Dec. 4, 2014

To: Members of the Colorado Joint Budget Committee
Senator Kent Lambert, Chair
Representative Millie Hamner, Vice Chair
Senator Pat Steadman
Senator Kevin Grantham
Representative Bob Rankin
Representative Dave Young

CC: John Ziegler
Megan Davisson

From:

Carol Meredith, The Arc Arapahoe and Douglas, co-chair CANDO Medical Mental Health Committee

Corry Robinson, JFK Partners, co-chair—Colorado Collaborative for Autism and Neurodevelopmental Disability Options (CANDO)

Marijo Rymer, The Arc of Colorado, co-chair CANDO Medical Mental Health Committee

Re: Colorado Mental Health Services and Behavioral Supports for People with Intellectual/Developmental Disabilities

Analysis of gaps in Colorado mental health services and behavioral supports for people with intellectual/developmental disabilities identified four major barriers to treatment:

1. Limited access to appropriate treatment, including crisis intervention, stabilization and prevention in the Colorado Behavioral Health system, for people with IDD;
2. Inadequate reimbursement and inappropriate service limits and definitions for people with IDD in the Behavioral Health capitated system as well as medical mental health benefits in the Colorado fee for service Medicaid state plan;
3. Conflicting requirements and confusion about diagnoses-based requirements limit access to assessments as well as treatment; and
4. Professional expertise and workforce capacity is sorely lacking.

Affected population:

1. Rates of children and adults with IDD who also experience mental illness or behavioral health crises is 35 to as high as 65% for those with an Autism Spectrum Disorder
2. Data from Colorado Children's Hospital regarding children with I/DD admitted to the emergency department for a behavioral or mental health crisis indicates that for every child eligible for I/DD services in CO, there is another child who does not meet eligibility requirements—the affected population is much larger than that of people eligible for HCBS Medicaid waiver services for people with I/DD.

Recommendations from the gap analysis are congruent with recommendations to the Governor from the Community Living Advisory Group submitted in September, 2014 and with

CHCPF's proposal to CMS for a State Integration Model grant to integrate physical and behavioral health.

First steps to address the barriers that could be undertaken in FY 15-16:

1. Complete cost analysis with accompanying actuarial study to ensure that people with IDD are fully included in the Colorado Behavioral Health system—similar to analyses done in 2013-14 to include cost of substance abuse treatment for all eligible persons in the Behavioral Health system.

2. Funding for pilot projects for cross-system response to behavioral health crises among people with IDD to include timely evaluation, treatment, therapeutic respite and follow up services—could be integrated into the Colorado Mental Health Crises Program but would require services appropriate for the needs of people with IDD. A pilot would require collaborative approaches to cross-system funding.

3. Systematic and strategic approach to increase capacity among licensed medical professionals, credentialed service providers and direct service personnel to provide medical and behavioral health services for people with I/DD. The plan could include incentives such as loan forgiveness, expansion of residency allotments, expanded training for nurse practitioners, and rate incentives for care coordination amongst primary care providers, mental health professionals, and behavioral specialists.

The members of CANDO are eager to assist the JBC in developing the frame work and cost estimates for the recommendations we propose to ensure that Colorado can fulfill the commitment to ensuring that all eligible children and adults—regardless of diagnoses—have access to mental health treatment and behavioral supports.

Dec. 4, 2014

TO: Colorado Joint Budget Committee

FROM: Marijo Rymer, Executive Director—The Arc of Colorado

RE: First Steps to Implement Recommendations from the Gap Analysis to Ensure Appropriate Behavioral Health Services for People with I/DD in Colorado's Mental Health System.

My name is Marijo Rymer. I serve as the Executive Director of The Arc of Colorado; we advocate for people with intellectual and developmental disabilties (I/DD)with the support of 11 local chapters of The Arc in Colorado. I am the co-chair of the Colorado CANDO Medical Mental Health Committee and as such, along with my colleagues here today, served on the steering committee for this project.

I echo Carol Meredith's thanks to the JBC for supporting this endeavor with an appropriation in 2013. And, I also thank the committee members for ongoing interest over the past year and a half.

People with I/DD experience mental illness, behavioral problems, medical difficulties and an assortment of other "slings and arrows" of life like all people do. Unfortunately, over the years, access to behavioral services for this populatiion through state Mediciad mental health systems has been difficult. That's the case for a variety of reasons—some based on system design, some based on reimbursement methodologies and some based on a lack of knowledge about the "primary cause" of mental illness or behvioral problems expereinced by people with I?DD.

Endless "chicken and egg" arguments can and have been made about which system should be responsible for what services. In the meantime, as our work shows and as many of you have learned first hand, for too many people—services are not provided by ANY system.

All persons eligible for Medicaid who have a need for mental health or behavioral services should be able to get an assessment and appropriate treatment regardless of whether or not they have an intellectual and/or developmental disabilty. The first step we should take is to ensure that the Colorado Behavioral Health system is properly structured and funded to cover the services and supports that people need.

In 2013, the General Assembly approved funding and other policy changes to integrate substance abuse assessment and treatment in the Colorado Behavioral Health system. Those changes were preceded by a thorough analysis of predicted usage and costs so that the capitated Behavioral Health System could be sufficiently funded to meet the needs.

A similar effort should be undertaken to ensure that the system can meet the needs of people with I/DD. Right now, from everything we have learned, that is not the case—adjustments must be made regarding rates, scope, and scale of services.

CMS requires that when states use a managed care/capitation based financing mechanism for Medicaid services that the methodology and rates are actuarially sound and sufficient to:

"*assure that payments are consistent with efficiency, economy and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area".* (1)

The Department should have a template based on the experience for integrating substance abuse assessment and treatment into the behavioral health system.

Lastly, before my friend and colleague, Dr. Corry Robinson, speaks to two other "first steps," I'd like to emphasize to the committee that the recommendations posed in the gap analysis report are fully congruent with recommendations made by the Community Living Advisory Group and with the state's application for State Innovation Model funding. Colorado is clearly committed to integrating medical and mental health service with all other publicly funded supports needed to live a health life. We need to make sure that people with IDD are fully included.

Again, my sincere thanks

(1) *http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Financing-and-Reimbursement.html*

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ANSCHUTZ MEDICAL CAMPUS

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December 4, 2014

TO: Colorado Joint Budget Committee

FROM: Cordelia Robinson Rosenberg, Ph.D., RN, Professor of Pediatrics and Psychiatry, Director, JFK Partners, University of Colorado School of Medicine

RE: First steps to Implement Recommendations from the Gap Analysis to Ensure Appropriate Behavioral Health Services for People with I/DD in Colorado's Mental Health System

I also want to express my appreciation for the opportunity these past 18 months. I am Corry Robinson and I am a Professor of Pediatrics and Psychiatry and Director of JFK Partners a program at the University of Colorado School of Medicine, Anschutz Medical Campus. In this position I over the past 21 years I have seen firsthand the impact of the implementation of managed care mental health services in Colorado and the impact of these policies on people with intellectual and neurodevelopmental disabilities.

