

Accessing Intensive Mental Health Services (AIMS) for Children Report:
The Co-Occurring Disorder Dilemma

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Executive Summary:

This paper addresses the widely reported but poorly documented problems in the coordination of Medicaid services for children and adolescents with co-occurring conditions with behavioral implications, including mental illnesses, developmental disabilities, autism spectrum disorder, traumatic brain injury, and fetal alcohol syndrome.

Even though the behavioral services and treatments appropriate for these conditions are often identical, the structure of Colorado's Medicaid program is such that families must qualify for help from different providers, using different eligibility criteria, often based on an arbitrary assessment of which behavioral problems are attributable to which diagnoses. The consensus among professionals in the field is that there is no diagnostic or clinical basis for this distinction. This administrative artifact leads to onerous difficulties for already overburdened families seeking services, and the potential denial of services to children who are both eligible for them and would benefit from them.

There appears to be widespread recognition of this problem among professionals and other stakeholders in the Colorado behavioral health and developmental disabilities communities. Families experiencing such obstacles most frequently report that they occur through informal denials, rather than a formal Notice of Action (NOA) that can be appealed or aggrieved.

It is the recommendation of this report that the state conduct a comprehensive study to determine the extent of the problem, what best practices it should implement, and, if appropriate, what changes can be made to better coordinate and integrate related behavioral health services.

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Section 1: Introduction.

Statement of the Problem.

This report addresses a widely recognized but poorly documented gap in the provision of mental health services to children and adolescents¹ on Medicaid who have co-occurring conditions with behavioral implications (which I will refer to throughout the report as the “Co-Occurring Disorder Dilemma”). Children who exhibit behavioral problems consistent with a covered mental health diagnosis, who also have such co-occurring conditions as developmental disabilities (DD), autism spectrum disorder (ASD), traumatic brain injuries (TBI), or fetal alcohol syndrome, are sometimes, perhaps frequently, formally or informally denied the mental health services to which they would otherwise be entitled.

My primary task, initially, was to determine the frequency and causes of the Co-Occurring Disorder Dilemma, and whether it requires a system-wide solution. Some of the reports received by those who informed me of this problem indicated excessive administrative barriers. Some indicated poorly trained in-take personnel and misinformation given to applicants as a result. In the course of researching and compiling the report, some of the underlying dynamics of the problem became clearer, and some strategies for improving access to covered Medicaid mental health services for multiple diagnosis children and adolescents began to emerge. These strategies, as discussed in detail in Section Seven below, involve identifying the different kinds of obstacles to access, how they interact, and potential institutional reforms to address them.

Cases coming to the attention of advocates and attorneys, and discussions with advocates, attorneys, providers and parents who have dealt with similar problems raised concerns that this might be a chronic, critical structural problem in the Colorado Medicaid program. In order to assess how prevalent this problem was, I simultaneously sought out quantitative data and anecdotal evidence. As discussed in the Methodology section at the end of this report, the research involved talking with stakeholders, reviewing documents, and requesting data, which was then sorted, distilled, assembled, and compiled to form this report.

¹ For the remainder of the paper, “child” and “children” includes infants through adolescents, until age 21.

The most critical conclusion that can be drawn from the evidence assembled is that some families, already burdened in extraordinary ways with children whose behavioral problems are onerous and overwhelming (often accepting this responsibility voluntarily by adopting children that others would not), are left without recourse, without assistance, and often with only desperation and frustration. They encounter a system that, to them, seems to be comprised of walls without doors. The evidence also demonstrates that this is not necessary. It is not dictated by limited resources but rather by limited imagination and resolve. Significantly superior outcomes are well within reach, outcomes more conducive to the individual and family welfare of those most directly impacted, and to our collective fiscal, economic, and social well-being.

This report examines one set of *systemic* problems in how we manage and provide mental health services to Medicaid-eligible children and adolescents. Nothing in this report is intended as an indictment of any individual or any particular organization, even when a critical eye is cast at the institution they represent or the incentives they are confronted with. The goal is to create systems that ensure optimal performance (including ensuring that the system most effectively selects and incentivizes the individuals within it), regardless of the particular individuals occupying particular positions at any particular time. The purpose of this report, then, is to help inform actions dedicated to realizing institutional reforms that reduce or eliminate the Co-Occurring Disorder Dilemma.

Basic Overview of Colorado Medicaid and Behavioral Health Services.

Medicaid is a federal program administered by the states that opt to participate in it (which all 50 states do), and funded jointly by federal and state governments. The Early Prevention, Screening, Diagnosis and Treatment (EPSDT) program is “Medicaid for children.” It eliminates the distinction between mandatory services (those that states must provide) and optional services (those that states may provide but don’t have to), obligating states to provide all medically necessary mandatory and optional services for all child and adolescent Medicaid clients. It also mandates a series of screening, diagnostic, and treatment protocols to ensure a higher level of intervention and care for children on Medicaid.

Colorado Medicaid, in compliance with federal law, is overseen by a single agency, the Colorado Department of Health Care Policy and Financing (HCPF). This agency is completely separate from the Colorado Department of Human Services (CDHS), and the Colorado Division of Behavioral Health (CDBH) within CDHS.

HCPF contracts with five regional Behavioral Health Organizations (BHOs) to manage the provision of behavioral health (i.e., mental health and substance abuse) services covered by Medicaid. The BHOs are paid a “capitated” rate, determined by the number of people on Medicaid in their region, their eligibility category, and the historical trends concerning costs per person. The services themselves are provided by Community Mental Health Centers (CMHCs) and provider networks that contract with the BHOs. This managed behavioral health care system is often referred to as “Capitated Medicaid.”

The five BHOs, seventeen CMHCs, and five specialty clinics are members of an umbrella nonprofit organization called The Colorado Behavioral Healthcare Council (CBHC). CBHC represents the interests of these members.

The BHOs are contractually obligated to manage the provision of medically necessary covered services (as outlined in Exhibit E of the state’s contract with the BHOs), that carry one of the covered procedure codes listed in Exhibit F of the contract, for one of the covered mental health diagnoses listed in Exhibit D of the contract, by a provider credentialed to provide that procedure for that diagnosis (as outlined in Exhibit O of the contract).²

Diagnoses, services, and procedures not listed in Exhibits D, E, and F of the state’s contract with the BHOs, but otherwise covered by Medicaid, are considered “medical” services, and are administered separately through a system by which providers bill the state for each procedure or service according to a predetermined billing schedule. This is called “fee-for-service” Medicaid. The four major co-occurring diagnoses (DD, ASD, TBI, and Fetal Alcohol Syndrome), and most services commonly associated with them that are covered by Medicaid, are covered under the fee-for-service system.

² For the BHO contract and exhibits, see <http://www.colorado.gov/cs/Satellite?c=Page&childpagename=HCPF%2FHCPFLayout&cid=1251568046976&pagename=HCPFWrapper>.

