

Themes from Gap Analysis Community Meetings and Survey

The Gap Analysis Project addressing the crisis intervention needs of people with neurodevelopmental disabilities and co-occurring behavioral health disorders. This project is an initiative of the Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options (CANDO). With the support of the Joint Budget Committee, the General Assembly appropriated \$50,000 to the Colorado Department of Human Services - Division for Developmental Disabilities (CDHS-DDD) to support this project. This document summarizes information gathered from community meetings, a public survey, follow-up of Children's Hospital Colorado patients, and a public CANDO quarterly meeting. This summary will be included in a report from the CDHS-DDD to the General Assembly to lay the groundwork for building a responsive system for coordinated services, crisis prevention, management, and stabilization for people with neurodevelopmental disabilities.

This initiative results from the work of the Colorado Autism Commission. The Commission decided that its work and goals must address all neurodevelopmental disabilities, not just autism. A number of conditions are included under the term neurodevelopmental disabilities, including intellectual and developmental disabilities, autism, fetal alcohol syndrome, traumatic brain injury, Down syndrome, fragile X, and others. Consequently, when considering these issues, please remember that they apply to all people with neurodevelopmental disabilities who possess a wide range of intellectual and adaptive behavior abilities. This new perspective addresses the needs of a population that is much more inclusive than those who have been historically considered to comprise the population of individuals with developmental disabilities in Colorado. The reason for this more inclusive perspective is twofold. First, the Department of Human Services recently revised its long standing criteria for developmental disabilities to include limitations in adaptive behavior in addition to intellectual disabilities. Second, while the more inclusive population with neurodevelopmental disabilities does not have the same level of daily support needs as the traditional developmental disabilities population, their co-occurring behavioral health disorders draw upon many public and private resources and services. By the time crisis intervention services are needed, some type of response is unavoidable. The drain on emergency response systems is considerable and uncoordinated, and the expense is exponentially more costly than if preventative measures are taken in advance.

From August 29 through October 24, 2013, the Gap Analysis Project for crisis intervention services for people with co-occurring neurodevelopmental disabilities and behavioral health disorders held 11 community meetings across Colorado. These meetings were co-convened by Community Centered Boards and Mental Health Centers, and were attended by approximately 300 people.

In addition to the 11 community meetings, a secure public survey was made available online at (<https://redcap.ucdenver.edu/surveys/?s=9UMnVv>).

By December 2nd, 97 providers responded to a survey about issues they have encountered in serving this population. The providers included psychiatrists, psychologists, social workers, first responders, behavioral analysts and other therapists, as well as host home, day treatment, and residential treatment providers. Provider responses to the survey were consistent with the themes identified through the community meetings.

- Providers working in: Mental Health Center (23%), Direct Service Providers (21%), Hospital (15%), Private practice (11%), School (11%), Other (19%).
- Time Practicing in Current Profession: 0-5 years (14%), 6-10 years (22%), 11-15 years (12%), 16-20 years (18%), 20+ years (31%), no answer (3%).
- Providers who have received training in caring for individuals with co-occurring diagnoses: Yes (63%), No (33%), No answer (4%).
- Providers who have ever had to professionally turn away treating someone with co-occurring diagnoses: Yes (51%), No (47%), No answer (2%).

Adults with co-occurring neurodevelopmental and behavioral health disorders, as well as parents and caregivers of individuals with co-occurring diagnoses, also were invited to respond to the survey. Collectively, follow-up from Children's Hospital Colorado (CHC) patients and the Gap Analysis public survey received 197 responses.

- Age range 6 years to 65 years.
- Developmental diagnoses (more than one could be chosen) were reported as autism spectrum disorder (71% CHC; 66% public survey), developmental delay (42% CHC; 34% public survey), intellectual disability (27% CHC; 37% public survey), Down syndrome (0% CHC; 6% public survey), cerebral palsy (6% CHC; 7% public survey), other developmental disability (24% CHC; 17% public survey), I don't know (0% CHC; 4% public survey).
- Behavioral diagnoses (more than one could be chosen) were reported as depression (32% CHC; 34% public survey), anxiety (57% CHC; 66% public survey), bipolar disorder (27% CHC; 24% public survey), other mood disorder (40% CHC; 24% public survey), ADD/ADHD (51% CHC; 41% public survey), psychotic disorder (4% CHC; 9% public survey), substance abuse/addiction (0% CHC; 2% public survey), other psychiatric diagnosis (35% CHC; 28% public survey), unknown (0% CHC; 3% public survey).
- The IQ range was 70 and below (25%, CHC; 42% public survey), IQ 71 and above (51% CHC; 35% public survey), I don't know/no answer (24% CHC, 23% public survey).
- The most common reasons for using the emergency department (ED) were threat to others/property (65%, CHC; 47% public survey), self-injury (40% CHC; 36% public survey), and thoughts of suicide (35% CHC, 19% public survey).
- The percentage of individuals contacting 911 (60% CHC; 30% public survey) and using ED services two or more times (74% CHC; 27% public survey) were reported.

