Intellectual and Developmental Disabilities

"Treating Substance Use Disorder in Individuals with Intellectual Disabilities: A Regional System Capacity Assessment"

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Abstract:	This mixed-methods study assessed substance use disorder (SUD) treatment for individuals with intellectual and developmental disabilities within California's regional center system. The system, a primary organization in California, coordinates and monitors services for these individuals. Data were collected with 21 service centers, with six vendored programs overseeing SUD services. This paper reports on those programs and analyzes qualitative data from seven service coordinators regarding overall SUD treatment. Both programs and coordinators identified barriers to treatment, such as a lack of training and inadequate service structures. Despite being formal referral targets, these programs often only offered adaptations for physical access. Proposed solutions included interagency collaboration and adopting a biopsychosocial model of care.

Abstract

This mixed-methods study assessed substance use disorder (SUD) treatment for individuals with intellectual and developmental disabilities within California's regional center system. The system, a primary organization in California, coordinates and monitors services for these individuals. Data were collected with 21 service centers, with six vendored programs overseeing SUD services. This paper reports on those programs and analyzes qualitative data from seven service coordinators regarding overall SUD treatment. Both programs and coordinators identified barriers to treatment, such as a lack of training and inadequate service structures. Despite being formal referral targets, these programs often only offered adaptations for physical access. Proposed solutions included interagency collaboration and adopting a biopsychosocial model of care.

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There is a wealth of research investigating the inequitable treatment of people with disabilities (Friedman, 2018; Schweik, 2009). More narrowly, Carson et al. (2010) discuss the devaluation of people with intellectual disabilities (PID), which they propose is evident by the way society encounters and characterizes PID. In the United States (US), practices and attitudes viewed as oppressive toward PID have been linked to policies, ordinances, social systems, and laws established to maintain social order within communities (Rembis et al., 2018; Trent, 2016). In 2000, one crucial step was taken in the form of the federal Disabilities Bill of Rights ("Developmental Disabilities Assistance and Bill of Rights Act of 2000", 2000), which states that PID have the right to equal access to "health-related activities," ("Developmental Disabilities Assistance and Bill of Rights Act of 2000", 2000) including treatment for substance use disorders (SUD).

Efforts to understand healthcare challenges for PID are hampered by a lack of evidence about systems of care and treatment modalities specific to ID (Bredewold et al., 2020). Data suggest that the prevalence of ID across the lifespan is 1-3% (Maulik et al., 2011; World Health Organization, n.d.). Among those diagnosed with ID, 85% will be classified in the mild range, and 10% will be in the moderate range (Harris, 2006). Little is known about the prevalence of SUD among PID, often due to diagnosis of ID overshadowing other diagnoses (van Duijvenbode et al., 2015). The limited research that has been conducted suggests a prevalence rate of SUD for PID between 0.5%-2.6% (Slayer, 2010; van Duijvenbode et al., 2015; van Duijvenbode & VanDerNagel, 2019). A separate review of Medicaid enrollees with a diagnosis of ID and/or autism spectrum disorder conducted between 2008 and 2012 found that the SUD prevalence rate was 1.0-2.2% among this population group and that the risk for SUD increased if there were co-occurring psychiatric disorders (Roux et al., 2022).

PID who use substances may be at higher risk than their non-ID counterparts for developing an SUD and often experience more adverse effects of substance use (SU) (Corrigan et al., 2003; Slayter & Steenrod, 2009; van Duijvenbode et al., 2015). However, research on

SUD treatment for PID is limited, especially in the US (Corrigan et al., 2003; Michael et al., 2008). In 2019, a systematic review on SU and ID found only seven published articles worldwide concerning screening for SU among PID, none of which were conducted in the US (van Duijvenbode & VanDerNagel, 2019). There is a clear health access gap for PID, who are simultaneously at risk from SUD and unable to access healthcare that is designed to identify or manage their unique SUD treatment needs. The specific factors that seem likely to contribute to the risk from SUD among PID include findings that: (a) legally-mandated deinstitutionalization of PID, and concomitant introduction of less-restrictive environments, have increased access to psychoactive substances of abuse (Nielsen, 2008; Walmsley, 2005); (b) PID who use substances may be at higher risk for developing SUD (Corrigan et al., 2003; Michael et al., 2008; Slayter & Stennrod, 2009; van Duijvenbode et al., 2015); and (c) adaptive healthcare of any kind that is appropriate for PID is rare (Cooper et al., 2004; Kitchin, 1998; Nielson, 2008; While & Clark, 2010). Further complicating the SUD treatment gap, many standardized SUD risk assessments have not been validated for PID (Naaldenberg et al., 2015).

In the US, few studies have examined systems and approaches to treatment for SUD among PID. Even basic information about how PID interfaces with SU treatment systems is often unexplored or undocumented. To begin correcting this deficit, this study was designed to examine SUD treatment practices for PID in a large regional system serving PID in California (CA) by (a) exploring service coordinators' perspectives toward SUD treatment and (b) examining SUD treatment programs available to the systemThe goal of this mixed-methods study was to produce a preliminary body of evidence that will inform future studies on the importance of the intersection of ID and SU.

Methods

Data for this study were collected in cooperation with Regional Centers in CA, an organization of 21 service centers coordinating services for PID and developmental disabilities. CA Regional Centers’ goal is to assist clients in living a productive and healthy life. To do so, service coordinators employed by the regional center prepare, implement, and monitor PID who access regional centers. Service coordinators assist in building a team of supports for each client using natural (e.g., family & friends), generic (e.g., county SUD treatment program, private SUD treatment center, paid for out of pocket or by insurance), and vendored services (programs explicitly designed to service the ID population and paid for by CA Regional Centers). To contextualize SUD treatment for PID in CA, this study explores both (a) service coordinators' perspectives towards SUD treatment and (b) the SUD treatment programs available to the system as vendors. The authors' institutional review board approved this study.

