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Brief Report

Addiction Recovery with Concurring Developmental Disorders

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Abstract

Thousands of individuals with problem drinking and drug misuse do not recover due to the lack of specialized programs that meet their needs. Individuals with substance use disorder may not have been properly diagnosed. These include learning disabilities from damage to the parts of their brains that control attention, concentration, memory, perception, impulse control, and judgment, that occurred from falls, violence, or motor vehicle accidents while under the influence or drug seeking. This under-identified but increasingly studied population has intensive, long-term support needs. The purpose of this study was to examine how individuals who are challenged with co-occurring disorders and impaired cognitive-behavior skills, concurring disorders, achieve and sustain sobriety.

Supported Sobriety addresses addiction recovery for those with concurring disorders: Substance use disorder, mental health disorders, and ID/DD, including autism spectrum disorder, a pervasive developmental disability, or other learning disabilities. Following actions included in Supported sobriety's mnemonic device SOBER, 56% achieved and maintain sobriety, 67% attend 12-step meetings, 72% are employed or seeking employment and 100% participate in

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recreation and/or faith-based activities. Research recommendations focusing on long-term outcomes and staff training are discussed.

Keywords: Addiction recovery; Autism spectrum disorder; Concurring developmental disorder; Intellectual disabilities; Supported sobriety

Introduction

According to SAMHSA's 2014 report, substance abuse and mental health services administration, over 8 million people in the United States are diagnosed as having a co-occurring disorder; that is, both a mental health and substance use disorder [1].

It is estimated that 1 in 59 people in the US are diagnosed as having autism spectrum disorder [2], according to the latest 2014 findings of the Center for Disease Control and Prevention. That is over 4.7 million Americans, and the number is increasing annually [3].

Another 4.6 million Americans live with intellectual or developmental disabilities. Approximately 2%-20% of those who live with ASD or intellectual disabilities also have a substance use disorder [4].

Individuals who have concurring disorders, that is, substance use disorder, mental health disorder, and an Intellectual Disability or Developmental Disability (ID/DD), learn differently. Their challenging situations are due less to their disease of addiction than to their lack of basic cognitive-behavioral skills needed for recovery. They may struggle to perceive the connection between their drinking or drug-taking, their poor decision making, and the inevitable consequences of distress or poverty. They may not be able to independently process how the tools of the program work and when to apply them to solve the problems of sober living. Current treatment doesn't adequately accommodate their need for support in applying recovery skills, nor does it provide for the long-term specialized support needed to become self-directed in their recovery. Currently, outpatient treatments follow standardized protocols, most participants do not complete standardized treatment, and many treatment specialists are not aware of the prevalence of multiple diagnoses. They therefore assume that multiple diagnoses are not significant or that the only significant diagnosis to address is the substance use disorder [5,6]. Without programs, these individuals may languish in our prisons, homeless shelters, on the streets, or in institutions. If they receive community-provider support, all involved become frustrated by repeated relapses, criminal activity, and other related crises.

To research this phenomenon, we asked, "How can individuals who are challenged with co-occurring disorders and impaired cognitive-behavior skills receive the gift of sobriety and avoid the possible consequences of the disease's potential progression toward prison, institutions, or death?"

Studies by Annand [4], Weiss [7], and the US department of health and human services, office on disability [8], suggest that the prevalence of those who have ID/DD as well as addiction ranges between 2 and 20%. A meta-analysis of eighteen papers published in Norway

about autism spectrum disorder and substance use disorder resulted in twelve studies reporting on the prevalence of these co-occurring disorders ranging between 1-35% depending on the clinical samples [9]. Studies in Belgium, Denmark, and the Netherlands concluded that prevalence was frequently underestimated because individuals with mild intellectual disabilities were most often seen only by a single service provider. This decreases the likelihood of appropriate identification of the symptoms or the need for treatment that more likely would occur if seen by multiple types of providers: One or more providers who either specialize in substance use disorders or at a minimum recognize the symptoms. This results in underestimating treatment and service needs [10,11]. A Swedish study found an increased risk for those with autism spectrum disorder, a pervasive developmental disability, to develop substance use-related problems, particularly those with co-morbid attention deficit hyperactivity disorder [9].