The community meetings and survey produced four main themes of where a gap exists for people who experience co-occurring diagnoses:

- A. System design and funding**
- B. Inter-system coordination**
- C. Support for families and caregivers**
- D. Knowledge and expertise**

The themes and issues reflect feedback obtained through the community meetings and surveys. Verbatim quotes from the surveys have been included to illustrate themes and issues. While these quotes represent the respondent's perceptions, the statement may not be accurate statements of actual policy.

A. System Design and Funding

- A1.** Colorado systems for behavioral health services and for services for people with neurodevelopmental disabilities create conflicting expectations and confusion about which system is responsible to address a presenting need that may have multiple etiologies.
 - A1a.** The service models for people with neurodevelopmental disabilities are based on long term supports; the behavioral health model is based on short term interventions, recovery and focused acute treatment modalities. It is difficult to coordinate services across these models because there may be needs that overlap.
 - A1b.** Collaboration between and among community providers of services and behavioral health providers for people with neurodevelopmental disabilities is difficult due to regulatory and funding complexities of both systems.
 - A1c.** There are conflicting statutes, regulations, and financing agreements about service provision, alignment, and coordination among all applicable oversight agencies at the state level.
 - A1d.** Diagnosis based criteria for access to behavioral health treatment limits capacity to provide services for some individuals with co-occurring diagnoses.
 - A1e.** Behavioral Health Organization contracts with the state require coverage of all eligible persons for behavioral health services, but do not require that providers develop capacity to serve all populations, either in numbers or expertise.
- A2.** Funding priorities, rates, and mechanisms are not flexible enough to ensure access to treatment and support for people with co-occurring neurodevelopmental disabilities and behavioral health disorders.
 - A2a.** There is no mechanism for payment of long term services and supports for people with neurodevelopmental disabilities in the Medicaid behavioral health managed services plan.
 - A2b.** Different reimbursement methodologies between services for people with neurodevelopmental disabilities (fee for service) and behavioral health services (capitated rates) are often in conflict.
 - A2c.** There are significant prohibitions to blending/braiding funding from different resource pools.

- A2d.** There is no incentive to prevent costs from occurring in other systems because of inadequate services in behavioral health and developmental disability systems—e.g. law enforcement, hospital visits, public schools, etc.
- A2e.** 37% of providers reported insufficient billing codes as a barrier to providing services and 57% report insufficient reimbursement from 3rd party payers as a barrier.
- A2f.** Many providers cited lack of providers who accept Medicaid as a barrier to services.
- A2g.** Many providers cited a lack of payment source as a reason they have had to turn away clients in this population who were seeking services. This turning away includes patients without insurance or patients with Medicaid who were determined not to have a qualifying diagnosis by the mental health system.
- A2h.** Several providers mentioned lack of coverage for Applied Behavior Analysis (ABA) services as a state Medicaid plan benefit or in behavioral health contract services as a barrier to providing service.

Caregiver quote: “We felt like we just got passed around. No one was willing to sit down and really figure out the problem. When we finally had a diagnosis, no one would take him as a patient because he was too far out of their comfort zone. I don't know if this was a policy issue, insurance issue, or what. It was an extremely frustrating and scary time.”

Caregiver quote: “When you leave the CES (*Children’s Extensive Support*) waiver and move to the SLS (*Supported Living Services*) waiver, the amount available for services is a drastic change. It would be nice to access some adult services without having to give up the ABA, or other therapies they need because of funding changes.”

