

COMMUNITY LIVING ADVISORY GROUP REPORT

Final Recommendations | September 2014

This report contains recommendations from the Community Living Advisory Group to the Governor of Colorado for improving the state's system of long-term services and supports.



TABLE OF CONTENTS

Foreword from Senator Betty Boyd, Chair	1
Preamble: A Declaration of Shared Principles.....	2
Recommendations	3
Improve the Coordination and Quality of Care in the LTSS System.....	7
Streamline and Simplify Access to LTSS	10
Simplify the State's HCBS Waivers	13
Grow and Strengthen the Paid and Unpaid LTSS Workforce	18
Harmonize and Simplify LTSS Regulations.....	20
Promote Accessible, Affordable, Integrated Housing.....	23
Promote Employment Opportunities for All.....	26
Support Implementation	30
Endnotes	33
Glossary of Terms.....	36
Appendix A: Members of the Community Living Advisory Group.....	38
Appendix B: Recommendations at a Glance	45
Appendix C: Resources Available on the Internet.....	47
Appendix D: Acknowledgements.....	48

Foreword from Senator Betty Boyd, Chair

On behalf of the Community Living Advisory Group, its subcommittees, and work groups, I am excited and proud to deliver this report to the Governor and to the Executive Directors of the State Departments of Health Care Policy and Financing, and Human Services. The Governor (Executive Order D 2012-027) challenged us to recommend changes for a long-term services and supports (LTSS) system that is responsive, flexible, accountable, and self-directed. I hope the reader will see in these pages our foundational commitment to person-centeredness and self-direction in Colorado's LTSS system.

The intention of these recommendations is to create a LTSS system that responds to the needs of all people, regardless of where they are on the age/ability continuum. We also believe that all parties in Colorado's LTSS system share a responsibility to use resources wisely: Coloradans who receive LTSS, the entities that offer and administer those services, and the entities that provide them.

The variety of stakeholders participating in the Advisory Group and its sub-groups included consumers, family members, other caregivers, advocates, providers, state and local agencies, and legislators. Throughout this process, we maintained the goal of transparency with all of our stakeholders.

The work that went into developing these recommendations has been nothing short of monumental. The Advisory Group met and worked for two years, created six subcommittees and several work groups that worked very hard to research efforts and innovations within Colorado and across the nation, polled constituents for input, and presented draft recommendations to the Advisory Group for consideration. Altogether more than 190 people contributed more than 3,000 hours of work on this report.

I thank all those who contributed their time, energy, and expertise to help create this forward-thinking report.

A handwritten signature in cursive script that reads "Betty Ann Boyd".

Senator Betty Boyd
Chair, Community Living Advisory Group

Preamble: A Declaration of Shared Principles

We, the members of the Community Living Advisory Group, share a common set of deeply held beliefs about how Coloradans should be able to access and direct long-term services and supports (LTSS) and about how Colorado's system of LTSS should help individuals lead happy, successful lives as full members of their communities.

We believe that all Coloradans have the right to live, work, play, and learn in communities of their choice as fully participating, contributing, and valued members of our society.

We believe that all Coloradans have the right to live a life based on inclusion, not segregation.

We believe that Colorado's LTSS system should respond to the needs of people, regardless of where they fall along the age/ability continuum.

We believe that all Coloradans should have access to the LTSS they need without having to impoverish themselves.

We believe that all parties in Colorado's LTSS system share a responsibility to use public dollars wisely: Coloradans who receive LTSS, the entities that offer and administer those services, and the entities that provide them.

We believe that Coloradans who receive LTSS have the right to direct those services and supports for themselves.

We believe that Colorado's LTSS system should be fundamentally person-centered and built on a foundation of consumer choice, cultural competency, dignity, respect, and freedom.

We believe that Colorado's LTSS system must offer the right services, at the right time, in the right amount, for the right length of time, in a place of the individual's choosing. We believe that decisions about what is appropriate should be made by individuals, not by the system.

We believe that Coloradans who receive LTSS deserve to chart their own destinies - as all Coloradans do, regardless of age or disability.

Recommendations

Colorado has historically been a leader among states providing long-term services and supports (LTSS) to people with all types of disabilities, enabling them to live in the community among family and friends. Shortly after 1915(c) home and community-based services (HCBS) waivers became available to states in the early 1980s, Colorado obtained approval for the second and sixth waivers granted by the Centers for Medicare and Medicaid Services (CMS), first for individuals with developmental disabilities and then for individuals who are older, blind, or disabled. In the early 1990s, Colorado became one of the first states to implement a single entry point (SEP) system, using a network of entities to determine eligibility for Medicaid and functional eligibility for most of its waivers. Today, Colorado is one of only three states to have a 1915(c) waiver that provides services to individuals with serious mental illness.

While Colorado can take great pride in its past leadership in this area, the state must also recognize that its existing system is ill equipped to meet the challenges of the 21st Century. For example:

- As the state's population grows, and there are more Coloradans who are older and/or have disabilities, the demand for LTSS will grow dramatically. This will place considerable strain on the state's LTSS workforce, its supply of adequate and affordable housing, and its transportation systems.
- Colorado's LTSS system is highly fragmented, making it difficult to deliver the coordinated, quality services that lead to better outcomes for consumers and sustainable costs for the state.
- Coloradans often do not know what services are available to them, or how to navigate the state's confusing LTSS system.
- The state's LTSS system is not sufficiently person-centered in that it does not uniformly provide opportunities for choice, control, and self-determination.

Recognizing the shortcomings of the state's LTSS system, Governor John W. Hickenlooper issued an Executive Order in July 2012 (2012-027) that created the

Office of Community Living within the Department of Health Care Policy and Financing (HCPF). The Order notes the need for a "strategic vision that will improve outcomes, recognize limited resources, break down silos, and promote self-direction and person-centered care."

The Governor's Order gives clear direction to HCPF to redesign all aspects of Colorado's LTSS system. It requires coordination among all related state agencies including, but not limited to, HCPF, the Department of Human Services (CDHS), the Department of Public Health and Environment (DPHE), the Department of Regulatory Agencies (DORA), and the Division of Housing (DOH) within the Department of Local Affairs (DOLA).

The Governor's Order also created the Community Living Advisory Group. The Governor charged the Group with recommending ways to reform the state's LTSS system. According to the Order, these recommendations were to be delivered by September 30, 2014, to the Governor and to the Executive Directors of HCPF and CDHS.

In 2013 the Colorado General Assembly passed a joint resolution (HJR 13-1023) that endorsed the Advisory Group's charge as expressed in the Executive Order and supported the underlying values of person-centeredness and self-determination. The passage of this resolution indicates strong legislative commitment to the steps needed to transform Colorado's LTSS system.

This report presents the final consensus recommendations of the Community Living Advisory Group and its subcommittees, which have met in person each month since August 2012. It represents more than 3000 hours of work by 190 stakeholders, with regular input from the wider public. Each subcommittee was co-chaired by a consumer or advocate and by a staff person from a Colorado state agency - HCPF, CDHS, or DORA.

In formulating our recommendations, we have been guided by a unifying commitment: to ensure that Coloradans who need LTSS get the right services at the right time in the right amount for the right length of time in a place of their choosing. We have

also been guided by a deep commitment to the core principle of person-centeredness, and to the related principles of self-determination and consumer direction.

Person-centeredness should serve as the foundation for all LTSS in all models of service delivery. A person-centered system sees each person as multi-faceted rather than defined solely by the age or disability he or she happens to have. As a tool to support system-wide person-centeredness, person-centered planning should be interactive and proactive, building upon a consumer's preferences, strengths, and goals to create an individualized support system. It should also be culturally responsive - written in the individual's preferred language, using person-first language and examples that reflect the individual's sense of cultural identity.

Self-determination is the value that should shape all services in a consumer's person-centered plan. The view of self-determination we have adopted here has six components:

- The freedom to decide how a person wants to live his or her life
- Authority over an individual budget
- The supports necessary to organize one's life in a meaningful way
- A responsibility to use public dollars wisely
- A recognition that individuals with a wide range of disabilities can contribute in meaningful ways to their communities
- A confirmation that individuals have important roles to play in a reformed LTSS system

Consumer direction emphasizes the power of people with disabilities to assess their own needs and make choices about the services that would best meet those needs. In a consumer-directed system, individuals have the option to choose their service providers; to manage how, when, and where their services are delivered; and to monitor the quality of those services. Consumers have control over whether they direct their own services at all. If they choose to direct their services, they control the extent of that direction. Programs should thus be designed so that consumers can elect the traditional agency model for some or all of their services. When consumers

exercise full self-direction, they (or their representatives) manage all aspects of service delivery, including the use of individual budgets.

The Advisory Group had six subcommittees. The names of those subcommittees, and their respective charges, appear below. The members of the Group and its subcommittees can be found in [Appendix A](#).

