

Project Connect:
Improving Addiction and Recovery Services for
People with Developmental Disabilities

The National Association on Alcohol,
Drugs and Disability

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and Disability

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Estimated number of persons with disabilities in the
U.S. needing AOD treatment services in 1999

- o Estimate (all) 3 – 5 million
SAMHSA formula based on number of persons currently served,
and estimated SUD rates in general population, 2000
- o Estimate (needing tx with disabilities 396,000 – 660,000
Assumption that PWD equally equally likely to experience SUD
as general population, and averaging disability population
prevalence from U.S. Census, SiPP, U.S. DOE

or



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Estimated number of persons with disabilities in the
U.S. needing AOD treatment services in 1999

Estimate (needing treatment with disabilities)

1,505,000 903,000 –

Based on observed rate of recorded disability in NY
Office of Alcohol and Substance Abuse Services
1999, treatment episode dataset = 0.301



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What the research tells us

- ▶ Persons with MR/DD use less than general population
- ▶ Alcohol use more likely than illicit drugs even in households with illicit drug use
- ▶ Patterns of use/abuse most likely learned from family
- ▶ Greater negative consequences from same amount of use



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Studies

- ▶ 18% of sample of community residents reported "misusing" alcohol (McGillicuddy and Blane, 1999)
- ▶ NJ study of 119 Medicaid claims & HIV+AIDS registry clients, 72% had a substance abuse problem, 56% were registered as IVDUs (Walkup, et al 1999)



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Studies

- ▶ 2% of clients in all AOD treatment programs in Pima County (Tucson), AZ had DD (NAADD, 1999)
- ▶ 2.3%/949 in Ontario AOD programs had developmental problems (Tvas & Rush, 1991)
- ▶ 13% out of a consecutive sample of people in 2 AOD programs had MR/DD (Westermeyer, et al, 1996)



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Risk Factors

- Family of origin
- Status transitions
- Use with medication
- Influence of "friends"
- Alcohol not viewed as a drug
- Societal messages and values
- Inaccessible prevention & education



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Risk Factors

"Client choice" issues blur screening or intervention policies

DD system weak on AOD, AOD system weak on DD

Each system's priorities, funding, definitions, mandates, and knowledge base differ dramatically

Mental illness co-morbidity may be 50% and therefore rehab needs increase exponentially



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MR/DD provider barriers

- Limited or no AOD expertise
- Small numbers needing AOD service
- Lack of training and treatment
- Funding restrictions
- System not set up to address AOD
- No clear policies/practices
- Staff AOD issues
- Client Choice issues



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AOD Provider Barriers

- Limited or no MR/DD expertise
- Small numbers needing AOD service
- Lack of training and treatment
- Funding restrictions
- System not set up to address MR/DD
- Increasing services standardization



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Alcohol & Drug Treatment Barriers

- Attitudinal
- Discriminatory policies, practices
- Communications obstacles
- Architectural issues



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Project Connect

A collaboration of Toward Maximum Independence (TMI), the National Association on Alcohol, Drugs and Disability (NAADD) and the San Diego Regional Center (SDRC) Recovery Task Force, and San Diego County Alcohol and Drug Services, funded by The California Endowment (TCE)



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Why San Diego?

- ◆ Long history of focus on the alcohol, drug and developmental disability issue
- ◆ Funder (TCE) cultivation
- ◆ Recovery task force
- ◆ Five recovery support groups throughout the county
- ◆ Receptive developmental disability provider community



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A one-year planning and needs assessment effort

- ◆ Archival document review
- ◆ Key informant interviews
- ◆ Client focus groups
- ◆ Professional focus groups
- ◆ Provider surveys (both addiction/recovery treatment and developmental disability services)
- ◆ Community advisory body (Recovery Task Force)



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Key Informant Questions

1. Briefly describe your organization and the professional position that you occupy. Do you work in the alcohol and drug or developmental disability field?
2. How long have you worked in your current capacity? Previous positions?
3. On a scale of 1-10 (with 10 representing MOST knowledgeable) how knowledgeable would you say you are about your field?
4. On a scale of 1-10 (with 10 representing MOST knowledgeable) how knowledgeable would you say you are about the (other) field?
5. Do you believe that people with developmental disabilities are more likely, less likely or have about the same likelihood of having problems with alcohol?



