Understanding the crisis faced by individuals and families of children with multiple diagnoses

January 2008

A joint project of





EMPOWER-COLORADO





The Federation of Families for Children's Mental Health Colorado Chapter

A joint project of





CONSUMER INITIATIVE



The Federation of Families for Children's Mental Health Colorado Chapter

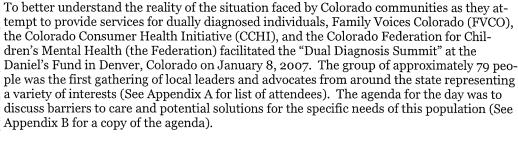
Dual Diagnosis Definition:

For the purposes of this summit dual diagnosis is defined as: a classification that involves more than one co-occurring diagnosis making the individual eligible for services in more than one service system. Examples of these services systems include: the developmental disability system, the mental health system, the school system, the juvenile justice system, elder care, and the substance abuse system.

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The Dual Diagnosis Summit, January 8, 2007



During the first half of the day, the larger group self-selected into six smaller groups. The assigned task for each small group was to document specific barriers to care/services faced by the following systems: developmental disability, physical disability, substance abuse, and juvenile justice. Small group discussions highlighted the many challenges to providing appropriate services for individuals with co-occurring disorders.

During the lunch break, staff members from FVCO, CCHI, and the Federation synthesized the information generated from the small groups. From the hundreds of identified barriers to care, six categories of overall systems barriers were clearly identified. They were:

Cross System Collaboration
 Network Adequacy
 Prevention/Lack of Early Intervention
 Cultural/Linguistic Competency
 Societal Values and
 Funding

Participants reconvened after lunch and the second half of the day was spent back in the small groups. Each group was asked to review the overarching system barriers and to begin to discuss potential solutions.

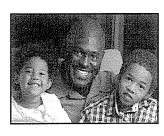


Colorado
families with
children with
multiple
diagnoses are
in real crisis.

Lessons Learned

The data reveal strong similarities between each of the identified systems when dealing with the complex issues of funding, coordinating and delivering supports to individuals with multiple diagnoses. Some of the key lessons learned from the Summit are:

- Colorado Families with children with multiple diagnoses are in real crisis.
- Professionals from all systems that serve the dual diagnosis population need to work in a coordinated and collaborative way to support cross-system service delivery and referral.
- There are not enough service providers in Colorado to meet the needs of the dual diagnosis population.
- Screening and early detection are difficult but crucial to providing effective treatment.
- Investing in quality services early on in a child's life is needed to end the ineffective and costly practice of only addressing needs at the point of crisis.
- Recognizing the complexity of the situation is the first step toward improving existing support systems and creating effective public policy to help people with co-occurring conditions.
- The definition of support system must be expanded to include the natural supports that a person brings to the table. These can include families and significant others and support systems that draw on an individual's native culture and linguistic community.
- To the largest extent possible, the individual's needs and expressed desires should direct funding for culturally competent services and supports.
- More capacity (i.e. hiring and training competent providers) is needed in the mental health system to provide timely and effective services to individuals with multiple diagnoses.



Overarching Systems Barriers



- -Training
- -Education
- -Resources,
- -Medical Necessity

Professionals that treat clients from multiple systems are not cross-trained to carry out cross-system coordination. From training to medical information each system shared the desire to have more knowledge around the support, treatment and/or how to work with populations that are eligible for more than one system of service. Other areas for ongoing trainings included: involving the client when negotiating multiple systems, working with individuals and families where English is not the first language, and identifying processes and barriers to obtaining the service. For example, the person needing substance abuse counseling who also is eligible for developmental disability services or the client with a mental health need who is in the juvenile justice system has difficulty getting the two systems to coordinate the benefits.

Current efforts on the part of state agency officials to collaborate are generally good according to most Summit participants, but some spoke of the lack of consistent cooperation between local developmental disability providers and mental health providers. Better coordination can be a difficult goal to achieve because success is often dependant on individual personalities and the specific program characteristics. Moreover, according to Summit participants, mental health funding and service cuts have forced mental health staff to cut back on any plans to collaborate with developmental disabilities agencies around service planning, coordination, and delivery.

