
Allocation utilized	Yes, at least some portion utilized	119,050 (99.6%)
	No, none utilized	499 (0.4)

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Table 3: Estimated coefficients and corresponding 95% confidence intervals (CI) for a weighted least squares regression model predicting the amount used by client (in \$), associated with client characteristics.

	Coefficient	95% CI	p-value
Sex (assigned at birth) (ref: Female)			< 0.001
Male	-114.10	(-146.40, -81.82) *	
Ethnicity (ref: White)			< 0.001
Asian	206.30	(-411.35, 823.94)	
Black	979.70	(769.53, 1189.90) *	
Hispanic	231.10	(33.12, 429.04) *	
Other	-846.70	(-1,070.30, -623.08) *	
Age (ref: under 3 years)			< 0.001
3 to under 5 yrs.	304.20	(250.13, 358.27) *	
5 to under 22 years	1488.00	(1,385.02, 1,591.13) *	
22+ years	2271.00	(2,121.86, 2,420.58) *	
Language (ref: Other)			< 0.001
English	259.10	(226.84, 291.34) *	
Living arrangement (ref: Care facility)			< 0.001
Parent/Relative/Guardian	8984.00	(8,085.10, 9,882.14) *	
Independent/foster living	10,090.00	(9,021.05, 11,154.03) *	
Autism (ref: No)			< 0.001
Yes	-1433.00	(-1,513.26, -1,353.73) *	
Cerebral Palsy (ref: No)			< 0.001
Yes	-1411.00	(-1,623.52, -1,197.60) *	
Epilepsy (ref: No)			< 0.001
Yes	-1225.00	(-1,392.07, -1,057.48) *	
Intellectual disability (ref: No)			< 0.001
Yes	-648.10	(-729.75, -566.40) *	
Category 5 (ref: No)			< 0.001
Yes	-2095.00	(-2,141.28, -2,047.80) *	
Other developmental disability (ref: No)			< 0.001
Yes	-531.70	(-631.65, -431.81) *	
Number of services	174.80	(150.69, 198.87) *	< 0.001
Total amount authorized	0.67	(0.66, 0.69) *	< 0.001
Total no. of clients = 13,639		R ² -adjusted = 0.9946	

IMPROVING UPTAKE IN REGIONAL CENTER SERVICES

Table 4: Estimated odds ratios and corresponding 95% confidence intervals (CI) for the odds of utilizing allocated funds associated with the corresponding predictors, using multilevel logistic regression.

	OR	95% CI	p-value
Sex (assigned at birth) (ref: Female)			0.885
Male	1.04	(0.6 – 1.7)	
Ethnicity (ref: White)			0.666
Asian	0.51	(0.04 – 7.47)	
Black	1.54	(0.22 – 1.07)	
Hispanic	1.23	(0.18 – 8.33)	
Other	0.80	(0.10 – 6.29)	
Age (ref: under 3 years)			0.056
3 to under 5 yrs.	0.40	(0.16 – 1.02)	
5 to under 22 years	0.28	(0.09 – 0.86)*	
22+ years	0.52	(0.14 – 1.94)	
Language (ref: Other)			0.030
English	0.53	(0.30 – 0.94)*	
Living arrangement (ref: Care facility)			0.042
Parent/Relative/Guardian	0.02	(0.001 – 0.55)*	
Independent/foster living	0.04	(0.001 – 1.02)	
Status (ref: Active)			< 0.001
Closed	0.20	(0.10 – 0.41)*	
Inactive	0.10	(0.04 – 0.30)*	
Autism (ref: No)			0.775
Yes	1.13	(0.48 – 2.67)	
Cerebral Palsy (ref: No)			0.789
Yes	0.87	(0.31 – 2.43)	
Epilepsy (ref: No)			0.632
Yes	0.78	(0.28 – 2.18)	
Intellectual disability (ref: No)			0.688
Yes	1.20	(0.50 – 2.88)	
Category 5 (ref: No)			0.516
Yes	1.33	(0.56 – 3.14)	
Other developmental disability (ref: No)			0.194
Yes	2.44	(0.64 – 9.33)	
Type of service (ref: MBHS)			0.003
MS	0.20	(0.02 – 1.80)	
RSS	0.08	(0.01 – 0.76)*	
RTGS	0.24	(0.02 – 2.82)	
TEW	0.50	(0.05 – 4.62)	
Service length (in days)	1.00	(1.00 – 1.01)	0.828
Service received by (ref: Client)			< 0.001
Caregiver	0.06	(0.02 – 0.26)*	
Both	0.18	(0.08 – 0.40)*	
Total no. of clients = 19,150		AIC = 4003.0	
Total no. of observations = 112,388		BIC = 4272.7	



Click here to access/download

Edited Manuscript

SCLARC Manuscript_R1.docx

