USC University Center for Excellence in Developmental Disabilities
Co-Occurring Developmental Disabilities and Mental Health Issues in Transition Aged Youth
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Substance Abuse in People With Intellectual Disabilities

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Introduction

- This workshop will increase participants' understanding of how to successfully deliver substance abuse services to individuals with developmental disabilities. Attendees will learn about the impact of substance use disorder on this population and how, through effective collaboration, to tailor treatment paradigms to meet the specific needs of this specialized population.

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Learning Objectives

- Understand the relationship of developmental disabilities and substance use with regard to prevalence and risk factors.
- Increase awareness of the key issues related to service utilization and access to treatment and recovery by persons with an intellectual disability. Be able to replicate a model of successful collaboration across service systems.
- Increase knowledge of treatment competencies and strategies for serving this population. Specifically, learn effective screening and assessment tools and how traditional treatment can be modified to address the learning needs of individuals with intellectual disabilities.

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Agenda

- Background - Developing these Materials - Collaboration and Cross Systems Cooperation
- Intellectual Disability and Substance Use Disorder (Prevalence, Severity/Impact, Special Considerations)
- How to Effectively Serve this Population "What Works!"

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Developing Collaboration & Cross- System Cooperation

- Alta California Regional Center Substance Abuse Reduction Project 2011-2014
  - Mental Health Services Act Grant administered by the Department of Developmental Services

Project Deliverables:

- Community Steering Committee (MHSA Joint Taskforce)
- Training for alcohol/drug providers
- Training for regional center service coordinators
- Training for regional center vendors (developmental disability professionals)

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Project Deliverables

- **Outpatient Treatment-Strategies for Change-** Expanded funding for an existing Medi-Cal program. Added opportunities for more sessions and home visits for ACRC clients. Provided funding for additional training of staff and facility improvements

- **Peer Recovery Mentors – Mexican American Addiction Program –** ACRC funding for the training and oversight of our clients that are in recovery to serve as mentors to those that in need of substance use treatment.

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Lessons Learned from the Substance Abuse Reduction Project

- Cross system collaboration is not only possible but welcome
- The incidence of co-occurring (SUD & ID) disorders is a significant barrier to successful utilization of ID Services
- Organizational champions are important

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DSM-5 Diagnostic Criteria for Intellectual Disability

Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:

- **Deficits in intellectual functions**, – *Teaching Style, Curriculum*
- **Deficits in adaptive functioning** - *Accommodations for individuals with developmental disabilities*
- **Onset** of intellectual and adaptive deficits during **developmental period**.

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DSM-5 Determining Severity of Intellectual Disability

- Based on adaptive functioning in 3 domains (NOT IQ SCORES)
- Age-relevant descriptors for different severity levels provided for each domain (Mild, Moderate, Severe, Profound)
  - Conceptual: ability to learn; information processing, approach to problem-solving;
  - Social: social interaction, communication, social cues, emotional regulation, social jugement
  - Practical: personal care, daily living tasks, ability to perform age-appropriate roles
- Based on degree of needed assistance and support

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Intellectual Disability cont.

Prevalence of Intellectual Disability

- 1 in 1000 individuals

Co-Occurring Conditions

- Mental Disorders, Cerebral Palsy & Epilepsy three to four times higher than general population.

Most Common Co-Occurring Mental and Nuerodevelopmental Disorders

- Attention-deficit/hyperactivity Disorder
- Depressive and Bipolar Disorders
- Anxiety Disorders
- Autism Spectrum Disorder
- Stereotypic Movement Disorder (with or without self-injurious behavior)
- Impulse-control Disorders
- Major Neurocognitive Disorder

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Prevalence – Co-Occurring ID and SUD

- Most research studies conclude:
  - The effects of even low levels of substance use by persons with a developmental disability tend to be more problematic because of **already limited judgment and impulse control.**
  - With **increasing focus on independent or supported living** for persons with a developmental disability, alcohol and drug use rates and associated problems are increasing.
  - A significant percentage of people with minor to moderate developmental disabilities **are already in publicly-funded treatment programs** but are not identified as persons with special needs. These individuals tend to have poor outcomes.

McGillicuddy (2006)

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Support and Prevalence

- Research indicates substance abuse prevalence for persons with Intellectual Disability depends partly on the level of supervision provided by the caregivers.