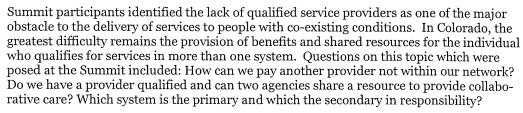


Difficulties
with
eligibility and
access to
needed
services
create
barriers (to
care)



- -Provider
- -Access
- -Benefit

Difficulties with eligibility and access to needed services stand as major challenges and create barriers to addressing the needs of individuals with co-occurring disorders. In addition, there is a lack of adequate training for service providers and professionals in the identification and treatment of dual diagnoses with appropriate evidence-based interventions. Providers are typically trained within one delivery system and unfamiliar with processes and procedures in co-occurring diagnoses.



Anecdotal information presented at the Summit indicates that many community mental health centers do not have adequately trained staff with the expertise to effectively provide services to individuals with cognitive disabilities. Other participants reported that access to clinical services by individuals with co-existing conditions was restricted due to narrow eligibility criteria set by individual services systems and the private health insurance companies. The most significant barriers to care as reported by summit participants were the lack of qualified mental health providers and the consequent overuse of medication and the provision of inadequate care and treatment.



Prevention

- Lack of Early Intervention

Screening and early detection are critical but often difficult to obtain. Individuals with dual or multiple diagnoses, especially children, are frequently not identified and when they are, their needs are too complex for the system in which they currently operate to adequately address. Consequently, their needs can be overlooked. In many instances, children or adolescents with dual diagnoses end up in the child welfare or juvenile justice system because their needs were not fully understood or addressed. Social stigma surrounds these service delivery systems impacting the care needed until after it is too late. Similarly, people eligible for other services may not be screened for eligibility for services from different agencies. For example, a teenager with developmental disabilities can exhibit depressive symptoms. But unless service providers in the developmental disability system are trained on how to identify symptoms of mental health disorders, an individual's needs are often missed until they becomes a bigger problem.

Cultural/Linguistic Competency

- -Different Systems
- -Rural vs. Urban
- -Traditional vs. Modern

Accessing services within different state agencies and/or systems for an individual with multiple diagnoses can be extremely difficult. Add to that equation an individual or family that does not speak English and the problems are only compounded. Cultural competency does not only apply to language barriers. There are also the problems faced by Coloradans who live in rural parts of the state where there are often fewer resources and a lack of qualified providers.

Systems of care represent an effective approach, but putting this way of operating into practice requires systems change and strong leadership. State and local systems must be committed to training staff to work with individuals from different cultures, in addition to coordinating with the individual's own natural communities, leads to the development of a uniquely qualified support system. When this type of cultural awareness and flexibility is built into the system it ensures cost-effective services for people with complex needs.

Societal Values

- -Stigma
- -Denial

All of the systems mentioned above and their related services were identified as fragmented. There was also evidence that individuals were receiving care in a "silo" Or, in other words, they were unable to access care from different systems because the system from which they first accessed care was either unaware of services available outside of that system or staff was not trained on how to handle the complex needs of dually diagnosed clients. This lack of coordination between systems and the inability to manage different care needs were identified by all systems.

Funding

Spending dollars on the front end of mental health in the form of awareness promotion and prevention is needed to put a stop to the ineffective and inefficient practice of only addressing an individual's needs when there is a crisis. At present, funding mechanisms and community needs are not in synch. Private insurance shifts costs to public programs by reducing in hospital care, limiting benefits, and restricting diagnosis codes.

Colorado Medicaid provides for episodic mental health treatment, counseling, and psychiatric care but cuts or restrictions in mental health funding have dramatically decreased the capacity of community mental health centers to provide timely services. The state mental health agency has minimal involvement in financing mental health services for persons with developmental disabilities. Additional funding to community mental health programs to improve staffing levels is crucial to any long term efforts to improve this situation.

Background on Target Population



The population of individuals with multiple diagnoses is increasingly recognized as a challenge to systems at the federal, state and local level. According to the Department of Health and Human Services Office on Disability in partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA):

"children with developmental difficulties have an elevated vulnerability to behavioral health issues including depression and anxiety. A literature review published in 2005 by Prout found that 25-48% of children with developmental disabilities also have emotional disorders. Within very specific diagnostic groups, such as Fetal Alcohol Syndrome or Fragile X Syndrome for example, the percentage of children with behavioral and emotional disorders may be far greater."