Twenty geographically defined Community Centered Boards (CCBs) are responsible for meeting the needs of individuals with developmental disabilities and developmental delays. Various advocacy organizations, advisory councils and committees, comprised of various kinds of stakeholders (including service providers, government agency officials, managed care CEOs/EDs, advocates, and “consumers”), intersect with and overlap the formal structure described above.

Section 2: Statement of the Goals of the Project.

The original purpose of this project was to look beyond the anecdotal evidence to determine the scope, intensity, causes, costs, and possible solutions of The Co-Occurring Disorder Dilemma. *However, research quickly revealed that a fundamental aspect of the dilemma is the degree to which relevant data is either not collected or not aggregated and analyzed, leaving little information other than anecdotal evidence available for consideration.*

Due to the relative lack of data, the project has evolved. Anecdotal evidence of the nature of the problem remained an integral component. However, rather than attempting to quantify it, emphasis shifted to an analysis of the underlying dynamics and issues involved. This analysis helps to frame consideration of the range of possible solutions, including programs currently in existence that do a better than average job of attending to the needs of multiple diagnosis children. Denials data generously provided by the Behavioral Health Organizations (BHOs) are also summarized and discussed.

This report does not address several related issues. Among them are deficiencies in funding, deficiencies in covered diagnoses and treatments, deficiencies in the availability of providers or facilities, or hospital denials of in-patient care to multiply diagnosed children in crisis. However, this report does touch upon the issue of the adequacy of training for providers and in-take personnel, since this is a crucial component of The Co-Occurring Disorder Dilemma.

Section 3: Anecdotal Evidence

Among the parents, advocates, program directors, and service providers that I interviewed, there is a widespread and deeply felt perception of a serious and pervasive problem that needs to be addressed. At a stakeholder meeting held by the Colorado Department of Human Services (CDHS), there was repeated discussion of what I am now calling the Co-Occurring Disorder Dilemma by various stakeholders and a murmur of acknowledgement by other attendees whenever it was mentioned. While popular perception of a phenomenon does not prove its existence, popular perception by professionals of a problem relating to their profession is at least suggestive and warrants due attention.

Other than such perceptions, the principal evidence for the existence of the Co-Occurring Disorder Dilemma is comprised of the personal stories of those parents of multiple diagnosis children who have encountered it. A few of those stories are recounted below.

Case Study One.

C (child) was placed in P's (parent's) home when C was 6, having suffered severe abuse in his birth home. His birth family, for instance, had tried to "cure" his Tourette Syndrome by pouring caustic chemicals down his throat.

C had a low IQ and was at times very violent, flying into uncontrollable rages. In one instance, he broke both the hands of his disabled adoptive father and cut his (the father's) face with broken shards of glass. He also frequently tried to hurt himself. When not suffering such an episode, however, he had a completely different personality, and would be overcome with remorse. This was a heavy burden for P and her husband, who undertook this responsibility few others attempt.

Despite this pattern of behavior, and his mental health diagnoses of mood disorder, PTSD, and OCD, his BHO never authorized residential services for C, even after episodes of extreme violence. The BHO said he would not benefit from behavioral health services, that his behavioral problems were a result of his developmental disability rather than his mental illness,

and that the behavioral issues were the responsibility of the Community Centered Boards (which address developmental delay issues) rather than of the BHOs.

On three occasions, once for six weeks, P managed to access the Neuro-psychiatric Special Care (NSC) in-patient and day treatment services at Children's Hospital, an excellent but overburdened treatment program for children with dual (or multiple) mental health and developmental disability diagnoses. NSC bills as a psychiatric treatment center under capitated Medicaid (requiring a mental illness diagnosis, as C had, and a BHO determination that the behavioral problems for which treatment is being sought is a result of the mental illness, as P had to advocate for). C had received medical services related to a suicide attempt, and, due to the bifurcated billing discussed below, could not access mental health services at the same time. While in the NSC center, follow-up surgery was required, but to get it, P would have had to have C discharged from the NSC unit and readmitted on the medical side. This would cause C to lose his place in the NSC unit and endure a six-month waiting list to get back in.

According to P, her BHO had told her that since C was adopted, C was social service's responsibility, but this is only true in dependency and neglect cases. When C was 12, social services placed him in the category of "at-risk youth" or "child out of control of parents," adding their interventions to the burdens that P was facing. Thus, one of the perennial problems of bringing in social services arose: P faced a threatened dependency and neglect determination. Having adopted a child with developmental disability and mental illness diagnoses, seriously abused in infancy, showing signs of PTSD and Reactive Detachment Disorder, desperately seeking appropriate care for this child, P found herself under a cloud of presumed suspicion.

During the course of this years-long ordeal, P had to use the emergency room as an alternative to the residential care that C needed, as is frequently reported in such cases. On one occasion, she had to wait in the emergency room until a bed opened up for C, bringing her husband and plugging his ventilator into a wall socket in the emergency room, and not going to the bathroom (which would have been considered "abandonment" of the child). After all that, C was not admitted because the BHO refused to cover the expense.

As numerous service providers, advocates, and family members have noted, only the most tenacious parents, who advocate relentlessly for their children, generally succeed in cutting through these kinds of obstacles. For instance, it was a threat by P to file an American with Disabilities Act (ADA) Section 504 complaint that first got the BHO to the table after continually refusing to provide mental health services.

Because of P's tenacity, some progress was made on the DD (fee-for-service) side. C was placed on the wait list for the children's extensive support (CES) waiver. The CES waiver is for DD children who need 24-hour line-of-sight care, and provides about \$30,000 of services, in-home behavioral support and respite care. P's CCB used local money for people on the wait list and provided in-home behavioral support. Eventually, the Colorado Cross Disability Coalition (CCDC) got everyone at the table to kick in something for in-home care, and talked about creating a virtual residential treatment center in the home. (C passed away due to complications related to his pre-adoption abuse before this could be implemented.)

Case Study Two.

Q (parent) adopted D (child) when D was two weeks old. There were immediate neurological symptoms. D was originally diagnosed with attachment disorder. Therapy helped a little.

D was later diagnosed with Schizophrenia, "mood disorder with psychotic features," and ASD, and received a year of day treatment. Q believes that the behavioral issues need to be treated regardless of the diagnostic labels attached to them, but relies on the mental illness diagnoses to access necessary and appropriate mental health treatments for D.

Despite the Schizophrenia diagnosis, Q's BHO refused to provide behavioral treatments appropriate to D's mental illness diagnosis, stating that the BHO does not provide services for Autism. Subsequently, Q used D's Schizophrenia diagnosis to obtain treatment, without disclosing that D also had ASD.

Q insists that the mere mention of the word "autism" provokes a negative response by BHOs and CMHCs. "You can almost hear the screeching of the brakes at the other end of the line." But Q

argues, as do many others (including clinicians), that Autism disrupts communication and social skills, resulting in behavioral symptoms that can be treated in the same way that behavioral symptoms associated with mental illnesses can be treated. However, Colorado Medicaid distinguishes between behavioral problems that are a result of Autism (or other developmental disabilities), and identical behavioral problems that are a result of a mental illness.

