

Addendum to the Summary and Recommendation Report

Stakeholder Feedback

Community Living Office

Division for Intellectual and Developmental Disabilities

November 18, 2015

Introduction and Background

This document is an addendum to the attached "Redesign Workgroup for Waivers Serving Adults with Intellectual and Developmental Disabilities Summary and Recommendation Report". As noted in the attached report, in 2012, the Community Living Advisory Group (CLAG) was charged with the consideration and recommendation of changes to the system that are necessary to ensure responsiveness, flexibility, accountability, and self-directed long-term services and supports for eligible persons that are beneficial to the citizens of Colorado. The CLAG and its subcommittees met from August 2012 through September 2014 and submitted a report of its final recommendations to the Governor's Office in September 2014.

From October 2013 through January 2015, a Waiver Redesign Workgroup met monthly to conduct an analysis of the services and supports currently available to individuals with Intellectual and Developmental Disabilities (I/DD); discuss and refine recommendations made by the CLAG, specifically working to ensure that the CLAG's recommendations would meet the needs of individuals with I/DD; and develop additional recommendations, either for additional services needed by individuals with I/DD, or for processes, policies, and practices that would be supportive of individuals with I/DD. In April 2015, the recommendations of this Workgroup were released publicly via the attached document.

In May and June 2015, the Department organized and hosted 10 stakeholder meetings across Colorado, designed to solicit input and feedback from additional stakeholders about these recommendations, with an emphasis on ensuring that the needs, voices, and concerns of rural stakeholders, parents and family members, individuals being served by the waivers, and providers were heard and documented. Additionally, these meetings were designed to exchange information on the redesign of the waivers supporting adults with intellectual and developmental disabilities, solicit feedback on the recommended changes, share ideas for improving services, and allow stakeholders to get to know Department staff and other community members.

The Department invited all stakeholders to attend and publicized the meetings through social media, communication briefs, meetings with providers and advocacy organizations, and post cards mailed to each individual enrolled a waiver serving adults with I/DD. The meetings were held in Grand Junction, Sterling, Loveland, La Junta, Alamosa, Durango, Colorado Springs, Denver, and Steamboat Springs. Additionally, one webex (phone in and/or computer-based) meeting was held for stakeholders who may have been unable to attend an in-person meeting. Each meeting followed the same basic agenda, which included a welcome and introductions, an overview of Medicaid, long term supports and services (LTSS), and home and community based (HCBS) waivers; and an overview of the stakeholder process used to develop the recommendations and gain additional stakeholder feedback on the recommendations. Stakeholders were informed that their input would be incorporated into an addendum to the recommendations report.

Following this introduction and information, open discussions were held about the recommendations made by the Workgroup, and the feedback was documented. Stakeholders provided feedback about service definitions and other recommendations, shared additional ideas, asked questions about services, and shared their concerns.



A total of 247 people attended these meetings¹, including parents and other family members, self-advocates, providers, and professional advocates. Meetings were facilitated by Health Management Associates, which also documented stakeholder input. Department staff provided subject matter expertise and answered questions about the waivers, services, and the recommendations. This addendum summarizes and documents the stakeholder feedback and the conversations that occurred at these meetings.

Stakeholder Process

Overwhelmingly, stakeholders were appreciative of the stakeholder process, and the multiple opportunities to make their voices heard. Stakeholders were particularly appreciative of the Department's successful efforts to publicize these meetings, and to travel across the state to talk with stakeholders in small, more rural communities.

Overall Input

The general concepts laid out in these recommendations were generally very well supported. Stakeholders were supportive of the recommendation to develop one waiver to serve eligible adults with I/DD. They were also very supportive of the concepts of more flexible, adaptable, and person-centered services, and of the inclusion of self-direction where possible.

However, there were concerns expressed about the finer details and decisions that would need to go into the actual waiver application, including constraints that inevitably arise when needs for services meet the realities of limited funding, federal, and state constraints, and other issues. Questions arose in every meeting about how these concepts would be "operationalized." The Department recognized and heard this concern and committed to continuing to engage stakeholders as the waiver application is being written, and to seek input and feedback as decisions need to be made to make the new waiver a reality.

The organization of this addendum aligns with the Recommendations Report, with input aggregated by recommendation.

