

ACHIEVING ACCESS TO HEALTH FOR ALL COLORADANS

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ISSUE BRIEF

EARLY CHILDHOOD SYSTEMS BUILDING FROM A COMMUNITY PERSPECTIVE

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To be healthy and ready for school, many young children and their families need support services from a variety of programs and organizations, such as early learning centers, nutrition programs, and pediatric, nursing, dental and mental health care providers. One approach to ensuring that families have adequate access to these types of services is to increase funding for individual programs and organizations.

Yet even when such programs are available in communities, there are challenges in connecting families to these services. This is because the array of learning, health and care services is somewhat of a hodge-podge with differing funding sources, unique program standards, eligibility and reporting requirements. And the result is that families often have a difficult time learning about, applying for and taking advantage of the services that could benefit their children.

The Colorado Trust and many other early childhood stakeholders are working to increase the coordination and integration of these services in order to build a system that helps to keep kids healthy and ready to learn, and is easier for parents to understand and navigate.

This brief explains what is required to build such a system, and how this kind of systems building work differs from direct services and program delivery.

This brief also illustrates the need for systems building at the local level from the perspective of children and families who experience systems directly, as well as through the eyes of the service providers who work within those systems.

WHY SYSTEMS BUILDING IS IMPORTANT

A system is a set of interrelated parts that interact and function together to produce a common outcome or product. Systems are everywhere – they can be ecological, mechanical, organizational, political, cultural and so on. To get the best possible results from a system, its individual parts have to work effectively as a whole. The term "systems building" refers to building a new system or working to improve an existing system that is fragmented, informal or missing key pieces.

An *early childhood system* encompasses an array of separate, more targeted systems, including health, education and human services, which have the common goal of achieving better outcomes for children, youth or families. These systems have multiple programs, policies, agencies or institutions at the national, state or local level. The goal of early childhood systems building is to help families get the care and support they need for their children in the most efficient and effective way possible.

There are a variety of reasons why it is critical that states, local communities, nonprofits, foundations and others work to create or change systems. As noted above, early care and education services for children are often fragmented and uncoordinated, leaving families frustrated and unable to get the help they need. The problem is not always that services and programs do not exist; it may be that people do not know about them, they have trouble accessing them or the services that do exist do not meet their needs. Without ensuring there is an effective *system* that supports and delivers those services, families will continue to struggle to get the care they need.

As well, foundations and the public sector make the best use of their funding when systems operate more efficiently. The demand for health, education and human services far exceeds available resources. When grants to provide programs and services end, those programs and services often end as well, unless the system has institutionalized them by integrating them into its policies and approaches. Spending limited dollars on improving systems rather than only supporting discreet programs is a key way to sustain lasting change.

SYSTEMS BUILDING AREAS OF FOCUS

1. CONTEXT	Changing the <u>political</u> <u>environment</u> that surrounds the system and affects its success
2. COMPONENTS	Establishing <u>high-performing</u> and quality programs and services
3. CONNECTIONS	Creating strong and effective <u>linkage</u> across the system
4. INFRASTRUCTURE	Developing the <u>supports</u> the system needs to function effectively and with quality
5. SCALE	Ensuring the system is comprehensive and works for all children

WHAT SYSTEMS BUILDING LOOKS LIKE

Systems building is an intentional, organized attempt to create or improve a system and the outcomes it produces. For example, the Build Initiative, a collaboration of national funders that supports state efforts to create comprehensive early childhood systems, has developed the five-part framework outlined below to help define systems building and its outcomes:

1. Context

Improving the political environment that surrounds the system so that decision-makers produce the policy and funding changes needed to create and sustain the system.

Outcomes of system building efforts focused on the system's context might include:

- Policy changes that expand or enhance programs
- Funding streams that are more flexible across programs
- Public engagement or mobilization
- New advocates or champions.

2. Components

Establishing high-performance programs and services within the system that produce results for system beneficiaries. Outcomes of system building efforts focused on the system's components might include:

- New programs or services
- Expanded program reach or coverage
- Improved program quality
- Increased operational efficiency.

3. Connections

Creating strong and effective links across system components that further improve results for system beneficiaries. Outcomes of system building efforts that concentrate on the system's connections might include:

- Coordinated eligibility assessments and applications
- Referrals occurring from one program to another
- Joint planning across system components
- Shared data systems for tracking individuals.