In initially establishing the mental health managed care, the exclusion of people with intellectual and developmental disabilities, was well intended. However over time this policy has proven to be antithetical to the changes that have occurred in approaches to healthcare. Our systems of health, mental health and long term supports and moving towards integration of all aspects of care and this population needs to be fully included in that integration. The forecasts for accomplishing this vision in Colorado system is over the next several years. In order for that vision to be reality for people with intellectual and neurodevelopmental disabilities there are several actions that we feel need to be taken as soon as possible. Ms. Rymer has outlined the need for the study patterned after the work done to combine substance abuse and mental health services into one system.

The two requests that I wish to speak to are pilot projects for crisis intervention and a comprehensive approach to building capacity statewide.

Crisis Intervention Pilot Projects: When we began this "Gap Analysis" project it coincided with the Governors announcement of the intent to build a crisis system for all in Colorado. We were determined that the population we represented needed to be assured access to that system. There is no resistance to inclusion of people with developmental disabilities in that system but there is acknowledgment that specialized training and supports will be necessary. For this reason we are urging funding for Pilot Projects that would provide the funding basis so that services could be provided when necessary and payments mechanisms worked out afterwards. We feel strongly from our experience statewide, that systems are ready to come together to work out such collaboration and are ready to commit to payment where they have that responsibility. In order to get started there would have to be state funding to put infrastructure in place. Our research into the START model has yielded considerable detail as to how it could work. However that knowledge needs to be applied in the context of what exists currently in Colorado's agencies. Again our experience gives us confidence that the stakeholders in Colorado across state and local agencies, advocacy organizations and families are prepared to come together in this regard and the opportunity to apply for pilot project funding would catalyze such efforts.

Address Personnel Capacity: Our third request is in regards to building personal capacity across all levels from physicians, specifically psychiatrists, to direct care personnel. We do not have adequate capacity across all levels of personnel. This lack of capacity is not specific to this population but is an issue across populations. There are number of strategies being used to increase capacity including telemedicine. In our recommendations we outline a number of steps that might be taken to develop such a comprehensive plan. State and local agency personnel are interested and would we believe be ready to collaborate in addressing this need.

In conclusion we feel that Colorado is in the process of developing and implementing a worthy vision of integrated healthcare. We believe that vision will only become a reality for Coloradoans with intellectual and neurodevelopmental disabilities if the agencies and stakeholders are given concrete encouragement to work across systems and reimbursement sources.

Again my sincere thanks

Dec. 4, 2014

To: Members of the Colorado Joint Budget Committee
Senator Kent Lambert, Chair
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Megan Davisson

From:
Dr. Corry Robinson, JFK Partners, Co- chair—Colorado Collaborative for Autism and Neurodevelopmental Disability Options (CANDO)

Carol Meredith, The Arc Arapahoe and Douglas, co-chair CANDO Medical Mental Health Committee

Marijo Rymer, The Arc of Colorado, co-chair CANDO Medical Mental Health Committee

Re: Colorado Mental Health Services and Behavioral Supports for People with Intellectual/Developmental Disabilities

Carol Meredith's testimony:

As a Mom who has been trying help my son with autism get the services he needs when he needs them in CO for the last 25 years, I want to personally thank you for funding this Gaps Analysis. As an advocate who has worked for the last 20 years trying to help others like my son, but with different diagnoses like Fetal Alcohol Syndrome, Fragile X, Angleman's Syndrome or Traumatic Brain Injury all with aggressive behaviors, self-injury or psychiatric diagnosis such as depression or psychosis- again thank you! It is so nice to know that our experience is not an anomaly – that many people have the same challenges, and it is not our fault – it wasn't because we didn't try really hard to help our kids. We have developed a system that is not systematic – it has multiple funding streams with multiple eligibility requirements, different rules and regulations for different programs. The research backs up the family's experiences – our kids with co-occurring intellectual and/or developmental disability (I/DD) and behavioral health needs are at significantly heightened risk of not receiving appropriate treatment and services.
Limited access to appropriate treatment, including crisis intervention, stabilization and prevention in the Colorado Behavioral Health system, for people with I/DD is difficult for all of us. We learned that inadequate reimbursement and inappropriate service limits and definitions for people with I/DD in the Behavioral Health capitated system as well as medical mental health benefits in the Colorado fee for service Medicaid state plan exists not just in the metro-area, but statewide. The conflicting requirements and confusion about diagnoses-based requirements limit access to assessments as well as treatment; and it is really difficult to find professional expertise because workforce capacity is sorely lacking.

Even though what we found out was somewhat depressing, the people we met throughout the state in various silos were wonderful to work with. We have developed a network of smart, passionate people who are committed to busting these barriers and simplifying the systems of care so that children and adults with I/DD and co-occurring mental health or behavioral disorders get what they need when they need it in homes and communities instead of wasting away in emergency rooms and jails. Everyone is eager to get started, so we humbly present the following first steps for your consideration.

First steps to address the barriers that could be undertaken in FY 15-16:

1. Funding for two pilot projects (urban and rural) for cross-system response to behavioral health crises among people with IDD to include timely evaluation, treatment, therapeutic respite and follow up services—could be integrated into the Colorado Mental Health Crises Program but would require services appropriate for the needs of people with IDD. A pilot would require creative approaches to cross-system funding.

2. Complete cost analysis with accompanying actuarial study to ensure that people with IDD are fully included in the Colorado Behavioral Health system—similar to analyses done in 2013-14 to include cost of substance abuse treatment for all eligible persons in the Behavioral Health system

3. Systematic and strategic approach to increase capacity among licensed medical professionals, credentialed service providers and direct service personnel to provide behavioral health services for people with IDD. The plan could include incentives such as loan forgiveness, expansion of residency allotments, expanded training for nurse practitioners, and rate incentives for care coordination amongst primary care providers, mental health professionals, and behavioral specialists.

The members of CANDO are eager to assist the JBC in developing the frame work and cost estimates for the recommendations we propose to ensure that Colorado can fulfill the commitment to ensuring that all eligible children and adults –regardless of diagnoses—have access to mental health treatment and behavioral supports.

Analysis of Access to Mental Health Services for Individuals who have Dual Diagnoses of Intellectual and/or Developmental Disabilities (I/DD) and Mental and/or Behavioral Health Disorders

November 1, 2014

Cordelia Robinson Rosenberg, Ph.D., RN
Professor of Pediatrics and Psychiatry
University of Colorado School of Medicine
Co-Chair – Colorado Collaborative on Autism and Neurodevelopmental Disabilities Options (CANDO) an Ad-Hoc Committee of the Colorado Developmental Disabilities Council

Carol Meredith, Co-Chair
Marijo Rymer, Co-Chair
CANDO Medical Mental Health Committee

Submitted to:
The Division for Intellectual and Developmental Disabilities
Community Living Office
Department of Health Care Policy and Financing

Supported by Interagency Agreement from Colorado Department of Human Services to University of Colorado School of Medicine, JFK Partners, July 1, 2013-June 30, 2014.

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Acknowledgements

The Medical Mental Health Committee of Colorado CANDO and JFK Partners want to acknowledge the hundreds of individuals who contributed to the Dual Diagnoses "Gap Analysis" activities and report.

From the initial conception of the project through the development of the report, the CANDO Medical Mental Health Steering Committee, provided guidance. Special thanks to Jeannie Losh who supported this effort through communications, arrangements, and numerous drafts of the products.

