



Building Bridges

For Children's Behavioral Health

Results of Statewide Family Survey and Youth Focus Group, January 2009

Addendum to: Results of Key Informant Interviews
and Focus Groups, September 2008

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**Colorado Department of Education, with funding from the
U.S. Dept. of Education, Office of Safe and Drug Free Schools**



Introduction

Building Bridges for Children’s Behavioral Health is designed to build a statewide system to support and sustain the integration of public schools and local behavioral health systems that will lead to increased access to behavioral health services and improved outcomes for school-aged children. It will accomplish this goal by integrating two complementary approaches currently in place in many Colorado communities: Positive Behavior Supports (PBS) from the education system, which is based on a preventive or public health framework, and System of Care (SOC) from the behavioral health system, which focuses on children and youth with serious mental health issues and those with co-occurring disorders. Both approaches have corresponding values and guiding principles that will drive the systems change process leading to a full continuum of behavioral health services and supports for Colorado’s students.

Participants and Recruitment. This document contains key narrative findings collected from a survey taken by Colorado parents with school-aged children and a youth focus group held at the Colorado Department of Public Health and Environment. Both provided unique opportunities to gain useful feedback on parent and youth experiences in schools and with other systems serving youth with behavioral needs.

Recruiters from family and consumer advocacy organizations and state agency partners were instructed to identify parents with children who have behavioral health needs to participate in the online survey. The youth focus group was conducted during a regularly scheduled meeting of the Youth Partnership for Health, the youth advisory board to the Colorado Department of Public Health and Environment.

Structure of the Survey and Focus Group. Participants involved with the survey or the focus groups were asked a variety of questions concerning their experiences within the school and community, and the ability for each to meet their/their child’s needs. Adult and youth participants were asked about both mental health and substance abuse needs. Responses from adults were heavily focused on mental health, while the youth were more likely to discuss substance abuse needs. The survey and focus group were analyzed together, looking for common themes and experiences between the parents and the youth.

As this report is an addendum to the original key informant and focus group results from Mesa County, part of the Building Bridges evaluation, the analysis explored the extent to which the information collected from statewide participants matched or did not match the themes identified in the Mesa County report. Please refer to the original report for a complete list overall themes: “Results of Key Informant Interviews and Focus Groups, September 2008”. The table on the following page outlines the Themes in both reports, identifying where overlaps exist.

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Category 1: School Capacity		# of Matching Theme in Mesa Report
Theme A	Children with special needs, including behavioral health issues, face judgment and misunderstanding from some of their peers, teachers, principals, and other school staff.	Theme 1
Theme B	Many teachers, principals, and other school staff need additional training to improve their ability to meet the needs of children who have behavioral health issues.	Theme 2
Theme C	A strengths-based, positive approach such as Positive Behavior Supports makes a significant difference in how families and children experience the school environment.	Theme 3
Theme D	Schools may be able to better meet the needs of children with behavioral health issues if they more actively engage parents and other volunteers available in the community.	Theme 4
Theme E	Youth need positive supports to address behavioral health needs and other challenges.	No matching theme

Category 1: School Capacity		# of Matching Theme in Mesa Report
Theme F	Accessing behavioral health and related services is difficult for parents and youth because of funding barriers, long waits, and problems with navigation.	Theme 5
Theme G	Youth need choices and activities for support that reflect youth perspectives and provide realistic, safe options.	Theme 6
Theme H	Providers use jargon that is unfamiliar to parents when explaining their child's behavioral health needs and the services or treatment routes available.	No matching theme
Theme I	The service delivery systems are not coordinated or able to deliver holistic, integrated services to families and children with behavioral health needs.	No matching theme

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Youth Focus Group Participants