Q noted one of the most oft cited disconnects resulting from this artificial distinction (discussed in more detail below): That Applied Behavioral Analysis (ABA) is an autism-specific treatment that has a behavioral health billing code. This means that ABA can only be accessed if the patient has a mental illness diagnosis, despite the fact that Autism (for which ABA is considered the standard of care) is categorized as a medical diagnosis. Q discussed (as did many other providers and advocates in my conversations with them) the need this imposes on parents and providers to rely on creative coding and labeling to navigate the system.

Q reiterated another frequently repeated observation: That it is hard to imagine someone who is not a professional advocate, or otherwise thoroughly versed in the intricacies of the system, navigating the system. Q observed that there are three systems responsible for responding to children's maladaptive behaviors: Education, Health Care, and Juvenile Justice. Each wants to shift the burden to the others. Moreover, since Juvenile Justice is the only one that cannot deny services, too many children in need of behavioral health services end up in the Juvenile Justice system.

Case Study Three.

E (child), who is diagnosed with psychotic disorder, autism, and mood disorder, has long suffered from explosive tantrums, auditory and visual hallucinations (sometimes "advising" him to act violently), anger, obsessive behaviors, volatile mood swings, and other symptoms. E is a teen-age male, who, like C in Case Study One, poses a risk to self and others. At home, E is often aggressive and demanding, damaging property, having difficulty with personal hygiene, and in general lacking independent living skills. R (parent) was particularly concerned for the safety of a much younger sibling also living in the home.

Despite these symptoms, as in the case of C described in Case Study One, the parent and other adults who have had contact with E describe him as “a sweet kid.” They perceive the symptoms of his mental illness to be distinct from his essential character as a human being.

E was placed in a succession of out-of-classroom programs by the school district, from kindergarten onward. He has relied on outpatient therapy and medication nearly all his life. He was hospitalized several times due to his behaviors at home. The BHO refused to pay for his last hospitalization, claiming that it was not due to a covered diagnosis.

R (parent) originally sought day treatment for E, in which E could receive both mental health and educational services, which had previously proven very useful. The BHO denied day treatment for E, insisting that in-home treatment was more appropriate and less costly. E’s doctors were adamant that E needed day treatment, that it was a medical necessity. The BHO insisted that the behavioral issues were due to E’s developmental disability rather than a covered mental illness (despite the ample mental illness diagnoses), and that day treatment “wouldn’t do him any good,” despite the fact that it had done him good in the past, and that his doctors adamantly recommended it for him.

In the course of negotiations on this matter, the BHO tried to place responsibility for E’s mental health care on the school district, insisting that it was a problem for Special Education to deal with. Eventually litigation was threatened, and the BHO made some concessions to avoid it, reversing its decision regarding day treatment, but authorizing it for an insufficient length of time. R continued to struggle with the BHO over the provision of appropriate and necessary mental health services for E.

R agreed to try in-home therapy, but it has not been very successful. Due to the continuing threat to the safety of E himself and others in the household, E’s psychiatrist and his clinician both recommended residential care for E, stating that "out of home placement in a residential setting is strongly indicated . . . [T]his level of care has the potential to improve [E's] psychiatric status and his functioning. [E] has responded best to a structured, supportive, therapeutic setting."³ Despite these strong recommendations, the BHO refused residential care, stating, “[E’s]

³ Quotes are taken from the ALJ decision reversing the BHO’s denial of residential services.

psychotic symptoms would not be expected to benefit from or require residential treatment level of care.”

R appealed the BHO’s decision, and received several independent evaluations confirming the need for residential care for E. In the light of this overwhelming evidence contradicting the BHO’s refusal of services, an Administrative Law Judge recently reversed the BHO’s decision to refuse residential services to E, ordering that the services be provided.

Anecdotal Evidence of Informal Denials (or “Non-Denial Denials”).

Almost all of the parents I interviewed reported similar experiences of receiving “informal denials,” either prior to, or in place of, formal ones (known as a “Notice of Action,” or NOA), which are necessary to initiate a grievance or appeal. In one particularly revealing incident, a CMHC had accidentally sent the parent the evaluating physician’s confirmation that the child had a covered mental health diagnosis and was eligible for services. However, the CMHC then informally denied that child services, neglecting to send a letter of denial. Another parent reported that her CMHC refused mental health services to her child with a mental illness, who had suffered a brain injury sometime *after* receiving his mental illness diagnosis, because “we don’t treat medical conditions here” (implying that since a brain injury is a medical condition, all behavioral problems will be attributed to it, despite the fact that the bipolar diagnosis predated the brain injury). A BHO official confirmed this decision, showing this parent the contract, which states that the BHO is not responsible for medical problems. No Notice of Action was issued.

One parent spoke of the confusing forms, the inflexibility of in-take policies and procedures, how when laryngitis made it impossible for her to participate in a scheduled telephone call, she was kicked back to the beginning of the entire process of applying for access to services. She was not provided information about respite care when she inquired into it. This parent, too, stated that she is not able to access services for her child if she mentions that the child has a developmental disability as well as a mental illness, although an NOA has never been issued.

Several parents, most advocates, and even many providers indicated that such informal denials occur with great frequency at various stages in the process, from intake to post-evaluation. Reports include clients being told by in-take personnel that violent behaviors by the child preclude eligibility for Medicaid covered mental health services, that such behaviors are a matter for the police and not for mental health care providers, or that network providers would have to be used. The parents then report receiving outdated provider lists with disconnected numbers or otherwise inaccessible or non-existent providers. Clients (particularly adoptive parents) have also reported being inappropriately referred to social services for conditions that are Medicaid's and not social services' responsibility to address.

Section 4: BHO Formal Denials Data

According to the data provided to me by CBHC and the five BHOs, there were 54 denials based on Co-Occurring Disorders (almost half by one BHO) issued by all five BHOs to no more than 49 individuals (not all BHOs indicated when multiple denials were issued to the same person) over an 18 month period. This data is difficult to evaluate for at least three reasons: 1) We have not been provided with the relevant denominator, which is the total number of multiple-diagnosis Medicaid eligible children who sought intensive services; 2) most of the personal stories related to me do not involve the issuance of NOAs (and thus are not included in this data) but do result in denials of services, raising the question of the prevalence of "informal denials;" and 3) this is self-reported data by the BHOs that cannot be verified, and is not subject to any independent oversight.

To underscore these points, one BHO reports only 8 denials for 6 individuals during the 18 month period under consideration, though one of the CMHCs affiliated with it has a widespread and intensely felt reputation among the mental health advocates and providers I talked with for overzealous denials of services, particularly to multiple diagnosis children. (One professional, in no way affiliated with that CMHC, told me that the medical director of that CMHC has explicitly stated that he considers any behavioral problem that occurs in a child with a developmental disability to be *by definition* a neurological rather than a mental health problem, and thus never the result of a covered diagnosis, despite the protocol developed to ensure that such blanket denials of mental health services to children with developmental disabilities are not public

policy.) Conversely, another BHO which includes a program with a stellar reputation for ensuring that multiple diagnosis children receive appropriate services, reports 11 denials of services, and gave by far the most complete and detailed information for each case of all five BHOs.