Representatives from Alliance (Community Centered Boards (CCB) and other IDD service provider organizations), Behavioral Health Organizations (BHO), and the Colorado Behavioral Healthcare Council (community mental health organizations) participated on the Steering Committee and provided critical assistance in arranging the community meetings. Many people contributed to both community and statewide meetings through very thoughtful presentations. Presentations from the Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options (CANDO) meetings can be found at http://tinyurl.com/coloradoGAP.

We also express our appreciation to the many families, advocates, providers, first responders and other stakeholders who participated in the surveys and community meetings. These individuals took precious time to participate and we sincerely hope that they will see the fruits of that time in access to needed services and support.

Finally, we want to acknowledge Senator Pat Steadman's advocacy and participation in the meetings with his recorded welcome.

Steering Committee

Harriet Austin, Ph.D. | The Arc of Jefferson, Clear Creek and Gilpin Counties
Michele Craig | HCBS-DD Waiver Coordinator, Colorado Department of Human Services, Division of Intellectual and Developmental Disabilities.
Sarah Davidon, M.ED | President, Board of Directors, Federation of Families for Children's Mental Health-Colorado Chapter, | Senior Instructor, JFK Partners, University of Colorado School of Medicine
Janis DeBaca | Co-Founder and Co Facilitator Colorado Respite Coalition | Parent of adult son with I/DD
José Esquibel | Manager, Prevention and Interagency Collaboration Unit, Colorado office of Children, Youth and Families
Peggy Hill | Chief of Operations Officer, Colorado Behavioral Health Care Council
Ellen Jensby, JD | Public Policy Director, Alliance
Carol Meredith | Executive Director, Arc of Arapahoe and Douglas Counties
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Shannon Zimmerman | System, Child and Family Advocate |Parent of son with autism and deafness

Analysis of Access to Mental Health Services for Individuals who have Dual Diagnoses of Intellectual and/or Developmental Disabilities (I/DD) and Mental and/or Behavioral Health Disorders

Introduction

Numerous national reports have examined the problems associated with inadequate access to appropriate mental health services for people with intellectual and/or developmental disabilities (I/DD). Recommendations center on the need for cross-system collaboration among mental health service providers, developmental disability service systems, and primary health care providers but problems persist. Excessive use of emergency services and psychiatric hospitals are two of the negative consequences of an uncoordinated system.

The Colorado Collaborative for Autism and Neurodevelopmental Disability Options (CANDO) was established to help implement the recommendations of the 2008 legislatively authorized Colorado Autism Commission. Scarcity of appropriate services in Colorado for children, youth and adults with dual diagnoses of behavioral health disorders and I/DD was identified as one of the most critical service issues. Recommendation 14 from the Commission report is to: "Improve access to quality mental health services for individuals with Autism Spectrum Disorders." [1, 2] Consequently, for purposes of this report, reference to I/DD has been broadened to include other conditions under the term neurodevelopmental disabilities, including intellectual and developmental disabilities, autism, fetal alcohol syndrome, traumatic brain injury, Down syndrome, and fragile X, as examples. The wider perspective addresses a population that is more inclusive than that of those who historically have been considered as eligible for services through the Colorado I/DD system.

The reason for this more inclusive perspective is twofold. First, the longstanding criteria in Colorado for determining a developmental disability were revised as of August 1, 2013. Revised rules now include limitations in adaptive behavior as an alternative to intellectual disability as an appropriate criterion when determining a developmental disability. Second, while this more inclusive population may not have the same level of intensive daily support needs as the traditional I/DD population, their dual diagnoses result in needs for services similar to people with an intellectual disability.

During the 2013 legislative session, the Colorado General Assembly appropriated $50,000 to the Colorado Department of Human Services (CDHS), to contract with JFK Partners University of Colorado School of Medicine to conduct an analysis of access to mental health services, especially in regards to intervention during and after behavioral and mental health crises for individuals with I/DD. The appropriated funds were used to identify gaps in services and recommend public policy changes to support cross-system collaboration to provide crisis prevention and, when necessary, intervention services for individuals with

[1] Although the Commission Recommendation 14 referenced individuals with autism spectrum disorders, the Commission supported a more inclusive approach for individuals with any neurodevelopmental disabilities.

[2] Colorado Autism Commission Executive Summary http://www.ucdenver.edu/academics/colleges/medicalschool/programs/JFKPartners/projects/Documents/EXECUTIVE%20SUMMARY%20-%20FINAL.pdf

dual diagnoses. The expectation at the time was that this effort would align with the Crisis Intervention Services for all Coloradoans initiative.

For the purposes of this report, the term "dual diagnoses" refers to people with I/DD with co-occurring mental health or substance abuse conditions and/or the need for functional behavioral analysis and treatments.

For purposes of this report, "behavioral needs" refers to services that analyze the function of the behavior and provision of services to change the behavior to achieve the function in an appropriate way.

This work and recommendations for policy changes occurs in the context of many policy initiatives that are or will be relevant to action steps that address the needs of this population. Development of these initiatives has been occurring over the period of the project, and should inform efforts to address access to needed care for individuals with dual diagnoses of I/DD and mental and/or behavioral health disorders. These initiatives, at a minimum, include:

- Colorado State Health Innovation Plan which has the goal of integrated medical, mental health, behavioral and dental care for 80% of Coloradoans. People with I/DD should be part of this initiative.
- The Office of Community Living and the Community Living Advisory Group
- Crisis Intervention Services for all Coloradoans
- Colorado Regional Centers Legislative Task Force
- Examination of Access to Care for Children with Developmental Disabilities in Foster Care
- Colorado Respite Coalition

Scope of Work

The specific activities included in the Scope of Work were to:

- Hold 11 Regional Meetings co-hosted by CCB's, Mental Health Centers, and BHO's that included invitations to multiple stakeholder groups;
- Establish a web portal with surveys to be completed by interested stakeholder groups.
- Analyze relevant statutes, policy and regulation documents
- Convene a statewide meeting to report findings and recommendations;
- Develop a comprehensive report of the analysis and recommendations developed from the analysis.

Implications of Capitation of Mental Health Services for Persons with I/DD

Colorado instituted capitation of mental health services in the mid 1990's. The decision to move to managed care for behavioral health was prompted by rising costs and lack of information about outcomes. The intent of capitation was to address all qualifying mental health conditions in a more cost effective manner. However, based upon existing legislation, treatment of conditions such as autism and intellectual disability (then mental retardation) were excluded from coverage as qualifying mental health conditions. The

legislation that established the exclusion (S93-113; CRS 10-16-104(5)) guaranteed access to treatment for some conditions under medical care rather than mental health care.

The Office of Behavioral Health (OBH) of the Colorado Department of Human Services (CDHS) offered guidance from the inception of the Colorado Medicaid Community Mental Health Services Program (CMCMHSP) that contractors were responsible for *assessment* of any individual to determine whether a person who came to them met criteria for a mental health diagnosis. However, not all communities have the capacity to meet the needs of this dually diagnosed population.

By report of parents to advocacy organizations some mental health centers discouraged applications for service from families when the individual already had a diagnosis of autism or intellectual disability. The explanations offered were that the mental health or behavioral issues were secondary to the developmental disability diagnosis and therefore not their responsibility, or, because they did not have clinical staff available with the specialized training needed to address the patient's needs. We could not determine how often and how many people were turned away or elected not to request services over the years as these instances are not monitored.