Participant Recruitment

Recruitment of vendored programs and service coordinators was conducted simultaneously and required assistance from local gatekeepers. In this case, the community service director at Alta California Regional Center, Sacramento, CA, facilitated contact with those gatekeepers. The director of that center was highly involved in the CA system and capable of facilitating contacts.

Vendored Programs

To recruit vendored programs, the director, with consultation from the first author, emailed the 21 centers within the Regional Centers system (the gatekeepers) requesting the name and contact information of all vendored SUD treatment programs being used by each center (those vendored programs were the potential subjects). The first author conducted follow-up using the Dillman method (Dillman, 1978) with centers that did not respond to the community service director's request using up to three emails and three phone calls. When the regional centers identified vendored service providers, the director and the researcher formally invited the vendored service program directors (or equivalent) to participate in the study.

Service Coordinators

Service coordinator recruitment began with the first author emailing community service directors of all 21 CA regional centers. Up to three emails were sent, separated by one-week intervals, requesting contact information for service coordinators at their regional center who had experience working with SUD and PID. Community service directors from nine regional centers responded with the name and contact information of a service coordinator at their regional center who had experience with SUD and PID (42.9% response rate).

In the second stage of recruitment, eligible interview candidates (service coordinators) identified by service directors at their regional center during the first stage were invited to participate via email. The study information was emailed to all nine individuals, of whom eight replied via email, expressing interest in participating in the study. During scheduling, an additional service coordinator stopped responding to correspondence. Thus, interviews were scheduled with seven service coordinators (77.8% participation rate).

Inclusion Criteria

Only program directors (or equivalent) that were vendored to provide or oversee SUD services to PID and service coordinators with experience working with PID and SUD within CA Regional Center system were eligible for inclusion in the study.

Survey Procedures for Vendored Programs

System Capacity Assessment of vendored SUD treatment for people with ID in CA-Survey were administered via hyperlink using Qualtrics, an online, secure survey platform. Access to the survey instrument was provided using a hyperlink. Requests to complete the questionnaires followed a modernized Dillman method. Program directors received up to three email requests to complete the questionnaire. Agencies that had yet to respond received a follow-up letter one week after the original letter was sent. The final request to non-responders was dispersed 6-7 weeks after the initial mailing. Three telephone reminders followed the emails to increase the response rate (Dillman, 1978).

Instrument and Measures

The survey was created using a combination of questions from validated surveys and toolboxes and questions assessed for face validity by an expert panel (n=5). The expert panel included two therapists who had extensive experience working with people with ID and SUD, a researcher who focused on ID, a day program assistant director who provided services to people with ID with SUD, and a director of community services for people with ID. The team of experts received the original survey questions and provided feedback. They requested minor word and term clarifications, and the first author made all requested revisions. The expert panel reviewed the survey again, and all members agreed on the understanding and purpose of each question (Creswell & Cresswell, 2017; Drost, 2011).

The survey was divided into five sections: (1) demographics, (2) knowledge of disability, (3) organization and ID, (4) SUD treatment, and (5) organizational aftercare. The survey had 29 questions; 7 were open-ended, and 22 were multiple-choice or yes/no questions. Eight of the 22 quantitative questions allowed/requested additional qualitative details to allow for further explanation (https://osf.io/bevng?view_only=12506234f8614311a0ed4af50531956f).

Interview Procedures for Service Coordinators

Qualitative results from this study are reported according to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) (Tong et al., 2007). Semi-structured interviews were conducted with service coordinators at CA regional centers. The interviews took place virtually using Zoom and were recorded. All names, regional center information, and service locations were removed from the transcripts for data security.

Theoretical Framework

The study, interview guide, and results analyses were explicitly conducted considering the International Classification of Functioning, Disability and Health (World Health Organization (WHO, 2005). Qualitative data were coded using *a priori* and emergent themes using the general inductive approach (Denzin & Lincoln, 2011). An interview guide helped to structure the interviews and ensured that key areas were covered and discussed. Predetermined central themes included the characterization of SUD treatment for PID within the CA regional center system, the role of the regional center in obtaining SUD treatment for PID, and the need for biopsychosocial treatment of SUD for PID, within which coders induced emergent subthemes.

Data Collection

All interviews lasted between thirty and sixty minutes. Each began with a description of the study's purpose and the administration of demographic questions. Interview questions focused on healthcare, mental healthcare, and SUD treatment. The transcripts were examined, and two coders concluded that data saturation had been reached. Notably, all participants had experience working with clients with SUD and ID, which likely increased the richness of the data.

Data Analysis

Transcripts were read several times to identify emerging themes. The text of the transcripts was highlighted according to analytic codes, which were condensed into meaningful categories and subcategories. Preliminary analyses were presented to the second coder, who then used the categories and subcategories to verify the coding scheme. The two coders identified two additional subcategories during the initial analysis. Two randomly selected transcripts were then independently coded by different coders to ensure a uniform understanding of the codes. A subsequent coding conference was held focusing on identifying and managing coding discrepancies. The researchers discussed their understanding of the themes, and no discrepancies were identified. The final coding scheme was used for all interviews (n = 7). Overall analyses were based on both *a priori* and emergent themes. *A priori* coding elements were: 1) the characterization of SUD treatment for PID within the CA regional center system; 2) the role of the CA regional center in obtaining SUD treatment for PID, and 3) the need for biopsychosocial treatment of SUD for PID. Following completion of the coding, a final data conference was held with primary analysts to confirm observations and determine priority findings.