Section 5: An Analysis of Relevant Issues

There are clearly numerous human, social, fiscal, and economic costs implicated in the failure to address this problem. The human costs borne by the individuals and families directly impacted are enormous, and well represented by the anecdotal evidence reported above. The social costs include increased prevalence of socially maladaptive behaviors that can at times become violent or criminal in nature. The fiscal costs are typical of those borne by society when we are “penny wise and pound foolish,” failing to invest in proactive policies that reduce far larger and more cumbersome reactive costs. One simple and obvious example is the overreliance on expensive emergency room care for chronic conditions rather than less expensive and more effective preventative treatment. The economic costs include reduced productivity and an increased burden on our juvenile justice and criminal justice systems due to the failure to proactively address this and related problems.

In order to avoid these numerous and onerous costs, we need to meet the challenge of resolving The Co-Occurring Disorder Dilemma. The major interrelated structural problems that need to be addressed and rectified are:

1. The bifurcation of capitated Medicaid for mental health problems, and fee-for-service Medicaid for “medical” problems (which include co-occurring conditions such as developmental disabilities, ASD, TBI, and fetal alcohol syndrome), despite the fact that this distinction often segregates identical behavioral problems requiring identical treatments, distinguished only by the context in which they occur.
2. The distinction made between identical behavioral symptoms according to the presence or absence of diagnostically and clinically independent co-occurring conditions.

3. The need to align covered diagnoses (i.e., diagnoses that are covered under either fee-for-service “medical” Medicaid or capitated “behavioral” Medicaid) with covered treatments in the same silo (i.e., treatments that carry a billing code that falls into either fee-for-service or capitated Medicaid, matching the silo of the covered diagnosis). This is exacerbated by possibly overly restrictive authorization of providers, even though clinical best practices require a more fluid matching of treatment, diagnosis, and provider according to particular confluences of circumstances.
4. The insufficient cross training of mental health care providers in issues specific to people suffering from co-occurring conditions (particularly DD and ASD).
5. Insufficient integration of services and coordination of service providers.
6. Insufficient assistance to clients trying to navigate the confusing and convoluted behavioral health care system.
7. Insufficient tracking and oversight of formal denials of services by independent contractors paid a set fee to manage the provision of mental health care services under Medicaid.
8. Non-existent tracking and oversight of the apparently more pervasive informal denials, such as clients potentially eligible for services being told on the phone or at the front desk that they are not.
9. Insufficient training of in-take personnel, leading to an increased frequency in the occurrence of informal denials.

Structural problems 1-5, above, can be categorized as “siloing” problems. “Siloing” refers to a separation and lack of coordination among interrelated services, agencies, and procedures. Siloing is widely understood among those involved in publicly provided human services to be a fundamental structural problem, obstructing the efficient and effective delivery of services. Siloing clearly is a major factor contributing to the difficulties facing families of multiple diagnosis children and adolescents.

Structural problems 6-9 can be categorized as “gateway” problems. Gateway problems are problems involving client access to services and navigation of the system.

As discussed in more detail in Section 7, these can be further subdivided into underlying structural problems (1-3), service provision problems (4-5), client assistance problems (6 and 9), and oversight problems (7-8).

The first type of siloing listed above is the administrative lynchpin of the problem. Diagnostically and clinically identical maladaptive behaviors can fall into one of two administratively distinct categories: Fee-for-service “medical” Medicaid, or capitated “behavioral health” Medicaid. The latter include behaviors deemed to be caused by a diagnosed mental health disorder, and thus the responsibility of the BHOs and their provider networks to cover. The former include behaviors that are deemed to be caused by any of various co-occurring conditions (Autism Spectrum Disorder, Developmental Disability, Traumatic Brain Injury, Fetal Alcohol Syndrome), and thus the responsibility of fee-for-service Medicaid to cover.

The second, closely related, example of siloing implicated in the Co-Occurring Disorder Dilemma is the segregation of exhibited behavioral problems into those associated with a mental illness, and those associated with some other co-occurring condition. According to Dr. Judy Reaven, a child psychologist with JFK Partners at the University of Colorado School of Medicine, there is no diagnostic or clinical justification for this distinction. There is general agreement with this view among other clinicians I spoke with, such as Cory Robinson, Director of JFK Partners, and Dr. Marianne Wamboldt, Chair of the Department of Psychiatry and Behavioral Sciences at Children’s Hospital. All three agree that this is the prevailing view among clinicians.

Dr. Reaven emphasizes that there is no basis for distinguishing behavioral problems manifested by a child (or adult) with a developmental disability from behavioral problems symptomatic of a mental illness. Neither in terms of what we know about underlying causes, nor in terms of the efficacy of standard treatments, does such a distinction have any justification. Since there appears to be no medical basis for making such a distinction, this administrative artifact both serves as an obstacle to the implementation of clinical best practices and facilitates the denial of mental health services to those who both need them and, by law, are entitled to them.

In Dr. Reaven's words:

Related to the artificial distinction between "behavior" that is symptomatic of DD vs. a mental health condition, is that clinicians are asked to independently treat "mental illness," and "autism or other DD" knowing full well that diagnostic complexity exists in most of the patients we see. It is nearly impossible to identify the specific symptoms that are only ASD vs. symptoms that are only mental illness. Finally – best practice would suggest that clinicians consider the whole child, as knowledge of the whole child must inform the specific treatment and modifications necessary for enhanced efficacy of the intervention. Not allowing clinicians to even acknowledge the complexity of patient's presentation in many cases can lead to a superficiality of treatment.

Related to this is a phenomenon known as "diagnostic overshadowing" (coined by Steven Reiss in 1983), a tendency to disregard the diagnostic indicators if behaviors can be attributed to a developmental disability instead of to the mental illness diagnosis consistent with the behaviors, even though the presence or absence of the developmental disability is generally not diagnostically relevant. Again, in Dr. Reaven's words:

Diagnostic overshadowing refers to the tendency to attribute behavioral challenges and mental health symptoms in an individual with DD or ASD, solely to the developmental disability or ASD, rather than assign an additional mental health diagnosis, even if the symptom presentation are all consistent with such a diagnosis; in other words, mental health symptoms are "overshadowed" by the DD/ASD and as a result are not appropriately identified or treated.

While co-occurring conditions can be *clinically* relevant, just as any number of other contextual factors can be, their presence does not generally imply that the use of standard mental health treatments and therapies will be ineffective. Rather, such treatments, as always, need to be adapted appropriately to the needs of the individual child. For instance, if a child has a developmental disability that affects his or her ability to communicate verbally, this is a factor that must be taken into account, not a factor that renders irrelevant the child's mental health treatment needs.