- **Care Coordination:**
 - Make care more effective by reducing duplication and gaps in care coordination.
 - Gather data about consumer experience, quality of care, and quality of life.
- **Consumer Direction:**
 - Support the implementation of full choice across all Colorado LTSS.
 - Promote the inter-related (but distinct) concepts of self-determination, consumer direction, and person-centeredness.
- **Entry Point/Eligibility:**
 - Improve entry point functions in the LTSS system.
 - Improve determinations of Medicaid eligibility and service level of need.
 - Explore the feasibility of presumptive eligibility.
- **Waiver Simplification:**
 - Increase the array of services available to consumers by simplifying the state's HCBS waiver system.
 - Make person-centered changes to the assessment and service planning process.
- **Workforce:**
 - Develop a workforce training program.
 - Professionalize the LTSS workforce by improving pay, standards, and supporting technology.
 - Improve the supports provided to family caregivers.

- **Regulations:**
 - Harmonize and simplify LTSS regulations to eliminate redundancy and conflict.
 - Build a regulatory foundation that supports self-determination, consumer direction, and person-centered practices.
 - Integrate and consolidate rules into a consistent, comprehensible body of regulations that enable individuals who receive LTSS to live independent, meaningful lives.

The Advisory Group as whole also considered recommendations on housing and employment.

We have taken several steps to make this report as reader-friendly as possible:

- We have organized the recommendations according to broad topic areas, which largely reflect the subcommittees they originated from.
- Where recommendations have overlapped, we have combined them.
- For each set of recommendations, we have provided a brief context and rationale, often with links to publicly available documents prepared by government agencies. Links to supporting documents prepared by the Advisory Group or its subcommittees can be found in [Appendix C](#).
- For readers who wish to see all of the recommendations in a compact format, we have included "Recommendations at a Glance" in [Appendix B](#).
- Rather than define all words and phrases that are specific to the domain of LTSS in the text, we have included a glossary.

IMPROVE THE COORDINATION AND QUALITY OF CARE IN THE LTSS SYSTEM

To remain independent and healthy, all individuals and families need coordinated care from multiple providers, including general practitioners, specialists, dentists, pharmacists, personal care attendants, and the "natural supports" provided by family and friends. Robust care coordination thus extends beyond the typical consultation between a primary care practitioner and specialists to include cross-system coordination.¹ Person- and family- centered care coordination requires matching the

appropriate level, type, and timing of services and supports to the needs of individuals and families. Poor care coordination poses particular risks for individuals with chronic physical, developmental, functional, and/or mental health challenges. Members of these groups must often depend on a family member to identify and coordinate the multiple sources of care they need. This can lead to an inefficient use of resources as well as to compromised quality and increased costs - for individuals, families, paid providers, and society as a whole. By contrast, good care coordination can produce a number of positive outcomes, including decreased visits to emergency departments, reductions in hospital stays, better integration with the community, more stable families, reduced costs, and better clinical outcomes.² Better care coordination can also reduce the likelihood that individuals will develop acute needs that increase their risk of institutional placement. It can also help individuals cultivate expertise in their own health care and become more responsible consumers of health-related services.

To improve care coordination in the state, we recommend that Colorado implement the changes we describe below.

Develop a single, unified care and service plan that can be widely shared

To support care coordination and optimize health and wellness outcomes, Colorado should develop an electronic record system that captures information on medical services and LTSS - what we will call a single, unified care and service plan record (CSPR). To support transparency and empowerment, consumers should own their CSPRs and have the authority to share their CSPRs with family members and providers, both paid and unpaid. CSPRs should identify the outcomes that consumers and their care team wish to achieve, and they should allocate responsibility for achieving those outcomes. CSPRs can eliminate the need for individuals and families to "tell their stories" repeatedly to a succession of new providers. CSPRs could play a vital role in emergency situations, when individuals are especially vulnerable to hasty transitions across systems.

To develop CSPRs, Colorado must create the data infrastructure that allows these plans to be updated in real time. To help lay the groundwork for CSPRs, Colorado

should leverage the Testing Experience and Functional Assessment Tools (TEFT) grant it has recently received from CMS, along with other data-oriented initiatives that help the state create personal health records that can be shared across provider systems, including those that provide LTSS.

Coordinate transportation services and funds and align policies across transportation systems

By connecting individuals to vital health and social services, an effective transportation system can help individuals preserve and improve their independence and decrease the likelihood of institutionalization. To improve transportation services in the state, Colorado should:

- Develop a simplified, streamlined system of transportation in each region, with harmonized requirements for reporting, funding, and eligibility.
- Develop innovative approaches to achieving customer satisfaction and to improving efficiency and effectiveness - for example, by pooling operations and by creating regional transit passes.
- Support collaborative short- and long-range planning at the state, regional, and local levels.

Improve LTSS price, quality, and performance data and make those findings publicly accessible

Currently, consumers and families often lack the information they need to make fundamental life-decisions about providers, services, and settings. Indeed, consumers often know little about the range of settings in which they can receive LTSS, about the performance of providers, or about the costs of services. Consumers and families need timely access to accurate, comprehensible information that addresses their specific needs.

To help consumers make better decisions about LTSS, Colorado should take several steps to improve the quality and availability of LTSS data:

- Update the "Quality Strategy" report issued by HCPF in 2007 to include consumer input.

- Under HCPF's Quality and Health Improvement Unit, establish one or more standing Joint Quality Committees that include staff from HCPF and LTSS consumers.
- Develop standard LTSS metrics and surveys, with feasibility testing and technical assistance as needed.
- Give individuals and families the information they need to consider all possible discharge and transition options, including information about home and community-based settings and information about qualified, quality providers.
- Improve LTSS cost and quality performance data and make information available online so consumers and families can "comparison shop" among providers and services across the spectrum of home- and facility-based options. In order to promote the continuous improvement of service quality, the state should share these data with a range of stakeholders, including consumers, LTSS workers and the agencies that employ them, and key state agencies.

Colorado should identify ways for consumers to monitor and evaluate the quality of LTSS from their perspective. As soon as technically feasible, the state should make the changes we have described to its data collection and reporting systems and use those systems to engage in continuous performance improvements.

STREAMLINE AND SIMPLIFY ACCESS TO LTSS

Colorado's LTSS system has evolved in an uncoordinated fashion, with little collaboration among provider entities. Some entities determine financial eligibility while others determine functional eligibility. Moreover, as we noted in the section on care coordination, multiple agencies serving the same client often lack the technology they need to share vital information. This severe fragmentation has made it difficult for individuals and families to navigate the system and get the services they qualify for in a timely manner and in ways that meets their needs and preferences.³

To improve its entry point and eligibility systems, we recommend that Colorado implement the changes we describe below.

Create comprehensive access points for all LTSS

All Coloradans would benefit from being able to access LTSS through common entry points, where they can obtain information and assistance and be assessed for community LTSS, regardless of age or existing disability. Colorado should make all LTSS accessible through a network of comprehensive access points. These access points would assess level of need and provide options counseling to help individuals choose the best service delivery model. Ultimately, a single agency should determine eligibility for particular programs. Once their eligibility has been determined, individuals should have the freedom to choose their case management agency. This arrangement would allow case managers to act more as partners with consumers than as gatekeepers of services. In addition, case managers would be able to conduct quality assurance to verify that consumers are receiving services as they expect.

In some cases it may be impractical to separate the functions of eligibility determination, case management, and service provision - for example, in rural and frontier areas, where there are few provider agencies. In those cases, it will be vital to erect "firewalls" within agencies to ensure that conflict of interest is minimized. A successful separation of entry point functions and case management responsibilities will require Colorado to provide adequate funding to support both functions.

Create and fund a system of LTSS that supports individuals of all ages with all types of insurance

By 2035, one in four Coloradans will be age 60 or over. Currently, the fastest growing segment of the state's population is age 85 or older⁴. Like younger individuals with disabilities, seniors will want to remain in their communities among family and friends. While Medicaid funds a range of community LTSS, those services are limited to individuals whose incomes are low and whose needs are high. To meet the LTSS needs of all Coloradans, the state should design, fund, and administer a LTSS system that makes services available to individuals who are not Medicaid-eligible, before their needs become acute enough to require an institutional level of care and before they become financially needy. This will require the state to use scarce public dollars intelligently and flexibly.

To meet the LTSS needs of all Coloradans in an open, inclusive way, the state should:

- Increase the range of non-Medicaid services available in the community.
- Increase funding under the Older Coloradans Act, which supports a variety of services that help seniors live independently, including home-delivered meals, meals at nutrition centers, transportation, and in-home services.
- Provide "Older-Coloradans-Act-like" services to people younger than 60 who do not receive Medicaid, including meals, transportation, legal assistance, home modifications, homemaker, and personal care.
- Develop new programs and services to complement existing Medicaid-funded LTSS, including Medicaid-funded home-delivered meals.

