



COLORADO DEPARTMENT OF HEALTH CARE POLICY & FINANCING

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Bill Ritter, Jr., Governor • Joan Henneberry, Executive Director

Responses to Public Comment received on Olmstead Report

Received 7/12/10 @ 10:51am

People First language is so important. I tried to read over the whole document, and on Pg. 53 under "I. Background and purpose" . . . at the end of the paragraph that refers to "the disabled". I think you really tried to refer to "people with disabilities" but that one may have slipped through.

Department response: Agreed. The document was reviewed and those changes were made. Thank you for your sensitivity to People First language – it *is* important.

Received 6/24/10 @ 2:21pm

My son is 22 yrs old. He was on the HCBS-SLS Waiver waitlist for 7 years and is on the HCBS-DD Waiver now for 4 years...since he turned 18 yrs.

I am a strong proponent of the federal bill called The Community Choice Act which comes from the Olmstead Law and movement. The CCA bill did not pass and has been coming up in Congress and the Senate for 13 years now.

I don't understand 'why' the institutional services are an entitlement, yet the Home and Community Based Services are not. It has been proven that HCBS is far less expensive and is far more individualized and humane to the 99 percent of persons with developmental disabilities who want to live in the community.

Individuals who are institutionalized are more at risk than those who live in plain sight of the public and not stuck away in a 'facility'.

Home and Community Based is where our energy is supposed to be gaining momentum. We're supposed to be moving persons with disabilities 'out' of institutions. So, herein lies the problem. Until we make HCBS an entitlement, our loved ones will continue to be captive in institutions or on waitlists, neither of which is a service or a choice. A waitlist is 'not' a service.

Please ask the Governor to read Olmstead and every other Colorado legislator as they come into office to read it as a protocol before being sworn in. It needs to be a very public act. If we aren't 'all' in this together, individuals with developmental or other disabilities will never live equal existences, valued in the public eye.

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Department response: The Community First Choice Option (aka, the Community Choice Act), is revisited in the Federal Patient Protection and Affordable Care Act of 2010. It would provide states the option to make current Home and Community Based Services (HCBS) benefits available under a state's State Plan, where all other Medicaid services are described. As the writer is aware, this would make HCBS benefits an entitlement under Medicaid. The State of Colorado is open to exploring this option. However, the Centers for Medicare and Medicaid have not yet issued guidance to states regarding the federal rules that would apply, what financial match will be offered to states and other key information that would inform how the state proceeds. We will add an action to the policy recommendation section of the *Olmstead* report to stay informed regarding federal guidance for this policy option and move forward with a feasibility analysis of this option once federal guidance is received.

Received 6/24/10 @ 12:45pm

I have been a quadriplegic with Long Term Care Options for 9 years in August. I receive CNA services as well as PCP homemaker services daily. I do not use the CDASS program and am able to manage the agencies very well that support the services that I need. Over the years I have had both reliable stable quality people as well as incompetent support.

Today I am managing the services I receive very well. I stand in a standing machine almost daily and have a good person providing CNA services which include but are not limited to bathing, dressing, & pooping, but much more.

As a result of my quality care, I feel compelled to better my position by exploring the option of Law School at Denver University. Specifically, I fit a niche as a quadriplegic with a disability. With a lucrative law degree focusing on Social Security and disability civil rights I could earn a living, get on with my life and not need SSDI.

Although I will need Home Health the rest of my life, I am confident I can function in society and earn a middle class income living with the constraints of Home Health and Medicaid if the laws change and I were re-educated well to fit my disability.

If you could help me obtain this specialized law degree by helping me pay for it, I could save the Federal Government a SSDI check every month. I am not willing to give up the Home Health & Medicaid which I need for the rest of my life. I would like the laws to change to make this happen.

There is no reason to force me to early retirement because I broke my back and need help with support services. Thanks in advance for your time and consideration.

Department response: The Colorado Health Care Affordability Act signed by Governor Ritter on April 21, 2009, will generate new revenue to expand public health insurance coverage to more

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Coloradoans. Among the health care programs included in the Act is expanded coverage to people with disabilities through buy-in programs. Working adults with disabilities who earn up to 450% of the federal poverty level will be able to buy in to Medicaid coverage. This program is anticipated to begin in summer of 2011. Additionally, the individual submitting this comment may want to seek assistance from the state Department of Human Services, Division of Vocational Rehabilitation. You may call them at: 303-866-5700 and find more information at: <http://www.cdhs.state.co.us/dvr/index.htm>.

Received 6/22/10 @ 4:01pm

Several comments about the report had been written when I went back to look up something. At that time, the Appendices were reviewed. Honestly, you should flip-flop the Appendices for the report. Information there is more accessible and better detailed.

The Executive Order asked for barriers to be removed. One barrier recently mentioned at a public forum is the lack of an alternate to the CCB system. Since the Executive Order mentioned "optimizing self-sufficiency", having the CDASS program for people with development disabilities that is created the same as CDASS for people with physical disabilities should be reviewed. This option could be looked at under Funding or Expand Current Array of Services.

Future opportunity to make comments as this plan goes forward is critical. The area of allowing anyone eligible for Medicaid to access all services would be very important to my family.

Department response: The writer expresses concern that there "is [a] lack of an alternate to the CCB system." The Department of Health Care Policy and Financing (the Department) and the Department of Human Services (CDHS) are currently considering options that address potential conflict of interest issues in the current Community Centered Boards (CCB) system based on recommendations made by the Conflict of Interest Task Force. Information about the task force and meeting notes are available via this link:

http://www.cdhs.state.co.us/ddd/COI_Documents.htm. Additionally, the Department is looking at the HCBS system as a whole to improve access to services as well as improve the administration of these services. The Department will involve consumers as well as other key stakeholders to identify barriers to access as well as how to improve the system.

Regarding the Consumer Directed Attendant Support Services (CDASS) benefit: CDASS is a Medicaid benefit under the Home and Community Based Services that allows clients to manage their personal attendant services. CDASS is currently available to individuals served by the Elderly, Blind, and Disabled (HCBS-EBD) and Persons living with Mental Illness (MI) waivers. In CDASS, you and/or your authorized representative can: hire attendants, even friends and family, based on qualifications that you set; train, supervise and fire your attendants; decide when and where you receive services; set wages for your attendants, within your monthly budget

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and choose someone you trust, like a family member or friend (an authorized representative), to help you manage the program.

The CDASS service delivery option is being developed for the DD waivers. This benefit was added to the Supported Living Services (HCBS-SLS) waiver and was approved by the Centers for Medicare and Medicaid Services but is not yet operational. The Department is delaying implementation of CDASS for individuals served by the HCBS DD waivers until concrete rules and protocols are established for the current program. The Department anticipates that enhanced rules and protocols will be in place by fall, 2010 and then making the CDASS program available for individuals served by the DD waivers will be re-visited.

Received 6/30/10 @ 6:11pm

Thank you for the opportunity to comment on the July 2010 draft of "Olmstead: Recommendations and Policy Options for Colorado."

While the draft appears to offer a comprehensive approach in response to the Governor's Executive Order to "Direct the Development of a Strategic Plan to Promote Community Based Alternatives for the Disabled Citizens of Colorado," we question why there is no mention or integration of recommendations developed in response to SB 05-173 (Policy Brief attached) and HB 07-1374.

SB 05-173 declared that "the state has an urgent need to create a community long-term care system prepared to address the needs of clients, provide the maximum service delivery and make the best use of available public funds." HB 07-1374 declared "that a systemic review of the long-term care program is in the best interests of elderly and disabled persons in Colorado and should be conducted to develop sustainability in the long-term care program. This systemic review should include recommendations for ways to determine the most appropriate placement of a client and to ensure that adequate funding is available to support a continuum of long-term care services."

In April of 2008, the HCPF Long Term Care Advisory Committee was presented a "Long Term Care Report Comparison" (attached) by HCPF staff, who charged the committee with development of an implementation plan for the recommendations from SB 05-173, HB 07-1374, and the Department's own internal assessment completed by Auerbach Consulting. The recommendations from both SB 05-173 and HB 07-1374 were developed by appointed advisory committees comprised of a diverse group of providers, consumers, and agency representatives with the overall goal to end our fragmented approach to planning, funding and provision of home- and community-based services (HCBS) for seniors and disabled citizens.

Out of concern regarding the limited progress in implementation of the aforementioned recommendations, our Association worked with Rep. Riesberg and Sen. Boyd to draft HB 10-1053 (attached). The intent is to restart the conversation re' these prior

recommendations and develop a strategic implementation plan for aging services for the state of Colorado that looks at a coordinated and integrated approach to the financing and delivery of HCBS. While we realize that HB 10-1053 was only recently signed into law, it builds upon the work of SB 05-173. Specifically, it moves forward the SB 173 principle to achieve more seamless financing integration between Medicaid Waivers and other funding streams such as Older Americans Act funds. It puts forth a specific recommendation to promote alternative rate-setting methods for community-based services, including an independent study to design and model cost savings of a tiered reimbursement payment system for alternative care facilities, and it directs regulatory changes to allow adult day programs to offer services targeted to consumers with dementia. HB 10-1053 also restates the need to develop a strategic implementation plan to move forward the recommendations previously identified as well as any new recommendations that may be appropriate.