Long term studies reported an average prevalence of alcohol use disorder is 30% in the US and that Alcoholics Anonymous (AA) serves a significant role in addiction recovery with over 53,000 groups in the US, and 115,000 groups worldwide [12]. It provides long-term, highly cost-effective support to assist those with addiction disorders achieve and sustain abstinence. 6,000 AA members within the US and Canada reported that through active participation in AA, 27% stayed sober in the first year, 24% remained sober between years 1-5, 13% stayed sober between years 5-10, 14% stayed sober during years 10-20, and 22% remained sober years 20 and longer [13].

Alcoholics Anonymous [14], prescriptive and inspiring statement from chapter five of how it works, postulates that sobriety is possible for most people who suffer from the disease of addiction if they have the capacity to be honest. Intellectual capacity is not listed as a pre-requisite. Recovery from addiction requires the willingness as well as the capacity to understand and respond to any significant adverse events that result from the abuse prescription medications, the use of illegal drugs, and/or drinking alcohol. Insight is usually followed by the development of action steps to amend the “wreckage of the past,” as Bill Wilson described it in Alcoholics Anonymous [14]; and an effective change in thinking and behavior to establish healthy relationships and community-mindedness. Recovery requires courage and acceptance. The development of these qualities reward all who participate in the program, as well as the growing wisdom to know how to solve problems they could not have solved before sobriety.

For challenged individuals with concurring disorders, that is, they have been diagnosed with substance use disorder, mental health disorder, and have a developmental disorder, learning how to live a sober life through current treatment programs or materials may be practically impossible. They may not be able to read and understand the recommendations outlined in the books. They may not drive, so cannot attend meetings easily or regularly. When in meetings, the in-depth and sometimes abstract content of others’ sharing may be difficult to process. The social rules of turn-taking, listening, and focused sharing may elude them. Insight, perception, and identification, essential tools to recovery, may not be readily applied. Just sitting still in a room full of people may be challenging.

Many individuals who are diagnosed with substance use disorder may not have formal learning disability diagnoses for a variety of reasons; some because they have compromised their ability to learn from the damage from illicit drug use to parts of their brains that control attention, concentration, memory, perception, impulse control, and

judgment, among other functions. Others may have acquired brain injuries from falls, violence, or motor vehicle accidents while under the influence or drug seeking [15]. Without a clinical diagnosis, previous educational records identifying a specialized educational plan, or self-report by an individual, it may be difficult to identify whether a person has a learning disability or ID/DD. While completing a standard intelligence battery of tests to identify individuals who may have undiagnosed intellectual disabilities, learning disorders, or acquired brain injury is not practical or even possible for most providers who do not specialize in this testing, there are brief screenings that may be administered to assist providers to identify these disorders efficiently. Using the Hayes Ability Screening Index is an effective instrument to identify individuals with an ID/DD who have a substance use disorder [16]. Another device is the simple screening tool for a learning disability [17].

Many people spend their lives without proper diagnoses yet struggle with everyday challenges in reading, writing, attention and concentration, processing information, and social or nonverbal communication, to name a few challenges. They will present to professional social, clinical, and human service providers as resistant or “not ready” for intervention when the true barrier is that the specialized way they need to learn recovery skills is not how classic or traditional recovery supports are provided. For many providers who may acknowledge co-morbidity of intellectual, developmental, and learning disorders with substance use disorders in patients receiving services, few, if any, formally screen or incorporate appropriate treatment interventions in those services [6].

These individuals who have concurring disorders arguably consume a significant amount of the service provider, judicial, and hospital time and funding. Jackson and Kroenke [18], reported that approximately 15% of providers’ caseloads include challenging individuals such as these.