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Key Informant Questions

6. Do you believe that people with developmental disabilities are more likely, less likely or have about the same likelihood of having problems with illicit drugs?
7. Do you believe that people with developmental disabilities are more likely, less likely or have about the same likelihood of having problems with prescription medications?
8. What do you see as the major barriers to improving alcohol and drug services for people with developmental disabilities?
9. How can these barriers be addressed?
10. Would you be willing to work towards improving access to alcohol and drug services for people with developmental disabilities?



Project Connect Findings

Alcohol and Drug Services Findings

- ADFS-1 Working linkages between alcohol and drug services and the developmental disability sector have improved, especially during the past 12-18 months, but substance use disorder treatment within the publicly-funded service system for this population is largely inadequate, and recent efforts to improve and strengthen the cross-system linkages are fragile and will require continuing support.
- ADFS-2 Alcohol and drug treatment providers are inadequately prepared and under-resourced to provide accessible, quality treatment to the target population. This has resulted in widespread reluctance to participate in remedial efforts.



Project Connect Findings

- ADFS-3 Despite the above finding, many professionals and policy makers within the alcohol and drug sector report that they are willing to work collaboratively to remedy the situation and in a few instances innovative and accessible services are currently being provided.



Project Connect Findings

Developmental Services Recommendations

- DSR-1 The San Diego Regional Center should continue with and finalize its efforts to vendorize alcohol and drug case management services for clients with alcohol and drug problems. Such vendorization has existed for more than 10 years at the Redwood Coast Regional Center and has been successful for helping dozens of regional center clients achieve and maintain recovery.
- DSR-2 The San Diego Regional Center should work with residential vendors to create one or more group homes set aside exclusively for clients in need of a clean and sober environment.



Project Connect Findings

- DSR-3 The San Diego Regional Center should develop systems to systematically assess all clients for substance use problems, provide appropriate alcohol and drug prevention services and monitor those clients who are in need of treatment and recovery services.



AOD assessment considerations

- Learning style
- Receptive and expressive language
- Family situation
- Living arrangements
- Social network – friends
- Case management



Treatment Considerations

- Behaviorally focused
- Shorter sessions and/or fewer tasks
- Medication evaluation
- Family involvement
- Injury prevention education
- Focus on peer pressure
- Modified 12-step approach can work



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Treatment modification

- Role playing and behavioral practice
- Consider reinforcement system
- Integrate plan with community services
- Assign mentor
- Longer treatment contract
- Plan aftercare immediately
- 10 minute focus in group



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Treatment modification

- Assertiveness training
- Socialization alternatives
- Remove distractions
- Video tape sessions
- Increase individual counseling
- Review, teach, review
- Pharmacology



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Resources

No Ordinary Pain, video, 18 minutes, by The Association for the Help of Retarded Children (AHRC) in New York City.

The AHRC provides specialized recovery services for people experiencing alcoholism and addiction who are also developmentally disabled. The video, *No Ordinary Pain*, presents the organization's experiences and uses interviews with clients and staff to illustrate the challenges of prevention, treatment and recovery for people with developmental disabilities.

To receive at no cost, contact: Rhonda Merriman, AHRC, 200 Park Avenue South, New York, New York 10003, phone 212.780.2500.



Resources

Picture-Talk

Prevention Curriculum Guides, by Alexander Boros, et al.

Students with developmental disabilities will eventually encounter situations where they need to know about alcohol and other drugs. They may have to make decisions about drug use. Picture-Talk is an informative, simple teaching method for educators, counselors and anyone working with this population around issues of substance abuse.

To order, contact: www.med.wright.edu/citar/sardi/rrtc.html



Resources

Substance-Related Disorders in Persons with Mental Retardation, by Peter Sturmey et al., NADD Press, Monograph Series.



Resources

More than Accommodation: Overcoming Barriers to Effective Treatment of Persons with Both Cognitive Disabilities and Chemical Dependency, by Jerry Annand, M.A.

In 1995 a multi-disciplinary team of providers in Portland, Oregon began working together to establish an effective treatment approach for persons with both cognitive disabilities and chemical dependency. The model they developed through five years of observation, experimentation, advocacy and just plain "in-the-trenches" hard work demonstrates the basic truth learned from their clients, "If we don't learn the way you teach, teach the way we learn."

To order, contact: Nightwing Publishing, P.O. Box 1143, Beaverton, OR 97075, www.nightwingpublishing.com, phone 800.514.4045, fax 503.646.0773.



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