4. Infrastructure

Developing the governance and administrative support structures that systems need to function effectively and ensure that services are high quality. System building efforts that focus on improving the system's infrastructure might result in:

- Governance entities to oversee and coordinate systems
- Consistent standards of quality across the system
- Education and training to ensure an appropriately skilled systems workforce
- Technical assistance to support systems development
- Defined roles and mechanisms for accountability.

5. Scale

Ensuring a comprehensive system is available to as many people as possible. The results of successful efforts to increase a system's scale might include:

- Availability of programs and services throughout a geographic region
- A comprehensive array of programs and services for system beneficiaries
- Long-term financial security to maintain the system over time
- Shifts in system ownership, meaning that a broad array of people involved in the system, especially those on the frontlines, assume responsibility for maintaining the system.

These five areas comprise the aspects of a system that, if developed or advanced, can produce broad impacts for the system's intended beneficiaries. Systems building efforts do not have to focus on all five areas, although most focus simultaneously on several areas.

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THE COLORADO TRUST'S EARLY CHILDHOOD HEALTH INTEGRATION STRATEGY

With the goal of improving health outcomes for children throughout the state, in 2008 The Trust announced a five-year, \$5 million strategy to support Colorado's network of Early Childhood Councils in building local systems that better integrate health and health care into Colorado's broader early childhood development system. While system rules and resources are usually defined at the national and state levels, most services are delivered at the community level. The Trust's strategy focuses on changing systems in local communities as that is where families experience the system firsthand.

Recognizing that Colorado's early childhood councils were already well-established in their communities and working to create systems change, The Trust has provided grants to 20 of the state's 30 local early childhood councils to supplement their state-level funding and allow them to better integrate health and health care into their systems.

"Working at a system level ultimately results in long-term changes in how business is done," said Linda Fellion, operations coordinator, Early Childhood Council of Larimer County in Fort Collins, Colorado. "The benefit of these pilot projects is that we can try things out on the local level and see if they work. If they do, they can feed into broader changes at the state and even the national level."

WHAT ARE EARLY CHILDHOOD COUNCILS?

Colorado's Early Childhood Councils are collaboratives of individuals and organizations that work to build a comprehensive, coordinated early childhood system to connect children and families to quality services within a county or group of counties. The intent of councils is to change the way early childhood stakeholders do business through collaborative planning, networking, funding, coordination and implementation. The councils focus on systems building to improve outcomes for children in four areas:

- Early Learning
- Family Support and Parent Education
- Social, Emotional and Mental Health
- Health

The goal is to create optimal developmental outcomes for young children by fully developing each of these areas and making sure that the programs and services in all four areas connect and support one another. Organizations representing the four areas collaborate to find ways to make the overall system work better for children and their families.

Colorado's Early Childhood Councils are a legislative expansion of the Consolidated Child Care Pilots that existed in the state from 1997-2006. Currently, 30 Early Childhood Councils are active in 55 of Colorado's 64 counties.

For more information: www.cde.state.co.us/early/ECC.htm.

The Early Childhood Councils are tackling several components of systems change based on the five-part model outlined above. While the councils do not provide health care services directly to families, they are working with service providers to improve how families find and move between services,

to minimize the duplication of services and to advocate for improvements in the quality and amount of services available to families in their area. Some ways that the councils are working on systems change include:

- Increasing the number of convenient sites where families can enroll in public health insurance
- Creating ways to link publicly insured families to health care providers who are willing to treat Medicaid patients
- Improving opportunities for children to have a medical home
- Getting children access to mental health assistance.

The example below presents one mother's struggle to get health care for her children and illustrates the challenges faced by beneficiaries and by service providers when a system doesn't work well. The example also demonstrates how the early childhood councils are working to address each of the systems-building elements described earlier: scale, connections, components, infrastructure and context.

» A FAMILY'S VIEW OF A BROKEN SYSTEM

Anna* stared at the letter and shook her head. She'd been rejected – again – for Medicaid coverage. This time it was for her son, Tyler, a six-year-old prone to scrapes and ear infections. Tyler was complaining that his ear hurt again. Anna knew that she and her three children were eligible for Medicaid coverage. But something seemed to always go wrong with her applications. Once, the state office rejected her application because it said she lived in another part of the state – an address she hadn't lived at for more than seven years.