To address barriers to treatment and provide an effective intervention for those with concurring disorders, a first of its kind, a 24-hour, recovery-oriented, person-centered support service called supported sobriety for adults living with concurring disorders was developed in 2013. Adult participants are supported in their homes with this unique approach that incorporates the 12-step model by specially-trained staff [19].

The supported sobriety 24-plan with its strategies and tools is a hybrid program and innovative clinical approach, designed to accommodate different learning styles. It provides daily repetition for the individual to be able to develop independence in knowing how and when to apply recovery tools to everyday as well as crisis situations. Supported sobriety is an approach designed to support and wrap-around formal recovery-oriented services such as the 12-step, outpatient, intensive outpatient, and inpatient programs. This curriculum assists those living with co-occurring disorders and ASD, learning and intellectual disorders, to acquire the necessary comprehension of the disease of addiction, and competency with recovery tools to achieve and maintain sobriety. Unlike traditional OP, IOP, and IP services, supported sobriety is not time-limited; there is no discharge or graduation. Support is ongoing. As in the 12-step program, individuals can learn, relearn, and practice the strategies and tools for their entire lives.

This intervention can be facilitated by any professional provider; clinicians, case managers, program directors, direct care staff, and other professionals who have training in this approach to co-occurring disorders, social learning, and ID/DD, including autism spectrum disorders [20,21].

There has been no existing program or body of research in this specific clinical area to serve as the foundation for this approach. This current model builds upon evidence-based practices and existing approaches such as the 12-step program, stages of change model, and CBT. Our approach also includes principles in the treatment of co-occurring disorders that are well-established as effective treatments for those living with mental health and addiction disorders. It adds creativity and flexibility to meet the diverse learning needs of the individuals who need these adaptations. Supported sobriety directly reflects the steps, traditions, and philosophy of the 12-step program that was originally established in 1935. Alcoholics Anonymous has arguably saved millions of lives through its spiritual, cognitive-behavioral approach to recovery, its reliance on the interdependence of other people in recovery, and each person's desire to achieve sobriety.

The premise of supported sobriety is to keep it simple and to act one's way into sober, right living: To practice patience and tolerance with ourselves and others; and to repeat these attitudes and actions throughout each day to achieve long-term successful sobriety. The only requirement to participate in this program is a desire to be sober.

To review the supported sobriety program, the grounded theory method was used to allow for ongoing comparative analysis regarding observations and slices of data collected on participant actions within the program [22]. Without existing research literature or theory, this qualitative approach sought to identify individuals' experiences, code observations, analyze reflections, and collect performance data relative to their individual goals. The purpose was to begin developing a theoretical framework to understand this phenomenon and increase awareness about the need for more specialized interventions for individuals with these support needs.

Program

Participants in our program are referred to the support program by the CT Department of Developmental Services (DDS). The criteria for selection are based upon requirements for eligibility to receive waiver services through DDS, a primary diagnosis of an intellectual or developmental disability, and to be eighteen years or older. Participants need to have a documented or self-reported history, or be in current use of illegal substances, misuse of alcohol or prescribed medication, and/or a diagnosis of substance use disorder. Because of the under-identification of substance use disorder within this population of individuals, self-reporting without clinical diagnosis is necessary in the selection process. All individuals participating in this program have experienced adverse events such as hospitalization, incarceration, homelessness, or institutionalization as a direct result of alcohol or illegal substance use. The results from this qualitative review discuss outcome for those individuals who declined to participate.

Using white's recovery capital scale [23], and other person-centered planning approaches, individuals and their support teams assess their recovery needs and determine recovery goals. These include maintaining sobriety, attending 12-step meetings, and developing relationships in the fellowship to support their sobriety. Also assessed,

are employment, family re-engagement, and community re-integration. Recovery progress is reviewed monthly, and individual plans are reviewed every six months.