- The 34 youth who participated were a mix of female (21) and male (13)
- Youth represented the following demographic groups:
 - White (14 youth)
 - Latino (9 youth)
 - African American (7 youth)
 - Native American (2 youth)
 - Asian American (1 youth)
 - Other (1 youth)
- Youth represented the following ages:
 - 14 years old (5 youth)
 - 15 years old (10 youth)
 - 16 years old (14 youth)
 - 17 years old (4 youth)
 - 18 years old (1 youth)
- Schools were represented from the following counties: Boulder (*Monarch HS, Peak to Peak Charter School*); Broomfield (*Broomfield HS*), Denver (*Bruce Randolph HS, Challenges, Choices Images, Denver Academy, Denver School of the Arts, DPS Online HS, East HS, South West Early College, West HS, JFK HS*); Douglass (*Chaparral HS, Ponderosa HS*); Eagle (*Eagle Valley HS*); Jefferson (*Arvada West HS, Chatfield Senior HS, Platte Canyon HS, Jefferson County Open School*); Larimer (*Rocky Mountain HS*); Moffat (*Moffat County HS*); Morgan (*Brush HS*); Arapahoe (*Cherry Creek HS, Hinkley HS, Regis Jesuit HS*)

Colorado Parents with School-aged Survey Participants

- In total, 51 parents described the needs of their 108 children, an average of two children per parent responding to the survey.
- Most parents reported living in urban, metropolitan areas in Colorado.
- Parents identified themselves as Caucasian (50 parents) or Other (1 parent)
- In total, 42 parents reported that their child had mental health needs
 - No parents stated their child had substance abuse issues, although some reported their child had received services at a substance abuse center
 - Six parents classified their kid's needs as "Other Health Issues" but clearly described the health issue as a mental health need (e.g. ADHD, PTSD, Bipolar). They have been included in the total above.
- Children represented the following school ages:
 - Less than 3 years old (5 children)
 - Preschool (6 children)
 - Grade school (51 children)
 - Middle school (18 children)
 - High school (26 children)
 - Voluntarily dropped out (2 children)
- Children represented the following issues, conditions, or disabilities*:
 - Mental Health Issues (53 children)
 - Physical disability (15 children)
 - Other health issue**(9 children)
 - Developmental disability (39 children)
 - Chronic health condition (12 children)

**Children may be represented in more than one group (e.g. have a mental health issue AND chronic health condition)*



Category 1: School Capacity

Theme A

Children with special needs, including behavioral health issues, face judgment and misunderstanding from some of their peers, teachers, principals, and other school staff.

Although parents commonly reported that they support the work schools are doing to provide a positive environment for their children, many did not experience broad support from principals, teachers, school staff and their child's peers. Some parents felt their children were being judged and misunderstood by staff and one reported overhearing a joke about their child. The youth participants reported similar feelings of being stigmatized and misunderstood, but from their point of view, disconnect resulted from teachers not reaching out to them and asking them about issues outside of school.

"I think schools should focus on the students and their problems. Like if a staff member sees a student that looks maybe down, they should take the time to just say, 'Hey are you ok? Do you need to maybe go talk to someone?' So basically take the time to care."

"As teenagers we live in the moment, so if one thing goes wrong we are in trouble."

"After you get in trouble or take steps to get help comes the stigma."

"Usually the teachers ignore someone sad or angry—they assume its school stress and you'll work it out on your own."

Youth Group Participants

A large group of youth also mentioned that they felt judged when they got into trouble, and once they were in trouble, they felt labeled with that reputation. A handful of students reported good connections with staff. They felt the staff members were open, did not judge, and made their difficult life situations more manageable by being supportive.

"They tend to get judged after they get in trouble for something. A huge percentage of the student body is involved in drinking or drugs, so you don't get judged unless you're really in trouble."

"Staff and counselors should not judge students about the mistake they have made in the past."

"The kids who open up to their teachers have a much stronger bond with them—more interaction. My math teacher this year puts an inspirational quote, and once or twice a week he'll explain what the quote means to him and talk about his own youth. I see people going up to him after class to talk about their life situations, so I think it works."

Youth Group Participants

Theme B

Many teachers, principals, and other school staff need additional training to improve their ability to meet the needs of children who have behavioral health issues.