We believe that the recommendations of these prior reports should be considered for inclusion and/or integration, or at least referenced where appropriate in this report. Otherwise, it is our opinion that we risk the perpetuation of a continued fragmented approach to the funding and delivery of HCBS for all eligible citizens of Colorado irrespective of age and/or disability.

Department response: We have linked a document on the Olmstead Implementation website that shows the response to the recommendations from the HB 07-1374 Advisory Committee. We have also linked a cross walk depicting the recommendations from SB05-173, HB 07-1374 and the recommendations from Auerbach Consulting, Inc. with the current status of each of the elements as known to date. The Department maintains that, while many of the recommendations in each of these documents are worth pursuing, additional financial resources are required to implement many of the elements. The LTC Advisory has agreed to re-visit these recommendations and review HB 10-1053 to study the future long term care needs of Coloradoans as well as pursue opportunities to optimize funding for home and community based services. These activities have been added to the Policy portion of this Olmstead report.

Received 7/1/2010 @ 6:17pm

I am making comments as a private citizen who has knowledge of both institutes through the committees with which I am associated & because I am the mother of a son who was treated twice at Ft. Logan for serious bipolar disorder disease and a substance abuse disorder, and although still ill, now living independently in the community.

First, congratulations on a project well done. Hopefully there will be the funding to implement at least some of the recommendations, especially those involving persons with a serious mental illness and or substance abuse problems.

Lack of funding and the reason thereof for these specific populations would be a subject for another letter.

My comments pertain to the two paragraphs concerning the identification of opportunities for appropriate discharge from the Mental Health Institutes. I also have a comment regarding the substance abuse counseling in the Array of Services section of the report.

This description of the institutes and their clients is very disturbing and inaccurate. The institutes in most instances do serve clients who are seriously mentally ill and may be a danger to themselves or others at the time of admittance. Most importantly, these clients are 27-10 certified and therefore really ill but are there short term for the most part and with proper treatment and medication can be better served in a less restrictive environment.

Please see that this paragraph clearly distinguishes between the forensics population at Pueblo and the civil population at both institutes. It currently gives the impression that the majority of clients have a criminal background.

In addition, the way this paragraph is written further stigmatizes persons with a mental illness who happen for a period of time to need more intensive treatment than that which is available from a community mental health center. Only a few clients require long term locked treatment units. Those who do are the ones who tend to be dangerous.

The dangerousness of the clients has nothing to do with the limited capacity of the institutes or their unsuccessful placement in other less restrictive settings. I would like to see the data that substantiates the last statement in the first paragraph.

The unsuccessful placement in the community has less to do with acuity of the disease (dangerousness??) than it does with the lack of funding and resolve of the mental health community and the voters of Colorado to provide these community housing and treatment arrangements for persons with a manageable mental illness.

The bed capacity data from 2008 is obsolete. 59 civil beds were closed at Ft. Logan in December 2009 and some increase in adolescent beds at Pueblo occurred at the same time. In addition, Pueblo has a new forensics unit. I would suggest contacting either Joscelyn Gay or Ken Cole for the most current data.

Again, if we provided the treatment and housing for civilly committed persons with mental illness that we provide for those who have committed a serious crime while mentally ill we would go a long way to becoming a more sane and sensible society.

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On the subject of Substance Abuse Counseling, I sincerely hope that this counseling takes into account the needs of those who have a substance abuse disorder along with their mental illness. The last I checked, Colorado is 50th in Medicaid funding for substance abuse. I don't believe that ADAD uses its SAMSHA funding appropriately for integrated treatment for this population.

In the list of members of the Core Group I failed to see anyone representing either ADAD or one of the substance abuse agencies. So I hope that the statement made on page 45 of the Array of Services accurately reflects that community's thinking.

Lesley, I appreciate the opportunity to make my thoughts public on these issues. I just hope that there will be funding to provide for some of the lofty goals outlined in the Array of Services component.

Department response: The Department agrees that the verbiage in the section about opportunities for appropriate discharge from the Mental Health Institutes and from the Regional Centers was misleading and contained incorrect and out-of-date information about bed-capacity and other key concerns. This section of the report was re-written as guided by these comments as well as comments from members of the Core Olmstead Team and more current information from the Colorado Department of Human Services, Division of Behavioral Health. Thank you for addressing these discrepancies.

Regarding concerns related to adding substance abuse counseling to the Array of Services list: we agree that while this list is a start, there is much work to do with key stakeholders to refine and define the elements in the list. As we proceed with implementation, we will be sure to invite representatives from the Division of Behavioral Health as well as providers of substance abuse counseling to inform the discussion.

Received 6/21/10 @ 10:10am

Aging and Disability Resource Centers (ADRCs) – In Colorado, referred to as the Adult Resources for Care and Help are programs to streamline access to long-term care services and supports for all individuals, not just those eligible for Medicaid. In Colorado, there are two ADRCs that work collaboratively with community, state and federal programs to help people with disabilities and elders access supportive services that can enable them to live in the most integrated and independent setting possible. The Agency on Aging and CMS are strategizing to expand current ADRC programs to additional communities.

Department response: This language was added to the report. Thank you for this additional clarifying information.

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Received 7/15/2010 @ 11:31am

I have reviewed “*Olmstead: Recommendations and Policy Options for Colorado*,” as a response to Executive Order D01109 issued by Governor Ritter in June 2009, and have the following comments:

Item 2d3—do you intent for the reference to be to the www.coloradohousingsearch.com website rather than CHFA’s website, or to both? It is unclear. To reach the broadest audience, we recommend both www.coloradohousingsearch.com and www.chfainfo.com.

Item 2f2, same comment as above.

Item 2i1—the funding for DOH is in no way related to the allocation process for the federal Low Income Housing Tax Credit (LIHTC), which is administered by CHFA. If you intend to recommend additional funding for DOH, it should be a new item.

Item 2i—prioritizing the lowest income for the longest time is a federal requirement for one of the priorities in allocating the LIHTC, and CHFA already does this. In terms of prioritizing service to special needs populations, CHFA has an annual public comment period for the subsequent year’s Qualified Allocation Plan (QAP), the plan which governs our allocation process in any given year.

The affected agency for 2i should only be CHFA. DOLA and DOH should be removed as they have no role in the LIHTC allocation process.

Department response: Regarding a website or other vehicle to link local housing resources to long term care services agencies (item 2d3, 2f2) – while we avoided mentioning a specific website, it is likely that www.coloradohousingsearch.com and www.chfainfo.com will be utilized.

Regarding item 2i1 – There is no intention to imply that the Division of Housing, located in the Department of Local Affairs should receive any funding as part of this action item. A new action item, item 2k2 was added to clarify this strategy.

Regarding item 2i – The Department of Local Affairs (DOLA) and the Division of Housing (DOH) were listed as partners to CHFA. It is understood that CHFA has the final authority in determining how LIHTC are allocated. Thank you for the opportunity to clarify.

Received 7/12/2010 @ 7:37pm

I would like to see movement to the top of the list on the waiting list situation in Colorado and around the country, The fact that 90 year old parents are caring for an individual

who is 50 years old is occurring more and more frequently, lifting, turning, supervising, taking outings etc they can no longer provide the help needed to avoid institutionalization or some other restrictive setting. Yet the waiting list means they wait, young adults getting out of high school wait for help they need to get them through their day as needed, yet they wait. I believe the Olmstead Act supports making sure everyone who meets the criteria receive the services they need, not just some, not when it is your turn to get some assistance, not when your parents die and it is a crisis. Please help stop the waiting now. I am not a Colorado residence but I know folks and vacation and just believe the Olmstead Act was meant to avoid things like waiting lists for services you meet the criteria for.

Department response: Additional language related to the waiting list for home and community based services was added to the report as it is a central concern for those at risk for living in institutional settings. Thank you for your comment.

Received 7/16/10 at 2:30pm

The Legal Center believes the Draft Plan is a good plan but also believes that it could benefit from some changes, additions, and refinements.

We have the following comments or suggestions to the Draft Plan:

- (1) Strike “clients” wherever it appears and replace with “individuals” (a more person-centered approach)
- (2) Encourage the designation of a single person (i.e., an Olmstead Ombudsman or Czar) to oversee implementation of the Plan, with that person reporting directly to the Governor.
- (3) Adopt a CROSS-SYSTEMS approach to the Plan to address the barrier of the lack of coordinated transition planning and to encourage greater collaboration across departments and agencies
- (4) Enhance existing Transition Services to include additional community-based resource persons to actually assist in the transition process – to be drawn from all the various disciplines and departments and agencies that work with different populations (along the model used by the Philadelphia Corporation for the Aging’s Nursing Home Transition program (see “The Great Escape,” by Peter Jaret, AARP Bulletin, 6/1/10, http://www.aarp.org/home-garden/housing/info-06-2010/the_great_escape.html) and make this a true advocacy model of service.

- (5) Encourage greater flexibility in the use of waiver funds –especially in serving individuals with dual or multiple diagnoses (greater “permeability”)
- (6) Direct additional attention to persons with mental illness, who appear to be placed, disproportionately, in long-term care settings (nursing homes).
- (7) In each of the populations to be served, there is a critical need for appropriate, affordable housing options with supportive services.
- (8) Explore greater use of the “Money Follows the Person” model utilized in transitioning persons from long-term care settings into community-based settings – across all programs. The philosophy behind this program is good and is applicable to other settings as well.
- (9) Bring together a standing HCPF stakeholder committee to address policy barriers to deinstitutionalization for action. The stakeholder committee would provide a place where individuals, advocates, and or providers can bring policy barriers to deinstitutionalization for action. This stakeholder committee should make a yearly report to the Governor on issues received, actions recommended, and what action was actually taken.