Notably, the second coder was intentionally selected for a more robust analysis. While the primary coder had previous experience with the research question at hand, the second coder had no previous experience with this research topic, decreasing the likelihood that assumptions, preconceptions, and expectations would substantively alter the data analysis findings and results.

Results

All 21 regional centers in the state of CA (100%) provided information about their vendored SUD service providers. Most (*n*=17) regional centers in CA did not have a specific vendored program to which they referred clients for SUD treatment services (though one of the seventeen typically referred to the vendor used by a nearby regional center). The remaining regional centers (*n*=4) provided contact information for all vendored SUD service providers that they used. Two regional centers reported referring clients to two different vendored programs, and two regional centers used one program each. Thus, six vendored programs were overseeing SUD services to PID within the Regional Centers of CA service system. It should be noted that five of the vendored programs were in the northern region of the state, and only one program was in the populous Los Angeles area.

Program directors (or equivalent) at five of the six vendored programs completed a cross-sectional survey designed to elicit information about the program’s policy and procedures, attitudes, barriers, aftercare, and factors surrounding treatment and treatment planning for people with SUD and ID. The remaining program director could not participate because the study occurred during a major COVID-19 surge in that region of CA.

In parallel, as described in the Methods, seven service coordinators were interviewed, corresponding to seven of the 21 regional centers. Table 1 demonstrates the *a priori* categories, emergent themes, and an exemplar quote. Four service coordinators worked at a CA regional center with no vendored SUD treatment provider, and three worked at a regional center with a vendored SUD treatment provider. <<Insert Table 1>>

Descriptive Data

Vendored Program Directors

Most program directors were female (*n*=3), white non-Hispanic (*n*=4), and working full-time (*n*=4). Participants' education levels varied, ranging from some college but no degree (*n*=1) to a doctoral degree (n=1).

Service Coordinators

Most service coordinators were female (*n*=6). The average number of years a respondent had worked at a regional center was eleven years, ranging from one to thirty years. The mean age of the sample was 42 years (*SD*: 8.3). The sample's race and ethnicity distributions were White non-Hispanic *(n*=4), White Hispanic (*n*=1), and Black Hispanic (*n*=2). All the service coordinators were working full-time. Four participants in the sample had a bachelor's degree, and three had a master's degree. Two of the participants held a supervisory role.

Knowledge of Disability

All vendored program directors at least somewhat agreed that PID are able to participate fully in life. However, participants generally disagreed to some extent (*n*=4) that PID are treated fairly in the US, with one outlier indicating slight agreement (the lowest level of affirmation that they are treated fairly that was available on the response scale. Most of the vendored SUD programs served the general population (*n*=4), indicating that between 1% and 25% of their clients had an ID, while one program exclusively provided SUD services to PID.

Service coordinators reported a clear lack of training about disabilities, specifically ID, among SUD service providers, including vendors and generic services.

> *Nobody working in substance abuse programs has any idea how to work with somebody who has an intellectual disability. So, what ends up happening is that there is no real treatment.*

The participants speculated about why this happens.

> *The clients are primarily going to [redacted] facilities, which typically the employees are LCSW or MFT's just banking hours until they can move on and do their next thing. And so, there's a lot of turnover. So, the quality of services is hit or miss.*

Service coordinators reported they often must spend time educating healthcare providers, including mental health and SUD treatment providers, on disabilities. *"The therapist doesn't know how to deal with disability. She asked me how to deal with it."*

Organization & ID

The responding service coordinators reported that PID with SUD often created a strain on the "*system*," which they generally conceptualized as the combined services provided by the regional center and other healthcare, judicial, and behavioral health service providers. Service coordinators indicated that numerous factors prevented the system from functioning and that these factors were two-fold: strains related to the service providers within the system and those related to the clients receiving the services within the system.

When describing other service providers in the system (including service coordinators), participants suggested that "*everyone is screwed*" so "*maybe they don't care,*" and people working within healthcare, judicial, and behavioral health services were "*not interested*" or "*too busy*" to provide adequate service and care to PID. Furthermore, services offered are voluntary, and clients have the right to refuse any service(s) offered. Service coordinators indicated, based on their experience, that PID with SUD typically have a co-occurring disorder and are usually receiving services (voluntary or court-ordered) from a variety of sources. Service coordinators providing case management for their clients are attempting to interface with all the providers within the system, not just SUD treatment providers. To assist the client with the navigation of their care, service coordinators use other colleagues as supports, such as independent living skills or supportive living skills workers. However, these services take time to be approved and a worker must be assigned from a vendored agency. Often, clients will refuse treatment or services during this waiting period. Service coordinators noted that their clients' behavior may be inconsistent with the treatment recommendations, or they refuse care entirely, which strains the system.

> *It is a revolving door. My client is a regular there (emergency room or emergency psychiatric services). They call me every other day. My number is on speed dial.*

Two SUD vendored facilities reported screening for ID. Both reported that they typically seek additional information from other sources to learn about their client's disabilities. One facility did not report screening for ID because diagnosis was a precondition for admission. Two facilities reported they do not screen for ID or any other disabilities.

All SUD vendored providers reported efforts to adapt their facilities and treatment modalities to accommodate ID. Adaptions such as ramps, handrails, special lighting, and modified bathrooms were reported. All directors indicated that their facilities provided increased time for clients with ID to complete paperwork. Four facilities reported having larger print materials, and two facilities reported offering alternatives to writing and/or reading. One facility noted that any physical changes must be approved by CA state licensing.

Two facilities reported that they did not have specific policies or procedures concerning the treatment and adaptations provided for PID. One facility reported that its policies and procedures were all geared towards PID because diagnosis was a precondition for admission. Two facilities did not answer this question.