Twenty-four-hour, five-step plan

Participants engage in daily, structured, recovery-oriented dialogues and activities based upon a 5-step, 24-plan. There is flexibility in the order and time each of the steps is completed based on individual preferences and scheduling, but the steps are as follows:

1. Individuals with staff read a daily meditation and practice one of several recovery coping strategies together. They reflect on the daily reading, let go of any lingering distress from the night before if necessary, and prepare for the day with hope and gratitude.
2. Individuals communicate with providers and others in the recovery or 12-step programs about how they feel and listen to how others feel or what they are going through today.
3. Individuals participate in a 12-step program meeting.
4. Individuals complete acts of service for others and themselves.
5. Individuals engage in self-reflection and meditation to review their day's "balance sheet" of positive and negative experiences, let go of the present day's stressors, and prepare for a restful sleep. These five steps are repeated daily to build skills through practice.

Recovery strategies and tools

The strategies in the morning and evening self-reflection and meditation steps, step one and five, are cognitive-behavioral-spiritual, designed to assist individuals to develop effective coping skills through daily practice and routine. Beginning the day with these assists an individual releases the previous night's stressful sleep or concerns if any, and looks forward to the day with gratitude, hope, and a positive attitude towards whatever the day may bring. Ending the day with meditation, prayer and practicing these strategies, assists individuals to decompress from the day's activities and to let go of the day's mistakes and pressures.

These activities are adapted to accommodate the learning styles and needs of those with differing or more rigid capacities. The activities include tailored positive self-talk and shifts in perspective or belief paradigms to help the individuals reframe situations in a way that helps them better handle stress and create opportunity for more productive outcomes. The completed strategy worksheets are stored in individual recovery binders; these create a journal for the individuals. The contents may include written worksheets, pictures, images, actual items from personal experience such as pay checks or photos, collages, paintings, and the like. Journals allow individuals to track their progress and reflect upon times they have successfully navigated conflict in relationships and situations.

Each day, individuals practice self-care and service to others. This is a keystone factor in 12-step recovery and all faith-based tenets for good citizenship. Good self-care and service help to build positive self-concept and a sense of empowering confidence that the individuals are useful and productive members of their community with something to contribute. Empowerment and positive self-concept are critical factors to successful recovery.

Twelve-step meetings

Staff attends 12-step meetings with the individuals to assist them meet other people in recovery, obtain a sponsor, and to role-model desired behavior in the meetings and with other 12-step attendees. Staff also help the individuals to process the recovery information that was discussed during the meetings. Strategies shared by others in the meetings are often helpful tools to introduce throughout the day or subsequent week to assist the individual apply the recovery strategies from the 12-step meetings in their daily lives.

Long term recovery support for individuals with concurring developmental disorders

It is critical to point out that individuals who need this hybrid program and approach have an ID/DD that is stable throughout their life span and that will not be lessened or managed through counseling, medication, or education. Many individuals with intellectual disabilities will most likely need much longer term, if not permanent, ongoing coaching, mentoring or recovery support to assist them to apply recovery strategies and 12-steps to the diverse experiences they encounter during their life spans. The goal will be to identify people in the recovery community or people in the individuals' lives who are willing to be trained in Supported Sobriety to provide these long term supports. Those with co-occurring disorders transition to the maintenance stage of change, able to independently employ the strategies and tools of recovery mental health and substance use symptoms. If they need prompting or assistance, many self-identify and self-correct; that is, ask for help, go to a meeting, or call their sponsors. Their symptoms may be more fluid and manageable through counseling, medication assisted treatment, psycho-education, and cognitive-behavioral intervention [24].

Training

Specialized staff training is required. This is provided to directors, managers, and direct care providers to maximize the potential for continuity and consistency in the approach. Implementing this 5-step program with an effective clinical approach requires knowledge of the components and the target skills for each strategy or tool, and how to creatively incorporate these strategies and tools in unanticipated and teachable moments throughout the day. Individuals with intellectual disabilities may struggle to apply what they have learned in one situation to another situation and need much more repetition and practice than those without intellectual or learning disabilities. Staff will need to identify these situations and apply supports as often as needed. The duration for support may vary, but staff will most likely be providing these supports with varying degrees of frequency, intensity, and duration for multiple months and years. Staff attends 12-step meetings with individuals with the goal of having the individuals develop the natural supports they will require to maintain long-term stable sobriety.