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Prevalence

- National Council on Alcohol and Drug Dependence
  - *"Alcohol and drugs are implicated in an estimated **80% of offenses** leading to incarceration in the United States such as domestic violence, driving while intoxicated, property offenses, drug offenses, and public-order offenses".*
- Alta California Regional Center Forensic Review Team 2009-2015
  - **332 ACRC Clients** (DD not ID only) with criminal justice involvement reviewed by interdisciplinary team
  - **77 assessed as needing Substance Abuse Treatment** as a component of a diversion plan or competency training plan
  - Approx. **23% of ACRC clients w/ CJ involvement** – drug or alcohol related

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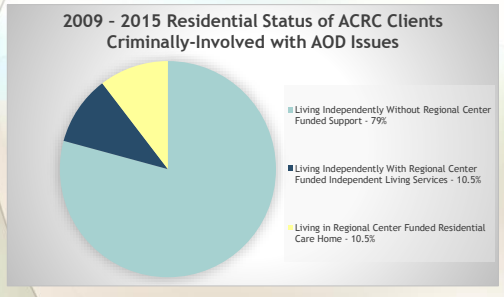
Prevalence – Resident Type



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Lower Treatment Utilization

People with intellectual disabilities, substance use (disorders), or serious mental illness appear to initiate and engage in substance abuse treatment at lower rates than their counterparts (persons who do not have these conditions) and also may remain in treatment for shorter periods of time while being more likely to drop out of treatment.

Slayter (2010)

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Critical Risk Factors

- 2007 Study in Northern Ireland of Substance Abuse Counselors yielded the following concerns regarding their patients with intellectual disabilities:
  - Vulnerability
  - Aggression
  - Psychological trauma
  - Sexual and financial exploitation by non-disabled peers,
  - Self-harming / overdosing
  - Getting involved with the police
  - Loss of structure in the person's day

Mc Laughlin D, Taggart L, Quinn B and Milligan V (2007)

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Critical Risk Factors

- Exposure to Substance Use in the Family
- Status Transitions
- Use with Medications
- Social Isolation and Influence of Friends
- Co-Occurring Substance Use and Mental Disorders
- Recognizing the Signs and Symptoms of Substance Abuse
- Lack of Exposure to Prevention Messages

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"I'm going to drink a lot of Budweiser tonight Tracy I promise you that."

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Risk Factors for Substance Abuse for Persons with Developmental Disabilities

- Poverty (public disability income) limits options for pro-social recreational activities
- Social stigmatization (being viewed as "retarded") decreases healthy social inclusion with people doing healthy activities
- Vulnerability to high stress, post-trauma sequelae (e.g. abuse and neglect) increases vulnerability to "quick fix" relief of emotional pain
- Undertreated physical pain increases vulnerability to obtain and abuse alcohol and street drugs

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Risk Factors Continued

- Judgement
  - Difficulty accurately judging others can be caused by exposure to high-turnover care providers who are strangers
  - Desire for friends, who are easily met in pubs, bars, or playgrounds where drug crowds gather
  - Desire for healthy sexual experimentation and experience is often thwarted or discouraged by family members and other caregivers
    - This can lead to secret sexual behavior including exchanging sex for drugs or drinks

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Risk Factors Continued

- Interpersonal relationships
  - Fear of socializing, dating, and sexuality can be eased by intoxication
  - Prescription psychiatric medications may cause disinhibition, dulled judgment, and may intensify effects of drinks and drugs
  - The natural desire to rebel and self-assert may be punished by caregivers but rewarded by users
  - Drug users like to share, so poverty may not be a barrier

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Risk Factors Continued

- Manipulation
  - People with intellectual disabilities may be more vulnerable to manipulation by others
  - People with intellectual disabilities are occasionally used to carry and deliver drugs
  - People with disabilities may have a learned ability to manipulate others to get things and attention for free
  - Some people are desensitized to, or seek feeling drugged, due to a history of being medicated for behavior problems

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Persons with Developmental Disabilities May Experience…

- "Learned helplessness"
  - Has been taught to many children and adults who have received
    - Custodial care
    - Overprotection
    - Poor education in self-responsibility

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Barriers to Treatment

- Ableism
- Discriminatory Policies, Practices, Procedures
- Communication Barriers
- Architectural Barriers

Annand (2002)