Department response: Thank you for your interest in these issues, your thorough read of the report and your thoughtful suggestions. Please find the Department’s responses to your suggested edits and additions below:

1. Person-centered language is important. The report was scanned and where possible the word “client” was replaced with the word “individual.” When specifically referring to people served by Medicaid, there are times when “client” is used as this is the Department’s convention.
2. An addition to the policy action plan recommending that the state designate a full time state position to be responsible for implementation and tracking of the recommendations in the report was made. Due to the impending transition to a new administration, assigning responsibility for this activity to an individual in the Governor’s office is impractical as it is unknown how the new administration will structure the office.
3. The concept of a “cross systems” approach is built into the report as indicated by the designation of responsible agencies for each action in the policy recommendations in Appendix A. Additionally, in many of the recommendations, a designated state agency is suggested to partner with appropriate community based organizations, thereby promoting the public-private partnerships needed to foster collaboration throughout the spectrum of home and community based supports.
4. Regarding enhanced transition services: this may be best addressed as part of the design of the array of supportive services recommended in the Array of Services section of Appendix A. As stated in the report, the services listed in the report are a first-pass and each of these services must be well-defined and prioritized. The report contains a recommendation to form

an Advisory committee of key state and community stakeholders to further develop and define the services.

5. and 8. Encouraging greater flexibility in funding as well as exploring future Money Follows the Person opportunities have both been added to the Funding section of Appendix A.
6. Attention to people with mental illness may be best addressed as part of the design of the array of supportive services recommended in the Array of Services section of Appendix A. As stated in the report, the services listed in the report are a first-pass and each of these services must be well-defined and prioritized.
7. In Appendix A, the reader will find an extensive cross-agency and cross-organizational approach to addressing housing issues. This section has been enhanced based on other public comments.
8. See number 5 above
9. This suggestion has been added to the policy section in Appendix A of the report.

Received 7/15/10 at 10:00pm

Recommendations

1. Deinstitutionalization/Disincentives from Nursing Homes;

There has been much talk about getting individuals out of nursing homes who could be better (and often less expensively) served in their own homes. I believe HCPF identified several thousand individuals in Colorado nursing homes who expressed an interest in living independently in their community of choice. Having worked in a nursing home for almost two years, I believe, one of the problems that has been encountered in the past is that there is no incentive by nursing home owners to transition individuals into the community. Nursing homes are competitive institutions and having an economy of scale (occupied beds) is vital to their economic interest. There are some social workers in nursing homes, however, who have taken the initiative to get clients out of these facilities who they feel could live independently. This professionalism, however, is rare. It is far easier to get into a nursing home than it is getting out, unless the resident is a major behavioral problem. Also, it is not always the fault of a particular nursing home that younger disabled persons reside there. Often family members, worried about their son/daughter or spouse, feel that nursing homes provide a safe environment relative to independent living. The resident in the nursing facility has a roof over his/her head and three meals a day. Unlike most of my colleagues in the disability rights field, I believe nursing homes serve a vulnerable population, but should be the last option after home and community based services has been deemed to be of little benefit. Also, nursing homes might serve as short-term placement until home and community based services (home modifications) are in place.

In the late 70's there was an arrangement between the Dept. of Social Services and one Nursing Home (Genesis or Summit Hall) to transition persons with disabilities into the community (at a HUD 202 project). While the program was, I believe, quite successful, the nursing home inappropriately believed that for a person to live independently, they

needed as much physical and occupational therapy as possible. There was no attempt to teach independent living skills like managing and Aide, understanding a bus schedule, enrolling in college, taking adult education classes, budgeting, etc. "Independent living" according to Judy Heumann, a long time disability rights advocate, "does not mean doing things physically alone. It is a mind process, not contingent upon a 'normal' body". As a result of this one time only program initiated over 30 years ago, some of those who made the transition adjusted well and others did not. Many of those participants who were successful got services from one of the Denver area Independent Living Centers. Their nursing home, for its effort, received a higher reimbursement rate relative to other nursing homes.

In 1976 I had, while working with Atlantis, I had the opportunity of visiting the Center for Independent Living (CIL) in Berkeley, California. CIL was the first major independent living center in the U.S. (and world for that matter) and was a model for the hundreds of Centers around the U.S. that were established as part of the Rehabilitation Act of 1978. Persons with extremely severe physical disabilities were living independently in the East Bay (Berkeley, Oakland, etc) by accessing a variety of services/resources. When I asked members of the staff if there were persons with disabilities living in nursing homes in the area, they said there were, however, CIL would meet with individuals and groups in these facilities to provide information and support to any individual wishing to transition into the community. Apart from serving younger disabled adults, CIL also provided services to older persons with disabilities in the community.

Recommendations: Medicaid should consider providing financial incentives to nursing homes that provide short-term (2-4 months) independent living services in cooperation with one or more of 10 independent living centers in the State. The Nursing Homes would get reimbursed after the client made a successful transition into the community (5-7 months after discharge).

Ombudsman or County SEP's should follow-up on particular residents (with disabilities) to determine if they can transition from the nursing home into the community. Upon approval, the SEP and/or independent living center should assist the client in applying for accessible, subsidized housing and explore other housing options immediately after the person enters the nursing home, since there are formidable wait lists for accessible/subsidized housing.. I think it is vital that persons with disabilities who have expressed an interest in moving from a nursing home to the community have total access to individuals representing organizations like the independent living centers, transition service coordination agencies, home health agency, advocacy groups etc. Individuals in such facilities should have easy access to telephones so they can made/receive calls from anyone from the 'outside'. (This may sound rather basic, but having been involved in transitioning people out of nursing homes in the past, it may take days or weeks to talk to a nursing home resident by phone!) Ideally, if there are a

few specialized/temporary nursing homes dedicated to transitions (and a higher reimbursement rate as I suggested), there would also be one or more computers and voice activated Dragon Dictate software persons can utilize to go online to, among many applications, seek more practical information related to independent living. And for persons in nursing homes who have expressed an interest in moving back into the community, there should be a person or small group of individuals who would contact that individual in the facility to see where they are at. This would be like a parole board of sorts to see if that person is motivated to live in the community and if resources are available to assist them. If nothing else, quarterly contacts would let the individual know that they were not forgotten.

2. Legislation for Parity among Long-Term Care Providers

As stated at the meeting last week and for years and years, there is an institutional bias regarding long-term care providers, a bias clearly favoring nursing homes. I believe it is far easier for a Medicaid pending recipient to get into a nursing home relative to getting home and community based services. This needs to change so a person who is in need of immediate services will truly have a choice on where and how they wish to live. While 'presumptive eligibility' will help narrow that gap, it has not, to my knowledge, been implemented. Additionally, nursing homes have, in statute, provisions to get annual rate increases. Yes, while the recession has frozen some of these increases, they will likely be unfrozen and get increases while home and community based Medicaid services and home health providers will not. I believe it is important to have parity or a level playing field between long term care providers, particularly home health and nursing homes. Toward that end, SB-09 263 was amended in hopes that the gap between rates will close and clients receiving long-term care services will get the services they need to live independently in the community and persons in nursing homes will get the care they need to be comfortable.

There are some formidable differences between the service delivery model vis a vis home health agencies and nursing homes. And there are some major similarities between them, many of which trump the differences. So what are the differences and why should home health agency providers get the same rates as nursing homes? Home health agencies serve people in their own homes, typically early in the mornings and late at night. The aides work alone and do not have the benefit of a co-worker (as in the nursing home) to lift a client from bed to a wheelchair. Likewise they don't have ready access to a nurse supervisor as an aide has in a nursing home. There is a great deal of traveling and expenses associated with traveling (particularly mileage and travel time). When the gas prices went up, mileage increased significantly.

Despite years of experience in home health service delivery, I cannot remember more than a few days over the last 30+ years when everything went according to a plan or schedule. Many Aides can't make a visit because they, their child, or their car is sick. This necessitates a back-up, on-call system that operates 24/7. Persons living in their own homes do not wish to be in bed all day or in their wheelchairs all night so a back-up system is imperative toward their independence and sense of security. Service delivery is compounded by a frequent shortage of staff, weather, etc. Home health aides oftentimes work irregular hours since clients like to get up early and go to bed later at night. Aides are able to shower clients daily and provide one on one care. I believe for the overwhelming number of people who meet the skilled nursing screen, it is far less expensive to get services in the community than in a nursing home. Perhaps one of the biggest differences is the rate increases between nursing homes and home health/HCBS and related providers.

Despite differences there are many similarities between the providers. To begin with, both providers do want to provide the highest quality of care to their clients/residents, most of whom are typically on Medicaid. These providers historically have had a high turnover in staff, incur great liability are heavily regulated and provide labor intensive services through their Aides, commonly known as CNA's (Certified Nursing Assistants). These C.N.A.'s are the backbone of long-term care and provide all those activities of daily living the client/resident cannot. These activities invariably include bowel, bladder and skin care, lifting or transferring in and out of bed/wheelchairs, etc. This is hard work that lends itself to a tremendous turnover among staff as well as high worker's compensation rates.