According to the 2011 Ombudsman’s Report, BHOs do (and are contractually authorized, perhaps required, to do) precisely what Dr. Reaven described above as impossible and irrelevant to do: differentiate between similar behaviors as in some cases an artifact of a developmental disability and in other cases an artifact of a mental illness. According to the report, regardless of the diagnoses that exist, there is “a reluctance on the part of plans to approve treatment services for behaviors that *may be* caused by a medical diagnosis (autism or traumatic brain injury) which are then exacerbated by mental health conditions, or vice versa” (emphasis added). The key phrase above is “may be,” because, while the BHOs are contractually empowered to make such distinctions, they are rarely diagnostically or clinically justifiable.

In fact, BHOs are authorized (perhaps required) to deny services for behaviors “associated with” a covered mental health diagnosis, if the BHO asserts that the behaviors are the result of a co-occurring condition rather than of the covered mental illness. Given that making such determinations reduces costs incurred by the BHOs, that such determinations are at times made in opposition to clinical recommendations, and that such determinations are not automatically reviewed, it is economically axiomatic that such determinations are likely to be made excessively.

But even were the clinically more relevant criterion relied on, that any behavior requiring treatment that is “consistent with a covered mental health diagnosis” be covered, it still is left to the BHO’s discretion to determine *whether* such a mental health diagnosis actually pertains, a determination not bound even by what their own CMHCs or independent mental health providers may say. Therefore, the BHOs may be economically influenced to assert that a behavioral problem exhibited by a child with a developmental disability is the result of the developmental disability rather than of a mental illness, even if that child has been clinically diagnosed with a mental illness, *and even if they were obligated to provide services for anyone they deem to have a covered diagnosis* (which is not currently the case). In practice, the BHO has complete discretionary power to determine whether the child has or does not have a covered mental health diagnosis. Moreover, such determinations are not subject to automatic review.

In other words, the BHOs have complete discretionary authority to determine, independently of clinical recommendations, *both* whether a client exhibiting behaviors consistent with a covered mental health diagnosis actually has that diagnosis, *and* whether, if so, the exhibited behaviors are the result of that diagnosis. (The decision can be appealed by the recipient, but there are many obstacles in their path. There is such a maze of bureaucratic hoops to jump through that already overburdened and untrained parents seeking behavioral health services for their multiple-diagnosis children are forced to either dedicate considerable time and effort that they can ill-afford and which may prove unsuccessful, or surrender to the system.)

The third type of siloing listed above requires that only therapies that carry a billing code associated with one or the other of the two administrative silos (capitated or fee-for-service) are administered only for diagnoses that are covered under that same administrative silo. In other words, a therapy coded as a behavioral health treatment cannot be used for a diagnosis whose billing code is fee-for-service, even if that therapy is the standard of care for that diagnosis. This administrative requirement obstructs rather than facilitates clinical best practices: Appropriate and covered therapies should be provided for appropriate and covered diagnoses, by any qualified and competent service provider.

The consequences of failing to allow any covered therapy to be provided by any authorized and qualified behavioral health provider for any covered diagnosis is to effectively deny covered services for covered diagnoses to eligible recipients; to reduce the quality of care to many of those who do receive services; and to force frustrated providers to work around these arbitrary obstacles by making a mockery of the labels that impose them in the first place.

Brian Tallant, the program director at Intercept Center (a joint program between Aurora Mental Health Center and Aurora Public Schools discussed below), offers the following example of this problem:

Best practices for the treatment of Autism is a combination of Applied Behavioral Analysis (ABA), speech/language therapy and occupational therapy. ABA is considered a behavioral health service, and typically has a behavioral health CPT (Current Procedural Terminology) code that corresponds to that service. Speech/language therapy,

as well as occupational therapy, are medical services and have corresponding medical CPT codes. Capitated (Behavioral Health) Medicaid has a list of covered psychiatric diagnoses, but excludes Autism as a neurological or medical condition, and therefore ABA interventions are not authorized based on the diagnosis of Autism. If a clinician provides ABA services under the diagnosis of Autism, and tries to bill medical fee-for-service Medicaid for ABA services, using behavioral health CPT codes, it is often rejected as being a “behavioral health” service, which should be covered by Capitated Medicaid. So you see how a child with Autism is caught between a system that excludes their behavioral treatment either by diagnosis (Capitated Medicaid), or by service code (medical fee-for-service Medicaid).

Brian Tallant describes how the provider is also caught up in the siloing of particular treatments for a particular diagnosis:

[T]he problem mostly rests with Applied Behavior Analysis (ABA), or other “behavioral” services, that are provided by a professional that has more of a behavioral health training and/or certification. These professionals can provide services that are best described by behavioral health service codes (ICD-9 codes), when they are authorized and approved for treatment of a covered diagnosis under capitated Medicaid. If a person has a medical diagnosis (excluded mental health diagnosis), such as autism or TBI, the behavioral therapist does not have medical ICD-9 codes that allow for billing under fee-for-service Medicaid. Behavioral services codes are rejected by fee-for-service Medicaid as being “behavioral health” services, even though they are qualified to provide those services, and they are treating a medical condition.

While this may be little more than a restatement of the problem of having to align covered diagnoses and covered treatments under a single silo, it draws attention to the fact that a provider fully qualified to provide the treatment that represents best practices for a given diagnosis may be prohibited from providing that treatment, simply as a result of how the treatment is coded.

The fourth and fifth types of siloing listed above involve the siloing of expertise, both by a lack of cross-training of service providers, and a lack of coordination among service providers. Due

to a lack of cross-training, clinical assessments are made by service providers who may not understand the relationships between, for instance, developmental disabilities and mental illnesses, and thus make diagnostic and clinical judgments that are only partially informed. Due to the lack of coordination among service providers, clients seeking services in one silo may not be directed to services appropriate for them offered in another. This siloing of expertise exacerbates the interacting dysfunction of the first three administrative forms of siloing by reproducing and reinforcing it at the level of service provision.

The final four structural problems listed above are not siloing problems, but are rather gateway problems involving breakdowns in assistance to clients and oversight of managed care providers. They interact with the five siloing problems by leaving clients to fend for themselves in a system posing numerous obstacles to their ability to access appropriate services.

Many parents of multiple diagnosis children who are also knowledgeable advocates for the interests of multiple diagnosis children note that no one who is not a trained advocate could possibly hope to navigate this convoluted and obstruction-strewn system effectively. The anecdotal evidence is rife with stories of parents being misinformed, misdirected, and given a general run-around, while dealing with the other onerous burdens of raising developmentally disabled and mentally ill children. Clearly, this nightmarish maze that such parents must try to negotiate, against obstacles both intentional and unintentional, is a major part of the problem with how this system functions..., or fails to.