Strengthen collaboration between statewide agencies and local Area Agencies on Aging (AAAs)

Creating a system of LTSS that can serve Coloradans across the life span will require close collaboration among agencies at the state and local levels. To this end, the state should:

- Support collaborations between the AAAs and HCPF on programs such as Colorado Choice Transitions (CCT), the state's name for the national Money Follows the Person (MFP) grant program, which helps individuals transition from nursing homes into the community.
- Encourage the ongoing efforts of the state unit on aging (SUA) to partner with foundations and other private-sector organizations that support programs for seniors and individuals with disabilities.
- Promote a coordinated and sustainable approach to the design, funding, and administration of LTSS programs.

Conduct a pilot study of presumptive eligibility for LTSS

Once individuals with disabilities apply for publicly funded services, it often takes months to fully certify their financial and functional eligibility. In the meantime, their situations often worsen, and families enter a period of crisis that leads to more intensive or costly care. One way to minimize the risks of lengthy waiting periods is to

use preliminary screens to grant "presumptive eligibility."⁵ Colorado should thus undertake a pilot study of presumptive financial eligibility for LTSS in three areas of the state - urban, rural, and frontier. The initial pilot should focus on individuals who are discharged from hospitals or who are seeking hospice services. This pilot should be evaluated to determine whether presumptive eligibility should be implemented for all LTSS.

Develop training modules for individuals working in entry point agencies and financial eligibility agencies

Colorado should develop training modules for staff who work in agencies that determine functional and financial eligibility. These modules should address technical, interpersonal, and personal competencies through online-training modules; one-on-one trainings within agencies; and annual trainings hosted by HCPF and shaped by guidance from consumers and agencies. On an ongoing basis, consumers and agencies should evaluate the effectiveness of these modules and make any necessary changes.

Create a toll-free hotline to help individuals and families learn about LTSS

To help consumers access LTSS more easily, Colorado should create a toll-free hotline that individuals can use to learn about their options for LTSS, regardless of how those services are funded. This toll-free number should link individuals to an agency with cross-system knowledge within their general geographic area. That agency, in turn, should provide individuals with options counseling on all available services. It should also provide "warm transfers" to the eligibility/entry point agency for that service.

SIMPLIFY THE STATE'S HCBS WAIVERS

The state's system of waivers for home and community-based services (HCBS) has become excessively complex. With 11 waivers offering different service packages, the system often fails to meet the needs of individuals and families, and it has become cumbersome for the state to administer.

To simplify its waiver system, we recommend that Colorado implement the changes we describe below.

Amend the Medicaid State Plan to include an essential array of personal assistance services

HCBS waivers were designed to augment the medical and health-related services provided in the Medicaid State Plan. Waivers have allowed many Coloradans to live successfully in their communities. However, many individuals who need LTSS do not have access to waivers, and their total needs often cannot be met by State Plan services alone. Indeed, the Colorado Medicaid State Plan limits or excludes many services that are necessary for people to live independently in their communities of choice. Notably, the State Plan does not include personal assistance services such as housekeeping and home modifications. Despite Colorado's historical leadership in community-based LTSS, the state has not added these essential services to its State Plan.

We therefore recommend that Colorado expand its Medicaid State Plan LTSS benefits to include personal care, homemaker services, health maintenance, behavioral supports, and mental health services, and it should make these services available regardless of diagnosis. To provide these services, Colorado could adopt the Community First Choice (CFC) State Plan option, which provides an enhanced federal match to states that offer self-directed personal assistance services. The feasibility of this option was recently examined [in a report by Colorado's CFC Council](#), which consists of consumers, advocates, and state staff.

Give participants in HCBS waivers the option to self-direct their services and to control an individual budget

Choice and control are vital components of any LTSS system, and consumer-direction has been shown to work well across the United States.⁶ Participants should have a range of options, from full consumer direction to full support by approved agencies. Participants who choose not to employ staff themselves should be able to choose between approved fiscal agents and employers of record.

Tailor case management to individual needs and preferences

The case management Colorado currently provides in its HCBS waivers varies from one waiver to another. In some waivers, the ratio of consumers per case manager is simply

too high to support a responsive, person-centered system and person-centered planning. Moreover, case management is often designed and delivered under a “one-size fits all” model, where regulations prescribe the number of annual contacts between a case manager and the person supported - regardless of what the consumer may need or prefer. In some waiver programs, consumers can choose their case management agencies, while in others they have no such choice.

In their current forms, case management systems in Colorado face a number of structural challenges, including high staff turnover; variability in the adoption of person-centered planning approaches; variability in the roles of a case manager (e.g., gate-keeper versus advocate; administrator versus service broker); and inconsistency in the training and qualifications of case managers.

To remedy these problems, Colorado should restructure its case management system so that:

- Clients have as much as choice as possible.
- The level of case management is tailored to the individual needs and preferences of the client and/or family.
- Training and consumer-to-case manager ratios are low enough to support a responsive, person-centered system.

Develop a new universal assessment tool to establish LTSS eligibility and to facilitate a person-centered process for all children and adults.

Colorado currently uses a single assessment tool to determine eligibility for all HCBS waivers - the Universal Long-Term Care (ULTC) 100.2. Approximately 30 other instruments are used for supports planning, resource allocation, transition support, and the setting of rates for services. The ULTC has a number of important limitations. It focuses primarily on activities of daily living (ADLs) such as bathing, eating, and dressing; it does not assess memory and cognition; and it does not easily support person-centered planning. As articulated in a recent [Final Rule by the Centers for Medicare and Medicaid Services \(CMS\)](#), person-centered planning is now a requirement

for all Medicaid-funded LTSS. This new tool could also be used to inform the determination of individual budgets.

Continue to implement the plan described in the waiver simplification concept paper

Colorado should continue to implement the changes articulated in the waiver simplification concept paper that HCPF submitted to CMS in November 2013. A copy of the concept paper can be found by following the Internet link in [Appendix C](#).

In particular, initial waiver redesign efforts should have the following goals:

- Design a single waiver for adults with intellectual and developmental disabilities (I/DD) to replace the HCBS DD (Residential Habilitation) and Supported Living Services waivers.
- Create a new waiver to support older persons, adults with brain injury, spinal cord injury, physical disabilities, and mental illness to replace the current system of separate waivers for these populations.
- Create a new waiver for children with I/DD to replace the current Children's Extensive Supports waiver and the Children's Residential Habilitation Program waiver.
- Amend the State Plan to address the needs of families and children with life-limiting illnesses, including the needs for palliative care and family bereavement services and/or children with other medically complex conditions.

These initial design changes will help modernize the state's waiver system and permit greater flexibility and individualization of supports and services.

The Children with Autism Waiver could be eliminated if appropriate treatment benefits are covered through the Medicaid EPSDT (Early and Periodic Screening, Diagnostic, and Treatment) benefit, and if HCPF develops an implementation plan based on the [recent guidance from CMS](#). Before Colorado amends its State Plan to include additional services, it should carefully examine its existing waivers to ensure that all essential services will be available, either in waivers or in the State Plan. The

state should modify its Medicaid buy-in option so that all families have access to needed services for children, regardless of income.

Provide a core array of services across all Medicaid HCBS waivers

Across populations, Colorado's current waivers offer a range of services with similar names but different definitions. For example, current waivers limit the availability of respite to certain populations and restrict employment-related services to persons with I/DD. In addition, the current service definitions are too prescriptive. While individual needs and preferences will vary, a core array of services and benefits should exist in all waivers, with definitions that provide as much flexibility as possible.

All Medicaid HCBS waivers should include the following array of services and supports:

- Personal support for ADLs and instrumental activities of daily living (IADLs), including decision making and support for health and safety (if not available in the State Plan)
- Health maintenance (if not available in the State Plan)
- Homemaker services (if not available in the State Plan)
- Behavioral supports (if not available in the State Plan)
- Personal coaching to develop goals and explore options
- Respite support for caregivers
- Therapeutic respite
- Home modifications
- Technology
- Non-medical transportation
- Vehicle modification
- Community and personal engagement, including support for employment and peer mentorship

Definitions of these services and supports can be found by following the Internet link in [Appendix C](#).

Address essential life domains in person-centered planning

Colorado's current HCBS waiver system limits the choices consumers have about how and where to live their lives. Residential options are restrictive and often focused on protection. Individuals who live in group settings seldom have choices about the people with whom they live or how they spend their time. Congregate environments limit community integration. Too often, all forms of risk are equated with danger. The recent [Final Rule](#) by CMS defines home and community-based settings to require that individuals have more independence, control, and opportunity. As noted earlier, the same rule requires states to implement person-centered planning in all aspects of HCBS delivery, so that plans consider the strengths, needs, preferences, and choices of every individual.

In light of these concerns, person-centered planning for all services in Colorado should address three essential "life domains":

- Living arrangements
- Health and safety
- Community integration

In all three life domains, special consideration must be given to the needs, preferences, and choices of families whose children need LTSS. More detailed discussion of these life domains can be found by following the Internet link in [Appendix C](#).