SOBER

SOBER is a mnemonic device to assist providers recall and implement the steps to supported sobriety.

Screen and assess for the presence of a learning disability.

Observe and identify the barriers to maintaining sobriety.

Build skills through the five-step, twenty-four-hour plan, strategies, tools, and 12-step meetings.

Educate in daily practice and participation.

Repeat to maintain and support sobriety.

Program Experience 2013-2017

Demographics

Twenty-one adult individuals have been admitted to the program since 2013 with scattered admissions throughout the 5 years; 19 males and 2 females. However, 3 males left the program prior to engaging in it, against advice, leaving eighteen in total. The age range is from 27-61 years old, with the average age being 44. The participants' ethnicities include 6 Caucasian, 6 African-American, 1 Caucasian/African-American, 3 Latino/a, 1 Latino/a/African-American, and 1 Native American/Caucasian. In addition to meeting the above criteria, 10 participants were also diagnosed as having one or more psychiatric disorders including antisocial personality disorder, anxiety disorder, attention deficit hyperactivity disorder, bipolar disorder Not Otherwise Specified (NOS), depressive disorder NOS, schizoaffective disorder, and schizophrenia disorder, paranoid type. Due to the under-identified psychiatric diagnoses with this population, it is not clear if more of the participants may have some, all, or different co-occurring psychiatric disorders (Table 1).

Gender	16 - Males	2 - Females	Diagnoses	
Ethnicity	Caucasian	6	ID/DD	18
	African-American	6	Substance use disorder	18
	Caucasian-African-American	1	Antisocial personality disorder	3
	Latino/a	3	Anxiety disorder	7
	Latino/a-African-American	1	Attention deficit hyperactivity disorder	1
	Native American-African-American	1	Bipolar disorder (NOS)	1
			Depressive disorder (NOS)	7
			Schizoaffective disorder	2
			Schizophrenia, paranoid type	1

Table 1: Demographics.

Sobriety and participation

Effectiveness of this clinical approach has been measured by ability to maintain sobriety, attendance at 12-step meetings, and relationships with those in the fellowship, employment, family re-engagement, and community integration as measured by community, faith-based, or recreational activities.

Fourteen, 78%, of the 18 individuals continue to express willingness to stay sober. Ten, 56%, have maintained continuous sobriety since admission, while eight, 44%, relapsed and four, 22%, restarted their sobriety shortly thereafter.

Four, 22%, of the eight who relapsed, expressed lack of willingness to participate in the program after starting. Two were ultimately re-incarcerated due to probation violations but were re-admitted upon their releases. One of those previously incarcerated selected to participate in the program is currently sober and engaging in positive recovery activities including AA meetings, job searching, and reengaging with friends and family. The other returned to the program

after being released from jail, but declined to participate in the program after re-admission, and is currently homeless. The other 2 who declined to participate in the supported sobriety approach continue to receive support in the community, but have not been able to stay sober, participate in employment seeking activities, or engage with family or friends. Their future remains uncertain, although we continue to provide outreach to re-engage their willingness to try sober living (Table 2).

Sobriety	Express interest in sobriety	14	78%
	Maintain	10	56%
	Relapse	8	44%
	Restarted after relapse	4	22%
Participation	Declined sobriety	4	22%
	Re-incarcerated for probation viol. readmitted to program after release	2	11%
	Re-incarcerated and declined readmission after release	2	11%

Table 2: Sobriety and participation.