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Shared Provider Challenges

- Limited expertise in each other's field
- Small numbers needing AOD service
- Lack of training and treatment
- Funding restrictions
- System not set up to address shared population
- Mental illness co-morbidity may be 50% and rehab sophistication and needs increase exponentially

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ID/ Provider Challenges

- No clear policies/practices
- Staff AOD issues
- Client choice issues

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AOD Provider Challenges

- System not set up to address ID
- Increasing service standardization
- Attitudinal
- Discriminatory policies/practices (medication)
- Architectural issues

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Discriminatory Policies, Practices, & Procedures

- Examples of common discrimination within the AOD treatment community
  - Refuse to serve clients who are taking medications
  - Clients must be ambulatory
  - Clients must have minimum reading participation
  - Clients are required to actively participate in group for minimum duration of time (ex. 1 hour)
  - Clients must provide their own interpreters
  - Fire regulations require everyone to evacuate the building on their own, without assistance
  - Animals/pets are not allowed

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Enabling vs Accomodating

- A treatment program has three discussion groups during daytime hours. A person with cerebral palsy asks to be excused from the third discussion group because of fatigue.
  - Denial Response: I'm sorry you're tired, but everyone has to attend all three meetings.
  - Enabling Response: If it's a problem, you don't have to go.
  - Accommodation: Why don't you take a rest period in late afternoon, and attend a third meeting, or alternative treatment activity, in the evening?

Annand (2002)

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An Enabling System

- Most people with developmental disabilities are supported by public benefit programs, regardless of substance use behaviors
- Prevented by the system from "hitting bottom"
  - May be less likely to be motivated to make changes in substance using behaviors
  - Example
    - Every time Bill walked downtown and got too drunk to find his way back to his supported apartment, a staff person would come and pick him up.

Phillips (2004)

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How To Know if You Are Enabling: Are you...

- Doing something for someone else that you haven't been asked to do?
- Doing something for someone else you don't really want to do?
- Doing something for someone else because you feel sorry for that person?
- Doing something for someone else that would be healthier or more consistent with societal norms for the person to do for him or herself?
- Doing something for someone else in a way that keeps you from taking care of your own needs?

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Recognizing Cognitive Limitations

- Clients may experience
  - Difficulty with insight
  - Slow to learn and understand
  - Memory recall is difficult
  - Cause and effect is not understood
  - Social skills may be poor
- Change from achieving understanding, insight, and acceptance to developing a routine of living that supports long-term recovery
  - Shift must be from cognition to behavior—"acting to change thinking"

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Recognizing Language Deficits

- Communication disorders
- Difficulty making one's needs understood
- Lack of basic information and vocabulary
  - "...impairments in cognitive and verbal skills make it difficult for many developmentally disabled individuals to articulate abstract or global concepts such as a depressed mood." (Silka, 1997)
    - Examples
      - Kevin, a thirty eight year old man with mild mental retardation and lacking effective expressive language skills went to a support group for alcoholics where his attempt at telling his story was met with snickers of derision. He never went back.
      - Ed, a twenty nine year old man with mild mental retardation was told by the worker at the social services department that he would need "documentation of income to qualify for low income housing." Ed had no idea of what she was talking about and continued to be homeless.

Phillips (2004)

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Recognizing Concrete Thinking

- Difficulty comprehending abstractions
- Extreme difficulty understanding "cause and effect" relationships
- Rarely benefits from analogous situations
  - Examples
    - Howie had been going to AA for twelve years and could quote all of the slogans, although he had no idea what any of them meant. He was attending because someone told him it would "help my drinking." He had not been sober during that entire period.
    - Sam enjoyed hearing the stories of people in an AA meeting. He could not however apply them to his own situation. To Sam, it was pure entertainment.

Phillips (2004)

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Recognizing Low Frustration Tolerance

- Easily Angered
- Very little ability to defer gratification
- Often not persistent about achieving goals
  - Lack of self-efficacy
- May not understand the goals and steps necessary to achieve them

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Recognizing the Desire to be Seen as "Normal"

- Unrealistic ideas of what "normal" means
- Unrealistic goals that often are set up for failure (being placed into G.E.D. classes or unsuitable job-training programs)
- Wanting to "fit in" by going to bars and buying drinks for everyone
  - Example
    - Susan is in a supported work program where she makes just enough money to supplement her public benefits. She cannot understand why she doesn't own a house, a car, and work in a "fancy office like they have on T.V."