Over the years there have been numerous attempts to recognize the lack of cross-system integration and recommendations to address the lack of coordination and difficulties presented by the inherent conflicts between a fee-for-service physical health care system and a capitated mental health care system operating side-by-side where there are incentives for each system to shift the care and cost to the other system. Efforts of particular note include: The Dual Diagnoses Summit convened in January 2008 as a joint project of Colorado Family Voices, Empower Colorado, Colorado Consumer Health Institute and the Federation of Families for Children's Mental Health, Colorado Chapter. The summit was convened to gather a broader understanding of, and develop recommendations to address, the crises faced by individuals and families of children with multiple diagnoses. The second is a report: Accessing Intensive Mental Health Services (AIMS) for Children Report: The co-occurring Disorder Dilemma. Together, these projects provide documentation of the longstanding identification of this problem.

The Community Centered Boards (CCBs), Behavioral Health Organizations (BHOs) and Community Mental Health Centers (CMHCs) have worked out various locally based agreements to coordinate services when someone enrolled in I/DD services also needs mental health services. Given the locally based nature of these agreements, access to care is uneven across the state.

Over the past years in efforts to address the needs of children and adults with dual diagnoses, families and advocates worked with legislators and policymakers to include "behavioral services" in the DD Medicaid Waiver programs. The Children with Autism Waiver was enacted in 2003. This waiver provides behavioral services to 75 children with the diagnosis of autism aged birth up to the day before the child's sixth birthday. Over the next decade, "behavioral services" were also added to the Children's Extensive Support Wavier, the Supported Living Services Waiver, and the HCBS-DD Waiver.

In principle, Colorado provides for assessment and treatment for individuals with dual diagnoses. Providers can apply and become eligible to provide Medicaid State Plan services under fee-for-service reimbursement. However, in practice, there are many disincentives for service providers to enroll as a Medicaid State Plan provider. Disincentives include rates that are less in the fee-for-service structure than in the managed care system, service hour limitations that do not reflect the time involved in treating persons with dual diagnoses, and diagnostic criteria that do not adequately capture the needs of a person.

Population of Children and Adults with Intellectual and Developmental Disabilities (I/DD)

There is no population-based resource that identifies the number of individuals who have I/DD alone, nor is there a source for those who are dually diagnosed in Colorado. Rather, the number can only be estimated based upon multiple sources. The same methodologies for these estimates do not exist for adults and children. For people with intellectual disability defined by several criteria, including an IQ below 70 on a standardized full scale assessment tool, the most common estimate is 1.5% of the population.[3] Given that the Colorado definition of eligibility for I/DD services includes significant impairment in adaptive behavior as an alternative criterion, more than 1.5% of the population can be expected to be eligible for I/DD services in Colorado. However, there is little guidance as to the additional number that become eligible based upon the adaptive behavior criterion.

Additionally, no source for identifying the numbers who become eligible in Colorado under the expanded criteria has been identified. The presence of significant impairment in adaptive behavior could add an additional one percent to the estimate of the size of the population likely to meet criteria for eligibility as I/DD, for a total estimate of 2.5% of the population. This estimate, however, will not include many individuals with autism, nor will it include many with other conditions such as fetal alcohol syndrome (FAS) or traumatic brain injury (TBI) occurring before the age of 21. Findings from the online and Children's Hospital follow-up surveys suggested that, for every person who meets I/DD eligibility criteria in Colorado, there is another person who has a developmental disability who does not meet the Colorado criteria and therefore does not have the I/DD system as a resource for services.

Dual Diagnoses among People with I/DD

The estimate of how many individuals with I/DD who also have mental illness is approximately one third of the I/DD population. The National Association for the Dually Diagnosed (NADD) has reported this figure for the past 30 years.[4] To further support this estimate, recent information from the National Core Indicators (NCI) Data Brief (May 2014)[5] found that 43% of individuals with I/DD need some extensive support to manage self-injurious, disruptive and/or destructive behavior. The NCI data brief found that those individuals who had a specific mental illness diagnosis were much more likely to have support needs. Respondents who needed behavior supports were significantly more likely

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[3] Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D. MR/DD Data Brief. Vol. 2, No. 1. April 2000. http://rtc.umn.edu/docs/dddb2-1.pdf.

[4] Information on dual diagnoses. The National Association for the Dually Diagnosed. Web Accessed June, 2014. http://thenadd.org/resources/information-on-dual-diagnosis-2/

[5] National Core Indicators data brief, May 2014; http://www.nationalcoreindicators.org

to take medication for psychiatric disorders. The NCI data also indicate that individuals with behavioral support needs have less favorable core indicator outcomes with respect to where they live, employment, rights and safety, relationships, positive view of staff and community inclusion.

Estimates of Adults in Colorado.

The best source of estimating the numbers of adults in Colorado who meet the criteria as having an I/DD is HCBS waiver data. There were (as of April 30, 2014) 4,736 adults served in the Home and Community Based Services for Persons with Developmental Disabilities (HCBS-DD) Medicaid waiver, and another 894 people on a waiting list (as of October 2013) who would accept services immediately if offered. There are 3,172 individuals served in the HBCS Supported Living Services (HCBS-SLS) Medicaid Waiver and another 2,405 people on a waiting list who would accept services as soon as available.[6] (In July, 2014, resources were made available to support all persons on a waiting list for HCBS-SLS services.)

As previously noted the National Association for people with Dual Diagnoses (NADD), estimates that 30-35% of people with an I/DD also meet criteria for a psychiatric disorder. Based upon waiver enrollment, the number of adults (over 18 years) receiving or waiting for waiver services in Colorado who are *likely* to have a dual diagnosis is *likely* to be between 3,362 and 3,923 individuals.

Estimates of Children in Colorado.

The best estimate for children who would meet criteria for dual diagnoses comes from the Colorado Department of Education's annual child count. According to the Colorado Department of Education, there were 90,388 students in Colorado identified with a disability in 2013. The data is reported according to mutually exclusive categories of disability as identified by the school district. The categories that appear most likely to include students who meet criteria of a dual diagnoses of I/DD and behavioral health needs include intellectual/multiple disabilities, emotional disability, autism spectrum disorders and traumatic brain injury. Of the students identified with a disability, 6,421 were identified with an intellectual disability, 6,039 identified with an emotional disability, 5,280 were identified with autism and 550 identified with traumatic brain injury. There are 18,290 students identified in these three categories. Assuming the NADD estimate that 30-35% may have dual disorders, an estimated 5,487-6,401 students in Colorado may be impacted by dual diagnoses. This number represents approximately 0.7% of the total student population (aged 3-21 years) of 863,561 in Colorado in 2013. [7]

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[6] Colorado Medicaid Waiver Disability Services & Waivers. Web. Accessed June, 2014. http://medicaidwaiver.org/state/colorado.html.

[7] Colorado Department of Education. Dec, 2013. http://www.cde.state.co.us/sites/default/files/Dec2013_TotalServedbyDisabilityWEB4-16-2014.pdf.

Information Sources

Surveys of Families

This project included several strategies for gathering information from stakeholder groups. These strategies included surveys, 11 community meetings, a statewide CANDO meeting and a meeting with state agency personnel.

