

**Children’s HCBS Waiver Interim Committee
Report to Legislative Council
November 2009**

I. Introduction

Currently, more than 900 children with chronic, long-term disabilities are waiting for services under four Children’s Home and Community-Based Services (HCBS) waivers. Along with their families, these kids are waiting years for vitally necessary health care services and benefits. The medications, therapies, formulas, diapers, durable medical equipment, and home health care that they need are not available through other funding streams.

Many of the kids and families waiting for services have private insurance (an estimated 80% based on testimony), yet coverage is often inadequate or lacks specific benefits for many of the high-cost services that children with special health care needs require, such as durable medical equipment, home health care, and mental health services.

Family Testimony: Kevin Devine testified before the interim committee that the family’s private insurance provider deemed their 3-year-old son’s wheelchair seat a “luxury item” and thus denied coverage. Following many calls and hours, the denial was reversed with the assistance of a community advocacy agency. Unfortunately, due to the delay in getting a properly fitted wheelchair, 3-year-old Robert suffered unnecessary, significant skin breakdown which required surgery.

While most of these children waiting for services qualify for “nursing home level of care,” providing services and allowing children to live at home whenever possible is more desirable for families and cost effective for the state.

II. Legislative Committee Members

The legislative committee consisted of eight members from both the State Senate and State House of Representatives. Both the President of the Senate and the Senate Minority Leader each appointed two members. Two members of the House of Representatives were appointed by the Speaker of the House and two were appointed by the House Minority Leader.

The table below identifies the attendance of committee members by meeting.

	Aug 10	Aug 25	Sept 1	Sept 24	Oct 6	Oct 20	Oct 27
Rep. Dianne Primavera, Co-Chair	Present	Present	Present	Meeting Rescheduled 10/27	Present	Present	Present
Rep. Cindy Acree, Co-Chair	Excused	Present	Present	↓	Present	Present	Present

	Aug 10	Aug 25	Sept 1	Sept 24	Oct 6	Oct 20	Oct 27
Sen. Moe Keller	Present	Present	Present	Meeting Rescheduled 10/27	Present	Present	Present
Sen. Shawn Mitchell	Present	Absent	Present (Arrived 9:35)	↓	Present	Present	Absent
Sen. Pat Steadman	Joined Committee 8/10/09	Present	Present	↓	Present	Present	Present
Sen. Scott Renfroe	Absent	Absent	Absent	↓	Absent	Absent	Absent
Rep. Marsha Looper	Present	Absent	Present (Arrived 10:15)	↓	Absent	Present	Present
Rep. Nancy Todd	Present	Present	Present	↓	Excused	Excused	Present

III. Committee Charge

Through House Joint Resolution 09-1026, the Colorado General Assembly created an interim committee. The charge of the committee was to understand why large waiting lists exist for HCBS waivers for children with chronic, long-term disabilities and discuss strategies and solutions for reducing the waiting lists for the 900 children in need.

The specific HCBS Waivers examined by this committee included: Children’s HCBS Waiver (C-HCBS), Children’s Extensive Support (CES), Children with Autism Waiver (CWA), and the Hospice or Hope Waiver.

The committee met a total of six times from August through October 2009 to solicit public testimony and accept input from the community. Interim committee members volunteered their time. No funds were provided for this committee; therefore, Legislative Council was unable to provide support. Instead, the committee was supported and staffed by two nonprofit organizations: Family Voices Colorado and the Autism Society of Colorado. A private grant from The Colorado Health Foundation was acquired to support an external project facilitator and to reimburse some costs of printing and support services to this committee.

IV. Summary of Children’s HCBS Waivers

- Children’s Home and Community-Based Services Waiver (birth through 17)
 - Provides Medicaid eligibility and case management for children meeting eligibility criteria of nursing home level of care
 - Number of children served: 1,308
 - **Number of children waiting for services: 500**

- Children’s Extensive Support Waiver (birth through 17)
 - Provides Medicaid, case management and additional services through the Community Centered Board for children with developmental disabilities and other special needs
 - Number of children served: 375
 - **Number of children waiting for services: 300**
- Children with Autism Waiver (birth through 5)
 - Provides Medicaid and specific services for children with medical diagnosis of Autism
 - Number of children served: 75
 - **Number of children waiting for services: 200**
- Children’s Hospice Waiver, or HOPE Waiver (birth through 18)
 - Provides Medicaid and end of life care services for children with a life limiting diagnosis
 - Number of children served: 200
 - **Number of children waiting for services: 0**

V. Summary of Meetings

Through the course of six meetings, the committee examined why large waiting lists exist for more than 900 children with special needs, as well as potential solutions to reduce the waiting lists for Children’s HCBS waiver services in Colorado. Each meeting provided an opportunity for public comment as it related to the committee’s agenda. Further, the committee heard from parents and received additional written testimony from families with children on the waiting lists at every meeting.