GROW AND STRENGTHEN THE PAID AND UNPAID LTSS WORKFORCE

Between 2010 and 2020, the number of individuals in Colorado who are 65 and older will increase by more than 60 percent and continue increasing for decades. If present trends are any guide, many of these individuals will have disabilities.⁷ To remain independent in their communities of choice, many of these individuals will need LTSS.⁸ National trends closely reflect those in Colorado: According to the Bureau of Labor Statistics (BLS), the size of the personal care workforce during the same time period will increase by 70 percent - by far the largest projected growth of any health-related profession. To meet this growing demand, the state must improve the size,

stability, and professionalism of its LTSS workforce. The state must also recognize that the composition of its LTSS workforce is highly varied, and includes certified nursing assistants, home health aides, personal care aides, caregivers, and respite providers, along with family and other unpaid caregivers.

To develop its LTSS workforce, we recommend that Colorado implement the changes we describe below.

Develop a core competence workforce training program for LTSS workers

Colorado should develop workforce trainings designed to improve the core competence of workers who provide LTSS. These trainings should be fundamentally person-centered and should be developed in partnership with consumer groups. The state should develop modules on topics such as care planning concepts in HCBS settings versus facility settings, person-centered planning, and tools to support consumer choice and control.

Design specialized trainings on critical workforce service areas

With the input of consumers, the state should adapt existing training materials or develop new training modules in specialized areas - for example, dementia, behavioral supports, and respite care.

Professionalize the paid LTSS workforce

To expand the capacity of the state's LTSS workforce, Colorado should develop recruitment and retention strategies to grow the workforce, promote career opportunities, increase the quality of services that individuals receive, and increase the pay of professional LTSS workers.

To professionalize the state's paid LTSS workforce, Colorado should:

- Explore the creation of a universal job description for paid caregivers that reflects a broad based knowledge and skill set applicable to different populations and community-based settings.
- Stay abreast of developments in the Department of Labor (DOL), especially the implications of the recent [Final Rule extending wage and overtime protections](#) to individuals who provide a wide range of domestic services.

- Study the legal, regulatory, and policy barriers that make it difficult to train and retain the LTSS workforce.
- Investigate strategies to relieve the debt that students incur while training to be LTSS workers.
- Develop training and support for unpaid caregivers.
- Investigate ways to make direct care training and certification more affordable by partnering with existing home care worker programs through community colleges, state Workforce Centers, and other related avenues.
- Conduct a marketing campaign with the partners named above to focus on the merits and professionalism of LTSS work, to promote the value and viability of this work as a career.

Provide respite for caregivers

Individuals who provide paid and unpaid care to older adults and individuals with disabilities often work long hours and perform physically and mentally demanding tasks. To help alleviate these demands - and thus preserve and grow the workforce - the state should:

- Develop respite caregiver trainings.
- Expand the availability of respite.
- Remove barriers that make it difficult to provide or receive respite.
- Expand the definition of respite to include alternative models such as the "bed and breakfast" model, which gives individuals with mental illness and their families the opportunity for "respite from each other" - to stay for short periods in alternative community settings, with the appropriate supports.
- Explore ways to provide benefits to the direct care workforce, including regular pay raises based on performance, retirement plans, vacations and holidays, and opportunities for professional development and career advancement.

HARMONIZE AND SIMPLIFY LTSS REGULATIONS

The regulations that govern LTSS in Colorado are codified in several places. For example, provider qualifications for I/DD services are established in two sets of

regulations: those governing home care licensure (primarily at 6 CCR 1101-1 Chapter XXVI) and those governing the Medicaid program (primarily at 10 CCR 2505-10). Qualifications are also established in the applications for Colorado's 1915(c) waiver programs. Often these qualifications are redundant or contradictory. DPHE rules focus mainly on health and safety, and they do not permit consumers to exercise much choice and control over how they live their lives. This regulatory paternalism is not person-centered and is thus inconsistent with the fundamental principles of self-determination and self-direction.

To harmonize and simplify its system of LTSS regulations, we recommend that Colorado implement changes we describe below.

Change regulations to support community living

To live full, independent lives in the community, individuals must be able to access the health-related services they need from the people they interact with most often, and with the assurance that these services are appropriately delegated and supervised. Colorado's Nurse Practice Act (NPA) may not always meet the needs of individuals who choose to live in their communities. The provider requirements established by HCPF in Medicaid HCBS waivers can differ markedly from those established by DPHE and DORA, which control licensure. Providers thus lack clarity about liability, and services defined as requiring "skilled" administration are often simply unavailable because the cost of scheduling skilled support on an intermittent basis is prohibitive.

To facilitate access to community services and to ensure appropriate oversight and supervision, Colorado should:

- Review and consider changing the licensure requirements for agencies that provide community-based or in-home services.
- Implement changes to, or waivers of, scope of practice requirements.
- Clarify the rules that govern delegation by nurses.
- Align the NPA with the needs of consumers living in their communities.

Require system-wide name and background checks

Colorado regulations are currently inconsistent about the requirements for the background checks that must be run on providers. For example, there are different standards for the owners of agencies and the workers who provide direct care. These standards should be consistent. They should require each worker to provide his or her name, aliases, Social Security number, date of birth, and address. Administrators and managers should also be required to provide fingerprints, which should be checked against federal and state databases.

Create a registry of workers who provide direct services to LTSS consumers

Consumers place great trust in the workers who provide them with care. To help individuals enjoy safe, self-determined lives, Colorado should develop a registry of workers who provide direct services to LTSS consumers. This registry should identify perpetrators of substantiated MANE (maltreatment, abuse, neglect, and exploitation) across the state's LTSS system, regardless of funding source (that is, both Medicaid-funded services and other services) or whether those workers were employed by an agency or working for themselves. The system should also support common standards to help consumers identify qualified workers who provide high-quality services.

Synchronize schedules for administering surveys across all LTSS programs

To protect consumers while also reducing intrusions into their daily lives, and to minimize redundancies across surveys, Colorado should administer surveys on a synchronized schedule across all LTSS services. The state should also streamline and standardize its requirements for incident reporting.

Amend regulations to support person-centeredness

Because person-centeredness and self-direction depend upon a robust regulatory foundation, we recommend that Colorado make technical and other rule changes to use person-centered language and support self-direction. These changes should include standardizing language and definitions and aligning rules with current practice. These changes will guide the development of person-centered best practices.

Consolidate rules that affect I/DD services and other LTSS

To support ongoing efforts to simplify the state's waiver system, we recommend that Colorado continue integrating and consolidating rules that affect I/DD services and other LTSS. The state should make the necessary changes to the Nurse Practice Act, to home care agency rules, and to the rules that govern the operation of the state's I/DD waivers and HCBS waivers that serve other populations.

PROMOTE ACCESSIBLE, AFFORDABLE, INTEGRATED HOUSING

According to the federal department of Housing and Urban Development (HUD), 7.1 million renting households had "worst case needs" in 2009, meaning they paid more than 50 percent of their income for housing and/or they lived in seriously substandard housing.⁹ The situation in Colorado is especially dire: In most metropolitan areas, the rent for a one-bedroom apartment approaches or exceeds 100 percent of the monthly Supplemental Security Income (SSI) for a single person.¹⁰ Beyond issues of affordability, individuals with disabilities and individuals who are older encounter a range of housing-related challenges, including discrimination and an insufficient supply of units with the modifications necessary to accommodate their needs.

To ensure that individuals with disabilities and individuals who are older can secure appropriate housing, we recommend that Colorado make the changes we describe below.

Expand housing opportunities for individuals who have disabilities and/or are older

To expand housing opportunities for individuals with disabilities and individuals who are older, Colorado should pursue a range of strategies:

- Reapply for the HUD's Section 811 [Supportive Housing for Persons with Disabilities Program](#), which provides funding to develop and subsidize rental housing with supportive services for very low- and extremely low-income adults with disabilities.
- Increase the number and availability of housing vouchers for permanent supportive housing.
- Support home ownership opportunities.

- Explore new strategies for financing housing, including tax credits, pooled matching funds, coordinated preferences, and a statewide Housing Trust Fund.

Promote compliance with the Fair Housing Act and Affirmatively Further Fair Housing

HUD has proposed a rule to require that state and local government entities affirmatively further the [Fair Housing Act \(FHA\)](#) - including those that receive Community Development Block Grants (CDBG), HOME Investment Partnerships (HOME), Emergency Solutions Grants (ESG), and Housing Opportunities for Persons with AIDS (HOPWA), as well as public housing agencies (PHAs). To help governments meet this obligation, HUD has indicated that it will supply guidance, data, and a template that can be used to complete an assessment of fair housing. This assessment would then link to Consolidated Plans, PHA Plans, and Capital Fund Plans.