In the early 70's, when I first started working in the long-term field, there was, I believe, a bias among referral sources toward nursing homes. This institutional bias has changed over the years, and more people who enter the Medicaid long-term care system are getting home and community based services. I have recently seen statistics that the nursing home census has actually decreased over the last 3-4 years. Moreover, the Colorado Dept. of Health Care Policy and Financing has estimated there are thousands of nursing home residents who would like to get home and community based services as an alternative. Nevertheless, the nursing homes are guaranteed rate increase while the community based providers have not. I am hoping you will address this shift and level the long-term care playing field among the providers.

Home Health	Nursing Homes
Live Alone	Congregate Setting – 150 others
Delivery of service more difficult	Delivery of service a little easier
Driving/inclement weather	Usually shift will stay (OT)

Consumers cannot be left in bed or w/c	Usually shift staying - basics
Individualized service – showers daily	Less individualized – showers 3/wk
CNA does not have direct supervision	CNA has access to nurses
Works alone – difficult transfers	Can work with other CNA to lift
Times all difficult – around consumer needs – work/volunteer need to be in certain places at certain times	Many CNA's like 8 hr shift, particularly ones without cars
Safety Issues – homes less accessible	Fewer Safety Issue
Low-income neighborhoods/crime	Not as much a problem/private parking
Homes/Apts not always accessible – cluttered, tubs, animals	Much easier to work when there is accessibility and equipment handy
Lots of possessions	Few possessions
Consumer's picky (appropriately)	Residents less picky (exceptions too)
Consumer's more likely to call Health D	Less likely
Less expensive for majority	More expensive for majority
Need an On-Call System	No on-call
Rates not increased through statute	Rates increased through statute
High Turnover of Staff (CNA's)-backbone	High Turnover of staff (CNA's)- backbone
Incontinence	Incontinence
Heavily Regulated	Heavily Regulated
Medicaid Major Funding Source	Medicaid Major Funding Source

Recommendations: Rate increases/decreases should be the same for all long-term care providers.

3. Choices in Long-Term Services not Always Addressed;

Many people go into nursing homes essentially against their wills and do not always have the tools to get out. Relatives don't understand the alternatives and believe their family member would be better off there (a roof over their heads and three meals a day). For the person with the disability who is legally competent and does not have a guardian, the nursing home staff should acknowledge their wishes, not the wishes of parents. Residents sometimes hear horror stories about the risk of getting home and community based services from nursing home staff members and are discouraged from taking the leap to independent living.

Recommendations: Again, nursing homes should be the last recourse of the long-term spectrum. SEP's should also serve the client, not his family, assuming he/she is competent. Perhaps a list of the least restrictive options (CDASS) to IHSS, to Home Health, to Assisted Living (although Assisted Living rarely takes individuals needing assistance with activities of daily living, particularly bowel care) up to nursing homes should be presented to every person entering the Medicaid long-term care system. Every attempt again is to look at the least restrictive environment.

4. Addressing Labor Shortages -Increased Demands for Services;

The Boomers are aging and starting to have some impact on the long-term service delivery system. Medical technology has enabled persons to survive (and thrive) after catastrophic events. Disability Rights and Parent Advocates are working with HCPF to develop Medicaid Waivers and provide much needed services to their constituencies, etc, thereby providing funds for attendants/direct service workers, etc. There has been a shift from institutional care to community based care. While new programs like Consumer Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) give consumers and agencies greater flexibility in hiring Attendants, I believe there will be labor shortages, particularly once long-term care services are made available to some of the 750,000 uninsured Coloradans. Part of this problem is related to the perceived undesirability of the job, namely dealing with bowel/bladder care, etc. I believe that almost every long-term care service provider that provides aide, personal care and attendant services has had, I believe, great difficulty in recruiting and retaining these service providers. I believe these individuals are the 'front line' of the long-term care system. When the front line breaks down, more skilled and more expensive services often ensue. If a C.N.A. or Attendant services are inadequate/inconsistent a person with a disability, like a spinal cord injury, might easily develop a bedsore/decubitus ulcer that will lead to more expensive skilled nursing and possible surgery and hospitalization. Many professionals working in long-term care talk about the high turnover among aides. I would say that for every 50 applicants who respond to one of our ads at the agency I direct, whether in the newspapers, Craig's List, specialized services/publications, etc, 10 actually fill out an application. Our agency does an interview, a CBI check and then arranges an orientation. Of the 10, maybe three turn out for the orientation. Our agency places these three individuals with existing C.N.A.'s and the clients they serve. After a week or two, we usually lose two and sometimes all three of these individuals! About 11 years ago, our agency spent approximately \$90,000 placing ads in various newspapers to recruit aides. Despite our efforts, we were constantly short-staffed and had to significantly limit our growth. We were able to provide services by paying lots and lots of overtime. We retained our client/consumer base because of these efforts and the fact that other agencies were in the same predicament. Every provider of long-term services has their own pay schedules. Some home health providers pay Aides by the hour and some pay by the visit. Some pay overtime and others do not. I would say from the experiences I have had with other agencies and the from information gleaned from the Homecare Salary

and Benefits Report (prepared by the Hospital and Health Care Compensation Service) the average hourly wage of C.N.A.'s in Colorado is between \$10-15/hour. According to the U.S. Bureau of Labor Statistics (May 2006) however, the median hour wages in 2006 for a C.N.A.'s was \$10.67. It was \$9.34 for a Home Health Aide (not certified) and \$8.54 for Personal and Home Care Aides. Wages tend to be lower in rural areas and higher in such areas as Boulder. I believe C.N.A.'s make less in facilities (nursing homes/assisted living), but have the advantage of working a straight eight-hour shift. In home health agencies that serve persons with severe disabilities services are provided several times a day including, early in the mornings and later at night. The needs of the clients do not always reflect the working needs of employees who sometimes work early in the morning and at nights as well as every other weekend and holidays. Because not everyone wants to work early and late, many employees are part-time and not eligible for health insurance or other employee benefits. I believe also that many employees in rural area cannot access health insurance because they cannot get the requisite number of hours to qualify. Personal Care Providers and Homemakers in Colorado make, I would estimate, between \$8-10/hour. I would say that a significant percentage of Aides and Attendants are women (often single moms) and minority group members who represent the ranks of the working poor. The various Aides, C.N.A.'s/Home Health Aides/Attendants/Personal Care Providers represent the most in demand occupations in the U.S. To compound low wages, Home Health Agencies employing CNA's/PCP's are exempt from time and a half (Overtime). It is my understanding that there are provisions with the Dept. of Labor exempting long-term care providers from paying overtime to C.N.A.'s/Personal Care Providers, etc.! Such individuals are classified as Domestic Workers. There is a safety issue for Home Health Aides who work with low-income disabled adults living in HUD housing. There are also safety issues regarding lifting and related duties;

As stated above, disabled adults needing assistance with activities of daily living like to get up relatively early and go to bed relatively late. Because there is a relationship between disability and income (the Urban Institute in their Comprehensive Needs of the Severely Disabled study mandated by Congress back in 1975) many disabled adults live in low-income, often HUD (Section 202) subsidized housing. Many of these housing units are in the inner city where crime rates tend to be higher than the norm. Essentially the more disabled one is, the less income he/she had available to them. In addition, most of the C.N.A.'s tend to be younger women, many of whom do not have cars and rely on public transportation. I have found that many adults with disabilities, due in part to the lack of available exercise options and their low-income status (inability to buy healthier foods) are overweight. While they may have lift equipment, they prefer the "personal touch" rather than the metal lifts. Too many Aides/Attendants run the risk of serious injury by doing such lifts.

Aides have no group lobbying for their interest and don't often have the time, energy or resources to make changes in their profession. As with most every profession, there is a disparity between the Medicaid rates of professional providers (Nurses and Therapists) and paraprofessionals (C.N.A.'s, PCP/Homemakers. This past April 2007, there was an

approximate 25% increase in the Skilled Nursing and Therapy (OT, PT, Speech Therapy) rates and a 0% increase in the C.N.A. rate! For sure, there are significantly more C.N.A. visits relative to the other disciplines, but the disparity was a little shocking for agencies that provide primarily C.N.A. services. I believe Nurses and Therapists appropriately have Associations that advocate for them, while C.N.A.'s, PCP's, Homemakers do not I don't have any real data substantiating this, but believe this to be pretty true, particularly for paraprofessionals who cannot get a full-time schedule due to the needs of the clients they serve.

As stated in the recommendation below, I mention the need for Aides to be represented. I strongly believe that any person who spends a couple of hours in the field with a veteran Aide providing services to a person with a severe disability would see the difficulty of the work and the skills utilized to meet the needs of the client. I hope to mail or deliver a DVD showing details of providing such services.