- State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders, April 2005

There is growing appreciation that a large number of children in the juvenile justice and child welfare systems have significant emotional needs and developmental disabilities as well.

Identification of Need

Investing in quality services early on ... is needed to end... addressing needs at the point of crisis

Due to the complex and specific needs of this population, individuals with co-occurring disorders are not easily identified. Additionally, the traditional structure of our existing system in which dually diagnosed individuals currently reside is not adequately equipped to treat and support them. For example, a child with a developmental disability may become involved in the juvenile justice system. Law enforcement officials and personnel may not be trained to work with children with a person with a disability. Less apparent but equally important is the awareness of the needs resulting from a co-occurring mental health disorder. The underlying mental health condition may go unnoticed and unaddressed. This is partially due to the complexity and intensity of the services that are often required. But, it is also a result of the following: the narrow focus of the respective systems, differing eligibility requirements for treatment within each system, and funding streams that were not created to take a holistic approach towards assessment and treatment.



It is a common fact of life for individuals with multiple disorders that they may not have all of their needs addressed. In some cases they are served in a system that is only willing or able to address part of their problem. In most cases they are deemed too difficult to treat and they do not receive the array of services they require. The consequences of these cases falling through the cracks can have a devastating effect on the individual and their families and on society as a whole.

As a result of our state's service systems inability to effectively coordinated care for individuals with dual diagnoses many children with multiple disorders may not have all of their needs met. Either they are served in one system that is able to address part of their problem, or they are the "unclaimed" children and youth who fall through the cracks and do not get the services that they require. The consequences of this neglect drive up the cost of care and may prove to be pervasive and long-term for the child, the family and our society. But it doesn't have to be this way:

"Inappropriate hospitalization, out-of-state placements by schools, custody relinquishment to child welfare, and incarceration by juvenile justice can sometimes be avoided when children's needs are identified early and when service decisions are driven by treatment plans that are child and family centered, comprehensive, and culturally appropriate."

- State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders, April 2005

Executive Summary

On January 8, 2007 the Dual Diagnosis Summit brought together a broad cross section of organizations representing individuals with co-occurring complex needs. The discussion focused on the barriers to care and potential solutions for the specific needs of this population. For the purposes of this paper a "dual diagnosis" is defined as when any combination of physical health issues, mental health disorders and/or substance abuse disorders co-occur.

The group coalesced to address the problems that exist across Colorado for families and communities are who are confronted with the challenges of treating and supporting individuals with co-occurring disorders. Because of the inherent complexity of individual needs it is virtually impossible to provide a "one size fits all" approach to provide effective care. The professionals and volunteers within the developmental disability system, the mental health system, the physical health system, the school system, the juvenile justice system, elder care, and the substance abuse system work hard each day to provide collaborative types of services and the supports individuals and families need.

While agencies and their staff people are effective in their respective areas, individual organizations are often times not equipped to provide the collaborative types of services and supports. Families report inadequate screening or early identification procedures. There is also the problem of inconsistent eligibility criteria, ingrained cultural differences across systems, and inflexible state and federal funding streams that make access to care across systems very difficult.

Despite the complexity of the current systems Summit participants brought up a few positive examples of individual agencies or advocacy groups who are successful in addressing the needs of consumers with dual or multiple diagnoses. There are success stories that other organizations can look to when attempting to establish best practices. These groups have found innovative ways to work together or combine services to treat and support the comprehensive needs of the individual with a dual diagnosis and their family.

In some parts of our state the practice of bringing together individual agencies and advocacy groups under one roof has allowed for greater coordination of services. In other instances, case managers from different support organizations were encouraged to network with one another to increase the level of coordinated services. There are many ways to streamline systems to allow access, increase cooperation and reduce poor outcomes. The Dual Diagnosis Summit was convened to expand and build on existing successful collaborations and to foster innovation in service delivery models for this population.



"I want to give (my child) the best possible care but...I don't know where to turn."

The Impact on Families: A mother's story



"Quite simply, I am exhausted. I've only had about two nights of sleep in the past week. My other two kids and I spend just about every hour of the day looking after my youngest son Paul. It takes two people just to hold him down during g-tube feedings and when we have to give him meds. I want to give him the best possible care but his outbursts and aggressive behavior is getting worse and I don't know where to turn. I've been told by my case worker that there is no system equipped to take care of all my child's needs. I know in my heart that he needs to be hospitalized but the hospital social worker says that 'There are no hospital beds for this type of case.' I've tried talking to so many different offices to get help for our son but each person tells me that they are not responsible for this type of diagnosis...