Often she just received a letter that said "denied," with no explanation. Anna was already stressed about a \$300 bill she received for a doctor's visit for her oldest daughter, Julie, eight, when there was a mix-up about Julie's coverage. Anna, a housekeeper, had applied for the state Food Assistance Program after her hours were cut. That application had triggered reconsideration by Medicaid, and she had been temporarily disqualified from the program.

Anna felt overwhelmed at the thought of calling the customer service office, being placed on hold, and waiting to talk to someone who might or might not help her. But should Anna risk bringing Tyler to the doctor without a Medicaid card? She couldn't afford to pay any more medical bills. Anna's was interrupted by a cry from Tyler. His ear *really* hurt, he said. Anna gathered him up and headed for the emergency department. She didn't know what else to do.

Stories like Anna's are all too common. Anna and the health care providers who try to help her are caught in a confusing array of disconnected services that don't provide the care and support Anna's family needs. No amount of programs and services – foundation or government-funded – will make a difference if seemingly simple tasks like getting a Medicaid application approved don't work for people like Anna. Anna needs to have access to a system that works to ensure her family receives health care and other services.

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^{*} Anna's story is a composite of several Coloradans interviewed for this brief. All of the scenarios described in the brief have occurred to Colorado patients and quotes are from actual Coloradans who have Medicaid coverage.

» EXAMPLES OF SYSTEMS BUILDING TO IMPROVE EARLY CHILDHOOD HEALTH

EXAMPLE: BUILDING SCALE

Ensuring the system is comprehensive and works for all children

Expanding Access to Public Health Insurance Application and Enrollment Assistance

The Problem: Anna, a 26-year-old with three children, has had continual problems being accepted for Medicaid even though she meets all of the eligibility criteria. At times her application has been denied because her income changed or because she applied for food assistance, which has different eligibility requirements. Other times, she forgot to include a piece of information on the 16-page form, which she must fill out yearly. Other times, Colorado's data system has denied her application for no apparent reason.

The Consequences: For Anna, the application process and its many hurdles are overwhelming. The county Medicaid application center in her town is a long bus ride away and only open during work hours. An overwhelmed customer assistance line in Denver often keeps her on hold for 30 minutes or more or asks her to leave a message so a specialist can get back to her. Once she submits an application, Anna must wait 30 to 45 days for approval.

During this waiting period, Anna often hesitates to obtain medical care for herself or her children for fear they have no insurance. In one frustrating incident, Anna's daughter was denied asthma medication because of a mix-up in her Medicaid coverage. Anna said that she went to her local pharmacy every day for 10 days before the situation was resolved. "I felt like nobody cared," she said. "I felt defeated by the system. I was worried that my daughter would get sick and I didn't know what to do. At one point, I just lay down and cried."

The Systems Building Solution: The early childhood council located in Grand Junction, Colorado – the Mesa County Partnership for Children and Families – is working to address this system problem through changes in the system's **scale**.

In Mesa County, a client like Anna might be able to resolve her problem by seeking enrollment assistance from a health advocate at a local nonprofit organization or clinic that understands the Medicaid application system and, in some cases, can enroll children and pregnant women immediately for Medicaid and give them a temporary card rather than wait 45 days for approval. The health advocate also has access to the Medicaid computer database and can see the status of a client's application and address problems that may cause a delay.

Health advocates such as these are one way to assist patients as they navigate the complex public health insurance process. The problem is that there are not enough advocates trained in the intricacies of the enrollment process to help people like Anna. And often such services are not well publicized. It was only luck that brought Anna to the advocate's office. Her mother-in-law heard about the office and told her.

The Colorado Trust

To increase the opportunities for clients to find advocates, hence expanding the scale of services to reach a greater number of families, the Mesa County Partnership for Children and Families is working to create an "every door is the right door" system in Mesa County. That means that no matter where Anna goes – her doctor's office, her son's early learning center, her daughter's elementary school – there will be someone who can help her fill out a Medicaid application and track it.

"Families don't know where to go to for help," said Cathy Story, director of Hilltop's Child & Family Center in Grand Junction and a member of the Mesa County Early Childhood Council. "Our goal in systems building is that there is no wrong door. If a parent goes to a school and her child is struggling with asthma, there is someone there who tells them what to do."