Waiver Simplification

Generally, stakeholders agreed with the recommendation to create one waiver to serve adults with I/DD. There were no objections noted conceptually regarding this, but stakeholders did express some fears about change – i.e., what will it mean for group homes, what will it mean for people, and how it will look in concrete terms. The Department heard and noted these concerns and made a commitment to continue to engage with stakeholders as the waiver application is written.

Waiver Service Recommendations

Personal Support, Health Maintenance, and Homemaker Services

In terms of personal support, health maintenance, and homemaker services, the primary feedback from stakeholders was in two areas. First, there was overwhelming support around the waiver covering support to people between tasks if needed.

¹ Grand Junction: 8 people; Sterling: 11 people; Loveland: 29 people; La Junta: 13 people; Alamosa: 2 people; Durango: 6 people; Colorado Springs: 29 people; Denver: 85 people; Steamboat Springs: 23 people; Webex: 41

For example, one stakeholder noted that her son needs someone in the house with him – not just task-related – but to make sure he's okay, he's following his schedule. This stakeholder was very supportive of this type of "supportive supervision" being covered as part of the new waiver.

Second, there were a number of comments and there was much discussion about the importance of licensing regulations and provider qualifications as these services are defined, to enhance service provision rather than complicate or limit it. For example, a stakeholder noted that personal care/home care currently does not require licensure and wanted to be sure this does not become a requirement.

Another stakeholder noted that in his geographic area, only a few agencies have opted into providing personal support services, in part because the licensure requirements can be challenging. This stakeholder noted that, if more people are eligible for the services, these agencies will be even more strapped to provide the services.

In several meetings, stakeholders asked if the Department is in communication with the Colorado Department of Public Health and Environment (CDPHE) and Department of Regulatory Agencies (DORA). The Department noted that the agency leaders will talk together about authorities, licensing, and regulation issues, and will work to partner and coordinate around these issues. Additionally, as the Department starts to work on service definitions, these will be shared with stakeholders, probably using a method similar to the benefits collaborative process. The Department will coordinate with, and hopes to get participation from, other state agencies.

Personal Coach

The personal coach service definition generated additional recommendations in three primary areas. The first was a recommendation that, if this service definition is included in the new waiver, the Department will need to include very clear language about the roles and responsibilities of a personal coach versus a case manager. The Department responded to this feedback by noting that this service is not intended to duplicate, overlap with, or preclude case management, and that, if this service definition is part of the new waiver application, there would be clear language around these roles and responsibilities.

Second, and on a related note, there was feedback about whether this is a needed service, or is duplicative and confusing. Some participants noted that case managers sometimes do not have enough time to do all that needs to be done, and that a personal coach could help fill some of these gaps. Some stakeholders noted that, if the person being served is able to truly choose the coach, then this could possibly be a great service. This could be a person who is "on the person's side" if there are issues between the person and their case manager. Other stakeholders thought this might be a duplicate service and that is may be more challenging for individuals being served to have to get to know more than one person, and build a relationship with more than one person.

Third, there was a recommendation that the Department think about whether this new service definition has the potential to create new risks around conflict of interest. For example, a personal coach would need to be completely separate from, and have no overlapping interests with service providers, to avoid any real or perceived situations in which a personal coach

recommends services to an individual being served which benefits their business or a business in which they have an interest. While many stakeholders noted that this service could be beneficial, one stakeholder suggested it should not be offered because of potential conflict of interest and potential duplication. The Department noted that the personal coach service would need to include safeguards to ensure it is not used to influence provider choice and/or be independent of all other service providers.

A few stakeholders asked if this was similar to mentoring or a service that had been available in a previous waiver (a "supported living consultant"). The Department noted that it is similar, and the personal coach would be someone who could help ensure that person-centered planning is implemented. The service is intended to be very flexible, to be used when needed, for example: when services are about to change, or when someone is faced with a possible decision about services or a decision about place of residence.

Respite

Stakeholders were supportive of this service definition and believe it is a critical service, including therapeutic respite. Many said this is a great recommendation and there is a huge need for these services.

Other feedback about respite services included a concern about the ability to find providers in rural areas. In response to this concern, in one stakeholder meeting, the group began to brainstorm possible sources for providers, including a recommendation that the Department explore graduate programs that train health navigators (i.e., at Otero Community College). Another concern that was expressed was a challenge around finding providers who are a "good match" for the individual being served and the family.