During June and July of 2013, a survey was sent to all families who had come to Children's Hospital Colorado (CHCO) Emergency Department for Psychiatric Services between 2010 and 2012 with a child who met criteria of an I/DD and a mental illness. The age range of the children was age 2 years to 17 years of age. The response rate to this survey was approximately 10%. There were 101 respondents who met criteria for dual diagnoses. In late July 2013, the same survey was made available to the public and advertised widely throughout the community meetings and by advocacy organizations. Any interested individual could elect to respond. One hundred and four unique responses were submitted to the public survey portal. The survey was available in English and Spanish. http://tinyurl.com/coloradoGAP. The invitation and surveys are included as Appendix 1.

Eighty-two percent of the Children's Hospital survey respondents were male. Forty one percent of the CHCO respondents were about children 8 to 12 years of age, 34 percent were 13 to 15 years of age and 26 percent were 16 to 18 years of age. The ages of the public survey respondents were: 28 percent age 8 to 12; 9 percent age 13 to 15; 19 percent age 16 to 18; and 44 percent age 19 and older.

The primary developmental disability diagnosis reported in the surveys was autism spectrum disorder, with intellectual and developmental disabilities also identified with slightly lower frequency. Psychiatric diagnoses that were most frequently identified were depression, anxiety and attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD). Mood disorders and bipolar disorder were also reported with some frequency. In both diagnostic questions, developmental and psychiatric, respondents were invited to check all that applied.

Issues such as threats to property or people, self-injury and thoughts of suicide emerged through the survey as primary reasons for Emergency Department (ED) visits. Sixty percent of survey respondents who indicated they have used the ED have used it because of threats to others or to property.

In the survey, respondents were asked to indicate the IQ level of the person they were reporting about. Of those who answered the question regarding IQ level, one third of the CHCO respondents had IQ's below 70. For the public survey 51 percent had an IQ's below 70. This distribution illustrates the point that many of the individuals about whom we are concerned are not likely to be eligible for services in the I/DD system as they meet neither the IQ nor the adaptive behavior criterion and, therefore have even more limited access to mental health services.

In the survey, people with both private and public insurance responded. For the Children's Hospital survey, approximately one third had publicly funded (Medicaid and CHP+) insurance. For the public survey, which includes a number of adults, approximately half had public insurance.

Surveys of Providers

One hundred and seven providers from a variety of settings responded, including providers of services such as mental health, education, direct care, and private clinical practice. A significant number of providers reported more than 20 years of experience in serving individuals with I/DD (n=34), and 62% reported training in serving individuals from this population. Forty-eight percent of respondents also indicated that they have had to turn away individuals with dual diagnoses. Reasons for turning people away included presenting problems that were not a covered diagnosis, lack of insurance, or a full caseload.

Providers identifying as "Other" included advocates, school administrators, case workers, probation officers and first responders. Barriers to service frequently cited were lack of access to emergency out-of-home placement and lack of access to services in a timely manner after an interaction with law enforcement. When law enforcement/first responders do identify an individual who requires mental health services, they reported being unable to provide placement or coordinate access to care in a timely manner due to lack of available providers. Further, lack of a means of safe transportation to care providers outside the metro Denver area was reported as a barrier for appropriate care.

Community Meetings

From August 29 to October 24, 2013, the project team held 11 community meetings across Colorado. These meetings were co-convened by Community Centered Boards and Community Mental Health Centers, and were attended by a total of 289 people.

The community meetings held across the state were hosted to:

- Obtain input into a cross-systems analysis of crisis prevention and intervention services;
- Hear the perspectives of individuals with intellectual/developmental disabilities who have used emergency services or received residential treatment or hospital care because of mental health or challenging behavior issues;
- Describe the current system of local services and supports for children, youth and adults with dual diagnoses to identify strengths and gaps in different communities;
- Obtain public input on policy recommendations for this population.

The agenda for the community meetings provided participants with the opportunity to: 1) discuss scenarios in which children, youth, adults and their families have experienced crisis situations and how the system worked for these individuals and families; 2) participate in an analysis of how crisis responses for people with dual diagnoses work or do not work in their community; and 3) contribute to the recommendations developed from this work. Panel presenters included representatives from school districts, families, mental/behavioral health providers, I/DD service providers, health care, early childhood and advocacy organizations.

Analysis of community meeting notes, survey results, and the statewide CANDO meeting produced four main themes characterizing where gaps exist for people who experience co-occurring diagnoses:

1. System access, design and reimbursement mechanisms
2. Cross-system coordination
3. Support for families and caregivers
4. Knowledge and expertise

Statewide CANDO Meeting

In December 2013, the Colorado CANDO committee hosted a meeting to present a preliminary report of the findings and community meetings. This meeting included two panels wherein participants were invited to address the issues Colorado faces with regard to people with dual diagnosis. These panels provided additional perspectives to further understand the complexity of systems and services from a cross-sector perspective and to inform the development of recommendations. Approximately 130 people attended the meeting.

State Agency Meeting to Review Policy Recommendations

On May 30 2014, a group of state agency leaders met with members of the steering committee. The draft policy analysis and recommendations document was distributed to the group before the meeting. Input was received that helped guide the final policy recommendations included in this report. Agencies represented included: Colorado Department of Education; Colorado Department of Human Services, Offices of Community Access and Independence, Child Welfare and Behavioral Health; Colorado Department of Health and Environment and Colorado Health Care Policy and Finance. This group was invited to make comments and recommendations.

Policy Analysis

During the winter and spring months of 2014, a subset of the CANDO Medical Mental Health Committee convened several times to develop policy recommendations. The deliberations of this group were informed by the results of the community meetings; follow-up conversations with community meeting participants, survey results, the statewide CANDO meeting, and review and analysis of state and federal legislation, Colorado rules and agency guidance. These deliberations resulted in identification of major barriers complicating access to appropriate services for people with dual diagnoses in the Colorado Medicaid Community Mental Health Service Program (CMCMHSP).

Barriers Identified

1. There is limited access to appropriate behavioral treatment for individuals with dual diagnoses.

Many people with I/DD who receive publicly funded services live in the homes of family members. After a person is temporarily stabilized through a hospital stay (if such an option is available) or a visit to the emergency department, there are limited publicly funded services available to the family to help them learn techniques to predict, and perhaps change, problematic behavior, prevent crises, and provide appropriate follow-up supervision and care. Without this support, families continue to use the emergency department and police to deal with behaviors that are out of their control or isolate the individual (or themselves) to keep the family safe. Parents responding to the survey

reported locking themselves and siblings in bathrooms or basements until violent behavior subsided.

The current gap in prevention and intervention services creates overreliance on law enforcement, first responders, and hospital emergency departments. These professionals are frequently not well versed in trauma-informed care for persons with I/DD. Follow-up support for the individual or the family is frequently unavailable. Crisis intervention training for first responders, while quite effective, is inconsistent across the state. There is limited integration and coordination among publicly funded services for this population, including law enforcement, emergency response systems, schools, behavioral health services, primary care providers, and IDD services.

Some children and adults who are on I/DD Medicaid Waivers can access behavioral services and respite care. For children who are not eligible for the Children's Extensive Support waiver (for example, children who sleep through the night), their families may have to turn to the Child Welfare system for support. Many families simply endure rather than choosing to become involved with the child welfare system.