Participant activities

Twelve, 67%, attend 12-step meetings regularly, and two, 11%, have 12-step sponsors. Nine, 50%, are employed, four, 22%, are seeking employment, five, 27%, are in employment skill-building training, and one, .05%, is living in skilled nursing facility. Eleven, 61%, are reconnected with family and have made friends in the community through recreation and faith-based activities. For the remaining seven, 39%, which includes some of those that relapsed, their families are not healthy recovery environments for them, or the individuals do not have identified family members (Table 3).

Recovery activities	Attend meetings	12	67%
	Have sponsors	2	11%
Employment	Employed	9	50%
	Seeking employment	4	22%
	Pre-vocational	5	27%
	Skilled nursing facility	1	.05%
Family/friends	Family involvement	11	61%
	Not safe/no family	7	39%

Table 3: Participant activities.

Discussion

The aim of the supported sobriety clinical approach is to provide informed and flexible interventions for providers to effectively support individuals to build essential coping skills to achieve and maintain stable sobriety. Without an existing comparable approach or program, it is difficult to analyze comparatively what about this approach is impacting the individuals specifically. Early data for this approach seem promising. Of the eighteen individuals who had not otherwise been able to maintain sobriety on their own and were residing in prisons or institutions or were homeless, more than half, 56%, achieved continuous sobriety, and less than half, 44%, relapsed. Some of those were able to restart their programs to restore their focus on sobriety. 50% obtained employment, and only two were re-incarcerated for short periods during their program participation. Most, 70%, are

enjoying family relationships, and all are engaged in the community in positive ways.

There were limitations to analysis of this program due to a lack of comparison programs except the four individuals who declined support. The supported sobriety 24-hour plan is voluntary and involves an approach that spans a significant time period over months and years for some individuals. Individuals were not adherent with the program continuously, nor did the staff consistently interact with the individuals according to the program guidelines. There were instances in which individuals refused to complete the daily exercises or attend 12-step meetings. During these periods, participants maintained abstinence. It is possible that the informal interactions with trained staff along with the recovery-oriented environment sufficiently supported the individuals to maintain sobriety. This may have helped to bridge recovery support until both individuals and staff re-engaged with the approach.

Engaging staff represents some challenges. This new approach requires training, and an appreciation of how the combination of the three disorders together (mental health disorder, substance abuse disorder, and developmental or intellectual disability), concurring developmental disorders, changes how we address individuals who have each diagnosis separately. This is just as supporting individuals with co-occurring disorders may involve more complex approaches than supporting those with each of those diagnoses separately. Some directors, managers, and direct care staff did not adhere to the routine of the 24-hour plan consistently. They, along with some case managers and family members, demonstrated resistance to acknowledging the individuals' addiction along with their cognitive limitations. Their perspectives are that the individuals, due to their developmental disabilities, are not able to access alcohol or drugs and so become addicted. Or, they may acknowledge the individuals' capacity to become addicted, but determine that the individuals are also capable of understanding how their drinking and illicit drug-taking behavior results in such adverse events as criminal arrests, being fired from their jobs, or being victimized while impaired in the community. A significant amount of time is spent meeting with staff and other team members to educate or re-educate them on the disease of addiction. They learn to appreciate that the individuals are "able to get into trouble they were not able to get out of on their own", so to speak. Staff are reminded that these individuals are not going to learn the same way others may, and that our approach and program are designed to address those learning differences to help the individuals build the requisite recovery skills to manage conflicts and stay sober successfully.

Future research is recommended to identify how the supported sobriety approach effectively addresses the needs of this population with concurring disorders. A long-term study to follow those individuals over another 5-10 years as they transition into living on their own in the community may offer insight into which elements of this new approach provide the greatest impact. Further studies may lead to the development of training for the public and other stakeholders such as family, friends, and those in the 12-step fellowship, who may be able to learn and apply this new and specialized approach to serve as critical natural supports. Combining natural supports with trained clinical supports may be necessary to assist this population to maintain stable sobriety over time.

It is critical to increase awareness and training, and to identify teaching concepts and practices that provide the greatest educational

impact so that we may effectively support all individuals who suffer with the disease of addiction.

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