Provider quote: “The biggest barrier is the way the I/DD and BHO (*Behavior Health Organization*) systems are set up. The Comp (*Comprehensive Services*) waiver expects the provider to provide all services other than acute services and the BHO system is set up to not serve people whose primary diagnosis is something other than a mental health diagnosis. There is lots of finger pointing at each other to provide services and the BHOs believe serving people with I/DD is not reimbursable.”

Provider quote: “Patients frequently get bounced back and forth between mental health agencies that will see individuals with mental health challenges but exclude patients who have co-occurring developmental disabilities and community agencies that work with patients with developmental disabilities but exclude patients who have co-occurring mental health challenges.”

Provider quote: “Every mental health center in the metro area needs to have dual diagnosis programs and providers who are willing to work with clients with I/DD.”

Provider quotes regarding having to turn down a client seeking mental health services:

Provider quote: “Generally this happens when the client has autism but no identifiable mental health disorder as I’m a Medicaid provider and Autism treatment isn’t covered by Mental Health Medicaid.”

Provider quote: “(When) I have done evaluations and deemed it necessary for a client to receive a certain level of care, which has been denied by Medicaid due to their diagnosis of ASD (autism spectrum disorder) or Intellectual Disability. This happens often and is extremely unjust.”

B. Intersystem Coordination

B1. Fragmentation of Medicaid covered benefits (either through Medicaid state plan or Home and Community Based Services (HCBS) waivers) for people with neurodevelopmental disabilities and co-occurring behavioral health disorders results in ineffective service provision and barriers for persons with co-occurring diagnoses to access needed services.

B1a. Emergency Departments are frequently used in crisis situations for people with neurodevelopmental disabilities and behavioral health disorders; Emergency Departments are ill equipped to address follow up needs.

B1b. Hospital Emergency Department staff, in general, are not well versed in trauma-informed care for people with neurodevelopmental disabilities.

B1c. There is a severe shortage of inpatient behavioral health treatment options for people with co-occurring diagnoses. The shortage is especially acute for higher functioning adults who do not have access to developmental disability services.

B1d. Available inpatient behavioral health options are not suitable for people with neurodevelopmental disabilities because of reliance on traditional approaches such as group therapy.

B1e. There are often few alternatives to hospitalization for services such as therapeutic respite and complex medication management. There are no step-down units or centers for sub-acute support.

B1f. There isn’t a clear understanding or consistent implementation of the various agency regulations regarding medication administration in respite services available through Medicaid HCBS waivers.

B1g. There is not cross-system care coordination among primary care, behavioral health services, and HCBS waiver services nor is there the ability to pay for this care coordination.

B1h. There is a severe lack of crisis follow up mechanisms that address cross system coordination: medication management, follow up services, as well as crisis prevention planning.

B1i. Access to behavioral health services and coordination services for people with co-occurring diagnoses who are not receiving HCBS Waiver services is almost nonexistent.

B1j. Primary care integration with services for people with neurodevelopmental disabilities and behavioral health disorders is lacking.

B1k. Inter-agency collaboration often does not go beyond local relationship building between provider organizations. True collaboration must start at the top of the responsible state agencies and must include the primary care community.

B1l. A significant gap exists in after-hours crisis support, creating an over reliance on first responders and hospital emergency departments.

B1m. Long term physical health and behavioral health services need to be better coordinated with attention paid to people with co-occurring neurodevelopmental and behavioral health disorders.

B2. There is limited and inconsistent integration among publicly funded service systems and disability and behavioral health services for people with neurodevelopmental disabilities and behavioral health disorders.

B2a. Law enforcement and other first responders are utilized for crisis situations but there is no systematic coordination among emergency, primary care, and long term service providers.

B2b. Little, if any, coordination exists among services provided for school age children with co-occurring diagnoses.

B2c. Transition support for children moving from Early Intervention (birth to age three) to school (ages 3 -21) and/or to HCBS waivers and transition from school to adult services are almost nonexistent, and where they do exist are poorly coordinated.

B2d. Crisis Intervention Training for first responders is not consistent (nor required) across the state.

Caregiver quote: “A single care coordinator that could be accessed 24 hours per day with access to the entire health record would be helpful. Someone to help plan and coordinate the needs of the whole person instead of trying to divide the person up between systems.”

Caregiver quote: “Doctors do not fully understand complex/hybrid medical issues and developmental disabilities. I believe that there needs to be more cross-medical/psychiatrist reviews of these individual cases to try to come up with a full diagnosis and approach rather than piece meal.”