Parents and youth frequently cited that some of the biggest barriers to student success in school were the staff's ability to understand behavioral health issues, the number of accessible behavioral health-related specialists in the schools, and whether or not staff members know appropriate services or interventions to help a child. Many parents reported that teachers were having difficulties discerning between behaviors attributed to mental health issues versus those relating to an underlying learning disability. For instance, one parent brought up that their child had a mental health issue and would often get frustrated in class but teachers accredited his frustration to a learning disability and not a mental health issue. The teacher may have utilized an intervention developed for learning disabilities, but did not realize a more effective technique existed that could be more highly aligned with the child's actual need.

Parents reported complications with the school's ability to provide appropriate, qualified staff for their children with both mental health and learning disabilities. One parent commented that many children have complex, multifaceted issues that would be best handled by a specialist; however, that option is not always available, so teachers could serve as an important bridge. More one-on-one time between a teacher and student was requested, but parents reported that the children who asked for this help were often targeted and bullied because they were taking up more of the teacher's time and resources in the classroom.

Youth shared similar issues as the parents, and suggested that teachers, specialists, and counselors should meet on a regular basis to discuss students' personal issues and then adjust their teaching style to best match the needs of students. Youth felt if teachers could better understand student issues, students might feel more connected to them. It might also help teachers be more sensitive of warning signs to watch for so students can get the help they need earlier before the problem escalates.

"Counselors should not have the exclusive responsibility for making sure kids are ok. They don't spend enough time with students to do that. The number of students in the school correlates really strongly to the number that fall through the crack. An open door policy on all issues is really important."

"Teachers need to be there to be the one to help them first. Most students won't ask for help."

"If possible, teachers should be approachable to the point of discussing drugs and alcohol without turning the student in. Educate why it's unhealthy."

Youth Group Participants

**Theme
C**

A strengths-based, positive approach such as Positive Behavior Supports makes a significant difference in how parents and youth experience the school environment.

When parents were asked if their child's school provided information about the PBS model, 40% said they received information about PBS, 33% said they did not, and 27% were not sure. When asked if they were ever informed about specific PBS events, 24% said they have been informed of PBS events, 55% said they have not, and 21% were not sure. Schools using the PBS model received positive feedback from parents stating that PBS created a more comforting and encouraging school environment, helped staff become more receptive to new ideas, suggestions, and interventions, and afforded children and teachers more choices to handle

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tough behavioral issues. Youth added that they liked PBS and gave lots of examples of the things they enjoyed about having PBS at their school.

“For my oldest child with DD, it makes the whole school seem so calm, easy going, and fun.”

“My son is comfortable at school and looks forward to attending.”

“My child could tell that the teachers were nicer and tried to help rather than criticize or complain.”

Parent Survey Participants

“Cherry Creek has a Care Scholarship—during your senior year you can apply and say what you’ve done for other people. It gets a lot of applicants—400-500 out of a class of 900.”

“My school had a super kid award—it was a pen and an award ceremony—I got it two years in a row, but they stopped doing it. Not many people knew about it—they didn’t really show much appreciation for people doing things right.”

“We have something called student of the month—you have to have good grades, but also be nice and earn it for more than just grades. You get a plaque and your picture taken—kids really want to get it.”

“We have these things called Husky tickets, and if you’re caught doing something good you get a Husky ticket, and then you get things once you have a certain number of them. The problem is that they are not really being given as reinforcement for good behavior. It’s not always given because you did something good. In general I think it has a positive effect.”

Youth Group Participants

A few parents had complaints about PBS, but they were directed at specific individuals that parents had a negative experience with and not the entire system or program. A handful of youth suggested that PBS was very effective but provided ideas about how PBS could be made more effective, such as increased incentives and more consistent distribution of awards.

“I do not believe that PBS programs are effective due to the nonchalant way they are executed. Bigger incentives such as scholarships can be more effective.”

“Awards do not affect me because of the differences in teachers’ policies in awards and the missing of people who are doing positive acts. If implemented, teachers must fully participate; individual awards are much less impacting on big schools.”

Youth Group Participants

Theme D

Schools may be able to better meet the needs of children with behavioral health issues if they more actively engage parents and other volunteers available in the community.