SUD Treatment

Service coordinators indicated that stigma surrounding SUD and related issues for PID appeared to manifest in a few divergent forms. First, a few of the service coordinators reported they intentionally do not bring up certain subjects (such as SU) while meeting with clients to avoid a potential adverse behavior (physical or verbal aggression or refusing/withdrawal from services). Second, service coordinators noted that the stigma of SUD from the system, including service coordinators, can potentially influence the type of care or case management provided. Some interviewees implied that the system may avoid or passively navigate the care and services of some PID, saying, *“Unfortunately, there is that stigma about if you have an addiction issue, you're weak-willed, or that you can't grow.”* They also reported stigma influenced all areas of SUD treatment for PID including the treatment providers making derogatory remarks. Interviewees reported they hear statements such as, "*we don't deal with those kinds,*" regularly.

All vendored program facilities reported making alterations to the treatment they provide to PID, but the level and type of alterations varied. Each facility reported modifications to the group materials used in the treatment for PID. Two facilities reported offering additional individual sessions for PID, and one (the one that reported serving only PID) indicated that it increased staffing up to a 3:1 ratio (staff:client) when necessary. That same program also reported increased use of probing questions during sessions to facilitate comprehension (for the client and facilitator), noting “*we truly assess client’s understanding.*”

The ID-exclusive SUD treatment facility additionally indicated that it provides clients with questions and topics that will be addressed in meetings one or two days prior to each meeting so that the client is able to discuss the topics before the meeting with their assigned staff member(s) at the program. The facility reported that by engaging in this practice, PID “*come to the meeting and are able to engage in meaningful discussions*.” This program specifically noted that their facility is committed to making modifications and adaptions. Additionally, this program reported that the most critical adaption were psychological modifications and that, “*competent and determined people need to be employed for this to work*,” for the treatment to be successfully because “*the staff must continually be asking, what should I do as the teacher to modify?*"

Three facilities reported having a set of curricula for SUD, and one of those facilities reported they use the same curriculum for PID and for persons without ID. However, despite being specifically asked to provide the name(s) of the curricula, these facilities did not provide the name(s) or type(s) of curricula used. One program reported they do not use a set curriculum, but that they address treatment holistically. They reported that they adopt and use concepts, materials, and techniques from acceptance and commitment therapy, trauma-based therapy, wellness and recovery plans, 12-step programs, and core attachment therapy. This program also reported particular emphasis on life skills development and verbal communication versus printed materials.

Four of the five facilities reported barriers to treatment for PID. The one program that did not report barriers choose not to answer the question; it is unclear if the director believed that barriers do not exist or if they chose not to answer the question for a different reason. Program directors noted that PID struggle more in group settings than in 1:1 settings because they may experience increased difficulty following the flow of the conversation. Respondents also indicated that PID generally experience increased hardships concerning reading and writing, along with elevated facilitator/client power struggles during treatment. In addition, two facilities reported that PID generally struggles with comprehension and concentration in treatment. The program that serves only PID reported that there needs to be more patient-centered treatment for PID and money to provide the needed treatment. Additionally, the program shared the impression that PID experience increased loneliness while in treatment compared with their non-ID counterparts and that there is an overall lack of diversity and disability training for staff.

When asked to describe the overall quality of SUD treatment provided to PID, directors from three of the facilities felt that the quality of the treatment provided was good to excellent; one thought it was fair, and one thought it was neither good nor poor quality. Three directors indicated that, all things considered, the SUD treatment program was meeting the needs of PID, whereas two reported that about half the time or sometimes the treatment needs were met. Finally, directors of three of the five facilities reported they needed more resources to administer SUD treatment to PID.

Some service providers indicated it would be valuable for vendors who are not explicitly SUD treatment providers to have a minimum level of experience or training about SU. This came up regarding residential homes called “board and cares” within the regional center, independent living support, and supportive living support. Service providers themselves, as well as their colleagues, also frequently indicated a perception of insufficient training on SUD. One participant reported, "*You just wing it. I am no substance abuse expert.*" The participants freely acknowledged their own and their peers' lack of knowledge relevant to SUD, *"We tell them generic resources like AA and NA, and it's like, good luck."*

All the service coordinators repeatedly indicated that SUD service providers lacked resources: "*there's so many holes," "we're stuck," "we don't have the services,"* are just a few examples. It was reported that generic programs are difficult to access due to insurance requirements, wait times, and a shortage of vendored programs, meaning NA and AA are often the first option to initiate any sort of SUD treatment process.

> *The programs are very full, and the wait can be quite long, six months. For someone who needs the help now. We just do not have the services. So, NA and AA are kind of my foot in the door.*

At the same time, service coordinators reported both NA and AA were rarely successful for PID as standalone services, *"It's just a band aid a lot of times because we don't have the supports."* Thus, some providers indicated that PID who are clients rarely receive SUD treatment unless alternative routes are facilitated. However, these approaches are also troubling. One of the routes to obtaining SUD treatment was for the client to become a part of the judicial system. *"There's nothing, it's awful. In my experience the best way my clients get treatment is for them to be arrested and go to court. And that's terrible."* Another route mentioned was to seek SUD treatment for their clients through the emergency room (ER)*, "I hate sending people to the ER, but it's kind of our best way to go."*In addition to not having SUD treatment programs available, the service coordinators reported a lack of vendors that provide SUD services to the clients. "*…if they [refuse treatment or are terminated from treatment] at one place, sometimes that's all we have. And it might just be that it wasn't a good fit…"*

Beyond the lack of training and resources, some participants discussed the lack of adaptations during treatment, an issue that was perceived to affect generic and vendored services alike. Participants noted the disjointedness of the system, indicating clients "*fall through the cracks*" due to the program's inability to deviate from their pre-identified program/requirements.