Additionally, some stakeholders noted that location of the respite services is critical. In particular, host homes might be good locations for respite services, but some home modifications may need to be done to accommodate the needs of some individuals. Also, stakeholders wanted to ensure that respite could be provided in the home under the new waiver.

Last, stakeholders noted that there is a need for behavioral health respite: providers with behavioral health training who can provide respite but can also provide therapeutic services to help people "get back to a better place" when they are in crisis. Therapeutic respite is often really behavioral health crisis intervention. There aren't resources to provide these services, including qualified behavioral health staff/clinicians.

Home Modifications

There was not a lot of discussion about the home modifications service definition. One area of discussion and recommendation that came out of these meetings was that the Department explore whether home modifications could available within host homes. The Department responded that there are federal limitations on the use of Medicaid funds for modifications to provider owned/controlled settings. The group asked the Department work with the Federal Government on this limitation. Another piece of feedback from one stakeholder was regarding home modification provider qualifications. This stakeholder reported that the enrollment process is difficult, the qualifications were too strict, and it is challenging to find a sufficient number of

willing and qualified providers. The Department clarified that home modification providers are currently subject only to applicable state/local building code and/or contractor licensing requirements, but noted that it is working to simply its provider enrollment process.

Assistive Technology

There were a few questions in the stakeholder meetings about what, specifically, would be covered in this service definition. The Department noted that the assistive technology definition should be broad, allowing for new technologies as they develop and will also support people learning how to use existing and emerging technologies.

A few pieces of feedback emerged around assistive technology. First, one stakeholder noted that it is sometimes difficult to get three bids for assistive technology. Second, a few stakeholders suggested that it is important to think about some assistive technology items that are currently seen as "recreational" but also might help calm someone, such as iPods. Another noted that, as more assistive technology is available and covered, like emergency response systems, having actual staff supervising someone may become less necessary. This stakeholder noted that some people don't want or need a person there with them all the time, and having a "life alert" and med machine are all they really need, and this supports greater independence. Voice prompting can also help reduce the need for live staff to do prompting, which can be better for people and reduce costs. Overall, stakeholders expressed a desire that this kind of technology be covered under the new waiver.

Behavioral Supports

Stakeholders provided feedback about this service definition in a few areas.

First, stakeholders expressed that access to behavioral supports is problematic. In some areas of Colorado, there are no (or very few) providers who take Medicaid reimbursement. Additionally, stakeholders expressed a concern that many behavioral health providers do not have expertise in providing behavioral health services for individuals with I/DD. Second, stakeholders reported that "caps" on these services can result in people not getting the services they need and ending up in crisis. A lack of behavioral supports is a primary reason "that we fail with some people". One stakeholder noted that when you see someone doing well, it is probably because they are getting the behavioral support services they need. Third, there was feedback that clarifying who is responsible (financially) for the behavioral supports is critical across the system. Fourth, stakeholders reported that there is a need for more immediate access to crisis behavioral services.

While some of this feedback is outside the scope of this waiver redesign effort, it will be kept in mind as the waiver application is developed, and the Department will continue to monitor other efforts across the state related to behavioral health and will partner with internal staff and other agencies as opportunities emerge.

Transportation

Stakeholders in rural areas made the recommendation that the new waiver should take into consideration the lack of public transportation in rural areas. These stakeholders noted that, for rural communities, transportation is expensive and that they recommended that rates should factor in the long distances sometimes involved in providing transportation in rural areas.

The Department noted that, while the discussion among the workgroup was heavily focused on public transportation, this service definition includes the ability to provide individualized transportation. Additionally, the Department noted that the workgroup's recommended definition is intended to provide supports beyond just going to and from a day program – it is intended to cover transportation needs where people need to go and support individuals where and how they choose to participate in their communities.

One stakeholder noted that public transportation is often difficult to arrange without a lot of notice and it would be helpful if cabs could be covered in the new waiver. The Department noted that it is working to make the waiver services as flexible as possible while delivering services in the most cost effective manner possible.

Community and Personal Engagement

Feedback around community and personal engagement was varied. One issue noted in several meetings was that current payment rates for community and personal engagement do not support individualized service delivery and if individual services in the area are to be provided, rates would need to support this structure. Stakeholders in several meetings also noted that these services are often challenging to provide in rural areas because of the distances people must travel to provide and receive services.