August 10 – Children’s HCBS Waiver Overview

The purpose of this meeting was to create an understanding among committee members regarding the four Children’s HCBS waivers. The committee heard from Jennifer Brodis, Long-Term Care Options, regarding the system called Single Entry Point (SEP) for families with a special health care needs child. The SEP system is a contracted entity in Colorado that establishes long term care eligibility for Medicaid. The SEP in counties may sit in the Adult Aging Services, County Health, CCB or a stand-alone agency. As each county does things differently, the issue of county autonomy became an understood confusion for families by committee members. It became evident how challenging it is for families trying to navigate the service systems from one county to the next.

In addition to the provider perspective offered by Ms. Brodis, Susan Johnson of the Developmental Disability Resource Center (DDRC) provided a snapshot for the committee regarding Colorado’s Community Centered Boards (CCB) system. Throughout the state, CCBs serve as an entry point and provider of care for many families of children with developmental disabilities (defined in Colorado by an IQ of 70 or lower).

The meeting concluded with family testimony from Traci von Lührte, a single mother living in Byers, on behalf of her 10-year-old son, Daniel. Daniel is Autistic and has cereal palsy. He has a feeding disorder and requires diapers. Traci's days are consumed with Daniel's care – bathing, feeding, diapering, and constant vigilance to prevent him from hurting himself or others. After being on a waiting list for six years, Daniel finally qualified for the CES waiver and the von Lührtes' daily lives, although still very challenging, are much improved.

August 25 – Navigating the System

The meeting began with testimony from Kevin Devine regarding his 3-year-old “bundle of joy,” Robert. Robert has numerous disabilities – scoliosis and a g-tube for feeding, are among them. As noted above, Robert's wheelchair seat was considered a “luxury item” and denied by his private insurance provider. Without the needed coverage, Robert was essentially forced to remain in an ill-fitting wheelchair, causing him to suffer unnecessarily. Unfortunately, before the denial was reversed, the young boy developed blood blisters that required surgery.

At this meeting, committee members had an opportunity to experience first hand the challenges families with a special needs child face every day in Colorado. Members of the committee were paired up and given a real-life scenario of a family trying to access and navigate through the system. The committee was provided a binder of information to help them better understand the complexity families experience when trying to secure care for their children.

Members from Colorado's advocacy communities, nonprofits, service providers, and other agencies who help families with special needs children volunteered their time to “staff” information tables for this exercise. Unlike in real life, committee members had the ability to go from one table to the next in order to find the right point of entry to help solve the particular problem in the scenario they were given. It was noted that in real life, it is far more difficult for families because they must figure out on their own how to get services for their kids. This may require hours searching online, shot-in-the-dark phone calls to various agencies, multiple visits to providers, months without care, and more.

Following the exercise, committee members shared their experiences and frustrations regarding the current and complex system that Colorado families must navigate in order to secure care for their children.

September 1 – Administrative Streamlining and Cost Efficiencies

Building off the experiences from the previous meeting, the focus of this meeting was to examine ways in which streamlining and cost efficiencies could be achieved through the four Children's HCBS waivers in order to provide services for families currently waiting for care.

Committee members heard from representatives from Health Care Policy and Financing (HCPF), including: Sue Williamson, Deputy Director; Barb Prehmus, Director, Long-Term Benefits Division; Bob Douglas, Legal Division Director; and Gary Ashby, Manager, Benefits Coordination. During the presentation, HCPF staff discussed current efforts underway to modernize enrollment and streamline the waiver application process. Also discussed were the

Department's efforts around "pay and chase" in order to ensure that Medicaid remains the payer of last resort, when a family has a private primary health insurance provider.

Following HCPF's testimony, representatives from the Office of the State Auditor reviewed recent audit findings regarding current practices among developmental disability providers (Community Centered Boards). This presentation was requested by one of the committee co-chairs to determine if financial efficiencies could be realized regarding the existing CCB system in Colorado. Currently, these entities determine eligibility as well as plan, provide, and evaluate service provision for clients.

John Miles, Developmental Disability Division Director of the Department of Human Services provided information to the committee regarding the program's efforts to meet the needs of Colorado families.

Maty Calderon provided testimony at the end of the meeting. Her child, 2-year-old Mateo is on the waiting lists for both the CES and the CWA waivers. Mateo has Autism and the family's private insurance only covers a small percentage of the recommended 20 hours of therapy per week that he needs. It is difficult for his parents to wait while Mateo misses out on meeting his potential.

September 24 – Rescheduled October 27

October 6 – Best Practices from Other States

To begin the meeting, the committee heard testimony from Heather Schichtel, whose 3-year-old daughter, Samantha, is on the waiting list for the Children's Extensive Support (CES) waiver. Samantha has been diagnosed with Mitochondrial Myopathy. She does not crawl, sit up, or walk. She is non-verbal, g-tube fed, suffers from seizures, and requires cauterization four times per day, oxygen, and monitoring through the night. The Schichtels are in need of home modifications, auto modifications and durable medical equipment.