> *It's not good. It hasn't been good. I've been doing this for 30 plus years. There's been a need. They fall through the cracks. They're not tailored making it to our consumer's needs. They're having the program and making our consumers fit in their program, as opposed to taking that individual, looking at their needs and who they are and trying to create a program around them. There needs to be a significant change.*

Organizational Aftercare

Two facilities reported that they do not follow up with PID who drop out of their program. One of these facilities reported that due to the nature of their funding, which is provided solely by the regional center system, they are not authorized to provide treatment if a client drops out of their program, but that clients are welcome to return to treatment if their funding from the regional center is reinstated. One facility reported attempting to follow-up with PID if they drop out of program but did not describe how or what the follow up entails. One program reported, "*the needs and preferences are not regularly met*" concerning follow-up care if a person drops out of the program. One facility did not answer this question.

Pertaining to aftercare follow-up, one program reported they provide additional referrals for "*mental health care*" post treatment. Another program reported the number of 1:1 sessions is increased prior to discharge and a case management team is assigned to PID to ensure transition from the services provided at the facility. One program reported that they accommodate to the best of their ability and "*do not discriminate*" yet did not expand on what this specifically meant. One program did not answer this question. Lastly, one program reported, "*the needs and preferences are not regularly met*" concerning aftercare follow-up.

Service coordinators frequently reported the need for a more holistic way of approaching and following up with PID in SUD treatment. Service coordinators identified clients often experience a "*revolving door*" and note that this experience as a motivating factor to reexamine and reconstruct SUD for PID. Service coordinators reported feeling that PID are "*way behind*" other persons receiving SUD treatment in terms of access to advances such as evidence-based practices, new research implemented in practice, harm reduction, screening, and interventions. A service coordinator stated, *"It's not the clients' fault. It's the way systemically things have gone. We have to look at every part of them-the whole social psychosocial system."*

According to the service coordinators, the entire way that SUD treatment for PID is being managed needs to be overhauled. They reported that it is not that the client can't succeed in SUD treatment, but that SUD treatment has not been developed in a way where clients can succeed in treatment. One coordinator reflected on a client who struggled because of *"…reading that was required. And there wasn't anybody that we could put in there to assist with that."* Service coordinators reported they often hear from SUD providers that clients are "*non-compliant*" or "*refusing to participate,*" when in reality, the client may be slow to process the information or not understanding what is happening due to their cognitive ability. Yet, all the service coordinators noted that SUD and PID should be individualized, and programs (vendored and generic) must consider alternative methods of instruction, care delivery, programing, and alternative opportunities to engage this underserved, understudied, and at-risk population.

Discussion

This study produced meaningful data that served to elucidate the state of SUD treatment for PID in CA. Even with an *a priori* understanding of the difficulties experienced by PID in obtaining treatment for SUD, these significant gaps in service affecting the entire state of CA were unexpected and had not previously been documented. Though these data were collected in a single state, they suggest the importance of research into SUD treatment for PID nationwide.

To contextualize these findings, it is important to understand some additional information. The Department of Developmental Services (DDS) in CA oversees the coordination and delivery of care to persons with developmental disabilities, which includes ID. This care is provided through the 21 nonprofit regional centers identified in this study. In 2020, 329,002 individuals were served by the 21 regional centers (“Lanterman Act”, 2021). Accessing services provided by the regional centers is voluntary, so this total does not represent all individuals in the state who have a developmental disability. The State of California Department of Developmental Services issued a report in December 2020 titled “Quarterly Consumer Characteristics Report Index” which noted that 98,350 of the people served by the regional centers had a diagnosis of only ID (no other developmental delays), 191,278 people had ID along with another developmental disability, and 137,724 people had no diagnosis of ID but had another developmental disability (autism, cerebral palsy, epilepsy, or other) (“Lanterman Act”, 2021). Based on this volume of clients, it would be reasonable to expect that it would be possible to analyze the rigor of SUD treatment services for this population. However, even though the cited statewide report (“Lanterman Act,” 2021) had specific sections dedicated to severe behaviors, special conditions or behaviors, dual diagnoses, medical problems, and special health care requirements, it did not have a specific section for SUD – even though SUD has been reported by service coordinators at regional centers as an issue of concern among PID and has been identified as something that warrants attention.

One key hypothesis that emerged from these results is PID accessing SUD treatment are entering a strained system. Specifically, our data suggested many practitioners working in the SUD treatment field lack knowledge or training on PID. Further, service coordinators and care providers (residential, day and vocational programs), who are more experienced with PID may be uninformed about SU and SUD. In systems where such a gap is identified, one potential solution may be to increase collaboration and provide cross-training to people working within the system on PID and SUD. At the same time, simply recommending such an approach may not be sufficient, since similar strategies have been suggested, but not implemented, in other areas of healthcare for PID (e.g., Brown et al., 2017).

Data obtained through this study suggest that SUD treatment for PID in the CA regional system may not be functioning as intended and may be in need of improvements in collaboration and communication among care providers. This finding is consistent with previous research concerning the need for increased collaboration among all care providers for healthcare in general, and for care of PID in particular (Zworth et al., 2019). The system described by the service coordinators portrayed PID as often receiving services from multiple agencies who were navigating different aspects of their care and life. Most programs reported minimal adaptations to services. Service coordinators were only privy to the information shared with them by the client, except in certain cases with vendored programs, so the program plans created often lacked vital information concerning the care of the individual. One possible solution might begin with research into procedures to promote person-centered care, specifically centralization of important information about care for PID with the service coordinator who is responsible for case management. Another option might be to investigate SUD prevention and treatment being incorporated into special recreation districts, day/vocational programs, and other ID specific services.