To comply with the requirements under HUD's [Affirmatively Further Fair Housing \(AFFH\)](#) rule, Colorado should:

- Work with the Colorado Olmstead Housing Coalition to develop messaging and dissemination strategies.
- Develop marketing materials and provide technical assistance on how housing providers can ensure compliance with the FHA.
- Market materials to consumers and advocacy groups to promote the objectives of AFFH, and provide easy access to a site where they can file fair housing complaints and receive updates on the status of those complaints.

Encourage PHAs to adopt preferences for individuals with disabilities

Nationally, the wait list for subsidized housing is long. For individuals with disabilities, the inability to find affordable, accessible housing in a timely manner greatly increases the likelihood that they will eventually require care in an institution. A key to avoiding this is to create housing preferences, so that individuals with disabilities receive priority on housing wait lists.

To preserve the choice to live in the community among family and friends, Colorado should:

- Identify the specific preferences that PHAs might adopt.
- Establish a baseline of the number and types of preferences currently adopted across all PHAs in the state.
- Partner with allied groups and coalitions to persuade PHAs to adopt preferences.

Provide information about housing resources through a web-based portal

Currently, information about housing in Colorado is scattered across a number of websites, with no centralized database that individuals can consult to learn about their options. To make it easier for Coloradans to find housing opportunities that meet their needs, the state should:

- In the near term, deploy a basic, searchable web-based application to provide access to housing information.
- In the longer term, move housing data into ColoradoHousingSearch.com, which would become a permanent, centralized database.
- Use data from the online system to assess the housing needs of individuals with disabilities and to identify gaps in the existing supply.

Develop a common housing application

Applications for subsidized housing in Colorado vary dramatically, both across and within regions. There is no common housing application that all PHAs and landlords can use. This variability can create confusion and frustration among prospective tenants, who must often provide the same information multiple times during an apartment search.

To minimize the barriers created by the application process, Colorado should:

- Finalize the common housing application form with input from a broad-based group of local PHAs.

- Market the common application to PHAs and landlords, so they are encouraged to adopt it.

PROMOTE EMPLOYMENT OPPORTUNITIES FOR ALL

According to the federal Department of Labor (DOL), the current unemployment rate in the general population is roughly six percent; among individuals with disabilities, the unemployment rate is more than twice as high. Moreover, among individuals without disabilities, the labor force participation rate approaches 70 percent, while the participation rate is less than 20 percent among individuals with disabilities.¹¹ In the next 20 years, as the population ages and more veterans return home, the number of people with disabilities is projected to double.¹² These trends will only increase the need to develop opportunities for market-rate, integrated employment. Moreover, individuals who are aging often profit from the social interaction that work provides.

In 2013, the National Governors Association (NGA) published a milestone report entitled "[A Better Bottom Line: Employing People with Disabilities](#)," which summarized a year-long initiative by the then-chair of the NGA, John Markell of Delaware, to address the employment needs of individuals with disabilities. The report reviewed a large body of research on the advantages to employers of hiring individuals with disabilities, and it encouraged governors to consider five key areas when advancing employment opportunities for individuals with disabilities:

- Make disability employment part of the state workforce development strategy.
- Support businesses in their efforts to employ people with disabilities.
- Increase the number of people with disabilities working in state government.
- Prepare youth with disabilities for careers that use their full potential, thereby also creating a pipeline of skilled workers to meet the needs of employers.
- Make the best use of limited resources to advance employment opportunities for people with disabilities.

To become a leader in supporting employment for all people, Colorado should embrace the recommendations in the NGA report and extend them to include individuals who are aging. Below we make five specific recommendations for Colorado

in particular that will help the state achieve leadership in this area and help all Coloradans find meaningful work at a fair wage in integrated settings.

Pursue a policy of Employment First, regardless of age or disability

In Colorado, as in other states, individuals with I/DD face a difficult employment challenge: The jobs available to them are often in sheltered workshop settings rather than in integrated community-based settings. In the past, Colorado has been a leader in promoting integrated employment for individuals with I/DD: Between 1988 and 1993, the share of individuals served in the state's Integrated Employment Program rose from 21 percent to 50 percent; by 2001, however, that figure had fallen to 34 percent.¹³ The picture has not improved since then. In 2012, 59% of the people with I/DD who received day services were served in segregated settings.

The Department of Justice (DOJ) recently addressed the problem of segregated employment in a major settlement with the state of Rhode Island, where 80 percent of residents with I/DD received services in sheltered workshops or facility-based programs. In support of the Supreme Court's landmark *Olmstead* decision, this settlement requires the state to provide supported employment in the most integrated appropriate setting, rather than in segregated sheltered workshops or facility-based day programs. (Details of this case can be found [on the DOJ website](#).) This case was the first of its kind - but likely not the last.

To fulfill its *Olmstead* obligations for employment, we recommend that Colorado pursue a strategy of Employment First. An Employment First strategy has several key features¹⁴:

- Employment is the first and preferred outcome for working-age youth and adults with disabilities.
- Individuals use a range of employment techniques to secure their places in the workforce, including typical or customized techniques.
- Employment provides benefits and pays at least minimum wage - preferably a living wage.

- Individuals have ample opportunities for integration and interactions with coworkers without disabilities and the public at large.

We recommend that Colorado capitalize on the 2014 [Workforce Innovation and Opportunity Act](#) (WIOA). The first legislative reform of the public workforce investment system in 15 years, WIOA improves access to workforce services for individuals with disabilities and requires better employer engagement. One of the chief goals of WIOA is to prepare individuals with disabilities for competitive integrated employment.

By pursuing Employment First, Colorado will not only be serving the needs of its citizens with disabilities - it will be making a sound economic investment: Supported employment yields a \$1.21 benefit to taxpayers for every dollar spent.¹⁵

Provide DVR with sufficient resources to ensure that individuals gain access to employment in a timely manner

As noted by the NGA, individuals with disabilities often have trouble finding employment; employers, for their part, often have trouble finding qualified candidates to fill open positions. Colorado's Division of Vocational Rehabilitation (DVR) helps to bridge this gap by matching employers with qualified individuals who find themselves left out of the workforce. DVR's federal match is high - for every 22.3 cents the Division spends, it receives 78.7 cents in return. Despite this high match - and despite the vital nature of its mission - DVR has not always had adequate resources to achieve its goals. We therefore recommend that Colorado provide DVR with the resources it needs to ensure that individuals gain access to employment in a timely manner.

Making the necessary resources available to DVR will pay sizable economic dividends for the state. By one estimate, disability beneficiaries who are employed through VR services provide a return on investment of seven dollars for every dollar spent.¹⁶ Funding DVR is a smart way to leverage limited public resources.

Disseminate best practices, professional training and development, and good employment outcomes

There are a number of federal programs that can help individuals with disabilities secure and maintain employment. The Social Security Administration (SSA) alone operates several such programs, including:

- Impairment Related Work Expenses (IRWE): For individuals who receive Social Security Disability Income (SSDI) and SSI, SSA deducts the cost of certain disability-related expenses that individuals need to work from their earnings. Examples of disability related expenses are items such as wheelchairs, certain transportation costs, and specialized work-related equipment. For individuals who receive SSI, SSA also deducts IRWE from earned income when determining SSI payments.
- Plan to Achieve Self-Support (PASS): SSA permits individuals who receive SSI to use a portion of their income to make investments that help achieve a work goal - for example, going back to school or getting specialized training to obtain a job or start a business. Having a PASS can help individuals qualify for SSI or increase the amount of their payments.
- Property Essential to Self-Support (PESS): SSA does not count some resources that individuals need to be self-supporting - for example, tools or equipment used for work or the inventory of a business.

Programs such as these can serve as cornerstones for gaining market-rate employment in integrated settings that individuals choose for themselves. Despite the importance of these programs, awareness of them is often limited, so individuals are not encouraged to take advantage of them. More generally, little is known about best practices for employment or about the positive outcomes that often result from applying those practices.

To raise awareness among agencies, staff, and consumers, and to encourage the use of supports that can lead to meaningful, well-paid, independent work in integrated settings, we recommend that Colorado disseminate best practices, professional training, and good employment outcomes.

Host a community summit on employment

To develop employment supports for individuals with disabilities and individuals who are older, Colorado will need to foster cooperation among many different groups of stakeholders. We therefore recommend that the state hold an Employment Summit including:

- Individuals with disabilities and seniors
- Employers
- Leaders of faith-based organizations, non-profits, and civic engagement organizations
- The state Departments of Labor and Local Affairs
- Veterans and senior organizations

Develop a "Colorado Hires" Program

As noted in the NGA report, successful employment for individuals with disabilities requires a strong partnership between employers in the public and private sectors. Moreover, the Executive and Legislative branches must collaborate to support business in their efforts to employ individuals with disabilities and to increase the number of individuals with disabilities who work for state government.

We therefore recommend that Colorado develop a "Colorado Hires" program, focused on helping people find suitable work at suitable wages. Moreover, we recommend that Colorado expand the scope of this program to individuals who are aging.