There were specific questions about whether individuals would be given an allotment and then be able to pick services they need up to that overall cost limit. The Department noted that these types of decisions have yet to be made, and that part of the Department's work over the next year will be to determine what utilization is expected to be of these services and what the rates will be, to develop provider qualifications, to explore and resolve regulatory issues, develop operational service definitions, and write the waiver.

Stakeholders asked if the waivers could pay for recreational activities in the community. The Department responded that waiver services can be used to support individuals in community participation, but the Centers for Medicare and Medicaid Services (CMS) Technical Guide states that services that are diversional or recreational in nature are not eligible for Medicaid reimbursement.

Additionally, stakeholders recommended that rates be available for services in groups versus individuals. For example, a rate for supporting a volunteer group rather than supporting individuals in volunteer work, one at a time.

Community Transition Services

Stakeholders reported being excited to see these services included in the recommendations.

Stakeholders noted that this should include coming from county jails, transitions from one group setting to another, transitioning from a family home to another setting, and transitions between waivers, noting that it could be important to have services cover some of the transition needs as people move from one waiver to another.

Stakeholders were very interested in exploring services that could be provided to individuals as they transition from the public education system and from child services to adult services, particularly service that will help ensure that individuals who are coming out of school settings

are well prepared for and linked to services. Stakeholders noted that when people finish with school, sometimes they access very few services until they enroll in one of the waivers and that, if there is a gap in services, by the time the individual is on the waiver, "we are basically starting over with them."

The Department noted some federal restrictions on this, including the requirement that waiver services cannot supplant what is available through the school system, but the Department is committed to partnering with other agencies to supplement their services and providing better support to individuals transitioning into adult services.

Dental Services

There were no recommendations around the dental services definition.

Health and Wellness Professional Services

Feedback from stakeholders included concern that this definition, because of its requirement that services are identified by a therapist/physician, is too narrow and follows the medical model. The Department noted that the waiver must ensure that services are provided by qualified professionals to ensure they qualify as covered services, services must be medically necessary or necessary for a person to stay in the community, and that services have goals and treatment outcomes. Otherwise, CMS would likely not approve them. Other feedback included a desire to make sure this includes services to help people maintain a healthy weight.

Specialized Medical Equipment and Supplies

There was very little feedback from the stakeholders about specialized medical equipment and supplies. Two points that were made were process related. First, there was a suggestion that there might be a need to more clearly articulate what is available in the State Plan under Durable Medical Equipment, in order to allow for a more effective determination of what is available in the waiver under Specialized Medical Equipment. This may help with the process issues. Second, a stakeholder suggested that processes related to first receiving a Medicare denial, then a Medicaid denial before getting a waiver to cover something should be streamlined if possible.

Vision Services

There were no recommendations around the vision services definition.

Residential Service Options

The primary recommendation from stakeholders around this issue was that billing for these services not be required to be done in 15-minute increments. Rather, stakeholders recommended that rates allow for billing by the day or other larger increment.

Stakeholders had feedback about the regulatory structures around residential facilities and recommended that the Department coordinate with CDPHE. They recommended that there may need to be some changes to regulations. The Department noted that it is working with CDPHE and other state agencies to review regulations and that the waiver redesign may be an opportunity to address confusing or conflicting requirements.



Stakeholders had a number of questions about leases. For example, if an individual has the rights of a lessee, do they also have the responsibilities of a lessee (such as a deposit, first and last month's rent)?

There was a comment that if people are being served in smaller settings, this will require more staff, which could be a challenge, especially given salaries and labor shortages in rural areas.

Stakeholders across the state expressed concerns about the cost of housing and the impact that high costs and low availability have on the individuals being served by these waivers. The Department recognizes that housing is a concern across the state and that finding low income housing is very challenging. Because Medicaid does not cover housing costs, opportunities to address housing shortages and high costs must be leveraged via other initiatives. The Department will continue to monitor other initiatives and leverage these as they arise.