This bureaucratic labyrinth, which serves interests other than those of the clients who need to access the system, is left largely unchallenged due to a lack of administrative resolve and oversight. *No state agency or advocacy organization is tracking formal denials of mental health services other than the independent (two nonprofit and three for-profit) contractors that have a financial incentive to deny them.* No state agency or advocacy organization is extracting and analyzing information about the reasons given for denials in cases that are aggrieved or appealed. No state agency or advocacy organization is attempting to systematically track or assess the apparently far larger problem of informal denials, in which applicants are obstructed from accessing services to which they are entitled in ways that do not result in a formal Notice of Action (NOA). The first step to remedying the Co-Occurring Disorder Dilemma is to rectify this

glaring lack of data collection and administrative oversight, and the enabling lack of sustained, focused advocacy insisting on such data collection and oversight.

Clearly, the imposition of new administrative burdens is not to be taken lightly. But the glaring deficiency in this case suggests that perhaps the current distribution of administrative burdens is not optimally targeted.

Section Six: An Example of a Program That Works Well

Intercept Center

Intercept Center is a joint program of Aurora Mental Health Center and Aurora Public schools, established in 1995, to accommodate the educational and behavioral health needs of Medicaid-eligible children from ages 5 to 21 with both a covered mental health diagnosis and a developmental disability. Aurora Public Schools provides the building, special education teachers, paraprofessionals, instructional materials, and itinerant special education staff and services, while Aurora Mental Health Center provides the mental health treatment services and personnel. Aurora Mental Health Center and Aurora Public Schools are currently putting together a Memorandum of Understanding to more fully formalize this joint venture.

Intercept Center operates as both a school and a day treatment center, with students receiving both their educational and behavioral health treatment needs in one location and under the auspices of one program. Intercept Center also functions as an intensive services outpatient clinic for multiply diagnosed children in the Aurora area. The relative success of Intercept Center in reducing or eliminating the gap in services encountered by many multiple diagnosis children on Medicaid is due, in large part, to the training of the mental health service providers there, and the assertive coordination with other facilities and programs to accommodate needs that fall beyond the parameters of the services that Intercept Center provides.

The success of such a program requires the willingness of the overarching Behavioral Health Organization (in this case, BHI), to permit a more rather than less inclusive determination of

eligibility for services, and the stewardship of a program director (in this case, Brian Tallant) committed to ensuring that applicants receive any and all services to which they are entitled, whether under the auspices of this program, or through another service provider more appropriate to that particular child's needs. Unfortunately, under our current overarching system, the satisfaction of these two necessary conditions is the exception rather than the rule.

While Intercept Center does not currently bill fee-for-service Medicaid to provide ("medical") services that are not covered under capitation ("mental health services"), it does coordinate with providers who do. Aurora Mental Health Center is contemplating expanding the Intercept Center program to provide behavioral services that are covered under fee-for-service Medicaid, as well as the behavioral services that are covered under capitated Medicaid.

Intercept Center does not provide residential services, but has a close relationship with Smith Agency, which is a child placement agency for foster care, and the provider of Serenity Group Homes and Serenity Learning Center. Intercept identifies children who need residential treatment, informs parents of the procedures to go through and of the various options available to them. In one case, Intercept assisted foster parents in expanding their business into a group home, which they wouldn't have been able to do without Intercept's support and guidance. Intercept Center providers also go into Residential Child Care Facilities (RCCFs), which serve children with developmental disabilities, to provide certain mental health services on-site (particularly, capitated Medicaid-covered individual and group therapies), but children in RCCFs must come to Intercept Center for medication to be administered.

Intercept Center is evidence of the fact that it is possible to design and implement a relatively well-functioning model under the auspices of Colorado's current Mental Health Medicaid system, but also, in its exceptionalness, of the fact that such models are not the inevitable by-product of that system. To the extent that we continue to operate within current parameters, one immediate goal is to ensure that the Intercept Center model is replicated as widely as possible. To the extent that we change those parameters, one intermediate goal is to ensure that the lessons of Intercept Center inform systemic and mandatory changes.

Section Seven: Possible Solutions and Recommendations

An Overview of Policy Goals

The principal recommendation of this report is that the relevant governmental agencies systematically research and remedy The Co-Occurring Disorder Dilemma, with persistent resolve and unflagging determination. Since this has not yet happened, and there is no evidence of it spontaneously occurring, the secondary recommendation is that all relevant advocacy groups place sustained, informed pressure on those governmental agencies and office holders to do so. The State of Colorado needs to commission a comprehensive study, incorporating data that either currently does not exist or cannot be accessed, and, based on that study, design and implement an affirmative plan to rectify the obstacles to access to mental health services faced by children and adolescents with co-occurring conditions.

The state has a number of options for addressing and rectifying the major interrelated structural problems listed in section five, above. We need to design and implement a set of policies which:

1. Eliminates the effect of bifurcation of Medicaid into capitated and fee-for-service enclaves, either by (ideally) eliminating the bifurcation itself or (more practically) perforating the wall between them sufficiently that it ceases to obstruct the diagnostically and clinically appropriate and necessary provision of services.
2. Eliminates the effect of administrative (diagnostically and clinically unjustifiable) segregation of identical behavioral problems according to whether they are administratively deemed to be the result of a mental health diagnosis or some co-occurring condition.
3. Eliminates the need to align providers, diagnoses, and treatments under one or the other of the two Medicaid silos described in numbers 1 and 2, above. This primarily involves eliminating the need to provide only behavioral therapies and treatments with a billing code that corresponds to the silo (either fee-for-service or capitated) that the behaviorally related diagnosis is covered under. A more flexible system is needed to ensure that any covered treatment for any covered diagnosis can be provided by any competent and qualified behavioral health service provider.
4. Ensures that behavioral health providers are appropriately cross-trained to know how to effectively diagnose and treat co-occurring developmental disabilities and mental illnesses.

5. Ensures the integration and coordination of services and service providers.
6. Ensures the shifting of the burden for navigating the complex and confusing behavioral health care system away from overwhelmed clients often poorly equipped to take on such a challenge, and onto designated and adequately trained personnel within the system itself.
7. Ensures comprehensive tracking and analysis of denials of services by responsible governmental agencies, and the exercise of adequate oversight of the BHOs contracted to manage the provision of covered services to those who are entitled to them. (The bureaucratic burden of doing so must be taken into account, and a careful cost-benefit analysis pursued, but it is clear that we currently have a sub-optimal level of such tracking and analysis in place, essentially “leaving the fox in charge of the henhouse.”)
8. Ensures a dedicated investigation and rectification of informal procedures by which services may be denied without any formal request for services ever being recorded, and thus no formal denial ever being issued.
9. Ensures that in-take personnel and other gate-keepers are adequately trained to record and follow up on all requests for services, to turn no one away on the basis of any peremptory assumption that clients seeking services are not entitled to services.

The structural factors and associated policy goals listed above fall into four categories: Underlying Structural Problems (1-3), Service Provision Problems (4-5), Client Assistance Problems (6 and 9), and Oversight Problems (7-8).