Recommendations: Increases in the Home Health Aide/C.N.A./IHSS/CDASS and Personal Care Provider/Homemaker rates may entice more workers. I think, however, there should be periodic "passthroughs" when adjusting Aide/Attendant rates. A "passthrough" is a mechanism many Medicaid state agencies, including Colorado, have utilized to assure that rate increases for C.N.A.'s go primarily to the employee not the employer/agency. Agencies in the past had to submit cost reports verifying that wages were in fact increased for the C.N.A.'s/PCP's etc. I would also recommend that Colorado residents who apply for nursing or medical school at CU be given "points" on their application if they work as an Aide/Attendant/Direct Service Worker in a long-term care setting for a minimum of 500 hours. Each 500 hours may count as "1" point in a rating scale. Potential nurses and doctors could start verifying hours after high school. I think this arrangement will make for better doctors/nurses and fill a pressing gap in our long-term care system. Hopefully board members who review applications will recognize the value of these experiences in making decisions regarding acceptance to nursing and medical schools. The same concept may also apply to Physician Assistants, Nurse Practitioners, Therapists, and other medical professionals. Medicaid "passthroughs" would help, particularly if done every few years. Aides would be wise to be represented by an Association that advocates for their economic interests. I think too Aides would benefit from a Center that would provide job opportunities, training, counseling, fulfilling CEU responsibilities, etc. Medicaid "passthrough" can be applied to wages and benefits. There is a need for a Multi-Employee Welfare Association (MEWA) whereby two different providers (like two separate home health agencies or a home health agency and nursing home, etc) can provide (proportionally) benefits to their mutual employee. Aides/PCP's should be paid overtime when they work 40+ hours a week. Perhaps there can be a tradeoff. Increase the rates with legislation, if feasible, and rescind such exemptions. This way the agency and employee can benefit. . The Medical Services Board should mandate that a person over, let's say, 100 lbs or so, be required to use a lift device to avoid injury to their Aides or themselves. _

5. There is a Scarcity of Personal Assistance Home-Based Services in Rural Areas/ Lack of In-Home Support Service (IHSS) Providers in Rural Colorado;

I believe there are many reasons for this, including: long distances between client; lack of C.N.A.'s to provide services; limited number of certified Home Health agencies; limited number of certified C.N.A. training programs, low-wages, difficulty in getting full-time work and benefits, etc. There is not an "economy of scale" in rural areas like there is in cities, hence service delivery is typically more difficult for home and community based agency providers. The In-Home Support Services (IHSS) can provide personal assistance services to persons with severe disabilities and is very apropos, I believe, in rural areas. It is essentially a cross between CDASS program and traditional C.N.A. services provided by a certified home health agency. The major advantages of the IHSS program, relative to home health, is that the key provider need not be a C.N.A., but could be a neighbor, friend, family member or any other individual. IHSS Attendants and Providers are not subject to the same regulations as home health. Unfortunately there are no IHSS providers, I believe, in rural areas. I believe there are only three or four in the State. There can be considerably more flexibility with this program and can be a harbinger for CDASS.

Recommendations: The Single Entry Point (SEP) should encourage consumers, who can manage their services, to gain entry into the CDAS program. The state and the SEP's should encourage existing long-term care providers to get certified to participate in the IHSS program. Medicaid may need to raise rates to encourage more participation.

6. Concerns about Utilization

The Dept. of Health Care Policy and Financing tried to establish "Norms" for clients receiving long-term, community based services many years ago. HCPF, who was paying for the services, wanted to essentially know how long various activities of daily living took. Did it take an Aide 10 minutes to dress a client or did it take 20 minutes? Then again, on certain days (like Halloween or Purim) it may take 25 minutes. It is a function of the home health agency and IHSS providers to establish a Plan of Care that is then signed by the client's physician (who takes Medicaid). HCPF essentially provides the funding addressed in the Plan of Care, but may audit documents (Aide timesheets) to see if the services were appropriate. If not, the agency will need to pay back Medicaid. While HCPF has the right to audit and assure the client and the taxpayer that services are rendered appropriately, I believe the present system either provides too much services or too little services, depending on the agency doing the Plan of Care. About two years ago many of the clients our agency was serving left us because another agency gave them significantly more hours of care than we did. While we would advocate for any client who needed care and was denied, we adhered to the rules and regulations as we knew them. This particular agency, which was part of a national chain, was cited by the Health Department for a number of violations and had

their office closed down in the Denver area. Almost all the clients that left our agency came back.

Recommendations: I think HCPF was correct in wanting to know what they were paying for. I believe HCPF or a contractor of HCPF should do comprehensive nursing assessments for all new clients entering the long-term system. This nurse, or preferably a multidisciplinary team, should establish a Plan of Care around the needs of the client and the rules and regulations of Medicaid. The client should have the right to appeal, however if he/she feels basic needs are not being addressed. HCPF may also want to see that client every year or three or four years to further assess their needs and Plan of Care. I think HCPF should formulate an RFP that will contract with a group of Registered Nurses (so long as they don't have any involvement with any long-term care provider) to perform these assessments. Since the agencies presently pay their nursing staff to do assessments, the agencies would pay for HCPF or the contractor to do these assessments.

6. Accountability a Problem in the Field;

In their Black Box of Home Care report in the late 1980's Congress talked about the vulnerability clients have when their home health provider comes to their home and the door is shut. While CBI checks and early monitoring and supervision address this vulnerability somewhat, there is still a question of accountability. Did the Aide or Nurse stay in the home for the two hours reflected on the Plan of Care or were they there for only 20 minutes, but claimed 90? A few agencies in the State use a telephony system that is an excellent means to actually track time and performance. An Aide or Nurse arrives to the client's home. She/he calls an 800 number and enters a code indicating he has arrived. The code is tied to the client's home phone so calls are red flagged if they were made elsewhere. When the Aide or Nurse leaves, they call the same 800 number and check off the duties performed. The Plan of Care for each visit is computerized and a voice will come on asking if, for example, the client was dressed, transferred, showered, etc. The Aide in the above case would depress "1" on the client's phone pad if the duty was performed, "2" if the client refused, etc. I believe if each agency had to use such a system, Medicaid would save a few million dollars. Additionally, client benefit from this system because it reflects the actual time an aide was in the home. About 10 years ago, PASCO did a pencil and paper study comparing the hours billed by Home Health Aides before HCPF changed the mechanism for payment of such services (basic and extended units). Essentially we compared timesheets before telephony and after. There was a glowing difference in that Home Health Aides typically billed for more hours of service when they did paperwork compared to the times reflected in telephony. Again, an hour a day that was not necessary, 365 days a year could add up significantly.

Recommendations: Medicaid may want to consider making this telephony system for agencies that provide home health, PCP, Homemaker and IHSS Attendant services mandatory.

8. End of Life/Need to Discuss Options/Alternatives/Choices

So much money is spent on terminally ill individuals during the last months of their lives. While this is not an Olmstead issue per se, I believe, the costs end of life care has an effect on long-term care funds and needs to be touched upon. *My daughter Zeva, was diagnosed in 1992 with a rare terminal disease when she was one year old. My wife and I met with a physician/geneticist from the Children's Hospital who counseled us regarding the disease (Tay-Sachs). When my wife and I asked her how Zeva would die, she said she would die of starvation if we didn't put in a feeding tube. While this physician was very generous with her time and cared about us, the emotionally charged language she used "starvation", was a deterrent to look at alternative approaches to her illness. As responsible parents (at least my wife), we would never starve our child to death! Several months later, my wife and I attended a National Conference on and met several parents who decided not to insert a feeding tube, but to let nature take its course. Interestingly the most vocal advocates of this alternative (letting nature take its course) were physicians, physicians who were parents of these terminally ill children! My wife and I read much about this issue and talked to many, many people, including hospice workers. We found that when the body was shutting down, the dying person did not crave food and, after a short time, did not even wish to drink water. If I go four hours without eating I feel like I'm starving and run to the refrigerator to get something to it. I don't think this is the case with someone actively dying. Yet, I found there was an institutional bias regarding treatment. I don't think my choice was right or wrong, it was just my choice. Some, however, said they would not have put in a feeding tube had they heard there was an option to this. Many, if not most of the parents I met through the Tay-Sachs Association, did insert feeding tubes. I always supported their decision and tried to send flowers when the operation was performed. A parent deserves knowing the pros and cons of various treatments from medical professionals. Physicians should try not to impose their biases, one way or another and should never use emotionally charged words like "starving to death" out of context. When an individual or a parent of a child is confronted with a diagnosis of a rare disease, they are oftentimes distraught and not always thinking too clearly. They tend to look for someone who can help them and that person is usually the doctor. There is a big difference between the medical needs of a person with a disability and a person who has a terminal disease.*

Recommendations: I believe medical professionals should try to objectively discuss the various pro's and con's related to treatment in a objective manner. I think preparing written materials on various options along the lines of something like the League of Women Voters do when objectively presenting both sides of a particular ballot issue would be greatly helpful. Pejorative language like "starving your child to death" is totally

inappropriate and medical schools should train future physicians about the important of language and choice.