Stakeholders also asked what host homes will look like under the new waiver. The Department responded that, regardless of waiver redesign efforts, under the CMS final rule, services that are provided under HCBS waivers must be provided in a home and community-based setting. If this setting is a provider-owned home, then there will need to be additional regulations or monitoring of these settings to ensure they are integrated in and support access to the greater community, provide privacy, optimize autonomy and independence, and comply with all components of the federal rules. Examples of these requirements that apply when a service provider also owns the residence include regulations around access to food, privacy, curfews, leases, etc. (These apply to family caregiver homes also.) Several people noted a concern that it will be hard to find host home providers, with all of these new regulations. The Department responded that these are federal regulations that the state must comply with, regardless of the waiver's structure or services. Additionally, the Department will be working with providers to support their transition.

Participant Direction of Waiver Services

The workgroup recommended that the new waiver offer a broad range of options around participant direction, from an individual doing none of this to an individual having both employer and budget authorities. Stakeholder feedback around participant direction of waiver services included the feedback that some individuals might want to do some of this, but might need assistance. Stakeholders recommended that the waiver ensure that these supports are available to people who may want to do this.

There were questions from a few stakeholders about which services could be participant directed and whether all services could be participant directed. The Department noted that the workgroup's recommendation was that all services for which participant direction should extend to as many services as possible, but that for some services, such as dental services or home modifications, the provider qualifications necessary make participant direction less feasible or desirable. The language that was recommended by the workgroup and by stakeholders was that participant direction should apply to all services to the maximum extent possible.

Stakeholders had some questions and concerns about monitoring and preventing exploitation of individuals being served. Several parents expressed concern about making sure that the new waiver does not place so much emphasis on participant direction that individuals do not have

the support they need to make good decisions. The Department noted that there will still be safeguards in place around participant direction.

Stakeholders generally thought that participant direction is a valuable option for waiver service delivery, and supportive of the individual's authority over services, and remarked it could be very helpful in obtaining quality providers, especially in rural areas. For example, in some rural areas, a provider may not be able to drive two hours a day to provide two hours of services, but a neighbor or family member might do it if they are funded to do so. Stakeholders noted that this helps with work force shortages and also, people want to have support from people they know.

Person-Centered Service Planning

Stakeholders noted that person-centered values and concepts should not be limited to service planning. Rather, person-centered practices should be incorporated into both service planning and service delivery. Therefore, the recommendation was made that this concept be renamed to "Person-Centered Approach".

Stakeholders had questions about how person-centered service planning would be accomplished using the existing Benefits Utilization System (BUS). Their feedback was that many service providers are doing a lot around person-centered planning already, but they struggling to figure out how to do this in the BUS. The Department understood this point and noted that the BUS will be replaced by a new case management tool along with the new Medicaid Management Information System (MMIS) in 2016.

Stakeholders stated there is a need for some accountability around person-centeredness – a way to ensure compliance with person-centered planning and service delivery. It was recommended this could be incorporated into payment and reimbursement. Another recommendation that emerged in this area was the idea of providing support to family members to help them understand and embrace person-centeredness.

Several stakeholders, particularly parents and guardians, were concerned about potential issues related to person-centeredness and safety. Specifically, they expressed a worry that if personcentered planning is not monitored carefully, an individual might make decisions that are not in their best interests, could be unhealthy, and/or could result in a lack of safety. This was an issue that was discussed in the meetings with a great degree of sensitivity, as having autonomy and being safe are important, but may sometimes be at odds. They also asked how personcentered care is provided an individual who doesn't have the cognitive ability to make their wishes known. The Department noted this concern and that person-centeredness doesn't mean people just make choices without support. Rather, it is about valuing an individual's preferences and encouraging their participation in their services and supports and moving away from an institutional preference. Balancing what is important to and what is important for the individual is fundamental to person-centered service planning and delivery.

There were also questions about how the safety of others aligns with person-centeredness. The Department noted that there is a lot of intersection. For example, rules around food for one person will affect other people in the same living situation. Stakeholders also commented that the fluidity in services that is proposed in the new waiver will make services more person-

centered. For example, if an individual's needs around food preparation and money management change over the course of the year, a person-centered approach will make it much easier to make changes in the services provided.

Financing and Reimbursement

Several stakeholders recommended that there be geographically based rates, with more expensive areas having higher rates, and less expensive areas having lower rates. One recommendation was that Department should look at school district funding methodology (differential funding based on cost of living) as a possible method for setting rates.