From an outsider's perspective, some people might think that our family is 'picture perfect'. Thankfully, Paul's dad has a good job. I used to work but had to quit to take care of Paul full time. All of our kids have special needs, either medical or educational, but they're all getting services from our local Community Centered Board. Paul's rages don't happen every day and when they do they only last for a short time. It's just so tiring for me and I don't have anyone except for my other two kids to help me look after Paul. I'm still waiting to hear back on whether we can get any additional family support for some respite care for me.

There needs to be significant political will to break down these so called "silos" and create opportunities for state and local systems to braid and blend funding.

I guess what caught us by surprise is how we went from dealing with the day to day management of Paul's disability to having to lock him in his room for fear that he might hurt me or my other kids. When he was smaller it was easier to keep him calm, but it has gotten to the point that I can't control him anymore. I don't want to give up custody to the state, but what else can we do? He needs to be in a treatment facility, and we've been told by our county case worker that relinquishing custody is the only way he can get the help he needs."

The Role of Public Policy

In addressing the needs of those with multiple diagnoses in Colorado, the role of public policy should be to identify and translate any effective strategies into permanent solutions. And, effectively addressing the problems of dual diagnosis patients requires efforts at the local, state, and federal levels to address the identified barriers to care.



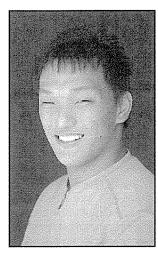
Senator Betty Boyd-Rally Day at the Capitol

Any potential legislation or changes in administrative rules should provide a structural and strategic public policy approach intended to indelibly change the way services are provided to individuals with dual diagnoses in Colorado. Consequently, future summits should include the participation of law makers and policy planners to consider critical strategies to improve care for

- Streamlining funding
- · Appropriate early screening and diagnosis
- · Enhanced cultural diversity
- Expanded early and emergency intervention

the dual diagnosis population. These strategies include:

- Targeted resources to recruit and train of service providers to work with this population
- · Coordination of public and private funding
- Training for families to become strong advocates for their children and themselves.



Dual diagnosis should be an expectation... and not an exception

Next Steps: State Strategies for Supporting Individuals with Co-Existing Conditions

As a follow up to the good work accomplished at the first summit, the next phase should involve the identification of the specific successful and the ineffective policies and practices currently in place for the provision of services to individuals with co-existing diagnoses and subsequently, the development of long-term systemic solutions to permanently eliminate these barriers faced by families who access care across multiple systems. This could be accomplished by convening panels that include policy makers and stakeholders around each of the lessons learned to generate solutions and assign responsibility for action steps and real policy change.

The problems faced by individuals with a dual diagnosis are multidimensional and at present no one institution is the obvious place to initiate such a plan. Resolution of the problems faced by this population will require vigorous leadership and coordinated efforts on the part of all agencies that serve the dually diagnosed to create a system that provides a sustained level of care and adequately addresses the needs of the individual at whatever his or her point of entry into the system.

It is clear that dual diagnosis should be an expectation for systems and service providers and not an exception. Failure to address this point results in poor outcomes and high costs for all systems involved. Most summit participants were united in their common call to create a "one stop shopping" protocol to meet the challenge of providing effective services to people with coexisting disorders. This translates to mean an integrated system planning process, where each funding stream, each program, all clinical best practices and staff education would be designed to proactively address the needs of individuals with co-existing diagnoses. And, potentially, in the long run a centralized office in each county that would house all of the respective agencies that serve individuals with dual diagnoses. Successful strategies for our state are possible and can be developed with good public policy and effective planning and collaboration. For those of us who see or experience first hand the tremendous obstacles faced by individuals with co-existing disorders we diminish ourselves if we do nothing. But we will enrich all Coloradans if we are successful.

The Impact on Families: A father's story

"We adopted Jason at age three. And at the time of adoption we knew Jason had some fetal alcohol effects since his birth mother did admit to drinking during her pregnancy. So we tried to set up all of the extra safety nets to address his behavioral and educational services to help with his extra challenges. 12 years later he now has a list of over 15 different diagnosis. My wife and I have found that the system was not equipped to handle all of his needs.