With grant funding from The Trust, Council staff will train people who work on the front lines of these organizations – places where people like Anna already go and have trusted relationships. After learning about the application process, these staff can work with families who need help filling out their applications for public health insurance. In turn, once families receive this help, they are expected to pass what they learn on to their friends, families and neighbors.

EXAMPLE: BUILDING CONNECTIONS

Creating strong and effective links across the system

Connecting Families with Physicians who will Accept Medicaid Patients

The Problem: Thanks to the help of her health advocate, Anna and her children are enrolled in Medicaid and have a temporary card she can use immediately. Her son needs to see a doctor for his persistent ear aches. Anna calls a medical practice that was recommended by her friend and learns that the practice is not accepting Medicaid patients. She asks for the name of another practice that does take Medicaid patients. The receptionist says she doesn't know of any.

Anna asks around for other doctors but can find none that accept Medicaid and are taking new patients. With no alternative, she takes her son to an urgent care center, which does not have any of her son's medical records or information about the fact that this is his fifth ear infection in two years. The health provider hurriedly prescribes another round of antibiotics and sends Anna and her son on their way.

The Consequences: Anna has no regular physician practice to take her children to and she continues to go to emergency rooms and urgent care centers, which treat the symptoms but do not treat the underlying problems that her children are experiencing. This results in expensive, fragmented and ineffective care.

The Systems Building Solution: Several early childhood councils are working to address this problem through changes in the system's **connections**, by creating links between places where families can enroll in public health insurance and places where they can get care.

Early Childhood Systems Building from a Community Perspective

Councils are creating directories of physicians who accept Medicaid and are taking new patients. They are distributing information about the availability of these directories through fliers at places where patients and their children frequent, including early learning centers, hospitals and notes sent home from school. The fliers include information on how parents can obtain the directory, including a website address.

In Mesa County, the council is establishing a system that rotates referrals of Medicaid patients to physicians so that no one physician practice is overwhelmed. When Anna goes to a health advocate to sign up for Medicaid, the advocate can look at the referral system and see which physician practice is next in line for a referral. This method may help encourage more physicians to accept Medicaid patients.

EXAMPLE: BUILDING INFRASTRUCTURE AND CONTEXT

Developing the supports the system needs to function effectively and changing the political environment that affects the system's success

Improving Opportunities for Children to have a Medical Home

The Problem: Anna has found a physician's practice that accepts Medicaid and has brought her son in to be seen for another ear ache. The physician is incredulous that Tyler has had so many ear infections and asks Anna if she's been following her previous doctors' instructions. Anna notices that the medical file clearly shows that she is on Medicaid. Anna also notices that the doctor is curt with her. As the doctor examines Tyler, she continues to exclaim that there is no reason for Tyler to have so many ear infections.

Anna, who is already stressed about her son's ear aches, shrinks into her chair. "They treat you like dirt when you're on Medicaid," Anna said, "You're scum. Why are they judging me? They don't know me and why I'm on Medicaid."

The doctor says that Tyler needs to see an ear, nose and throat specialist. She makes a note on Tyler's chart and tells Anna that someone in the office will be in touch with a referral.

For her part, the doctor is overwhelmed by seeing so many patients like Anna who continually bring their children in with recurring problems and who don't seem to follow instructions. She is also frustrated by the low reimbursement she receives for treating Medicaid patients, who have often complex needs.

Anna waits a week and does not hear from the doctor's office. She calls and reaches a busy medical assistant who says that she will have to pull Tyler's file, but cannot get to it that day. After months of calling, someone at the physician's practice says that the referral must have gotten lost. Finally, six months after the initial visit, Tyler sees a specialist and has tubes inserted in his ears.

The Consequences: By the time Tyler sees the specialist, he has had two more painful ear infections. Because of hearing loss brought on by his many ear infections, his speech is delayed. He receives speech therapy for several months, which would likely have been avoided if he had had his ear infections treated properly.

The Systems Building Solution: Several early childhood councils are working to address such problems by making changes in the system's **infrastructure** and **context**.

In recent years, there have been several efforts to create a "medical home" for patients. This means that one health care provider is responsible for overseeing and coordinating a patient's care. To be considered a medical home in Colorado, provider practices must adhere to several standards of care, including treating families as partners in their care, providing connections to supports and services in the community and providing after hours and weekend access to medical consultation.