There is a severe shortage of both outpatient and inpatient behavioral treatment options for children and adults. Those that are available often rely on traditional approaches such as group therapy, which may not be suitable for people with I/DD. There is a need for therapeutic respite for this population where assessments of behavioral and physical conditions can occur in a systematic, coordinated fashion, medications can be managed and evaluated, functional behavior plans can be developed and caregivers can learn to implement the plans. Therapeutic respite could also function as a step-down service for individuals to receive coordinated care and avoid hospitalization.

The new Colorado Crisis line and services and supports in the mental health system may eventually help to fill the gap in community-based crisis support, if these entities are adequately trained to assist this population. However, it will take time and an intentional focus on training needs to develop this capacity.

2. Conflicts within existing requirements create barriers to service.

In researching existing state and federal requirements, the project team identified widespread support for providing behavioral health services for people with dual diagnosis ranging from broadly worded federal requirements to specific local agency agreements. However, some specific requirements appear to conflict with the contention that such services should be provided within the behavioral health system to all persons regardless of diagnosis.

The most challenging point is at the direct service level where a final decision is made to provide or not to provide behavioral health services. These individual decisions are likely to be influenced by the availability of qualified providers, the overall demand on limited resources, and historical divisions of responsibilities, and disagreement on whether the primary diagnosis is I/DD or behavioral health.

Appendix 2 contains an extensive, but not exhaustive, list of state and federal references to behavior health services for people with dual diagnosis. This list includes examples of policies, agreements, contracts, rules and regulations, legislation and rulings related to lawsuits. The following are a few examples of how the provision of behavioral health services is supported at the various levels.

State laws, rules and contracts, such as the Behavioral Health Organization contract, support the provision of services stating, "The Contractor shall provide (*sic*) medically necessary behavioral health services to Members with non-covered diagnoses (Traumatic Brain Injury, Developmental Disability, Autism, etc.) when the member presents with a co-occurring mental health or substance use disorder diagnosis." However, the mental health or substance use disorder must be determined to be primary in order for the BHO to pay for services.

At the same time, some existing regulations present challenges for supporting the holistic needs of the individual. The Home and Community Based Services (HCBS) Medicaid Waiver Assurance (#5) states, "The State assures that Federal Financial Participation (FFP) will not be claimed in expenditures for waiver services including, but not limited to, day treatment or partial hospitalization, psychosocial rehabilitation services, and clinical services provided as home and community-based services to individuals with chronic mental illnesses if these individuals, in the absence of a waiver, would be placed in an IMD (Institution for Mental Disease)…" For example, if a person who has ongoing behavioral support staff through a Medicaid waiver is hospitalized, that same knowledgeable staff person could not be paid to consult or provide those behavioral supports in the hospital setting for continuity of service. These types of regulations create gaps in the ability to access services across systems when services are covered under different funding sources.

Some laws are intended to balance protections of individuals with intellectual and developmental disabilities (I/DD) with appropriate access to services, such as C.R.S. 27-65-102 (14) which states in part, "Developmental disability is insufficient to either justify or exclude a finding of mental illness within the provisions of this article." This direction provides clarification that the impact of a developmental disability is to be considered separately and apart from whether a mental illness is present but can present confusion when a provider must determine which diagnosis (mental health or developmental disability) is the primary "driver" for the problem behavior.

Perhaps the clearest direction regarding assuring access to care for this population can be found at the implementation level of policy and practice in the Colorado Department of Health Care Policy and Financing (HCPF) Behavioral Health Organization (BHO) Practice Standards, dated September 19, 2011, which states, "People with developmental disabilities should be afforded the same access to mental health services as the general population. The intent of this document is to ensure that the presence of a diagnosis of developmental disability does not decrease the diagnostic significance of any accompanying mental illness."

There is also a clear trend with legal precedent being set through court rulings as a result of lawsuits that find, for example, "Serious and Persistent Mental Illness (SPMI) and Serious Mental Illness (SMI) specifically include individuals who otherwise satisfy the relevant criteria

and who have a co-occurring condition, such as a substance abuse disorder, developmental disability, acquired brain injury or other condition."

On October 15, 2014 the Colorado Division for I/DD issued a Communication Brief titled: "Behavioral Health Organizations (BHO) Practice Standards: Evaluation and Treatment of Covered Mental Health Illness (MI) in children, youth and adults with Developmental Disability (DD)". The Communication Brief includes Exhibit J Developmental Disability for the FY 2014-15 BHO contract. The Exhibit affirms that any person with "DD or organic brain pathology" shall have access to evaluation for a covered psychiatric diagnosis through the Colorado Medicaid Community Mental Health Services Program (CMCMHSP). This contract does allow for authorizing services according to the relative contribution of covered and non-covered DD and/or organic brain pathology conditions and any collaborative arrangement in place between the BHO and the CCB involved with the individual. The effort to so attribute symptoms seems to be inconsistent with the current values emphasizing integrated care. This Communication Brief and Exhibit J are included in Appendix 3.

3. Inadequate reimbursement and inflexible funding systems create barriers to service.

Reimbursement mechanisms are generally established for specific services for a targeted group. For example, long-term services and supports often needed by people with I/DD are reimbursed through fee-for-service HCBS Medicaid waivers, while behavioral health services for Medicaid-eligible individuals, which do not include long-term services and supports, are reimbursed under the capitated managed care system.

Primary care providers, hospitals, first responders and emergency departments are reimbursed under a mix of per diem rates and fee-for-service. It is difficult to coordinate services across separate service systems when the individual may have needs that overlap the separate systems and those systems have different mechanisms for payment. Additionally, there is no mechanism for payment of long-term services and supports for people with I/DD in the Medicaid behavioral health managed services plan or emergency/stabilization services.

Many survey respondents (including providers) cited a lack of providers who accept Medicaid as a barrier to services. Several providers mentioned lack of coverage for Applied Behavior Analysis (ABA) or similar services as a Medicaid State Plan benefit or in BHO contracts as a barrier to providing service. Collaboration between and among community providers of I/DD services and behavioral health providers can be difficult due to the regulatory and reimbursement complexities of both systems.

The survey also identified problems with conflicting statutes, regulations and financing agreements about service provision, as well as alignment and coordination among applicable oversight agencies at the state level. Reimbursement systems, rates and mechanisms are not flexible enough to ensure access to treatment and support for people with dual diagnoses. Support for families is often an integral piece of treatment for a person with dual diagnoses but such support is not available under existing systems. It is recognized that some of these barriers are generated at the federal level and some at the state level, which creates additional complexity to resolving the issues.

Within each reimbursement method are built-in safeguards to prevent duplicative billing, avoid fraudulent claims and assure accountability for the use of taxpayer funds. Viewed in

isolation, each system has its own justification for selecting a particular type of reimbursement structure and prohibited practices. However, these safeguards can also create unintended consequences restricting coordination between reimbursement mechanisms for people who have complex needs that must be met through multiple service systems and multiple reimbursement arrangements.

For example, it is difficult to coordinate reimbursement for a person who is enrolled in long-term services and supports (i.e. waiver services), is also admitted to a psychiatric unit and who, during that stay experiences an acute medical problem. The person must be discharged from one service and admitted to the other service in order to get the necessary care without violating any of the numerous billing and reimbursement requirements. The alternative is that one service gets paid and the other does not get paid for service provided during the stay.