There were four regional centers that used vendored programs and 17 regional centers that did not. All regional centers reported that they were required to utilize generic services prior to accessing a vendored service per the Lanterman Act (“Lanterman Act,” 2021). Generic services were described as county mental health care, services offered through the client’s insurance, and/or narcotics anonymous or alcoholics anonymous. Service coordinators that were interviewed (representing seven of the 21 centers) unanimously agreed that the generic services do not meet the needs of their clients, which highlights the importance of collecting and analyzing information about vendored programs. As a next step in service provision after generic services, vendored programs agree to provide specific care to persons with developmental disabilities. Therefore, it was surprising that this study found self-reported lack of policies related to services and adaptations occurring during SUD treatment for PID in vendored programs serving mixed populations.

Assessment of Services

Data obtained from the vendored SUD programs and service coordinators identified an abundant number of barriers that appeared to adversely influence the quality of care and the likelihood of treatment success. These barriers were reported across all areas of treatment, from intake to facilitation methods to discharge. However, one program reported a different philosophy of care than the other programs. All the vendored SUD programs reported making physical adaptations to the facilities being used. However, specific adaptations that extended beyond mitigating the impact of physical limitations (e.g., to address behavioral needs) generally were limited, apart from increased time allotment for paperwork, which all programs reported offering to PID. Again, it is notable that within the entire regional center system of CA, there was only a single vendored site that specifically was structured to provide SUD treatment to PID; that program reported numerous differences from the others, typically in ways that aligned with the current evidence basis for providing care to PID (Lennox et al., 2010; Lennox et al., 2015; Navas et al., 2019; Patel et al., 2020).

Effective SUD Treatment for PID

Individuals with higher IQs at baseline demonstrate a greater improvement in the quality of their coping skills (Kiluk et al., 2010). Relatedly, studies consistently suggest that people with mild cognitive impairments have lower retention in SUD treatment programs (Aharonovich et al., 2008; Teichner et al., 2002). Further, a Dutch study found that cognitive impairments are often undetected during SUD treatment (Bruijnen et al., 2019). Failing to detect these impairments may have critical consequences for treatment, such as misinterpreting a patient’s motivation towards treatment (SAMHSA, 1998). For example, PID may exhibit appropriate social and communication skills but may have severe problems with “memory, decision making, planning, or learning comprehension” (SAMHSA, 1998). Additionally, PID may present with seemingly noncompliant or socially inappropriate behaviors to deflect attention from their limited functioning (SAMHSA, 1998).

Studies repeatedly have concluded that PID would benefit from the development of improved screening tools to identify SU and that SU treatment services for PID need improvement (Priester et al., 2016; Taggart et al., 2008; VanDerNagel et al, 2013; van Duijvenbode & VanDerNagel, 2019). Various fields have consistently demonstrated that adaptations are necessary for improvement in the quality of services for PID (Carr et al., 2016; Flecher et al., 2016; Frielink & Embregts, 2013; Kerr et al., 2014; Navas et al., 2019; Nicolaidis et al., 2020). Further, several studies have found specific adaptations in clinical practice – though not specific to SUD – are important to providing evidence-based care to PID (Frielink & Embregts, 2013; Lennox et al., 2010; Slayter & Steenrod, 2009). Therefore, it is surprising that mixed (ID and non-ID) population vendored programs identified by regional centers to provide specific care to PID did not state specifically how or what types of facilitation or curriculum adaptations they employed. Only two vendored programs reported offering additional sessions to PID, one of which served PID exclusively. The latter program was the only program mentioning assessing comprehension of forms (e.g., intake, screening). Of further note, the majority of the programs reporting barriers to treatment for PID did not identify correlated adaptation(s) that could resolve these barriers. This study is unable to determine why this might have been the case.

Potential Factors Underlying Barriers for PID

Service coordinators described "*a system*" consisting of combined services provided by the regional centers and other healthcare, judicial, and behavioral health service providers. Notably, service coordinators perceived this complex system was divided into silos, with different entities only able to provide care for one condition at a time. Service coordinators indicated meaningful concerns when applying the medical mode (silo care)to PID due to high likelihood of co-morbidities and potentially complex health needs beyond ID. Further, service coordinators often implied that such a disjointed approach may not account for the social determinants of health for this underrepresented group, such as strain on the system, stigma, lack of provider training, lack of systemic resources, and lack of adaptations for ID. Prior research concerning PID with comorbidities and other health conditions (e.g., diabetes, epilepsy, mental health) has identified a need to specifically tailor healthcare services for PID (Brown et al., 2017; Rights under the Lanterman Act, 2020; Whittle, 2018). Our findings suggested similar needs may be present for SUD treatment. We hypothesize, but cannot conclude without extensive further study, that the lack of identified or practiced adaptations may be connected to the medical model of care, which focuses on what is ‘wrong’ with an individual (Brosco, 2010; Carey, 2003; Ervin et al., 2014; Shakespeare et al., 2009). Because the medical model is designed to fix what is wrong, and ID is not appropriately described as a ‘fixable disorder,’ this model’s approaches and strategies may often be inapplicable when treating PID (Carey et al., 2017; Ervin et al., 2014; Patel et al., 2020; Shakespeare et al., 2009). We raise the possibility here that the medical model of care may inadvertently reinforce barriers to SUD treatment for PID because practitioners may not account for the often-substantive variations required for best-practice care of PID.