SUPPORT IMPLEMENTATION

The recommendations of the Community Living Advisory Group represent an essential milestone in the transformation of Colorado's community LTSS system. However, to effect the changes we have recommended, Colorado must sustain its commitment to reform. We here make several final recommendations related to implementation.

We believe it is essential to continue involving the people who have worked hard to develop the recommendations in this report. By continuing our work together, we believe we can capitalize on the strong relationships we have built and the deep

knowledge we have gained over the last two years and thereby ensure that Colorado succeeds in its plans to transform its LTSS system.

We recommend that the Community Living Advisory Group retain its current membership for one year to provide feedback and advice as the state begins to implement these recommendations. Over the coming year, the Advisory Group should meet three to four times, with more frequent meetings as needed.

In a related vein, we also recommend that the subcommittees of the Advisory Group continue to meet as needed around these recommendations in the form of Action Committees. Whenever subject matter expertise is required, these Action Committees should provide technical assistance and input on specific topics. The membership of each Action Committee should reflect the membership of the current subcommittees: Each should include staff from all relevant state departments as well as diverse stakeholders, including LTSS consumers. These committees should meet as needed and report to the Advisory Group.

Finally, we recommend that Colorado take full advantage of the 12-month, \$225,000 [No Wrong Door \(NWD\) planning grant](#) it recently received from the federal Administration for Community Living (ACL). In ACL's vision, a NWD System will make it easy for people of all ages, disabilities, and income levels to learn about and access the services and supports they need. This planning grant will prepare the state to apply for a much larger round of implementation funding from ACL that will likely become available next year.

Conclusions and Next Steps

Governor Hickenlooper's Executive Order noted the need for a "strategic vision that will improve outcomes, recognize limited resources, break down silos, and promote self-direction and person-centered care." Colorado needs the right LTSS system for the future - one that simultaneously meets the needs of individuals to stay in their communities of choice among family and friends and achieves long-term fiscal sustainability.

The recommendations we have provided in this document are designed to accomplish these goals. In particular, these recommendations, when implemented, will create a system that will help people maintain and improve their ability to live independently in their communities of choice, among family and friends.

We recognize that the essential fiscal analyses for these changes still need to be performed. To that end, we recommend that the Governor send the necessary reports to the Joint Budget Committee (JBC) and to other committees of reference.

We also recommend that the Governor present copies of this report to key state agencies, many of which contributed to these recommendations: DHPE, DHS, DOLA, DORA, and HCPF. We also recommend that the Governor provide copies to our federal partners, including CMS, ACL, DOL, HUD, and the Rehabilitation Services Administration (RSA), both to keep them informed about Colorado's progress and to invite their participation in the work that lies before us.

If Colorado is to succeed in transforming its LTSS system, it must develop a detailed project plan that includes at a minimum:

- A list of resources available to complete the necessary tasks (both staff time and costs)
- A prioritization among tasks, so that it is clear how changes are being made and what resources are being used to make them
- A regular assessment of the state's quality monitoring and improvement efforts, with timely adjustments as need

We recommend that the Governor work closely with stakeholders to develop this joint plan so that Coloradans can work together toward a shared understanding of better, more sustainable future for community LTSS across the state.

Endnotes

¹ Hofmarcher, M. M., Oxley, H., & Rusticelli, E. (2007). *Improved health system performance through better care coordination*. Organization for Economic Cooperation and Development.

² Palsbo, S. E., Mastal, M. F., & O'Donnell, L. T. (2006). Disability care coordination organizations: Improving health and function in people with disabilities. *Professional Case Management*, 11(5), 255-264.

³ Sinn, T., Bloemen, E., Clark, B., Downs, A., Goeken, D., and Triedman, N. (2013). *The first step: Fixing Colorado's system of long-term services and supports*. Colorado Health Institute. Retrieved July 1, 2014 from

http://www.coloradohealthinstitute.org/uploads/downloads/LTSS_First_Step_publication_for_web.pdf

.

⁴ Colorado Department of Local Affairs, State Demography Office (2012). *Aging in Colorado*. Retrieved August 15, 2014 from

<http://www.colorado.gov/cs/Satellite?blobcol=urldata&blobheadername1=Content-Disposition&blobheadername2=Content-Type&blobheadervalue1=inline;+filename%3D%22Aging+in+Colorado.pdf%22&blobheadervalue2=application/pdf&blobkey=id&blobtable=MungoBlobs&blobwhere=1251810346699&ssbinary=true>.

⁵ Brooks, T. (2011). *Presumptive eligibility: Providing access to health care without delay and connecting children to coverage*. Georgetown University Health Policy Institute. Retrieved July 1, 2014 from http://ccf.georgetown.edu/wp-content/uploads/2012/03/Presumptive_eligibility_20111.pdf.

⁶ Mahoney, K. J., Fishman, N. W., Doty, P., & Squillace, M. R. (2007). The future of Cash and Counseling: The framers' view. *Health Services Research*, 42(1p2), 550-566.

⁷ Colorado State Demography Office (2014). Figures derived from tables generated August 1, 2014 from https://dola.colorado.gov/demog_webapps/pagCategory.jsf.

⁸ AARP Public Policy Institute. (2012). *Across the States: Profiles of Long-Term Services and Supports - Colorado*. Retrieved August 1, 2014 from http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-colorado-AARP-ppi-ltc.pdf.

⁹ U.S. Department of Housing and Urban Development. (2011). *Worse case housing needs 2009: Report to Congress*. Washington, D.C. Retrieved July 1, 2014 from http://www.huduser.org/portal//Publications/pdf/worstcase_HsgNeeds09.pdf.

¹⁰ Technical Assistance Collaborative (2013). *Priced out in 2012*. Boston, MA. Retrieved July 1, 2014 from <http://www.tacinc.org/media/33368/PricedOut2012.pdf>.

¹¹ United States Department of Labor, Office of Disability Employment Policy (2014). Retrieved September 6, 2014 from <http://www.dol.gov/odep/>.

¹² Disability Funders Network (2014). *Disability stats and facts*. Retrieved September 6, 2014 from <http://www.disabilityfunders.org/disability-stats-and-facts>.

¹³ Winsor, J., Butterworth, J., and Cohen, A. (2005). *Research to practice: Innovations in employment supports: Colorado's state Division for Developmental Disabilities*. University of Massachusetts, Institute for Community Inclusion. Retrieved August 27, 2014 from <http://www.communityinclusion.org/pdf/rp39.pdf>.

¹⁴ Griffin-Hammis Associates (2009). *About Employment First*. Retrieved September 6, 2014 from <http://www.employmentfirst.net>.

¹⁵ Cimeria, R.E. (2010). National cost efficiency of supported employees with intellectual disabilities: 2002-2007. *Journal of Intellectual and Developmental Disabilities*, 115(9), pp. 19-29.

¹⁶ Council of State Administrators of Vocational Rehabilitation, as cited in National Governors Association (2013). *A better bottom line: Employing people with disabilities*. Retrieved August 27, 2014 from <http://www.gao.gov/assets/600/592074.pdf>.

Glossary of Terms

1915(c) waiver: Under §1915(c) of the Social Security Act, states may ask the Secretary of Health and Human Services - through the Center for Medicare and Medicaid Services - to waive mandatory aspects of the Medicaid program, including comparability (the requirement that individuals have access to the same set of services, regardless of diagnosis) and statewideness (the requirement that all services be available in all areas of the state). States may also choose to set limits on the number of individuals who enroll in waivers.

Agency with Choice: In contrast to a traditional agency, an Agency with Choice vendor shares responsibility for the supervision and management of an employee with the self-directing consumer. The Agency with Choice is responsible for employer responsibilities such as payroll, taxes, and insurance, while the consumer is responsible for selecting the employee, setting the employee's hours, and managing the employee's responsibilities. The Agency with Choice and the consumer share responsibility for the training and evaluation of employee performance. The consumer maintains the right to dismiss the employee from working with him or her, while the agency maintains the right to determine whether an employee is dismissed from the agency.

budget authority: Under several Medicaid authorities, states may provide individuals with a budget that includes some or all of their service and support funding and the ability to exercise decision-making authority and management responsibility to purchase goods and services authorized in their service plan. With the aid of counselors and a fiscal agent, individuals assume responsibility for managing their individual budgets.

employer authority: As an option for providing self-directed services, states may allow individuals to select and manage their own staff. States can offer two models of employer authority: 1) the "co-employer" model, also known as "agency with choice"; and 2) "a common law employer" model, where participants or their representatives are the legal employers of their workers.

employer of record: An employer of record is the organization or entity that is legally responsible for paying employees, including dealing with employee taxes, benefits, and insurance.