Pivotal to meeting the needs of people with dual diagnoses is the ability to access appropriate reimbursement sources through cross-systems care coordination. Current barriers that limit reimbursement from different resource pools (e.g., primary care, behavioral health services, and Home and Community Based Services (HCBS) waiver services) preclude the ability to pay for care coordination as a stand-alone service. Various federal and state policies seem to inhibit cross-system collaboration essential for addressing a person's needs holistically.

Coordinating care across systems is quite challenging, even though the person's multiple needs occur simultaneously. To prevent cost shifting to other systems (e.g., law enforcement, corrections, hospitals, public schools, etc.) because of difficulty accessing behavioral health and I/DD services, cross collaboration among systems must be facilitated to meet the complex needs of people with co-occurring diagnoses.

4. Professional expertise and workforce capacity to serve the population is lacking.

A major barrier to effective and coordinated treatment is the capacity of the workforce to address the needs of this population. The workforce involves many professionals and direct care providers (including families) who serve people with dual diagnoses. The professionals include psychiatrists, psychologists, psychiatric nurses, school nurses, social workers, licensed professional counselors, physical, occupational therapists and speech/language pathologists, among others. These professionals express a need for receiving specialized training in serving individuals with I/DD.

Policy Recommendations

The outcome of the community meetings, surveys, interviews, research and analysis resulted in the following recommendations to improve services and supports for people with dual diagnoses of mental or behavioral health disorders and I/DD:

1) **People with I/DD should have appropriate access to mental/behavioral health services in parity with the general population in the Colorado Medicaid Community Mental Health Services Program (CMCMHSP).**

A. Eligibility for services and supports should be expanded to include behavioral problems in addition to specific psychiatric diagnoses.

B. Services and reimbursement under the system should have greater flexibility to provide services and supports, including Applied Behavior Analysis and other treatment models needed to assist individuals with I/DD to attain behavioral health and a higher level of functioning.

C. State agencies that are part of, or interact with, the CMCMHSP should collaborate to seek needed changes to policies and reimbursement structures, including statutory and regulatory authorizations that facilitate and support cross-system collaboration between parents/caregivers, mental health service providers, health care providers, and long-term services and supports.

D. A crisis intervention and prevention system of supports and treatment for persons with dual diagnoses should be included in the implementation of the plan for Crisis Intervention Services for All Coloradoans. The START model (**S**ystemic, **T**herapeutic, **A**ssessment, **R**espite & **T**reatment) or similar comprehensive model should be considered as an evidence based practice based on a cross-system model for crisis intervention for individuals with dual diagnoses in Colorado.[8] Details of one possible Crisis Prevention and Intervention proposal for Colorado are included in Appendix 5.

E. A crisis intervention training program specific to the needs of people with dual diagnoses should be standardized and available statewide to all first responders.

2) An analysis of cost of serving the behavioral/mental health needs of individuals who are dually diagnosed should be undertaken.

HCPF recently expanded services and covered diagnoses through the Colorado Medicaid Community Mental Health Services Program [9] to include enhanced rates to cover assessment and treatment for substance abuse disorders. This expansion could serve as a potential model for the inclusion of individuals with I/DD diagnoses.

Pilot or demonstration projects could be used to fully understand the implications of the change and to facilitate statewide transition to the selected approach. No matter which structure is chosen, getting the needed services to the person with the dual diagnoses must be at the center of decision-making.

3) Care Coordinators should have the authority to operate across systems for I/DD services, mental health services, and primary care services.[10]

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[8] University of New Hampshire Center for START Services, http://www.iod.unh.edu/Projects/start/description_history.aspx.

[9] On January 1, 2014, the BHOs began including substance use disorder as a Medicaid benefit. Rate ranges were developed for each of the five BHOs independently using methodology that is consistent with the Centers for Medicare and Medicaid Services (CMS) guidance for the development of actuarially sound rate ranges. After the rate ranges were developed for each BHO, payment rates were developed by HCPF. The payment rates for each BHO were compared to the actuarially sound rate ranges developed by Optumas to ensure that they fell within the range.

[10] The Community Living Advisory Group report recommended Care Coordination System that is consistent with this recommendation. People with I/DD should be included in whatever system Colorado pursues in response to the Community Living Advisory Group recommendations.

A. Care coordination, in collaboration with the primary care physician, should include authority to develop a plan to treat, in a holistic manner, the identified functional needs regardless of reimbursement system.
B. Care coordinators should have access to a person's complete record of medical care plans, individualized education and support plans, including services and supports, in order to integrate primary health care into the treatment plan, optimize coordination of services and supports and manage overall costs.
C. Strategies for facilitating cross-system access to information while protecting confidentiality need to be investigated and implemented. A master consent form and/or a personal health record should be investigated as a possible strategy.

4) Supports and services should consider the holistic needs of the individual and his or her community-based support system.

A. Intervention should be designed in graduated levels from prevention to crisis intervention with the primary goal of providing services in the home and maintaining the individual in the least restrictive community setting.
    i. Short-term, in-home assessment and stabilization services should be available to all families prior to behaviors deteriorating into a crisis situation and requiring more costly emergency response and interventions.
    ii. Based on professional assessment, if short-term, in-home intensive services are not viable, than short-term therapeutic services should be available in out-of-home settings for all age groups. A full range of assessment and stabilization services should be provided, including, as needed: medication and dietary review, functional behavior analysis, intensive behavior therapy, development of planned crisis prevention, response, and long-term management, and follow-up post short-term therapeutic services.
B. Parents/caregivers should be supported as a valuable asset and included in any treatment meetings.
C. Respite care should be provided for parents/caregivers.
D. A graphic illustration of components of such a system of supports and services is included in Figure 1.

5) An integrated system of monitoring should be developed to ensure that desired outcomes are ultimately achieved at the individual and systems levels.[11]

A. A two-tiered ongoing evaluation process should be developed to determine if:
    i. Specific prevention and intervention services provided to individuals are effective in reducing the need for crisis intervention and placement into more costly service settings and in achieving the desired outcomes, and

[11] The Community Living Advisory Group report included recommendations for quality monitoring. Such a system, if enacted, would meet the intent of this recommendation assuming that any I/DD population specific issues are included in the meeting.

ii. Crisis response services were well-coordinated and able to keep or return the individual to the most appropriate community-based setting.

B. A statewide oversight and monitoring system should be developed to (a) ensure the adequacy of qualified provider networks, including long- and short-term care and emergency/stabilization services, (b) provide a consumer friendly appeals process, and (c) evaluate the overall cost effectiveness of care services.

6) Specialized cross-training should be provided to increase the effectiveness of assessment, prevention, intervention, and crisis response.