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Seventy-one percent of parents reported that their child's school was able to support their children academically. In contrast, only 55% reported school support for their child's general health, and 42% reported support for mental health. Of the parents who were satisfied with the school's ability to support mental health, only 50% reported having children with mental health issues. This might suggest that although schools had mental health services available, the services themselves may have lacked in perceived quality or fit for their children. Survey results support this idea, 65% of parents received information about the school's mental health services, but only 42% believed that the school can provide ample mental health support.

Youth mentioned that oftentimes they cannot get the help they need directly at school because there were not enough available counselors, they feared other students would find out if they saw the counselor, or felt limited with what they could share in a session (coursework and school vs. behavioral health and life issues). Youth reported that it would be helpful to have more resources, such as teaching youth how to advocate for themselves, have a counselor on-call, or provide more specific support groups.

"The counselor is not always there and we can't talk to him—we can talk about classes and stuff, but not our problems."

"At Denver Academy the quiet students slip through the cracks when something horrible is happening to them—teach them to advocate for themselves or have the teachers check up on them. Teach skills before they are in a crisis."

Youth Group Participants

Theme E

Youth need positive supports to address behavioral health needs and other challenges.

Youth were asked to give feedback on behavioral health programs at their schools and they reported that substance abuse programs focused on punishment and mandatory rehabilitation were not as effective as those focused on drug abuse education (e.g. why drugs are wrong, reasons why youth should stop using drugs). Youth suggested that they would feel welcome and less awkward if there were opportunities through programs to break down boundaries between staff and students. Several youth said that their parents did not see the importance of having them talk to someone about their problems at school and mentioned it would be helpful for schools to educate parents about the benefits of counseling and other related programs. The programs, pledges, and codes of conduct focused on empowerment seemed to address youth's needs better than those focused on enforcement and penalties.

"I like that they teach us skills on our mental health, like taking 10 breaths to cool down."

"We should have staff (like on-call counselors) seeking students versus students seeking help from staff. They could check up on students and teachers could have a set number of students to monitor and build relationships with."

"There's a support group at the school in Jeffco where I intern and they can talk about whatever is going on with them."

Youth Group Participants



Category 2: Community Capacity

Theme F Accessing behavioral health and related services is difficult for parents and youth because of funding barriers, long waits, and problems with navigation.

Parents had many concerns with accessing services and most often reported the following seven concerns:

- **Financial burden:** There were not enough approved doctors or qualified medical centers that took Medicaid, therefore many parents ended up paying out-of-pocket.
- **Insurance changes, inconsistencies, and restrictions:** Parents are limited to geographic constraints for doctors and worked hard to find ones that they felt were caring and respectful; however, insurance companies often changed their list of approved doctors, which led parents to feeling frustrated about having to “start over” with a new doctor, and often resulted in parents paying high out-of-pocket costs to stay with a doctor they liked.
- **Specialists:** The wait time to see specialists was lengthy and insurance was too selective about which procedures and treatments are covered for specific disorders (e.g. autism and neurological disorders).
- **“Red tape”:** Some specialists required parents to get referrals for particular disorders and treatments, often equating to more co-pays and time spent getting pre-authorizations. The convenience of “just going” and being helped was not there.
- **Navigation:** It was difficult for parents to navigate what services and providers were covered in the private sector. Doctors often provided recommendations for other providers, but many times these people were not covered under parents’ existing insurance.
- **Providers’ perceptions:** Children with severe needs were given the most resources but many parents reported that doctor’s said their children’s issues were “not severe enough,” so they did not get the assistance and care they needed.
- **Short on staff:** It could often be weeks before parents had the ability to make appointments which created barriers to initial access and consistent follow-up care.

“It felt like our lives need to be falling into little pieces before really getting the help we needed. It seems like they don’t care if we stick with them or with a specific program—just getting people in and out.”

Parent Survey Participant

Theme G Youth need choices and activities for support that reflect youth perspectives and provide realistic, safe options.

Youth repeatedly mentioned a lack of congruency between what youth want and what they actually get. They explained that youth did not enjoy being punished but would rather learn what

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they did wrong and what changes they could make in the future. Youth would like choices and activities reflecting fairness and value to them and mentioned if these choices and activities were not available, it might reduce their likelihood to use services at all.