"...the system was not equipped to handle all of (our son's) needs."

It was hard to even access the services he needed. Plus, they were very expensive. We started out using all of our private resources. We lost all of our savings, my wife had to quit her job to stay home and take care of Jason. And, we racked up huge credit cards in order to try to help him. We finally had to go back to Child Protection (who we adopted through) to help us pay for a residential treatment center. But, when he came back home, after only six months, with very little after-care support Jason got into some legal trouble. It was at this point Jason was transferred over to the Dept. of Corrections and he ended up in two additional, more restrictive placements.

It's unbelievable when I think about it but by the time he was 15 years old, he had five different psychiatrists and 10 different specialty doctors at nine different clinics, agencies or hospitals. Jason was seen by 12 different counselors, seven different Social Workers, six different placements, four different attorneys, five different Judges, three different correctional officers and *hundreds* of staff from a variety of agencies and placements who worked with my son. These numbers would have been more than cut in half had we been allowed to access the services we needed when we needed them.



Appendix A

List of Participants

Name		Organization			
Edie	Winters	Adams County Social Services Department			
Rhonda	Damerau	Adult Protective Services			
Jenny	Pool Radway	Alzheimer's Association			
Claudine	Ryals	Alzheimer's Association			
Carol	Meredith	Arc of Arapahoe/Douglas			
Edna	Frantela	Arc of Aurora			
Jo Lynn	Osborne	Arc of Jeffco			
Louise	Todd-Stoll	Arc of Jefferson, Gilpin, and Clear Creek			
Barb	Cleland	Aurora Mental Health			
Sarah	Arvin	Aurora Mental Health			
Betty	Lehman	Autism Society of Colorado			
Cami	Learned	CCB Partners			
Dan	Teuter	CCMCN			
Linda	Babcock	City of Denver			
William	Went	client of Rich Gebhart			
Michael	Kirby	client of Rich Gebhart			
Cheryl	Haun	Co Chapter National MS Society			
James	Dean	Co Legal Services			
Doyle	Forrestal	Colorado Behavioral Healthcare Council			
Molly	Brown	Colorado Community Managed Care Network			
Megan	Floyd	Colorado Federation of Families for Children's Mental Health			
Lily	Boyce	Colorado Federation of Families for Children's Mental Health			
Khanh	Nguyen	Colorado Health Foundation			
Hillary	Johnson	Colorado Health Foundation			
Haline	Grublak	Colorado Health Networks			
Dr. Herb	Jacobs	Colorado Medical Society			
Denise	McHugh	CSI			
Ricky	Toll	Denver Options			
Nina	Cruchon	Denver Options			
Jennifer	Grawe	Developmental Pathways			
Maureen	Nicolais	Developmental Pathways			
Gary	Nitta	Division of Youth			
Evalyn Maria	Morreo	El Centro Esperanza			
Cynn	Connais	El Paso County Co-Occuring Collaborative			
Shawna	Turner-Ruegg	Exempla Behavioral Health Services			
Jen	Vasquez	Family Voices			
Kelly	Stahlman	Family Voices			
Sarony	Young	Family Voices			
Christy	Blakely	Family Voices			
Virginia	Appel	Health Care Program for Children with Special Needs			
Carol	Plock	Health District of Northern Larimer County			
Janelle	Patrias	Health District of Northern Larimer County			
Kathy	Jensen	Hep C Connection			
Julie Lind		InNet incompany			
Carolyn	Kwerneland	JCDHE			
Mary	Thornton	Jefferson Center for Mental Health			
April	Hepner	Jefferson Center for Mental Health			
Lisa	Strub	Jefferson Center for Mental Health			

Lu'Ann Reeder Jefferson County

Libby Stoddard Larimer Center for Mental Health

Pat Doyle Legal Center for People with Disabilities
Heidi Van Huysen Legal Center for People with Disabilities
Liz Fuselsier Legal Center for People with Disabilities

Lori Woods Long Term Care Options

Allison Krone MCPN

Katie McIntyre MSW student
Lacy Berumen NAMI Colorado
Cheri Bishop NAMI Colorado

Brian Tallant National Association Dual Diagnosis/ Aurora Mental Health Center

Paula Sustin National MS Society

Wayne Maxwell North Range Behavioral Health or call

Anne Mitchell Northerst Behavioral Health

John Daurio Office of Adult, Disability, and Rehabilitation Services

Dborah Trout Office of Behavioral Health and Housing
Teresa Devlin Ombudsman Medicaid Managed Care