9. Better Utilize Independent Living Centers

There are independent living centers in Boulder, Colorado Springs, Craig, Denver (2 of them), Durango, Fort Collins, Grand Junction, Greeley, and Pueblo. Some of these Centers have been in existence for 30 years or so and are deeply committed to preventing institutionalization or promoting deinstitutionalization. These Centers provide several core services, including: advocacy, information and referral, peer counseling, and independent living skills training. They also provide housing referral, attendant management, and a variety of related services. In the 1970's, the Independent Living Resource Utilization Project of The Institute for Rehabilitation and Research in Houston, Texas received a grant from the Rehabilitation Services Administration to implement a six week live-in program designed to assist severely physically disabled persons in learning independent living skills. The program, New Options, developed a comprehensive Training Manual addressing such areas of independent living as: attendant management, financial management, functional skills, living arrangement, medical needs, mobility, sexuality, social skills, time management, and vocational/educational opportunities. While a little dated, this Manual provided practical information to individuals with disabilities living in nursing homes or with parents. Most of the instructors were peers (persons with disabilities who were living independently). I will mail or deliver portions of this Manual to you by the end of the week.

10. The Demand for Accessible, Affordable Housing for Persons with Disabilities far Exceeds the Supply.

In 1976 the Atlantis Community received a grant from HUD and the City of Denver Community Development Administration to assess the needs of persons with severe disabilities in the Denver area. In 1976 there was a glaring scarcity of resources to assist a person with a severe disability wishing to live independent even if they were a Medicaid recipient. Housing was scarce and almost totally inaccessible, RTD had very limited transportation services (and those they had were a result of prolonged demonstrations directed toward them), home care was very, very limited, etc. Many persons with disabilities, whether living in a nursing home or with their parents, choose not to transition into an independent living setting unless they could get Section 8 subsidies. While Section 8, particularly Vouchers, are very important, I believe that the independent living centers could: (1) identify accessible and modestly priced apartments/houses and (2) establish a service whereby persons with disabilities seeking to live independently could become roommates and pool their resources and share expenses, like rent. Every attempt should be made to seek individuals that are compatible with one another. When the late Wade Blank of the Atlantis Community was alive, he would drive around areas of Denver that were relatively accessible/affordable, close to where most of the Aide/Attendants lived, adjacent to RTD, etc. Two persons

who wanted to live independently would then share their resources to pay for rent that was not subsidized. I should note that, like non-disabled persons, every attempt should be made by service provider to help persons with disabilities secure housing around their needs. Sometimes it may take two or more years to secure a Section 8 certificate or make it to a HUD Section 8 building, but it is worth applying early and following through when these resources become available.

Recommendations: HUD should consider providing more Section 8 Vouchers to persons with disabilities needing accessible and affordable housing. Section 8 Vouchers would enable a person to live wherever they choose. One need not be in an area where there are major crimes. Hopefully the consumer will look at locating/relocating in a safe area, near a bus line and near where the Aide “pool” lives. The Medical Services Board should consider establishing a second “tier” of assisted living geared to persons who need skilled care. The standards should be higher (total accessibility, more room, - like a real apartment, etc) as would be the reimbursement.

10. There is Little Coordination of Transition Services Among Various State Agencies

I believe there are dozens of state/local agencies, non-profit organizations and individuals (parent/advocates, etc) throughout Colorado that are interested in transition services for young adults with disabilities, whether they are graduating from High School, living in a nursing facility, wanting to move out of their parents home, etc. The Children’s Hospital is looking at transitions from youth to adulthood primarily from the health/medical perspective, while the Local Education Agencies (School Districts) are addressing transitions from an educational perspective. There are, once again, Independent Living Centers who are dedicated to independent living and a host of other agencies who have an interest in improving the lives of persons with disabilities. HCPF is committed to transition service coordination, particularly in funding services enabling persons with disabilities move from a nursing home to the community. Unfortunately, I believe, there is little if any coordination between the various agencies involved in transitions. This lack of a coordinated efforts makes transitions a rather ‘hit or miss’ proposition.

Recommendations: I would propose HCPF take the lead in forming an Olmstead Implementation Council that would not only continue to deinstitutionalize younger people from nursing homes to the community, but prevent unnecessary institutionalization. I believe this could be done through a coordinated effort from a host of agencies, including: Independent Living Centers (two , one urban and one rural); HCPF; State and Local Education Association; Children’s Hospital; SEP; Vocational Rehabilitation; Family Voices; CCDC; Mental Health/BHO; DD Planning Council; Community Center Board; HUD; Local Housing Authority; physicians (such as Dr. Barry Martin and/or Stuart Ferguson) who serve adults with disabilities; Second Chances (a new non-profit dedicated to transitions); Home Health and/or HCBS provider; Nursing Home; and Peers (individuals with disabilities that have transitioned from an institution to their own homes).

Perhaps the proposed Olmstead Implementation Council could be a subcommittee of the HCPF -LTC Committee.

Department response: Thank you for your interest in these issues, your thorough read of the report and your thoughtful suggestions. Please find the Department's responses to your recommendations below:

Recommendation #1: Medicaid should consider providing financial incentives to nursing homes that provide short-term (2-4 months) independent living services in cooperation with one or more of 10 independent living centers in the State. The Nursing Homes would get reimbursed after the client made a successful transition into the community (5-7 months after discharge).

Department: It is true that, nationally and in Colorado, the current long term care services system is designed to favor ease of placement of individuals into nursing home or other facility-type settings rather than maximizing the chances of placement into the most appropriate environment for a qualified individual based on the individual's choice, which may be their home or another community based setting. Two major contributors to this issue are how nursing facility rates are determined and that nursing facility care is in a Medicaid agency's State Plan while supportive home and community based services are not in the State Plan and therefore, not an entitlement. This report makes policy recommendations that address both of these issues. In the Funding section of Appendix A, the intent to explore finding strategies to encourage capacity building for home and community based services is in the original draft and the intent to pursue new Money Follows the Person funds was added to the Funding recommendations. In the policy section of Appendix A, the intent to explore the "Community First Choice" option which would allow a state to add HCBS waiver services to the state plan was added.

Recommendation #2: Rate increases/decreases should be the same for all long-term care providers.

Department response: As above, the Department is in the process of exploring funding strategies to encourage capacity building for home and community based services.

Recommendation #3: Again, nursing homes should be the last recourse of the long-term spectrum. SEP's should also serve the client, not his family, assuming he/she is competent. Perhaps a list of the least restrictive options (CDASS) to IHSS, to Home Health, to Assisted Living (although Assisted Living rarely takes individuals needing assistance with activities of daily living, particularly bowel care) up to nursing homes should be presented to every person entering the Medicaid long-term care system. Every attempt again is to look at the least restrictive environment.

Department response: The notion of a continuum of services based on the needs and the wants of the individual receiving services is aligned with the Department's and CDHS' vision of what home and community based services may look like in the future. CDHS and HCPF are in the

early stages of discussing HCBS waiver modernization to make system easier to access and navigate, streamline administration and increase accountability to individuals receiving services in terms of quality and efficiency. Additionally, the public awareness section of Appendix A contains a number of recommendations related to disseminating information about options for LTC services.

Recommendation #4: Increases in the Home Health Aide/C.N.A./IHSS/CDASS and Personal Care Provider/Homemaker rates may entice more workers. I think, however, there should be periodic “passthroughs” when adjusting Aide/Attendant rates. A “passthrough” is a mechanism many Medicaid state agencies, including Colorado, have utilized to assure that rate increases for C.N.A.’s go primarily to the employee not the employer/agency. Agencies in the past had to submit cost reports verifying that wages were in fact increased for the C.N.A.’s/PCP’s etc. I would also recommend that Colorado residents who apply for nursing or medical school at CU be given “points” on their application if they work as an Aide/Attendant/Direct Service Worker in a long-term care setting for a minimum of 500 hours. Each 500 hours may count as “1” point in a rating scale. Potential nurses and doctors could start verifying hours after high school. I think this arrangement will make for better doctors/nurses and fill a pressing gap in our long-term care system. Hopefully board members who review applications will recognize the value of these experiences in making decisions regarding acceptance to nursing and medical schools. The same concept may also apply to Physician Assistants, Nurse Practitioners, Therapists, and other medical professionals. Medicaid “passthroughs” would help, particularly if done every few years. Aides would be wise to be represented by an Association that advocates for their economic interests. I think too Aides would benefit from a Center that would provide job opportunities, training, counseling, fulfilling CEU responsibilities, etc. Medicaid “passthrough” can be applied to wages and benefits. There is a need for a Multi-Employee Welfare Association (MEWA) whereby two different providers (like two separate home health agencies or a home health agency and nursing home, etc) can provide (proportionally) benefits to their mutual employee. Aides/PCP’s should be paid overtime when they work 40+ hours a week. Perhaps there can be a tradeoff. Increase the rates with legislation, if feasible, and rescind such exemptions. This way the agency and employee can benefit. . The Medical Services Board should mandate that a person over, let’s say, 100 lbs or so, be required to use a lift device to avoid injury to their Aides or themselves.

Department response: Appendix A contains a fairly robust plan to examine recruitment, retention and training issues for the direct service workforce. The recommendations include developing an advisory group to address the concerns mentioned in your comment.

Recommendation #5: The Single Entry Point (SEP) should encourage consumers, who can manage their services, to gain entry into the CDAS program. The state and the SEP’s should encourage existing long-term care providers to get certified to participate in the IHSS program. Medicaid may need to raise rates to encourage more participation.