Medical homes have access to all of their patients' medical records, including those from other physicians, so, for example, they can make sure that the prescription that they are writing doesn't interact with prescriptions from other doctors.

If Anna had access to a medical home, she would not have to feel any different because she receives Medicaid coverage. Physicians receive higher reimbursement rates for Medicaid patients when they are using a medical home approach. Additionally, Tyler's medical records would not be filed away until the office had made an appointment for him to see a specialist because medical homes have case managers who help coordinate patient care.

While many initiatives exist to establish medical homes, often in the same community, they are sometimes uncoordinated. Without coordination of these medical home initiatives, there is a strong chance that these attempts at system change will fail. The early childhood council in Mesa County is helping to build an infrastructure that facilitates the development and smooth functioning of medical homes in the county. They are bringing together three medical home initiatives in their local community to coordinate efforts and discuss standards of quality and opportunities for information sharing. They are also educating providers on how to implement a high-quality medical home approach.

Additionally, many councils are addressing the context – or political environment that surrounds and affects the system that provides health care to publicly insured patients – by advocating for policy makers to increase reimbursement for physicians who accept Medicaid patients. Medicaid reimbursement is traditionally low, and Medicaid patients often have complex health problems, making some physicians reluctant to take on many patients with public insurance coverage.

EXAMPLE: BUILDING COMPONENTS

Establishing high performing and quality programs and services

Getting Patients Access to Mental Health Assistance

The Problem: Anna's youngest son, Sam, age four, has been biting children at his early learning center. He has been kicked out of four centers already, and Anna is running out of options. None of the staff at the centers seem to know how to handle Sam's behavior, and Anna is at a loss as well. She noticed that Sam's behavior problems began around the time her husband lost his job as truck driver. Tensions have run high in the household, and Anna and her husband argue often. Recently, her husband moved to Idaho, where his brother lives, to look for another job.

The director of the center does not want to expel Sam. But she and her staff do not have the training to address Sam's behavior problems and they don't know where to refer him for specialized care. In the meantime, the other parents are threatening to remove their children from the center if Sam doesn't go, placing the director's business in jeopardy.

The Consequences: If Anna doesn't find a solution soon, she'll have to quit her job and stay home with Sam, putting the family in further financial peril.

"More and more children are acting out in child care centers," said Susan McColl, a nurse specialist who works as a consultant to several early learning centers in Larimer County, Colorado. "We're seeing kids with massive tantrums who are hurting themselves, other kids and even their teachers," McColl said. "I think life is rough right now. Parents need more help with parenting as stressed as they are with the economy and the job situation. The teachers are trained but they're not trained in these issues."

The Systems Building Solution: Several early childhood councils are addressing this problem through making changes in the system's **components**, or the services and interventions available to the system's beneficiaries.

The Early Childhood Council of Larimer County is improving the services available at early learning centers by training staff in standardized tools and techniques to help them respond to children acting out and to refer children to mental health professionals if necessary. If educators are trained to respond to challenging behavior, such as biting and temper tantrums, then children are less likely to be shuffled from one center to another.

Working with the Early Childhood Council in Larimer County, McColl has developed a referral sheet for early learning centers of mental health providers who will see children with behavioral problems, including children on Medicaid. The sheet also has a checklist of problematic behaviors. When educators at the centers make referrals, they have the checklist to help them accurately describe the behaviors. The checklist is also a starting point to help center staff understand where they need more training, McColl said.

» CONCLUSION

Many funders and advocates are focusing on the policies and support structures needed at the state and national levels for early childhood programs and services to become more coordinated and comprehensive. While this is crucial to creating positive outcomes for children, the way a system operates on a local level also determines how families experience these programs and services. Local communities – including service providers, parents, business leaders, nonprofits and government agencies – can find ways to coordinate and maximize resources dedicated to early childhood health and development within their own communities, so services are more accessible, efficient and tailored to their needs.

This kind of systems building isn't easy. It requires thinking on a broader, more comprehensive level and working with different organizations that often have competing demands. Systems building is an investment that can pay dividends for years to come. Through systems building, families like Anna's can get the care they need for their children.

The framework for systems building described in this brief is broadly applicable. Beyond early childhood health and development, it can be applied to public health systems, health care delivery systems, education systems and others to illustrate the systems that people navigate every day.

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