Phillips (2004)

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Recognizing Deficits in Sound Judgment

- Difficulty understanding "cause and effect" relationships for judgment making
- Tendency to be impulsive
- Difficulty learning from life experience
  - Especially relevant for specific diagnoses, such as Fetal Alcohol Syndrome
- Example
  - A forty five year old woman with intellectual disability opened her apartment door to a perfect stranger at two o'clock in the morning. She was raped. Why did she open the door? "He sounded like he would be mad at me."

Phillips (2004)

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Recognizing Unrealistic Expectations

- Well-meaning workers in all service providing agencies tend to be unaware of the developmentally disabled person's limitations and have ascribed to the notion that anything a normal person can do, so can a person with intellectual disability - only slower
- This can be a "set-up for failure"
- Example
  - Stewart, a 37 year old man with mild intellectual disability and traumatic brain injury as the result of a pedestrian-car accident, told a young worker that he wanted to study to become a psychologist. She enrolled him in a G.E.D. program which was so far beyond his ability, that the G.E.D. program referred him to a job training program for people with intellectual disabilities. Stewart is currently bagging groceries. He feels like a failure and has become increasingly dysphoric. His drinking has increased.

Phillips (2004)

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Accommodations for….

Seeing	Hearing	Speaking
Braille	Sign language interpreters	Provide alternatives—writing, letter board, iPad
Taped written materials	Assistive listening devices	Ask client or coworker about communication preferences
Large print	Loop system	Remember, the person has years of experience finding ways to communicate
14 point, san serif materials	Hand-written notes	
Room lighting	Quiet environment	
	Identify speaker in groups (raise hand)	
	Speak clearly facing client or coworker	

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Accommodations for….

Thinking

- Written materials at 2nd grade level or less
- Expectations clear and easy to understand
- Repeat and check understanding
- Check literacy including learning disabilities

Feeling

- Clear instructions, expectation, and requirements
- Reduce ambiguity
- Recognize stigma

Moving

- Survey environment for barriers
- Develop plan for alternatives and/or removal

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Accommodations for….

Program Access

- Everything doesn't need to be accessible
- Goal is equal participation in programs
- Level the playing field

Overall

- Flexibility
- Alter how goals are achieved, not the goals themselves
- Maintain expectations

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Models of Treatment and Support

- Preventing Substance Abuse and Mentoring Sober Living
  - Stresses the absolute importance of creating "sober community"
  - Accessing assessment, treatment, and recovery services
    - AA and Social Model
      - Requires ability/capacity for
        - Cognition
        - Reflection & Insight
        - Reading
        - Writing
        - Identification
- Harm Reduction
  - A set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use to abstinence
  - Meet substance users "where they're at," addressing conditions of use along with the use itself

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Harm Reduction

- Recovery = Any Positive Change
  - Values the development and maintenance of a non-judgmental partnership enabling the client to make well-informed, empowered choices
  - Recovery is envisioned as a process; the client sets the pace and parameters of that process and any steps forward are valued
- Harm Reduction & Abstinence
  - Harm reduction and abstinence are highly congruent goals
  - Harm reduction expands the therapeutic conversation, allowing providers to intervene with active users who are not yet contemplating abstinence
  - Harm reduction strategies can be used at any phase in the change process

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Goals & Outcome Expectations

- Shift from understanding and insight to developing a routine
- Use aphorisms as the tools. "if it ain't broke, don't fix it"
- Relapse must really be accepted as a learning tool and not a reason for discharge
- Progress must be measured by change in the ratio of using abstinent days and by reduction of harm
  - Emphasis on progress, while not replacing the goal of abstinence, must be valued by both staff and client.
- Quality of life may not change much because the enabling environment in which the client lives, however life satisfaction will improve

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Staff Members Must

- Develop patience with clients and tolerance for frustrating behaviors
- Be persistent (persevere in the face of seemingly overwhelming odds against recovery)
- Respond immediately to both abstinence-producing and abstinence-destructive behaviors
- Develop a tolerance for the need to repeat, repeat, repeat processes and information
- Don't lie to, for, or about the client
- First remember the old adage
  - "If you give a man of fish you feed him for a day. If you teach a man to fish you feed him for a lifetime"

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Thank you!

- For more information visit :

  www.altaregional.org/mhsa-grant

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