“Wouldn’t you rather have award systems rather than punishment? But if it’s cheesy and no one really knows what it’s about it doesn’t resonate.”

“In my area, by the time you’re an upperclassman, the majority of people are either drinking or smoking weed. I think there needs to be a different approach, to get people to stop drinking or smoking on the weekends—a coupon is not going to do it.”

“You can lead a horse to water but you can’t make it drink. There was a shooting at my school a couple of years ago, and after they had a lot of counselors available, but I don’t know anyone who took advantage of that. I know I have a lot of great teachers I could talk to after school, but I don’t know what you can do to make students take that step. MH or SA services—means something is wrong with you, and there’s a bad connotation about them.”

“Programs and services—it’s demoralizing to admit to yourself that you need them. You think of rehab—you think, oh I’m not like Britney Spears, I don’t need rehab. You don’t want to admit that you’re as bad off as you are, but I don’t doubt that they are effective.”

“This year we also have a fairness committee, so if you’re having trouble with something unfair, you can talk about it.”

Youth Focus Group Participants

Theme H	Providers use jargon that is unfamiliar to parents when explaining their child’s behavioral health needs and the services or treatment routes available.
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Parents reported that they have a lack of information about what services might be available in their geographic location or the best treatment routes for their children. Confounding this issue were difficulties parents had knowing what the “correct” words were to explain their children’s needs to doctors. Parents felt that doctors did not always understand the content they were trying to get across which may have resulted in doctors getting an incomplete picture of their child’s problems.

Theme I	The service delivery systems are not coordinated or able to deliver holistic, integrated services to families and children with behavioral health needs.
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Parents reported that mental health and substance abuse systems do not appear to be working together as well as they could. Parents said this issue was salient when they tried to access services for their dually diagnosed (mental health and substance abuse) children; they were unable to receive services from either system because their children’s issues did not fit the mold of being solely mental health or solely substance abuse. Parents voiced that providers were not seeing the whole child but appeared to focus on the specific parts they felt they could help.

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Additionally parents reported difficulties with HIPAA (Health Insurance Portability and Accountability Act) and organizational information sharing barriers. Parents felt that information sharing between providers took too long, especially when their child were going through rapids changes and needed immediate help. Parents also reported that doctors were unable to accommodate their varying appointment needs, such as last-minute cancellations, availability to reschedule close to the original appointment date/time, and records distributions to new doctors/specialists before their scheduled appointment time. Parents expressed that dealing medical problems alone were not that bad, but dealing with medical and mental health services for their children at the same time got complicated.

“There has only rarely been an accurate sharing of information between providers, unless I take on that role.

“Providers always seem to face technological inefficiencies and organizational bureaucracy, so I do too.”

“I’m sick of signing lots of forms for each provider!”

Parent Survey Participants



Conclusion and Recommendations

The analysis of the online parent survey and Youth Partnership for Health focus group yielded analogous findings to the previous analysis of key informant interviews and family, youth, and staff focus groups in Mesa County. When schools utilized a strength-based approach, such as PBS, both parents and students reported positive feedback; however, youth suggested that their needs could be better addressed if their school could tailor support to fit individual needs.

Youth focus group participants and parents' participating in the online survey suggested a handful of changes to the schools, mental health providers, and other systems. Consistent recommendations heard from multiple participants are outlined below:

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- Increase training on behavioral health for teachers, principals, and other school staff including identifying children with behavioral health needs and responding effectively to their needs.*
 - Ensure youth-tailored, strength-based strategies such as PBS are fully implemented within all schools and with all school staff.*
 - Address barriers to accessing services, which may require addressing gaps in the service array, and increase individual school's awareness of and competence at referring parents to appropriate services.*
 - Create more youth friendly choices and activities for support that focus on value, fairness, and empowerment.
 - Expand and facilitate communication between parents and schools about working together to address and promote healthy behavioral health strategies for children.
 - Generate a common language with schools, parents, and doctors around behavioral health issues to help minimize misunderstandings and maximize appropriate attention and care to the issues.

* Denotes a similar recommendation found in the key informant and family, youth, and staff focus group report earlier in the year.