The Gateway Problems (6-9) are problems at the point of interface between clients and the mental health care system. They involve insufficient oversight of the formal and informal ways in which clients are refused services (7 and 8, respectively), and insufficient guidance and inaccurate information provided to clients seeking services (6 and 9, respectively). The Service Provision Problems are problems that affect access to services by dispersing rather than consolidating service provider expertise. They involve insufficient expertise regarding multiple diagnosis issues within individual service providers (4), and insufficient coordination of expertise among service providers (5). The Underlying Structural Problems are problems embedded in the administrative structure of Colorado Medicaid. They involve, collectively, an incongruence between the administrative structure for the delivery of mental health services, and the clinical reality of the delivery of mental health services.

Specific strategies for addressing the Co-Occurring Disorder Dilemma involve addressing specific combinations of the above policy goals for specific purposes. For instance, as Intercept Center's success illustrates, by addressing the Service Provision Problems and one Client Assistance Problems -numbers 4, 5, 6 and 9- local programs can dramatically reduce the Co-Occurring Disorder Dilemma on their own initiative (and with the support of their BHO). By concentrating and coordinating expertise in both mental illness and developmental disabilities, and ensuring that there is an open gateway to that consolidated expertise, a local program can distinguish itself even in the context of the other six unresolved structural problems.

Numbers 4, 5, 6 and 9 can be addressed proactively, by any BHO or CMHC that chooses to take the initiative. Thus, significant local improvement in the provision of services to multiply diagnosed children can be accomplished even in the absence of statewide public policy changes. However, a sustainable and reliable statewide paradigm shift will almost certainly require overarching public policy refinements. And even such relatively successful local programs as Intercept are limited in the degree to which they can effectively address the Co-Occurring Disorder Dilemma by a lack of facilitating statewide policies.

The Oversight Problems and related policy goals, 7-8, suggest a second strategic avenue comprised of direct advocacy for immediate and easily implemented administrative reforms. These do not require any major structural changes, simply superficial changes in policy that implement more diligent administrative oversight of the mental health managed care system.

Finally, the far-reaching statewide administrative structural changes conducive to eliminating or reducing the Co-Occurring Disorder Dilemma are summarized in numbers 1, 2, and 3, above. These would require significant legislative and administrative action, and are thus higher hurdles to clear. Progress on Underlying Structural Problems neither requires nor is a requirement of progress on either Gateway or Service Provision Problems. Long-term structural strategic goals and short-term immediately ameliorative strategic goals can be pursued independently and simultaneously.

A recommended comprehensive strategy for those who choose to act on this report, therefore, is to seek immediate widespread, either centrally directed or CMHC by CMHC, implementation of 4, 5, 6 and 9, while simultaneously working toward both the superficial administrative policy changes suggested in numbers 7 and 8, and the eventual implementation of long-term policy goals 1, 2, and 3.

A Survey of Specific Solutions

This section briefly examines examples of three different kinds of approaches to addressing The Co-Occurring Disorder Dilemma: 1) a broadly applicable and assertive social institutional approach (Medical-Legal Partnership), 2) a managed care-level administrative approach (Expanded BHO Contract), and 3) a flexible and accommodating provider-level administrative approach (The Medical Home Model). These three approaches are not mutually exclusive; they can be combined in part or in whole to form a comprehensive strategy for addressing The Co-Occurring Disorder Dilemma.

Medical-Legal Partnership: Medical-Legal Partnerships (MLPs) involve integrating lawyers into the health care team available to clients, to address the non-medical factors affecting their health. As The National Center for Medical-Legal Partnership (NCMLP) puts it:

Medical-legal partnership (MLP) is a new patient care model that aims to improve the health and well-being of vulnerable individuals, children and families by integrating legal assistance into the medical setting. MLPs address social determinants of health and seek to eliminate barriers to healthcare in order to help vulnerable populations meet their basic needs and stay healthy.⁴

One form of MLP is the inclusion of lawyers on a health care provider team to address exacerbating conditions that health care providers are neither qualified nor empowered to address, such as mold-infested housing aggravating the condition of an asthmatic child, or lack of food and heat creating health risks that cannot be resolved through medical treatments alone. In a sense, this is another reduction of “siloeing,” such that the various kinds of circumstances that

⁴ <http://www.medical-legalpartnership.org/>

combine to create or exacerbate medical problems can be addressed in tandem with the medical treatment itself.

More generally, a Medical-Legal Partnership is the combination of advocacy and medical treatment, so that patients' rights are protected in service to the provision of adequate health care that is not divorced from the broader social institutional context in which it occurs. As the above quote from the NCMLP website illustrates, such legal advocacy integrated into the "medical setting" could serve a vital role in placing sustained pressure on Colorado Medicaid's administrative apparatus to address and resolve the structural defects that result in The Co-Occurring Disorder Dilemma. More broadly, the establishment of Medical-Legal Partnerships throughout Colorado's health care system would provide institutionally integrated patient advocacy to address all such problems as they arise.

In the present context, a Medical-Legal Partnership would involve an alliance of behavioral health care providers and legal advocates working together to ensure that their clients receive the full range of behavioral health care services to which they are legally entitled, and to ensure that the services received are accessible, coordinated, and appropriate.

Expanded BHO Contract (or similarly unified management of care): One possible solution to the difficulties faced by families of multiple diagnosis children, favored by the Colorado Behavioral Healthcare Council (CBHC, the umbrella organization for the BHOs), would be to expand the state's contract with the BHOs to include in their mandate responsibility and compensation for providing all covered services for all covered behaviorally related diagnoses, whether currently categorized as mental illness or in some other way (such as a by-product of a developmental disability). Alternatively, care could be managed under the umbrella of one of the emerging organizational coordinated care structures, such as Accountable Care Collaboratives (ACCs) or Regional Collaborative Care Organizations (RCCOs).

Another, similar solution would involve authorizing and equipping BHOs and CMHCs to provide all behavioral services, some covered by capitated Medicaid, and some charged to fee-for-service Medicaid, according to their billing codes. These solutions would address some of

the factors contributing to the current systemic deficiency, but would leave many of the other contributing factors intact. As such, they are, at best, partial solutions.

Some advocates are concerned that these solutions would merely perpetuate the problem in a new guise, since the BHOs, intended as cost reducing intermediaries, are incentivized to deny services whenever possible. This may be a legitimate concern, but, when coupled with the Medical-Legal Partnership approach described above, the added vigilance thus provided might help to mitigate and counterbalance any overzealousness to deny services on the BHOs' and CMHCs' part. This combination might be a robust way to institutionalize, as a permanent feature of the Medicaid behavioral health landscape, a vehicle for negotiating the inherent tension between efficiency (i.e., cost-cutting) and protection of patients' rights.