Next, via conference call, the committee heard a presentation from Meg Comeau from the Catalyst Center at Boston University. The Catalyst Center is a national center dedicated to improving health care insurance and financing for children and youth with special health care needs. Ms. Comeau provided information regarding efforts under way in other states, including Medicaid Buy-In programs and Catastrophic/Safety Net Funds which work with HCBS Waiver programs to provide care for children with special needs and their families who are in crisis and have no alternative means for care. Questions arose regarding "super waivers" and Ms. Comeau offered to have a colleague of hers present at the next meeting. In concluding, Ms. Comeau also spoke to 1115 Waivers and 1915B Waivers, which are different structures for HCBS Waivers.

Val Saiz from the Colorado Respite Coalition testified next. Ms. Saiz addressed respite care and a family's need for external supports when they have a child with special health care needs. Specifically, Ms. Saiz spoke about efforts in Nevada, Oregon, and Massachusetts, as well as the National Respite Act. Colorado does not currently have any type of respite program.

After committee members learned about the importance and need for respite care, Christy Blakely from Family Voices Colorado began a discussion around the fact that many families on the Children's HCBS waiting lists don't need all of the services offered through the waivers. However, they have no other way to access the few services they need, such as help purchasing diapers and/or formula, or respite care without seeking all of the services provided by the waiver. As a result of that conversation, the committee began to explore the possibility of bulk purchasing through the state.

The meeting concluded with testimony from Kayse Boice, whose 5-year-old daughter, Jordan, is waiting for access to Autism services through the CWA waiver, which ends at the age of 6. If her daughter does not receive services by age 6, she will start at the bottom of one of the other Children's HCBS wait lists. Jordan's family has paid for as much therapy as they can from a bonus they received last year, but they are still unable to meet her needs.

October 20 – Follow up and Findings

The meeting began with testimony from Cheryl Dewey. Her 4-year-old son, Cameron, has Autism and is on the CWA waiting list. Cameron receives SSI Medicaid, but does not have private insurance. Therapies needed to assist Cameron are available through waived services and not the state Medicaid benefit package. Cheryl said that her family is on the brink of being destroyed. As she stated, "Cameron is a daily force that wears on everyone." She testified that she and Cameron's siblings used to joke about the fact that if Cameron was having a bad day, then everyone was having a bad day, but it's not a joke anymore.

During the course of the previous meeting, as well as in earlier discussions, the issue of "global waivers" or "super waivers" was raised. In an effort to learn more, the committee invited Dr. Sally Bachman, also from the Catalyst Center of Boston University, to share information regarding other states' efforts in this area. In the end, what the committee found was that various states had sought 1115 Demonstration Waivers to address barriers around Medicaid, but, no state has actually secured a "super waiver" to address barriers faced by families with special health care needs children waiting for HCBS waiver services.

The committee asked Bob Douglas, Legal Division Director from HCPF, back to discuss the Department's efforts around "pay and chase" and existing practices to ensure Medicaid is the payer of last resort. In addition, the committee invited representatives from the Department of Regulatory Agencies' Division of Insurance to address current practices around third party recovery efforts. In attendance were Commissioner Marcy Morrison, Deputy Commissioner of Consumer Affairs Peg Brown, and Director of External Affairs Jo Donlin.

The meeting ended with testimony from Christine and Ed Quayle, who brought along their 2½-year-old son, Brian. Due to the cost of care for their son, The Quayles were forced to downsize and recently sold their home in order to have the resources necessary for their son's care. Ed, a police officer, and Christine, a nurse, both work to provide for the son they waited to have. The family has private insurance, but it does not begin to cover Brian's many complex,

medical needs. In fact, the Quayles brought Brian to the meeting in a loaned wheelchair from Kid's Mobility. They also testified that their son's needs include an evaluation, orthotics, surgeries and equipment, which they have not been able to access through public or private health insurance. They are waiting for two different waivers.

October 27 – Proposed Committee Legislation for 2010

The committee reviewed various ideas raised throughout their previous five meetings and reviewed potential pieces of legislation for 2010. The bills that passed out of committee are discussed below.

VI. Recommendations, Findings and Proposed Legislation for 2010

a. **Catastrophic Children's Fund** (respite, diapers, formula, and other safety net services not available through existing funding): This measure would provide one-time funding for families in need. Representative Todd is the House Sponsor and Senator Steadman is the Senate Sponsor.

b. **Denial Appeals Process ("pay and chase")**: This measure aims to increase third-party recoveries for the purpose of creating an Ombudsman office for families seeking or enrolled in any Children's HCBS waiver, and to provide funding for services to families in need. Senator Steadman and Representative Loper are sponsoring this measure.

c. **Administrative Streamlining**: Representative Acree and Senator Mitchell will carry this measure, which authorizes HCPF to create a universal application and single point of entry for HCBS waivers for children.

d. **Group Purchasing**: Representative Acree is the House Sponsor for this measure and Senator Keller has agreed to be the Senate Sponsor. This measure directs HCPF to negotiate agreements with suppliers so that families waiting for access to waivers can purchase medical supplies or equipment at a lower rate.