Colorado Department of Health Care Policy & Financing response to Public Comments on the *Olmstead* Report, July 2010

Department response: The SEPs currently present consumers with all of their options related to obtaining long term care services, including CDASS. SEPs also can help an individual identify an In Home Support Service (IHSS) agency in their area. Entities interested in becoming recognized as an IHSS agency can go to this link for more information:

<http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1212398222653>

Recommendation #6: I think HCPF was correct in wanting to know what they were paying for. I believe HCPF or a contractor of HCPF should do comprehensive nursing assessments for all new clients entering the long-term system. This nurse, or preferably a multidisciplinary team, should establish a Plan of Care around the needs of the client and the rules and regulations of Medicaid. The client should have the right to appeal, however if he/she feels basic needs are not being addressed. HCPF may also want to see that client every year or three or four years to further assess their needs and Plan of Care. I think HCPF should formulate an RFP that will contract with a group of Registered Nurses (so long as they don't have any involvement with any long-term care provider) to perform these assessments. Since the agencies presently pay their nursing staff to do assessments, the agencies would pay for HCPF or the contractor to do these assessments.

Department response: Currently all new qualified individuals entering the long term care system receive a functional assessment, an assessment of need and an assessment of their living environment to determine the appropriate services and care plan. The individual always has the right to appeal and assessments are re-done on an annual basis. It is important for the state to closely monitor SEPs in ensuring that individuals are receiving the services in their care plan and that these services are appropriate to their needs.

Recommendation #7: Medicaid may want to consider making this telephony system for agencies that provide home health, PCP, Homemaker and IHSS Attendant services mandatory.

Department response: It is important for the state to manage expenditures appropriately so while this system may be a good investment, it may not fit in with current budget priorities.

Recommendation #8: I believe medical professionals should try to objectively discuss the various pro's and con's related to treatment in a objective manner. I think preparing written materials on various options along the lines of something like the League of Women Voters do when objectively presenting both sides of a particular ballot issue would be greatly helpful. Pejorative language like "starving your child to death" is totally inappropriate and medical schools should train future physicians about the important of language and choice.

Department response: Agreed. The ethical decisions surrounding end of life issues are difficult to navigate and the sensitivity of the individuals informing the decision-making process is an essential component to enable caregivers and individuals to make decisions most appropriate for them.

Recommendation #9: HUD should consider providing more Section 8 Vouchers to persons with disabilities needing accessible and affordable housing. Section 8 Vouchers would enable a person to live wherever they choose. One need not be in an area where there are major crimes. Hopefully the consumer will look at locating/relocating in a safe area, near a bus line and near where the Aide “pool” lives. The Medical Services Board should consider establishing a second “tier” of assisted living geared to persons who need skilled care. The standards should be higher (total accessibility, more room, - like a real apartment, etc) as would be the reimbursement.

Department response: The Housing recommendations found in Appendix A address many of the areas you mention including using an interagency approach to maximizing the number of units available to people with long term care needs.

Recommendation #10: I would propose HCPF take the lead in forming an Olmstead Implementation Council that would not only continue to deinstitutionalize younger people from nursing homes to the community, but prevent unnecessary institutionalization. I believe this could be done through a coordinated effort from a host of agencies, including: Independent Living Centers (two , one urban and one rural); HCPF; State and Local Education Association; Children’s Hospital; SEP; Vocational Rehabilitation; Family Voices; CCDC; Mental Health/BHO; DD Planning Council; Community Center Board; HUD; Local Housing Authority; physicians (such as Dr. Barry Martin and/or Stuart Ferguson) who serve adults with disabilities; Second Chances (a new non-profit dedicated to transitions); Home Health and/or HCBS provider; Nursing Home; and Peers (individuals with disabilities that have transitioned from an institution to their own homes).

Perhaps the proposed Olmstead Implementation Council could be a subcommittee of the HCPF -LTC Committee.

Department response: The Olmstead report contains a number of recommendations for advisory committees and an additional recommendation to the policy action plan designating a full time state position to be responsible for implementation and tracking of the recommendations in the report was made. The LTC Advisory will be kept apprised via a formal reporting process as to the status of implementing the recommendations.

Received July 19, 2010 at 8:43am

My name is _____, but I have always gone by “_____”. I am forty-eight years old and I have had quadriplegic Cerebral Palsy since birth. Thank you for this opportunity to voice my concerns regarding DSW quality and retention.

I have had multiple serious difficulties involving the quality of my direct care workers. I used to go to a day program that was totally insufficient for my needs. In addition, the DSWs seemed to have a vendetta against the developmentally disabled. I started attending the program when I was fourteen, and continued attending it until I was forty-two. The problems with unqualified and vindictive DSWs spanned that entire time period.

The atmosphere at the day program was demeaning and degrading from the beginning. Although my motor abilities are greatly limited, I have always had control over the functioning of my bladder and bowels. The problem is that I have CP. Just because I have control does not mean I have control quickly. In order to be a good client, a client had to “go” in a short period of time. They had a little timer that they would set for five minutes when they put you on the toilet. If you weren’t able to go in that amount of time, you were out of luck. Somehow the DSWs did not at all seem to understand what my having a muscular disability meant. They would always tell me, “I know you’re smart and you can do this” as they held me on the toilet. The problem is that control of one’s muscles is not a direct intellectual function. Just because I was smart enough didn’t mean I physically could. The staff did not seem to understand the difference.

This ignorance of basic disability knowledge went much further. My muscular inability to release my bladder and bowels within a five-minute time period was interpreted as open defiance. I was quickly put on a behavioral program to address my “refusal” to go to the bathroom. I knew that I needed to relax, but like most people with CP, when I get nervous, my muscles contract and I have even less control over them than I do normally. I knew that if I wasn’t able to go, I was not only out of luck, but I was also in big trouble. Every day, I couldn’t go, and I ended up spending the rest of the day in a corner by myself. I couldn’t even get out of the corner to do my physical program. Everything they wanted me to be able to do with my hands was brought to a little desk in the corner. One of the goals of the program was supposed to be for clients to have other people to socialize with. As it was, I spent every day alone as a punishment for having CP. I don’t think that this would have happened if the agency had put more funds toward educating DSWs about the medical aspect of disabilities. If they had, I think that my DSWs would have understood my disability better and concentrated their efforts on things that I could control and that I could learn to do, like reading, for instance.

The lack of DSW training about disabilities was also reflected in my OT/PT programs. Every day at the day program, I was expected to perform physically therapeutic tasks. This was supposed to mean that I was learning how to control my muscles as best I could, but it really turned into an exercise in physical frustration. If I was able to do the hand-coordination exercises one day, chances were good that my muscles would be too tired to do them the next. I was expected to perform the tasks anyway. When I couldn’t, staff members would stop speaking to me. This is, of course, a totally ridiculous response to a medical problem. The problem was that my staff didn’t understand and thought of most things that happened in negative-behavioral terms.

I don't understand where it comes from, but the DSWs at my Day Program seemed to run on vindictiveness. I of course had the normal behavioral issues of any kid growing up at home, but I was perfectly behaved at the Day Program. The problem was that it totally didn't matter. I got in trouble for everything I did. I got in trouble even for things totally beyond my control. Every morning, the staff took "roll call". The way this worked was that the staff would call out the clients' names and the clients were supposed to answer "here" and raise their hand. If you couldn't say "here" clearly, you got in trouble. I would sit there with my hand up and would repeatedly say "here" as well as I could, but they would refuse to acknowledge me because I didn't say the word clearly. Additionally, the staff would have a meeting every week. They left the clients in the room with them while they met. I got in trouble for hearing what was going on at the meeting. At that time in my life, I was able to propel my wheelchair backwards with my feet. I could have gone out of the room without help, but then I would have been in trouble for leaving. Day program was simply a daily series of retaliatory events which went on for twenty-eight years.

I think the biggest problem I have encountered with services, though, is the abysmally low rate of pay -- minimum wage -- that direct care staff receive for their work. This has led to many odd people taking care of me. Some were harmless but frankly crazy. Others were not so benign. In the early 1990s, my Day Program hired a man named "Jim". It is hard to find intelligent, stable people who are willing to work for minimum wage when the work requires a huge degree of patience, training, knowledge of disabilities, and doing restroom duty. Jim is an example of how things can turn out when you are hiring from the bottom of the barrel. Jim was married, but he told me repeatedly over the course of three years that he would "go out" with me if he were single. This clashes with my religious beliefs, which everybody at the day program knew. I believe that if you are married, you shouldn't be talking to anyone else that way but your spouse, so hearing a married man sexually harass me for three years was extremely traumatizing. I have had to work through some Post-Traumatic Stress Disorder problems because of it. Jim went further and made comments about my desire to be sexual with male staff. I can't really convey here how terrifying it is to be talked to that way every day for three years and not know if the situation was going to turn physical, or if the other workers would even intervene if it did. I had to go out on day trips with him a lot, just him and me. I'm not quite sure how I got through it with my sanity intact. I have absolutely no ability to defend myself physically. I am totally at the mercy of whoever agencies can find who will accept such a physically and psychologically demanding job for less than they could make at McDonald's flipping hamburgers. What it really boils down to is that I am not a hamburger. The people entrusted with my care should be well-qualified, ethical workers. There are some incredible, wonderful staff out there who dedicate their lives and sacrifice their backs to work for next to nothing, but most good workers find that they cannot live on such a low wage and move on, creating excessive and unnecessary turnover. At some point the DD system and society as a whole need to look at valuing clients above hamburgers.