Other possible reasons for lack of adaptation my include a lack of resources to adapt the services which they provide. For example, programs may be under-staffed; there is a concern about the lack of SUD treatment specialists in the US (Durbin et al., 2017), which exceeds even the notable provider shortage for many types of healthcare (Haddad et al., 2022; Prunuske, 2020). Alternately, programs may not have truly understood the barriers facing PID until they were asked to reflect on them, either in this study or through some other mechanism. From there, it may still be difficult to implement changes to address barriers, or even to know how to identify appropriate adaptations (Lennox et al., 2001; Lennox et al., 2013; Perry et al., 2014).

There have been significant developments in implementing the care of people with disabilities internationally (WHO, 2005), however the US has lagged behind its global counterparts in the fully implementing the concepts of the biopsychosocial model of care (Degener, 2017; Scullion, 2010). Despite calls to action in the 2005 Surgeon General's report on the health of PID (U.S. Department of Health and Human Services), health disparities for PID have persisted over the last 15 years, often due to lack of research (e.g., Krahn et al., 2015; Naaldenberg et al., 2015) These barriers result in health care needs not being met and contribute to increased health complications (Durbin et al., 2017; Krahn et al., 2015; Shakespeare et al., 2009). This is even more evident concerning PID who use substances, as research has shown that PID that use substances often experience more debilitating effects and may be at higher risk for developing a SUD (Durbin et al., 2017; Slayter & Steenrod, 2009; Williamson et al., 2017). That high level of risk, though, is inconsistent with the description of service availability derived from this study.

Limitations

There are limitations to this study. First, only vendored programs in CA regional centers were recruited, so generic services (e.g., local AA or NA chapters) were not surveyed. At the same time, this study covered the most populated state in the US, and the regional center apparatus is the formal state-based mechanism through which PID access SUD treatment. Vendored services are also the next step following generic services, the latter of which service coordinators typically found insufficient to meet the needs of PID. Thus, the data, while limited in scope and in number of respondents, reflect a fairly sizeable component of a state-funded SUD treatment apparatus for PID. In addition, the interviews with service coordinators were perceived to meet the standard of inductive saturation. Second, only one service coordinator was interviewed at each regional center that agreed to participate, and all service coordinators were purposefully selected due to their experience working with PID with SUD; service coordinators without experience working with SUD may have a different experience and viewpoint concerning navigation of care if a client were to be display symptoms of SU or SUD. Third, the data were self-reported and thus subject to biases common to those types of data. The intention of this study was not to produce highly generalizable data per se but rather to identify significant themes and concepts to inform future research. It should also be noted that the delivery of care for PID differs from state to state, and these findings are particular to CA. However, as noted previously, it was also fairly comprehensive, consisting of five of the six vendored SUD providers to which PID might be referred by CA regional centers and coordinators for seven of 21 regional centers. Indeed, the size of the possible/eligible sampling frame is, in itself, a notable finding. Fourth, this study was conducted during the COVID-19 pandemic, particularly during a surge in CA. During this time, many of these programs were conducting virtual programming for the first time, experiencing loss of staff, and dealing with the loss of remuneration; service coordinators were working from home so that these data may have been affected. Lastly, this data cannot be generalized due to the nature of state level differences in the managing of disability care. Thus, further research is needed to explore geographic regions in the US to determine how SUD treatment is provided to PID.

To be clear, this paper is not intended to be used as the single basis or source of evidence for any major policy shifts but rather to serve as generative information that can facilitate subsequent research and evaluation work.

Implications for Practice

SUD treatment providers face challenges in providing SUD treatment to PIDs. Educational preparation for SUD treatment providers, along with the employees at the facility, appears to be needed. The reported gaps in knowledge, if true, have the potential to create meaningful barriers to providing effective and quality treatment. Unfortunately, due to the multifaceted nature of PID care, SUD treatment programs that serve PID will likely have to proactively seek guidance and support to implement best-practice approaches to treating PID.

Vendored programs are uniquely positioned in CA to provide the holistic and person-centered treatment that PID requires. As such, vendored providers within the CA regional center system need to address SUD within the PID population if it is to be accomplished at scale.

General vendored programs can provide their expertise in finding solutions to the barriers faced by PID when accessing generic SUD treatment. Lastly, it seems important for SUD, disability, and healthcare researchers to extend collaborations to construct the body of research pertaining to PID and SUD, specifically concerning studies to identify ways to minimize barriers (e.g., implementation and feasibility studies) and the development of validated screening approaches.

Conclusions

PID with SUD are a population experiencing substantive disparities across the healthcare continuum. Our mixed-methods study found that few of the relatively small number of vendored SUD treatment programs within the CA regional system are set up to serve PID. Most programs did not specialize in SUD treatment for PID, despite being utilized for that type of service, and identified numerous barriers to care for this population. Additionally, SUD treatment provided to PID was strained and affected by both client and provider stigma. Providers for PID reportedly lacked training and knowledge about SUD, while SUD treatment providers appeared to lack training and knowledge concerning PID. Data suggested a lack of resources and adaptions for treatment and research to support evidence-based interventions. These results are closely aligned with previous research stating PID is poorly supported in healthcare in general (Lennox et al., 2001; Lennox et al., 2015; While & Clark, 2010).