Medical Home Model: The Medical Home Model (sometimes called “patient-centered medical home,” or PCMH) involves a centrally coordinated, continuous and comprehensive system of care led by a primary care physician. Intercept Center (described above) incorporates some elements of the Medical Home Model, in which the program director coordinates with other service providers to deliver coordinated and comprehensive care (and educational services) to children in the program. As discussed above, using Intercept Center as an example, the Medical Home Model is most adept at addressing issues 4, 5, 6 and 9 (cross-training of service providers, coordination and integration of services, and better assistance to clients in navigating the system). The Medical Home Model is often considered the best way to keep children with mental illnesses, developmental disabilities, and Autism Spectrum Disorder in the least restrictive environment, and provided with the most comprehensive and appropriate treatment plan.

In the context of reducing the effects of siloing in Colorado Medicaid's delivery of behavioral health services, the Medical Home is a potentially essential partner to higher level solutions. If, for example, the BHOs' contract were to be broadened to include management of care for all behaviorally related conditions, the Medical Home would be the ideal vehicle for coordinating and integrating that care. Thus, in one possible integration of these three approaches, the Medical-Legal Partnership could hold the BHOs accountable, while the Medical Home could implement their comprehensive mandate on the ground.

Conclusion

A combination of inherent financial incentives, excessive discretionary power by independent contractors, inadequate oversight, inadequately trained personnel, and inadequate availability of mandatory services helps to produce the gap in services experienced by children and adolescents with multiple mental health and developmental disability (or other “medical”) diagnoses. An administrative structure comprised of siloing in multiple, interacting ways (in terms of diagnoses, treatments, providers, and billing) obstructs rather than facilitates the coordination of services. And a lack of resolve among responsible agencies has left this problem largely unaddressed.

Previous attempts to close this and related gaps have proven insufficient. Protocols for clients with co-occurring DD and MI diagnoses, and co-occurring TBI and MI diagnoses, have done little to solve the problem. The Child Mental Health Treatment Act (CMHTA, or “HB 1116”), designed to provide access to residential treatment services without recourse to Social Services (which generally requires a Dependency and Neglect action, exposing parents to the risk of losing custody of their children in order to access vital services), has too often simply been disregarded or misunderstood. General awareness of the Co-Occurring Disorder Dilemma is widespread among advocates, affected clients, and individual service providers, but sustained pressure to resolve it has not yet been applied.

This difficulty in accessing necessary services, sometimes essential to the safety of the affected child and others in the child’s household, imposes an onerous burden on families already overburdened with the challenges of caring for children with multiple mental health and developmental problems. Solutions exist and can be implemented, ranging from the local and partial to the systemic and far-reaching. It is incumbent on all stakeholders to do their part to ensure that these solutions are implemented.

Methodology

The research for this report consists primarily of meetings and conversations with 1) parents who have had difficulties accessing mental health services for their multiple diagnosis children; 2)

professional advocates for those with mental illnesses and developmental disabilities (frequently also parents of mentally ill or developmentally disabled children); 3) the executive director of an advocacy organization for adoptive families (adoptive families being disproportionately impacted by this problem); 4) Mental Health program directors and service providers; and 5) governmental agency officials and contractors.

Among the governmental agency officials, nonprofit executive directors, advocates and service providers I interviewed, met with, or corresponded with in the course of researching this issue are Marceil Case (HCPF Mental Health Specialist), George DelGrosso (Executive Director of CMHC), Brian Turner (CMHC), Janine Vincent (Ombudsman for Colorado Medicaid Managed Care), Julie Reiskin (Executive Director of Colorado Cross-Disabilities Coalition), Mary Ann Harvey (Executive Director of The Legal Center), Pat Doyle (Rights Advocate at The Legal Center), Deborah Cave (Executive Director of Colorado Coalition of Adoptive Families), KimNichelle Rivera (Outreach/Research Coordinator for Empower Colorado), Judy Reaven (Clinical Psychologist and Director of the Autism and Developmental Disabilities Clinic at JFK Partners, an interdepartmental program of Pediatrics and Psychiatry at University of Colorado School of Medicine), Cordelia Robinson (Director of JFK Partners), Betty Lehman (then Executive Director, Autism Society of Colorado), Marianne Wamboldt (Chair of the Department of Psychiatry and Behavioral Sciences at Children’s Hospital), Brian Tallant (Program Director, Intercept Center, Aurora Mental Health Center), and Sarah McNamee (Early Intervention Service Provider, LCSW).

Among the documents I reviewed while preparing this report are the BHO Contract with the State of Colorado; the Ombudsman’s reports for 2009-2011; the written criteria for BHOs to follow in the treatment of co-occurring mental health diagnoses and traumatic brain injuries; the written criteria for BHOs to follow in the treatment of co-occurring mental health diagnoses and developmental disabilities; a 2009 Primer on the mental health safety net published by the Colorado Health Institute; a 2011 updated report by The Mental Health Funders Collaborative on “The Status of Mental Health Care in Colorado;” a 2004 Urban Institute report on “Access to Children’s Mental Health Services under Medicaid and SCHIP;” a 2008 Department of Health and Human Services Inspector General “Review of Colorado Medicaid Mental Health Capitation and Managed Care Program;” a 2009 DBH and WICHE Mental Health Program “Population in

Need” study; a 2008 report commissioned by HCPF on “Colorado’s Medicaid Mental Health Services Program: Issues & Future Direction;” “The Maze,” a 2009 report by Colorado Covering Kids and Families on barriers to access to Medicaid and CHP+ faced by eligible children and families, with a recommendation for streamlined access; some working papers on the clinical issues involved; and various provider and advocacy group newsletters.

Requests for both qualitative and quantitative data regarding the Co-Occurring Disorder Dilemma were made to the Colorado Department of Health Care Policy and Financing (HCPF, the single agency that oversees the Colorado Medicaid program), the Colorado Ombudsman for Medicaid Managed Care, various advocacy groups, and the five Behavioral Health Organizations.

With the exception of the five Behavioral Health Organizations (BHOs) themselves, no one was able to provide any hard data on the prevalence of The Co-Occurring Disorder Dilemma. The various advocacy groups contacted were unable to provide any relevant data other than the shared impression that The Co-Occurring Disorder Dilemma is a pervasive problem. HCPF, in response to a CORA request, provided raw grievance and appeals reports which contained no information relevant to the issue at hand. The Ombudsman did not follow up on an offer to send me relevant data.

With the assistance of George DelGrosso and Brian Turner of the Colorado Behavioral Healthcare Council (CBHC), four of the five BHOs contracted by the state as managed care providers for Colorado Medicaid supplied me with data summarizing the reasons for all of their formal denials, resulting in a Notice of Action (NOA), over the last fiscal year and the first half of the current fiscal year, to child and adolescent Medicaid clients with multiple diagnoses. (Access Behavioral Care, the fifth, provided only the raw number of denials -25- for the 18 month period reported on, and no other information. I was assured that this was due to technical difficulties and not a desire to withhold the information. The CEO of ABC, Rob Bremer, conveyed his willingness, through Brian Turner of CBHC, to work with me one-on-one to fill in that information if I so desired.)