JC Carrica Partnership for Progress

Christin Mcleod Probation Officer, 17th Judicial District

Jesse Ulmer Senator Ken Gordon's Office

Janis Debaca Tri County Health Department/HCP

Tracy Price-Johnson JFK

Grace Ormsby
Laurie Picus
Jacquie Stanton
George Dunn
Don Vancil
Rich Gebhart
George DeCourno

Appendix B

Dual Diagnosis Summit Monday, January 8, 2007

The Daniel's Fund

Agenda

8:30 - 9:00 am: Sign in, coffee and network

9:00 - 9:30 am: Welcome and introductions-

9:30 - 9:45 am: Defining Dual Diagnosis for today's summit

9:45 - 10:15 am: Creating a common language: establishing ground rules and definitions of developmental

disability & mental health terms

10:15 – 11:00 am: Identifying outcomes for today's summit:

Present grid and discuss target audiences to which we present summit outcomes

White/Policy paper to legislators

208 Health Reform Commission

Other outcomes as identified by participants

11:00 am - 12:00 pm: System Specific facilitated small group session

SMALL GROUP TASK:

Identify the barriers in specific systems and across systems

System Specific Groups:

- -Physical Disability and Mental Health (x 2)
- -Juvenile Justice and Mental Health (x 2)
- -Developmental Disability and Mental Health (x 2)
- -Substance Abuse and Mental Health

12:00 – 1:00 pm: Lunch on you own

1:00 - 2:15 pm: Facilitated large group cross system session-

"What's it going to take?" -Strategically identify solutions to the identified barriers

2:15 - 2:30 pm: Review of today's work and ideas for future follow up

2:30 - 2:45: Please complete the evaluation form prior to leaving

Appendix C

Additional Resources

Juvenile Justice

National Center for Mental Health and Juvenile Justice

http://www.ncmhjj.com/

National Center for Mental Health and Juvenile Justice: Resource Kit

Improving Services for Youth with Mental Health and Co-Occurring Substance Use Disorders Involved with the Juvenile Justice System

This Resource Kit was prepared by the National Center for Mental Health and Juvenile Justice of Policy Research Associates, Inc. through a contract from the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

http://www.ncmhjj.com/resource kit/Default.htm

http://www.ncmhjj.com/resource kit/special cooccur dis.htm

Co-Occurring Disorders References

Abstract: This chapter provides an overview of the issues confronting youth with mental health disorders who come in contact with the juvenile justice system. It is directed toward those who work with this population as a means of providing knowledge and improving the delivery of services to these youth. Available From: American Correctional Association, 4380 Forbes Blvd., Lanham, MD 20706 http://www.aca.org.

Mental Health

http://www.nimh.nih.gov/

Articles & Research

"Evidence-Based Practices: Shaping Mental Health Services Toward Recovery" http://mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/cooccurring/default.asp

Co-Occurring Disorders: Integrated Dual Disorders Treatment Toolkit http://mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/cooccurring/consumers.asp

Psychiatric Services (Journal of the American Psychiatric Association)

http://psychservices.psychiatryonline.org/cgi/collection/dual diagnosis patients

"Co-occurring Psychiatric and Substance Disorders"

By Norman G. Hoffmann, Ph.D.; Todd W. Estroff, M.D.; Susan D. Wallace, M.S., LCDS

http://dualdiagnosis.org/resource/publications/previous-issues/psichiatric-substance-disordes

"Adolescents Growing Up in Stressful Environments, Dual Diagnosis, and Sources of Success" By Albert R. Roberts, PhD, DABFE & Kevin Corcoran, PhD, JD http://brief-treatment.oxfordjournals.org/cgi/content/abstract/5/1/1

 $\hbox{``Identifying Co-Occurring Disorders in Juvenile Justice Populations''}$

Ana M. Abrantes; Norman G. Hoffmann, Brown University; Ronald P. Anton, Day One for Youth and Families; Todd W. Estroff

http://vvj.sagepub.com/cgi/content/abstract/2/4/329

"Prevalence, Severity, and Co-occurrence of Chronic Physical Health Problems of Persons With Serious Mental Illness"