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Sample Selection of Regional Centers of California

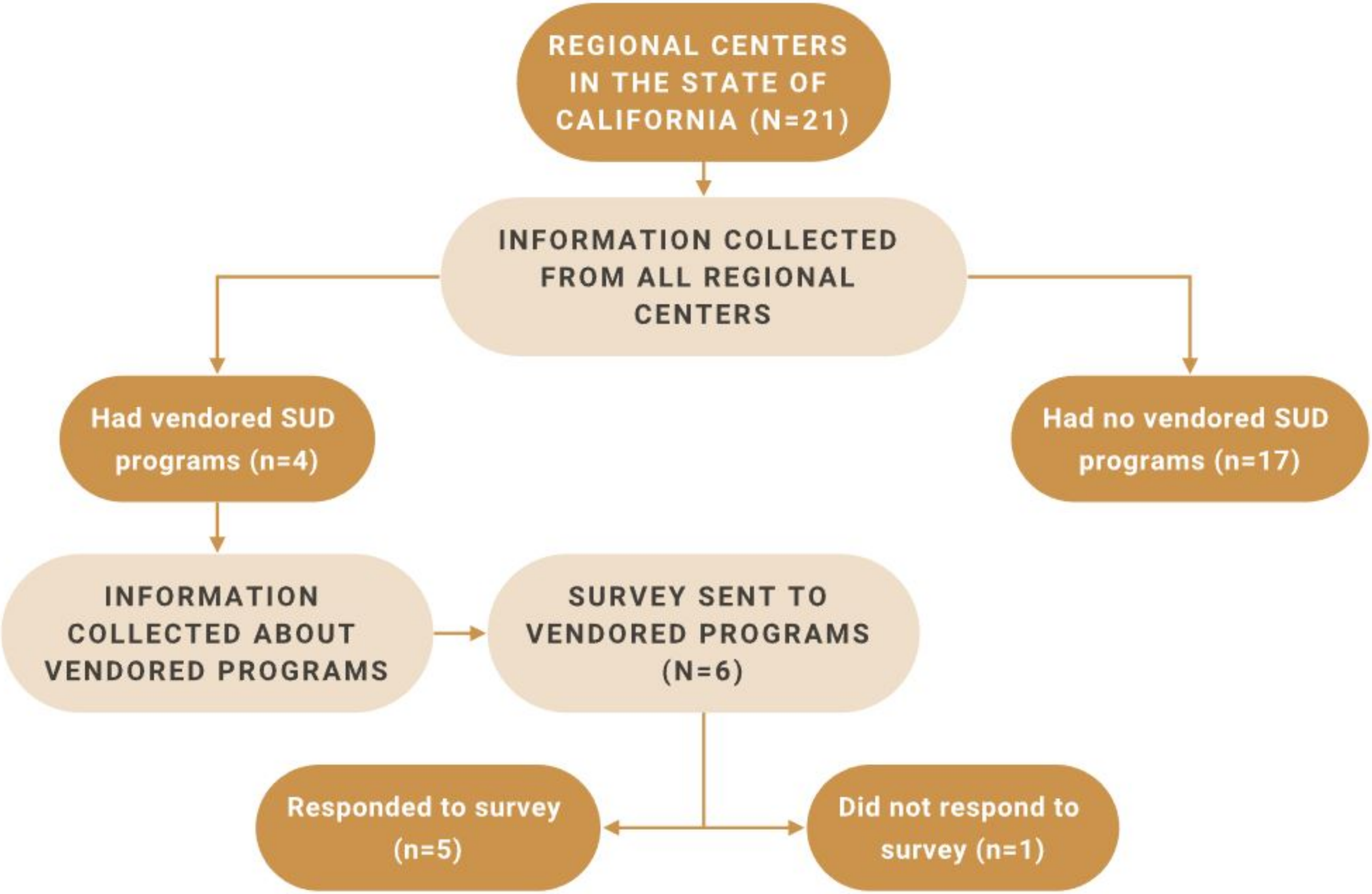

Figure 1.

Table 1:
Service Coordinators Characterization of Substance use Disorder for People with Intellectual Disabilities (N = 7)

A Priori Category	Theme	Exemplar
Characterization of SUD treatment for PID within the CA regional center system	Strains on the System	*"We referred him to 10 different programs, and he doesn't want to stay. And he was here (emergency psychiatric services) the other day. And then he left, we tried, he got combative and left and blah, blah, blah. So that's pretty much how it goes."*
	Stigma	*"The clients all that have substance use disorder tend to also have a criminal history, they tend to have a certain profile. They tend to be a little higher functioning. They tend to have a mental health diagnosis. We tend to stereotype those clients."*
	Lack of Training	*"These agencies or these programs have no idea. If someone comes in with an intellectual disability or on the spectrum, they're going to give them the same kind of scripts that they've given for years."* *"I think that employees (at the regional centers) need to be educated better to be more knowledgeable about what are 12 step programs, just very basic information."*
	Lack of Resources	*"We have something called a clinical team. I may go there because they can approve things that we (the service coordinator) can't. They may be able to work funding out through exceptions in a roundabout way. But again, that takes time it can be a month or two out before you see clinical team and you got to get the client there too. It's like a bunch of steps. Sometimes we get to the clinical team and the client is already arrested for something major."*
	Lack of Adaptions	*"It's kind of hard when you're working with the program that says 'well this is our training. Our box is substance abuse.'"*
The role of the regional center has in obtaining SUD treatment for PID	Level of Care is Dependent on the Service Coordinator	*"I really try to advocate as much as possible and I try to make sure that they don't fall under the cracks."*

	Need for Collaboration	*“We tend to use county services a lot because they have a relationship with us. They know that when we're referring a client they're coming from the regional center. We tend to follow up with them and if it’s a forensic case, then they (county services) know because they have to provide a report every court hearing. There are some generic resources that may not know (the client has a disability) unless we reach out and talk to them.”*
The need for biopsychosocial treatment of SUD for PID		*“I wish there was more alternative drug rehabilitation process, like holistic approaches. Adding those type of services would be life-changing for a lot of our individuals.”*

Supplemental Material

Supplemental Material

11.2024_Supplement _Sx_Capacity_IDD.pdf