Caregiver quote: “...Policy and procedures for first responders (ex: police) should become standard practice. Every community seems to have their own version and it shows a lack of training. CCB's and other advocacy programs should help with training for first responders. Policy and procedures should be uniform.”

Provider quote: “Fee for service payments don't work well since so much of the health care services that are needed happen, or should happen, outside an office visit. Lots of care coordination is needed and currently is not reimbursed.”

Provider quote: “Families don't seem to have understandings of their rights and federal laws, also negotiating through the billing and advocacy systems are almost impossible for many.”

Provider quote: “There are limited resources within the county outside of the school. Many parents report they have struggled to access services or even where to start looking for services for their child/youth.”

C. Support for Families and Caregivers

C1. Many children and adults with neurodevelopmental disabilities receiving publicly funded services live in the homes of family members. Services should be designed to address the needs of people in this context including respite, integrated care coordination, preventative behavioral supports, crisis prevention and stabilization.

C1a. CO has not defined and supported payment for therapeutic respite that addresses medication management, behavioral interventions, stabilization and crisis prevention.

C1b. Scheduled respite does not exist for all caregivers.

C1c. There is not a billable service for critical supports and services for families (especially siblings) when family members experience crises.

C1d. Services that enable family stability are essential for all persons with co-occurring diagnoses, yet such services are not deemed to be medically necessary.

C1e. Child welfare system is ill-equipped to support foster families caring for children with co-occurring diagnoses.

C1f. Residential providers (e.g. host homes) need respite and support, as well as families of origin and foster families.

Caregiver quote: “Talk w/ both parents and kids w/ diagnoses -when treating, treat family as well as person diagnosed. Sibling therapy would be AWESOME in a crisis.”

Caregiver quote: “Agencies SAY they offer emergency respite - but couldn't ever take someone like my [child]... If there was this option, maybe the unpaid parent caregivers wouldn't be broken into pieces and have to go to the extremes of constant ER visits and expensive residential care.”

Caregiver quote: “Having two diagnosed neurological disorders should qualify a child for an IEP (*Individual Education Program*). Children with High-Functioning Autism deserve more social/emotional/executive functioning support using an IEP despite having above average intelligence. A 504 is NOT covering all of the bases or making educators accountable for providing parents with essential communication needed for cohesively managing all aspects of support and interventions. Objective persons need to be present for writing and

implementing these important special education supports. Parents need support in navigating these meetings and knowing what by law their children are entitled to.”

Provider quote: “Colorado does not have options for in-home supports to help prevent patients from going to the Emergency Department when out of control behaviorally. CCBs and mental health centers are not equipped to manage high needs children. NSC is only inpatient unit for this population in the whole state with only 4 beds. When families are in crisis, their only option is the ED. We do not have adequate outpatient, in-home, day treatment, or residential placement options for people with developmental disabilities.”

Provider quote: “There is a lack of appropriate crisis services, when individuals are out of control due to behavioral issues or have significant intellectual disabilities and/or medical problems, there is no inpatient setting who is willing to serve them.”

D. Knowledge and Expertise

D1. Cross system knowledge is not required or incentivized. Skill development and capacity building is needed for primary care, and for neurodevelopmental, and behavioral health providers to treat children and adults with co-occurring diagnoses.

D1a. CO does not have an infrastructure that ensures:

D1a1. Coordinators in all provider agencies who understand behavioral health and other publicly funded service systems,

D1a2. Providers trained in differential diagnoses,

D1a3. Behavioral health system providers who understand neurodevelopmental disabilities, and developmental disability service providers who understand behavioral health service provision.

D1b. There is a lack of psychiatric specialists with expertise in serving people with neurodevelopmental disabilities.

D1c. CO rules are minimally flexible regarding provider requirements in rural areas.

D1d. Tele-health is not well utilized.

D1e. Respite providers are not receiving adequate cross-disorder/cross system training.

Caregiver quote: “Turn-over is huge. It always feels like we are starting over with providers.”

Provider quote: “There is a lack of understanding on the treatability and methods of treatment by most providers and systems.”

Provider quote: “Many providers do not feel comfortable and/or have not been adequately trained to provide services to this population. In areas that are more rural, the lack of providers is a major barrier to treatment. Further, it has been supported by research that early intervention is highly important, and many providers also need more training with very young children.”