Danson R. Jones, Ph.D., Cathaleene Macias, Ph.D., Paul J. Barreira, M.D., William H. Fisher, Ph.D., William A. Hargreaves, Ph.D. and Courtenay M. Harding, Ph.D. http://psychservices.psychiatryonline.org/cgi/content/full/55/11/1250

Comprehensive coverage of dual diagnosis populations & issues:

http://www.nmha.org/go/information/get-info/co-occurring-disorders/dual-diagnosis

Web Resources

Mental Health America: Dual Diagnosis page http://www.thenadd.org/

The Association for the Dually Diagnosed (NADD)

www.thenadd.org

National Center for Mental Health and Juvenile Justice

http://www.ncmhjj.com/

COCE: SAMHSA's Co-Occurring Center for Excellence http://coce.samhsa.gov/

Dual Diagnosis Website

http://users.erols.com/ksciacca/

MedlinePlus

http://www.nlm.nih.gov/medlineplus/dualdiagnosis.html

Help Guide: Dual Diagnosis: Information and Treatment for Co-occurring Disorders

http://www.helpguide.org/mental/dual diagnosis.htm

National Alliance on Mental Illness

http://www.nami.org/Template.cfm?Section=By_Illness&Template=/TaggedPage/ TaggedPageDisplay.cfm&TPLID=54&ContentID=23049

Dual Diagnosis and Addiction Treatment Programs and Centers Dual http://www.dual-diagnosis.net/

Dual Recovery Anonymous

http://draonline.org/dual_diagnosis.html

SAMHSA: Substance Abuse and Mental Health Services Administration

http://www.samhsa.gov/scienceandservice/cod.aspx

Foundations Associates Integrated Alcohol and Drug Treatment

http://dualdiagnosis.org/

http://dualdiagnosis.org/co-occuring-disorders (Co-Occurring Disorders)

http://dualdiagnosis.org/resource/educational-links (Educational Links)

Appendix D
2005/2006 National Survey of Children with Special Health Care Needs
Colorado Chartbook Page

Estimated number of CSHCN: 149,000

	Falle %	Nation 5	National Chartbook Indicators S	ingin V	Na-	
Percent of children who have special health care needs	12.5	13.9	Child Health		100%	
CSHCN Prevalence by Age	Constant Change of the Constant of the Constan		CSHCN whose conditions affect their activities	23.4	24.0	
Age 0-5 years	8.4	8.8	usually, always, or a great deal		44.0	
Age 6-11 years	13.0	16.0	CSHCN with 11 or more days of school absences due to illness	14.3	14.3	
Age 12-17 years	16.1	16.8	Health Insurance Coverage			
CSHCN Prevalence by Sex			CSHCN without insurance at some point in past year	12.7	8.8	
Male	14.6	16.1	CSHCN without insurance at time of survey	5.4	3.5	
Female	10.4	11.6	Currently insured CSHCN whose insurance is inadequate	34.6	33.1	
CSHCN Prevalence by Poverty Level		MINISTER SERVICE SERVICES	Access to Care			
0-99% FPL	9.7	14.0	CSHCN with any unmet need for specific health care services CSHCN with any unmet need for family support	20.0	16.1	
100-199% FPL	12.1	14.0		5.0	4.9	
200-399% FPL	13.1	13.5	services	5.0	4.5	
400% FPL or more	13.3	14.0	CSHCN needing a referral who have difficulty getting it	24.9	21.1	
CSHCN Prevalence by Hispanic Origin a	CSHCN without a usual source of care when sick	6.5	5.7			
Non-Hispanic	13.7	15.0	(or who rely on the emergency room)	6.5	6.5	
White	13.4	15.5	CSHCN without any personal doctor or nurse Family Centered Care	0.0	0.0	
Black	15.6	15.0	CSHCN without family-centered care	32.6	34.4	
Asian		6.3	Impact on Family	02.0	04.4	
American Indian/Alaskan Native		14.5	CSHCN whose families pay \$1,000 or more out of	27.7	20.0	
Native Hawaiian/Pacific Islander		11.5	pocket in medical expenses per year for the child			
Multiple Races	21.2	17.9	CSHCN whose conditions cause financial prob- lems for the family	23.9	18.1	
Hispanic	8.9	8.3	CSHCN whose families spend 11 or more hours per week providing or coordinating child's health	8.4	9.7	
Spanish Language Household	2.8	4.6	care		20.0	
English Language Household	13.7	13.1	CSHCN whose conditions cause family members to cut back or stop working	20.6	23.8	
MCHB Care Outcomes State						
CSHCN whose families are partners in dec	59.1	57.4				
CSHCN who receive coordinated, ongoing,	48.2	47.1				
CSHCN whose families have adequate private	59.1	62.0				
CSHCN who are screened early and contin	65.5	63.8				
CSHCN whose services are organized in w	87.8	89.1				
Youth with special health care needs who r care, work, and independence	47.0	41.2				

Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than or equal to 30%.

Citation format: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved [mm/dd/yy] from www.cshcndata.org

^{****}Prevalence data only available for States where this minority group makes up at least 5% of total population of children in the State.

January 2008

Dual Diagnosis Definition:

For the purposes of this summit dual diagnosis is defined as: a classification that involves more than one co-occurring diagnosis making the individual eligible for services in more than one service system. Examples of these service systems include: the developmental disability system, the mental health system. the school system, the juvenile justice system, elder care, and the substance abuse system.

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Key Lessons Learned

- Colorado Families with children with multiple diagnoses are in real crisis. They are shuttled between the various state service systems and are not getting the services and support they need. Our state's most vulnerable and needy citizens are forced to go without services because systems and providers are incapable or unwilling to provide care to individuals with multiple diagnoses.
- Professionals from all systems that serve the dual diagnosis population need to work in a coordinated and collaborative way to support cross-system service delivery and referral. There are too many different systems that families must see in order to access services. There needs to be significant political will to break down these so called "silos" and create opportunities for state and local systems to braid and blend funding. And there must be a centralized office to oversee all systems that serve individuals with multiple diagnoses that will coordinate funding, enforce policy, and provide accountability.
- There are not enough service providers in Colorado to meet the needs of the dual diagnosis population. And those that do exist are not consistently trained to support and treat people with multiple diagnoses. Providers are often just as frustrated with the current system because of lack of training on how to screen for other possible diagnoses or because their system's funding is not flexible enough to allow them to treat across diagnoses. Professionals from multiple systems need to be cross-trained to support cross-system coordination and referral. A more efficient system would provide for the treatment of an individual's specific needs rather than addressing their respective diagnoses.
- Screening and early detection are difficult but crucial to providing effective treatment. Because of the way the various systems currently function, the specific needs of this population are often not easily identified. Diagnoses can go unnoticed and unaddressed. This is due to the complexity and intensity of the services these children require. But it can also be traced to rigid systems, eligibility requirements, interventions, and funding streams that are not set up to take a holistic approach toward assessment and treatment. As a result, these children with multiple disorders may not have all of their needs met.
- Investing in quality services early on in a child's life is needed to end the ineffective and costly practice of only addressing needs at the point of crisis. Colorado must invest the time, energy, resources, and funding into early diagnosis. Early screening and diagnosis coupled with quality services that are provided when a child is young will save the state untold hundreds of thousands of dollars (see appendix d) that it will have pay later into the juvenile justice, court, and social service systems. This says nothing of the cost savings for families in the form of time, finances, and productivity if they receive quality services when their child is young.



Speaking on Behalf of Children and Youth with Special Health Care Needs

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A Letter from Family Voices Colorado

In our work with thousands of individuals and families of children with special health care needs over the years, we have consistently found that persons eligible for services from multiple systems call our office for assistance more often than those with a single area of need. Both consumers and providers involved in different service agencies and systems face complex challenges in obtaining necessary care for persons with needs that cross disciplines of mental health, developmental disability, education, juvenile justice, substance abuse, and elder care.

It is our hope that through the insights of this white paper, continued dialogue and progress will begin to take shape. The systems today are fragmented, and complex to navigate. Some of the recommendations in this paper are clearly focused on streamlining and collaboration, two of the concepts Family Voices strongly supports in resolving this problem. Family Voices and the other organizations which collaborated on this paper are committed to seeing a positive change happen for the many who have needs which require assistance from multiple service systems.

Sincerely,

Christy Blakely, Executive Director

Family Voices Colorado

To download additional copies of this report visit the Family Voices CO website:

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