EPSDT: Early and Periodic Screening, Diagnostic and Treatment (EPSDT) - a Medicaid benefit that provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid.

fiscal agent: States that provide self-directing individuals with an individual budget must also provide those individuals with a fiscal agent (sometimes call "financial management services," or FMS). Fiscal agents help individuals understand their billing and documentation responsibilities; perform payroll and employer-related duties (e.g., withholding and filing federal, state, and local income and unemployment taxes); purchase approved goods and services; and monitor budget expenditures.

full agency: In the full agency model, traditional vendor agencies assume full responsibility for the hiring, supervision, and management of workers.

individual budget: Expressed as a dollar amount, an individual budget represents the anticipated cost of services and supports determined to be necessary and sufficient to meet an individual's needs.

options counseling: Options counseling is an interactive decision-support process the helps individuals and families identify and select long-term services and supports that meet the individual's needs, preferences, values, and circumstances.

Appendix A: Members of the Community Living Advisory Group

Current Members of the Community Living Advisory Group

Name	Role/Affiliation
Irene Aguilar	State Senator
Craig Ammermann	Volunteers of America
Gavin Attwood	Brain Injury Alliance of Colorado
Betty Boyd	State Senator
Renee Boyes Walbert	Parent to Parent of Colorado
Suzanne Brennan	Colorado Department of Health Care Policy and Financing
Katherine Carol	Colorado Developmental Disabilities Council
Patrick Coyle	Colorado Department of Local Affairs, Division of housing
Kasey Daniel	Legal Center for People with Disabilities and Older People
George DelGrosso	Colorado Behavioral Healthcare Council
Dustin Dodson	Grand River Hospital District Extended Care and Services
Guy Dutra-Silveira	Pikes Peak Area Council of Governments / Area Agency on Aging
Mark Emery	Imagine!
Ian Engle	Center for People with Disabilities
David Ervin	The Resource Exchange
Cheri Gerou	State Representative
Jean Hammes	Northwest Colorado Council of Governments
Jack Hilbert	Douglas County
Grant Jackson	Mesa County Human Services
John Kefalas	State Senator
Randy Kuykendall	Colorado Department of Public Health & Environment
Ruth Long	Colorado Commission on Aging
Viki Manley	Colorado Department of Human Services
Anne K. Meier	Legal Center for People with Disabilities and Older People
Carol Meredith	The Arc of Arapahoe & Douglas Counties
Sam Murillo	Family Voices
Keith Percy	ADAPT
Don Rosier	Jefferson County
Marijo Rymer	The Arc of Colorado
Jayla Sanchez Warren	Denver Regional Council of Governments
Jose Torres	Colorado Cross-Disability Coalition

Name	Role/Affiliation
Linda Worrell	AARP
Melody Wright	Centura Health
Dave Young	State Representative

Former Members of the Community Living Advisory Group Members

Name	Role/Affiliation
Liz Fuselier	Legal Center for People with Disabilities and Older People
Joscelyn Gay	Colorado Department of Human Services
Chris Herron	Colorado DD Council
Jack Hilbert	Douglas County
Shelley Hitt	Legal Center for People with Disabilities and Older People
Claire Levy	State Representative
Dr. Barry Martin	Metro Community Provider Network
Julie Reiskin	Colorado Cross-Disability Coalition
Joni Reynolds	Colorado Department of Public Health & Environment
Ellen Roberts	State Senator
Vivian Stovall	Colorado Commission on Aging

Members of the Care Coordination Subcommittee

Name	Affiliation/Role
Ed Arnold	Parent
Chris Collins	Alliance Colorado
Dustin Dodson	Grand River Hospital District
Drew Kasper	Colorado Access
Lisa Keenan	Value Options, Co-Chair
Natalie Matthewson	Rocky Mountain Options for Long Term Care
Eden Mayne	ARCH Coordinator, Boulder Co Senior Services
Aileen McGinley	Advocacy Denver
Elaine McManis	CDPHE
Gary Montrose	Colorado Long-Term Assistance Providers
Kelly Morrison	Larimer County Dep't of Human Services
Lois Munson	Senior Counseling Group
Tiffani Rathbun	HCPF

Name	Affiliation/Role
Shari Repinski	Rocky Mountain Human Services
Sarah Roberts	Department of Healthcare Policy and Financing (HCPF), Co-Chair
Corry Robinson	University of Colorado Denver School of Medicine
Camille Thompson	Christian Living Communities/Leading Age
Jose Torres-Vega	Colorado Cross-Disability Coalition
Heidi Walling	HCPF
Tim Wheat	The Center for People with Disabilities
Patricia Yeager	The Independence Center
John Zabawa	Seniors' Resource Center
Ryan Zeiger	Personal Assistance Services of Colorado

Members of the Consumer Direction Subcommittee

Name	Affiliation/Role
Martha Beavers	Colorado Department of Health Care Policy and Financing
Jeannie Benfield	Advocate and Caregiver
Robin Bolduc	Spouse, Parent, Attendant
Jo Booms	Consumer
David Burgess	CHARG Resource Center
Ellen Caruso	Home Care Association of Colorado
Mary Colecchi	Consumer
Penny Cook	Culture Change Coalition of Colorado
Candie Dalton	Colorado Department of Health Care Policy and Financing
Tyler Deines	Colorado Department of Health Care Policy and Financing
Julie Farrar	Council Staff, Colorado DD Council, Co-Chair
Joscelyn Gay	Colorado Department of Human Services
Ed George	Consumer
Max Grange	Consumer
Marti Holmes	Colorado Department of Health Care Policy and Financing
De'vorah Kappers	Consumer and Advocate
Rebecca Kurz	Colorado Access
Sally Langston	Colorado Department of Health Care Policy and Financing
Vince Luke	Association for Community Living, Boulder/Broomfield
Jen Martinez	Colorado Department of Health Care Policy and Financing
Ed Milewski	Center for People with Disabilities, Boulder

Name	Affiliation/Role
Kelly Morrison	Larimer County Department of Human Services
David Moya	Consumer
Liz Pahr	Developmental Disabilities Resource Center
Keith Percy	Center for People with Disabilities, Boulder
Charles Rehfeldt	Montrose County Health & Human Services
Jeff Roberts	Advocate
Dawn Russell	ADAPT
Jayla Sanchez Warren	Denver Regional Council of Governments
Bob Semro	Bell Policy Center
Linda Skaflen	Arc of Adams County
Todd Slechta	PeopleCare Health Services
Gabrielle Steckman	Public Partnerships of Colorado
Vivian Stovall	Colorado Commission on Aging
Jo Tansey	Colorado Department of Public Health & Environment
Steve Valente	Dungarvin Colorado
Nancy White	Colorado Department of Health Care Policy and Financing
Josh Winkler	ADAPT
Ailsa Wonnacott	Association for Community Living, Boulder/Broomfield

Members of the Entry Point Subcommittee

Name	Role/Affiliation
Jill Accame	Parent of Individual with a Disability
Paul Baranek	Value Options
Sean Bryan	HCPF
Todd Coffey	Department of Human Services, Co-Chair
Russ DenBraber	Christian Living Communities
Bryan Gannon	Jefferson Center for Mental Health
Julie Geiser	Alamosa County Public Health Department
Amelia Groves	Boulder County
Dixie Herring	The Independence Center
Beverly Hirsekorn	HCPF
Vicki Johnson	CDHS
David Klemm	Rocky Mountain Health Plans
Susan Langley	Denver Hospice

Name	Role/Affiliation
Kathy Martin	Rocky Mountain Human Services
Chandra Matthews	Access Long Term Support Solutions
Kyle Nash	ADAPT
Dave Norman	Area Agency on Aging of Northwest Colorado, Co-Chair
Aaron Pasterz	Center for People with Disabilities
Casey Ryan	InnovAge
Peggy Spaulding	CDHS
Kerry Stern	CDHS
Linda Taylor	Grand Junction Center for Independence
Evelyn Tileston	Older Adult Consumer
Jose Torres	ADAPT
Brittani Trujillo	Jefferson County Department of Human Services Eligibility
Renee Walbert	Parent to Parent
Alan Wiley	Adult Care Management, Inc.
Donna Zwierzynski	Vivage Quality Health Partners

Members of the Regulatory Subcommittee

Name	Role/Affiliation
Louise Apodaca	Community Activist
Jacqueline Arcelin	Colorado Department of Regulatory Agencies
John Barry	Colorado Department of Health Care Policy and Financing
Emily Blanford	Colorado Department of Human Services, Co-Chair
Perry Boydston	Douglas County Human Services
Ellen Caruso	Home Care Association of Colorado
Candie Dalton	Department of Health Care Policy and Financing
Tyler Deines	Colorado Department of Human Services
David Ervin	The Resource Exchange, Co-Chair
Judy Hughes	Colorado Department of Public Health & Environment
Ellen Jensby	Alliance Colorado
Rich Larsen	Colorado Springs Senior Homes
Cindi Lichti	Developmental Pathways
Aileen McGinley	Advocacy Denver
Elaine McManis	Colorado Department of Public Health & Environment

Name	Role/Affiliation
Carol Meredith	The Arc of Arapahoe & Douglas Counties
Thom Miller	Colorado Department of Public Health & Environment
Heidi Walling	Colorado Department of Health Care Policy and Financing
Ryan Zeiger	Colorado Long Term Assistance Service Providers