Stakeholders also recommended that the Department examine caps, or limits, in services, noting that some caps are problematic. One example is that of needing day habilitation services five days per week, but the limits only allowed for four. Stakeholders also recommended that rates throughout should support individualized services and there may need to be a balance of group versus individual services.

The idea of, over time, incorporating incentive payments to providers based on meeting certain quality standards was discussed. The Department noted that, if such a process is undertaken, there would be an extensive stakeholder input process around this as well. Stakeholders expressed appreciation for that, and a few made recommendations for future consideration. For example, if there is funding to create incentives, some stakeholders expressed a preference for using that funding to ensure that there will be access to services in rural areas. Others noted that the incentive structure should ensure that organizations are not penalized for things they have no control over, like not having enough workforce to meet a goal that is tied to an incentive. Still others noted that incentive payments would need to be sufficient to drive the desired change.

Waiver Development and Implementation Council

Stakeholders were in favor of the Waiver Development and Implementation Council, and there were no recommendations around this.

Other Recommendations

Timeline

There was a recommendation that the Department run the old waivers and the new waiver in parallel, at least for two years; and that some people enrolled in the persons with Developmental Disabilities (HCBS-DD) waiver might stay on it for even longer. Other stakeholders recommended that the Department consider pushing out the July 2016 implementation date because it seems like a lot of change to have occur in a short time period.

SIS and Assessment

Several stakeholders asked about whether there would be revisions to the Supports Intensity Scale (SIS). The Department responded that work on the SIS is outside of the scope of this waiver redesign work, but that others in the Department are working with stakeholders on how needs are assessed and what tools are used.

Resource Limitations

Stakeholders expressed a concern that, with a new waiver, individuals currently being served on the existing HCBS-DD waiver will not have access to all of the services they currently receive, in order to make available additional funding to meet unmet needs for clients served on the Supported Living Services (HCBS-SLS) waiver. Some stakeholders expressed a concern that their family member, who is receiving services via the HCBS-DD waiver, may experience rationing of services, in part to eliminate the wait lists.

Stakeholders noted that caps on services are problematic and prevent people from getting the services they need when they need them. Some stakeholders made a recommendation of higher caps or flexibility for clients who need more hours of supervision in order to live at home noting that, if we really want to do person-centered care, we need to make sure the waiver is flexible enough to meet their needs and keep them out of institutional settings. Discussion of caps including an awareness of the reality of limited funding, and that, regardless of the waiver design, there will be limits on services, simply because the economics of program design require limits.

In several meetings, stakeholders asked how these services will be paid for, given limited funding and resources. The Department responded that the State will project costs for services as they are defined, and then will work with the legislature to request the necessary funding. The Department acknowledged that there are limited resources and that it is not possible to rule out a wait list, but the Department is working to ensure that services are available when people need them and will continue to work with the legislature to request the funding necessary to do so.

Provider Shortages

While this is issue touched on in several areas above, it is worth nothing that, in rural communities, stakeholders expressed concern that they may have housing, but they may not have adequate staffing and an insufficient work force. Also, individualized care requires more staffing, and is more costly. In some communities, stakeholders expressed concern that because there are so few people accessing these services in their geographic area, it is not very enticing for providers to come here. Providers do not think a business is sustainable because there are not enough people to serve. This results in little provider choice for waiver participants and minimal competition among providers.

Provider Qualifications

Also of note were recommendations around provider qualifications. Stakeholders expressed concern about high provider qualifications to administer medications, and new qualifications that may be hard to meet, thereby limiting the provider pool. Stakeholders recommended a better balance between ensuring safety, but without the provider qualifications being so complicated (i.e., don't need a nurse to do everything, like medications).

Working with Other State Agencies

Stakeholders recommended that the Department work closely with other state agencies on rules and regulations that may need to be changed to accommodate the new waiver, and to explore whether there are areas that may be over-regulated. The Department responded it is

committed to working with DORA and CDPHE on licensing regulations and determining which services require licensure and which do not.

Staff Turnover

Stakeholders noted that staff turnover is a problem because pay is so low for people who provide direct services. They noted that this has a direct impact on the ability of providers to provide person-centered planning, and it has a direct impact on access because there are not enough providers. There was no recommendation made around this issue, and the Department noted that it is aware of these issues.