A. Training should be available for parents/caregivers to improve their ability to provide support in the home, monitor and evaluate behaviors and understand appropriate courses of action prior to a situation escalating to a crisis level. Access to such training should be a fundamental element of the service system available to all families;

B. The workforce in the mental health system should be surveyed to determine their perceived training needs for crisis response to, and evidence-based mental health treatment of, individuals with I/DD;

C. A comprehensive, multiyear training plan should be developed to address needs identified in the survey;

D. Training and coaching of providers to achieve practice fidelity in appropriate Evidence-Based Practices should be provided for this population;

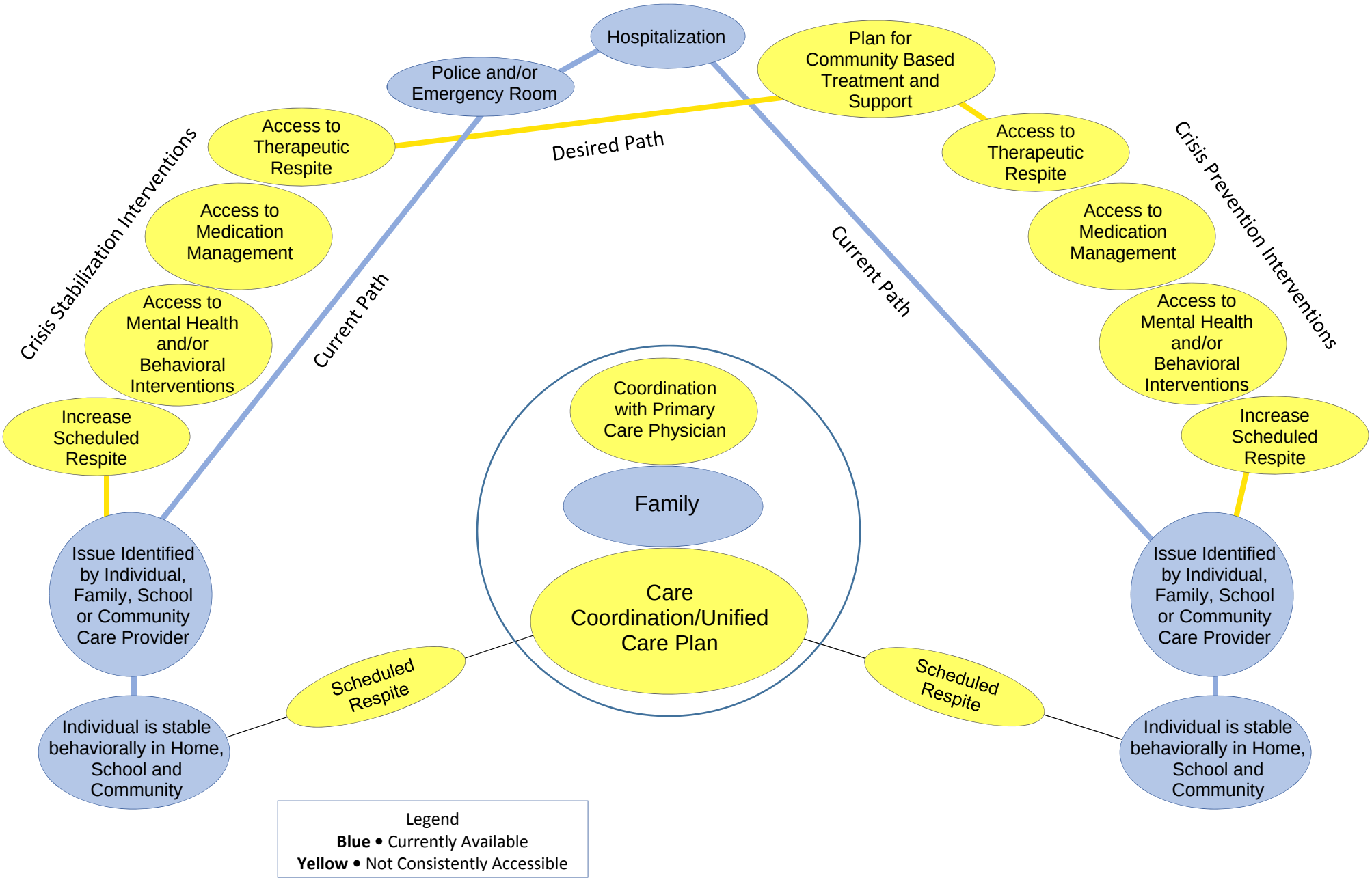
E. Cross-training between behavioral health and I/DD service providers should be provided for professionals from multiple disciplines to gain confidence and skill in working with people with dual diagnoses and increase the availability and expertise of qualified providers;

F. Incentives should be provided for professionals from multiple disciplines to gain confidence and skill in working with people with dual diagnoses;

G. Training and supports in cross-system care coordination methods and practice should be developed and implemented;

H. Cross-system team collaboration via actual or virtual meetings should be supported through agency policy and financing.

Figure 1. Crisis Intervention and Prevention Model for Children and Adults with Dual Diagnoses



Conclusions

The Steering Committee began this project aware of significant problems in access to care for individuals with I/DD who also had mental and/or behavioral health disorders.

- Colorado has severely limited capacity to provide hospitalization or alternative care during periods when the person's (child or adult) behavior requires crisis intervention and stabilization.
- In theory, people with I/DD have access to service from the mental health centers. However, in practice, the perception on the part of many mental health providers that any psychiatric symptoms are secondary to the I/DD and, therefore, not amenable to mental health treatment has limited access to care. Further, there are insufficient numbers of providers with the knowledge and skills needed to successfully treat people with these dual diagnoses.
- Parents on the steering committee reported that current systems provided limited to no follow-up care after a crisis occurred.

Through the surveys and community meetings, the above problems were validated and in many cases the problems were more significant than expected. One of the unexpected findings was the number of people affected who do not meet Intellectual and Developmental Disabilities (I/DD) eligibility criteria. Another unexpected finding reported through community meetings and the surveys was the extent of involvement and commitment by First Responders. Many families reported having to call 911 when their family member's behavior became unmanageable. The consistency of issues raised across the state was notable, as well as widespread expressions of helplessness in all areas of the state across all categories of stakeholders. While people were eager to participate in the meetings, frequently, there was a sense that nothing will change.

Access to mental health care and adequate behavior supports is an issue across the country. The exclusion of I/DD from the Colorado Medicaid Community Mental Health Service Program has exacerbated the problem in Colorado as many clinicians feel they are required to segment their treatment according to different payment mechanisms. Providers report being exhausted and discouraged by their inability to meet the needs of people with dual diagnoses.

The exclusion of I/DD diagnoses from CMCMHSP almost twenty years ago, while well intended, has had the perverse effect of suppressing development of capacity for treatment of this population. While there are many providers who are interested in serving this population, the disincentives of lack of flexibility in the fee-for-service system in contrast to that offered by managed care arrangements, lower rates and multiple procedural barriers for authorization to provide service, combine to significantly suppress access to care.

It was noted in the introduction to this report that Colorado has a vision for fully integrated systems of primary health care, specialty care, behavioral health care and dental care. Individuals with an I/DD and dual diagnoses must be part of that vision.

For people with I/DD and dual diagnoses, such a vision must include the following tenets:

- Access to behavioral health services, that are appropriate to their intellectual and adaptive levels and modes of communication;
- Access to services based upon need rather than diagnosis;
- Access to providers who have training in accommodations necessary for effective treatment for individuals with dual diagnoses;
- Access to a person-centered individualized plan that is holistic in scope and includes a stabilization plan for times of crisis;
- Access to appropriate short-term out-of-home care in times of individual or family need;
- Access to adequate in home behavioral supports when stabilization can be accomplished with in-home care; and
- Access to a care coordination process that is informed about and assists with access to all of these elements.

Access to this vision will only become reality if providers are allowed to work across systems of care and reimbursement sources.