Members of the Waiver Simplification Subcommittee

Name	Role/Affiliation
Gavin Attwood	Brain Injury Association of Colorado
Sara Avrin	Aurora Mental Health
David Bolin	Accent on Independence
Patricia Cook	Gerontological Society
Tim Cortez	Department of Health Care Policy and Financing, Co-Chair
Tyler Deines	Division for Developmental Disabilities
Gerrie Frohne	PAD-CO
Sarah Hoerle	Department of Health Care Policy and Financing
Roger Jensen	
Susan Johnson	Developmental Disability Resource Center
Cindy Lichti	Developmental Pathways
Carol Meredith	Arc of Arapahoe and Douglas Co.
Sam Murillo	Family Voices
Brittany Newcomb	Atlantis
Tim O'Neill	Foothills Gateway
Barbara Ramsey	Division for Developmental Disabilities
Jan Rasmussen	Association for Community Living
Vicki Rodgers	Jefferson Center for Mental Health
Marijo Rymer	Arc of Colorado, Co-Chair
Bonnie Silva	Health Care Policy & Financing
Linda Skaflen	Executive Director, Arc of Adams County
Kevin Smith	
Lori Thompson	Division for Developmental Disabilities
Jose Torres	Colorado Cross-Disabilities Coalition
Dyann Walt	Mesa County Dept. of Social Services
Susie Walton	Jefferson County Social Services

Name	Role/Affiliation
Barb Wilkins-Crowder	Adult Care Management, Inc.

Members of the Workforce Subcommittee

Name	Role/Affiliation
David Bolin	Accent on Independence
Katherine Carol	Colorado DD Council
Ellen Caruso	Home Care Association of Colorado
Colleen Casper	Colorado Nurses Association
Deb Center	Colorado Center for Nursing Excellence
John Dandurand	The Human Services Network of Colorado
Janis De Baca	Tri-County Health Department, Parent of adult son with IDD, Colorado Respite Coalition
Cassidy Dellemonache	Arc of Colorado
Lorraine Dixon-Jones	Colorado Department of Public Health & Environment
Ian Engle	Northwest Colorado Center for Independence
Julie Farrar	Council Staff, Colorado DD Council, Co-Chair
Jean Hammes	Alpine Area on Aging
Grant Jackson	Adult Services, Mesa County Human Services
Judy James-Anderson	Imagine! Behavioral Health Services (Colorado Assn of Nurses for the Developmentally Disabled)
Colin Laughlin	Colorado Department of Healthcare Policy & Financing
Lynn Lonzanida	CDASS Employee / Family Caregiver
Tim Markham	Colorado WINS
Bobbie Mecalo	Colorado Commission on Aging
Mary Pat DeWald	Evergreen Nursing Services
Hanni Raley	Arc of Aurora
Georgia Roberts	Colorado Department of Regulatory Agencies, Co-Chair
Corry Robinson	JFK Partners
David Rodriguez	Consultant
Val Saiz	Colorado Respite Coalition
Amy Scangarella	Colorado Department of Healthcare Policy & Financing
Jeremy Schupbach	Alliance Colorado
Todd Slechta	Adult Home Care Services, Delta, CO
Ryan Zeiger	PASCO

Appendix B: Recommendations at a Glance

Improve the Quality and Coordination of Care

1. Develop a single, unified care and service plan that can be widely shared.
2. Coordinate transportation services and funds and align policies across systems.
3. Improve LTSS price, quality, and performance data and make those findings publicly accessible.

Establish a Comprehensive, Universal System of Access Points

1. Create comprehensive access points for all LTSS.
2. Create and fund a system of LTSS that supports individuals of all ages with all types of insurance.
3. Strengthen collaboration between statewide agencies and local Area Agencies on Aging (AAAs).
4. Conduct a pilot study of presumptive eligibility for LTSS.
5. Develop training modules for individuals working in entry point agencies and financial eligibility agencies.
6. Create a toll-free hotline to help individuals and families learn about LTSS.

Simplify the State's System of HCBS Waivers

1. Amend the Medicaid State Plan to include an essential array of personal assistance services.
2. Give participants in HCBS waivers the option to self-direct their services and to control an individual budget.
3. Tailor case management to individual needs and preferences.
4. Develop a new universal assessment tool to establish LTSS eligibility and facilitate a person-centered planning process.
5. Continue the plan detailed in the waiver simplification concept paper.
6. Provide a core array of services across all Medicaid HCBS waivers.
7. Address essential life domains in person-centered planning.

Grow and Strengthen the Paid and Unpaid LTSS Workforce

1. Develop a core competence workforce training program for LTSS.
2. Design specialized trainings on critical workforce service areas.
3. Professionalize the paid LTSS workforce.
4. Provide respite for caregivers.

Harmonize and Simplify Regulatory Requirements

1. Change regulations to fully support community living.
2. Require system-wide background checks.
3. Create a registry of workers who provide direct service to LTSS consumers.
4. Synchronize schedules for administering surveys across all LTSS programs.
5. Amend regulations to support person-centeredness.
6. Consolidate rules that impact I/DD services and other LTSS.

Promote Affordable, Accessible Housing

1. Expand housing opportunities for people who have disabilities and/or are older.
2. Promote compliance with the Fair Housing Act and with Affirmatively Further Fair Housing.
3. Encourage PHAs to adopt references for individuals with disabilities.
4. Provide information about housing resources through a web-based portal.
5. Develop a common housing application.

Promote Employment Opportunities for All

- Pursue a policy of Employment First, regardless of disability.
- Provide DVR with sufficient resources to ensure that individuals gain access to employment in a timely manner.
- Disseminate best practices, professional training and development, and good employment outcomes.
- Host a community employment summit.
- Develop the "Colorado Hires" program.

Appendix C: Resources Available on the Internet

General

- [2014 Olmstead Plan](#)
- [Presentation on Aging to the Community Living Advisory Group](#)

Care Coordination

- [Presentation of Care Coordination to Community Living Advisory Group](#)
- ["Long-Term Services and Supports: Assessing the Quality of Life of the LTSS Consumer"](#)
- ["Care Coordination Resource Guide"](#)

Entry Point and Eligibility

- [Presentation of Entry Point to Community Living Advisory Group](#)
- [System Transformation Graphic](#)
- [SEP Minority Report](#)

Waiver Simplification

- [Waiver Simplification Recommendations to Community Living Advisory Group](#)
- [Waiver Simplification Concept Paper](#)
- [Life Domains document](#)
- [Services and Supports worksheet](#)

Workforce

- [Workforce Presentation to Community Living Advisory Group](#)
- [Workforce Recommendations Memorandum \(by Lorraine Dixon-Jones\)](#)

Housing

- [Housing Group Presentation to Community Living Advisory Group](#)

Employment

- [Employment Group Presentation to Community Living Advisory Group](#)

Appendix D: Acknowledgements

The Community Living Advisory Group thanks two individuals in particular for their instrumental work in guiding the work of the Group:

- Senator Betty Boyd - for strong leadership as Chairperson of the Advisory Group
- Lorez Meinhold - for invaluable representation of the Department and leadership in the early work of the Advisory Group

The Advisory Group also thanks the following people for their help in preparing this report:

- Lisa Carlson of Engaged Public, LLC - for inspired facilitation and planning
- Gurudev Khalsa of the Spring Institute for Intercultural Learning - for thoughtful and balanced subcommittee facilitation
- Ed Kako of Mission Analytics Group, Inc. - for very effective and thoughtful integration of recommendations and principles in the Final Report
- Jeff Pryor, Alex Mitchell and Judy Hudson-Trujillo of Pathfinder Solutions, Inc. - for early leadership and facilitation in this process
- Henry Claypool - for help in planning and facilitating the Fall 2013 Advisory Group Retreat
- Martha Roherty of the National Association of States United for Aging and Disabilities - for help in planning and facilitating the Fall 2013 Advisory Group Retreat

The Group also thanks the Subcommittee Co-Chairs for their passionate leadership, communications, stakeholder outreach, and their many, many hours of work:

Subcommittee	Co-Chairs
Care Coordination	Lisa Keenan, Value Options Sarah Roberts, Colorado Department of Health Care Policy and Financing
Consumer Direction	Julie Farrar, Colorado Developmental Disabilities Council Joscelyn Gay, Colorado Department of Human Services
Entry Point	Dave Norman, Area Agency on Aging of Northwest Colorado Todd Coffey, Colorado Department of Human Services
Regulatory	David Ervin, The Resource Exchange Emily Blanford, Colorado Department of Health Care and Financing
Waiver Simplification	Marijo Rymer, the Arc of Colorado Tim Cortez, Colorado Department of Health Care and Financing
Workforce	Julie Farrar, Colorado Developmental Disabilities Council Georgia Roberts, Colorado Department of Regulatory Agencies