Unfortunately, that is not the end of the Jim story. The thing that most puzzles me is why the situation was allowed to continue unchecked for three years. It is not because nobody knew. On the contrary, everyone in the building knew what was going on. I complained every day about the sexual remarks he was making toward me, but DSWs did nothing to change it. I don't know if this lack of action was a part of the retaliation against me for being disabled, but I have to wonder. The agency had all the liability incentive in the world to stop it, yet they did not. They let it continue, and even sent me out alone with him, while knowing that I was terrified of him. Well-qualified, well-paid, ethical workers would have stopped this kind of behavior at its inception.

Happily, the picture is not all bad. Two years ago, I moved into a group home run by Community Residential & Respite. The head of the agency and her staff have given me incredible support. Retaliation is nonexistent at CR&R, but I still find that it is hard for my DSWs to make enough money to support their families. Though we have a lot of good workers, many just cannot afford to stay in the field. I would like to see DSWs get skilled-job pay and better/more affordable benefits. I'd also like to see CR&R get paid to train new workers, as I just recently found out that they do not. This is a very strange arrangement, and a very costly one considering the high rate of DSW turnover. The money being spent to train workers who don't stay could be put to much better use training workers with incentives to remain at the job.

Department response: Thank you for your thoughtful comments and for sharing your story. Your comment reflects great insight regarding the issues surrounding the Direct Service Workforce that the Direct Service Workforce action plan found in Appendix A of the report hopes to address thoroughly. The Department will be grateful for your insight and assistance as we move forward in assembling a stakeholder group to address issues relating to recruitment, retention and training of the Direct Service Workforce. Again, thank you for sharing.

Received July 19, 2010 at 9:00am

Thank you for the opportunity to submit my comments. I have worked in the DD system as a direct service worker, as a direct service worker/house manager, and as a case manager. I have worked for two CCBs and one service agency. Though I am now disabled, I work six to twelve hours a week as a secretarial aide to [a woman with quadriplegic cerebral palsy].

My experience with the quality of DSWs and DSW turnover has been abysmal. There are many DSWs who do not care about the clients they serve. There are many who have taken the job in order to have someone to actively subjugate (Please see [the previous comment]). There are many who are undereducated. There are some who are just not intellectually qualified enough to understand their duties. There are some DSWs who are intelligent, diligent, and dedicated, but they often burn out because they end up

carrying the load that uncaring workers shirk and non-bright workers can't master. Often, dedicated DSWs end up leaving the job because they just can't make a living at it.

One thing I have frequently encountered with DSWs (and regrettably also some case managers and supervisors) is an attitude that people with DD are less than human, and are more a class of objects which are to be ferried from place to place as programs dictate. I think this is in part due to society's ignorance about DD, but I think that a huge part of the problem is that DSWs are often hired from the bottom of the barrel. DSW pay often starts at minimum wage. This means that DSWs are being entrusted with the care of an often high-needs human being for the same compensation as they would get for flipping hamburgers. Alarming, what I have found is that if a worker can't make it in food service or janitorial work, they can still find work in DD services. This is because if someone doesn't flip the burgers, someone notices. If someone doesn't clean the toilets, someone notices. If a man with DD sits in his own feces for three days, nobody notices. This is not how we want the DD system to run - but this is currently how it's running.

Many DSWs simply do not see their clients as human beings, and do not care what happens to them. That last above is a true story. The man's house staff didn't like taking him to the bathroom, so they usually sent him to us soiled (I worked at his Day Program). That particular incident was on a Monday, so the fecal matter had dried onto his skin during the weekend. It had to be soaked off with wet paper towels and removed a bit at a time. It took a couple of hours. Unfortunately, the fecal matter had dried to the point that when it came off, it took the top layer of testicular skin with it, even though I was cleaning as gently as I could (I have never heard anyone scream so loudly in my life before or since). DSWs not really caring about clients puts clients' lives and health at risk daily. Fecal matter contact with open testicular skin is a huge infection risk, but I doubt that the DSWs in question ever considered the risk to which they were exposing the client. There are simply a lot of DSWs who can't make it in any other job and thus end up in the DD system out of desperation. They don't like the job, they don't like the clients, and they don't like to work. This has to stop.

My experience with undereducated but dedicated workers is that they have the drive and the ability, but are just lacking training. Training in the DD system varies widely in quality. This needs to change. I had exceptional training at the first CCB I worked at and some great training at the second CCB. The service agency I worked for had very poor training. I was a DSW/house manager with them for four months, during which time I had to totally train most of my staff from the ground up. The long-term (three years) house manager before me had become addicted to a substance and had let matters at the house slide considerably. Most of the clients' medication had not been ordered in over a year (I can't say much more, as there is currently litigation against this agency). All of the DSWs had been instructed to mark off all the clients' meds as having been given at the beginning of each shift, regardless of the fact that the medication wasn't

even present in the house. When I came in and changed the rules, my two most dedicated DSWs mutinied and refused to do it the “wrong” way. I directed them toward training materials and got the matter sorted out. Once they understood what they were supposed to do and why, they were excellent workers. A standard of knowledge and certification programs for DSWs would definitely help in this area.

Workers who are unqualified intellectually, however, are another matter. Leaving people with complex needs in their care is a recipe for disaster. Unfortunately, I have seen a large number of DSWs who fit in this category. I once had a thirty-minute debate with one of my DSWs about whether or not saliva was a body fluid. He said it wasn't, and refused to wear gloves when feeding a client who had Hepatitis B. I insisted it was, and re-directed toward training materials, but it did no good. I spent an inordinate amount of my time explaining and re-explaining basic procedures to him. A client with quadriplegic CP died on my first day of that job. I had met him just about fifteen minutes earlier. His breathing sounded horrible because of all the phlegm in his lungs. I asked that the nurse see him immediately and my suggestion was laughed off because according to the DSWs (and my supervisor, unfortunately), his breathing “always” sounded like that. Fifteen minutes later, he stopped breathing due to phlegm blocking his airway (I had been whisked back to the main office for training). Efforts to resuscitate him were unsuccessful. His autopsy showed that he had had advanced pneumonia. Though I didn't quite realize the severity, I knew something was wrong just from listening to him breathe. It should have been obvious to any DSW that there was a problem, but it was not, and the man died because of it. I am serious when I say that DSWs make the difference between life and death for clients. I have seen it illustrated firsthand. Qualified DSWs are a must.

Not all examples of DSW lack of intellect are that drastic, but I have still seen a lot of close calls. I have witnessed a DSW leave a wheelchair-using client who had no ability to control his chair at the top of a long, steep ramp with his brakes disengaged. When I pointed this out to the worker, she explained that she had seen an old friend come into the building and had to talk to her, and told me that the client had been in no danger since he didn't actually roll down the ramp. I shudder to think that anyone with a basic understanding of gravity would not see a problem with this. I have heard the same DSW laughingly admit that she had blown her mind on alcohol and cocaine and that was why she could no longer think. I've heard a different DSW talk at length in front of DD clients about how all people with DD have been touched by Satan, daily. The same DSW explained to me that a client who had Dissociative Identity Disorder was possessed by demons. This was said in front of the client, who was perfectly capable of understanding what was said. The same DSW once couldn't figure out what [a client] wanted when she was repeatedly pressing her talker button and the talker was saying “drink” over and over. That was back when [the client] still ate orally, and she had gotten a bit of food stuck in her throat and needed to wash it down. When I asked a supervisor why on earth the woman had been hired, she explained that the agency “needed a warm body”. This DSW was the only choice the agency had had. Continuing such hiring practices is

simply madness. People with DD should not be exposed to harm and degradation by the people who are hired to keep them alive and emotionally healthy.

There is a desperate need for the “lower level” DD system employees to get better compensation and benefits. Somehow the DD system upper levels - and society at large - seem to see DSW work as “unskilled”. Nothing could be further from the truth. Rather, DSW quality makes or breaks the entire system and makes the difference between client life and client death. It doesn’t matter what planning and restructuring are done in the upper levels to improve service quality or prevent conflicts of interest if DSWs are paid so poorly that they cannot make a living even when they are working full time (or more); if the feet are of clay, the system will fail and clients will pay the highest price. What happens under current conditions is that even when an agency can find qualified staff, they can’t retain them. If qualified, dedicated DSWs can’t feed their families; the bulk of them will not stay at the job. Agencies will thus squander the (unfunded) money necessary for training new staff over and over again as workers come and go. This is extremely inefficient and highly detrimental to clients. If DSWs and other “lower level” DD system workers were paid better and could be retained over long periods of time, the system would save a ton of money that could then go to enriching clients’ lives.

I have heard upper-level employees say that they are the ones doing the “real work”. I have heard lower-level employees say that they do the “real” work. The truth of the matter is that every level of worker in the entire DD system is doing the “real” work. Each level is dependent on the success of the others, and each level must be trained thoroughly and compensated fairly in order for the system to work.

Department response: Thank you for your thoughtful comments and your insight from the perspective of a Direct Service Worker. Your comment reflects great insight regarding the issues surrounding the Direct Service Workforce that the Direct Service Workforce action plan found in Appendix A of the report hopes to address thoroughly. The Department will be grateful for your insight and assistance as we move forward in assembling a stakeholder group to address issues relating to recruitment, retention and training of the Direct Service Workforce. Again, thank you for sharing.