

**Adult IDD Waiver Redesign Stakeholder Meeting
September 24, 2019
DRAFT Stakeholder Notes for Approval**

Stakeholder Attendees in the Room

Charlene Willey
Carol Meredith
Maureen Welch
Kay Speake

Bob Lawhead
Stephen Shaughnessy
Sarah Leeper
Jessica Eppel

Stakeholder Attendees on the Phone

Linda Kranz
Deana Cairo
Laurel Rochester
Pat Chamberlain
John Klausz
Kevin Graves
Regina DiPadova
Heidi Haines
Rob Hernandez
Karen Roberts

Leslie Rothman
Kidron Backes
Gerrie Frohne
Linda Gleason
Ellen Jensby
Shawna Boller
Sara Sims
Tamara French
Jodi Walters
Kendra Kettler

Staff Attendees in the Room:

Candace Bailey
Alicia Ethredge
Lori Thompson
Hayley DeCarolis

Tasia Sinn
Rebecca Spencer
Matt Baker
Kelly O'Brien

Getting Started:

Tasia Sinn of HCPF opened the meeting as facilitator in John Barry's absence, at 1:11 p.m. Today's subject is to review and discuss the "IDD Waiver Redesign Project Cost Modeling Report" by Bolton. All meeting materials can be found at the HCPF Waiver Redesign webpage. Tasia made housekeeping announcements for the meeting including plans for the Parking Lot for today's meeting, requests for being respectful, keeping on time and working toward moving forward.

Tasia conducted participant introductions for those in the room and on the phone. The HCPF Mission and Vision statements were reviewed. The meeting notes from July 25, 2019 were accepted as presented without further comment.

Stakeholder Co-Chairs Report:

1. Bob asked if the consensus discussion about live edits would occur. Candace confirmed that this discussion would occur later during the meeting.

2. Bob: While people need to be respectful, this does not rule out opportunity for controversy as being acceptable. Controversy can co-exist during the meeting. Candace confirmed.

Open Forum #1:

1. Gerrie: How to find what has come in to HCPF's electronic mailbox since that has been announced as an input receiver? Alicia announced the electronic mailbox site as HCPF_IDDWaiverRedesign@HCPF.state.co.us and explained that nothing has been received. Alicia mentioned that John Barry has distributed the inbox email address to all stakeholders, as well as the language suggestions gathered from Bob Lawhead, David Bolin, and others. Questions about this can be referred to John Barry.
2. Bob asked about stakeholder access to source documents for the Bolton work. Understanding of the Bolton report will be challenging without Excel spreadsheets, the Washington formula, SIS scores, assumptions and other work behind the Bolton report.

Bolton Actuarial Report:

Lori Thompson began the recap of the Bolton Actuarial Cost Model report with its highlights. In the cost model, Bolton projected the estimated costs of three combined IDD populations waiver scenarios, plus the "Do Nothing" baseline scenario. Actuarial expertise was chosen from outside of HCPF because HCPF needed a cost estimate baseline for this waiver redesign work and to help to develop the Needs-Based Criteria to project those costs. The waiver redesign initiating legislation, HB15-1318, included no funding for any services in the combined waiver, but did provide funds for a contractor to estimate consolidated waiver costs. Bolton builds on existing data, SIS data, utilization data and PAR data. Bolton conducted nationwide research for new innovative services, rates and utilization. Bolton also aligned Support Levels and developed Individual Support Plan Budget Limits (currently called SPALs). Bolton found only one other state, Washington, that used a Needs-Based Criteria for 24/7 Residential Services. Bolton estimated costs of applying Washington's Needs-Based Criteria to this combined population and to the waiting list. Washington also used SIS data which also matched Colorado. The goal of waiver redesign is the foundational principle taken directly from HB15-1318 and from the Community Living Advisory Group (CLAG), "An array of broad, flexible services, and spectrum of service delivery options that enhance individual choice, autonomy, and community engagement."

Estimated Cost Assumptions:

1. Assume that all SLS members meeting Daily Support Needs would elect Residential Services.
2. Assume that DD members will use new services at the same rate as SLS counterparts.
3. The cost of Added services is based on research from other states and Colorado data.

Take-aways from the Bolton report:

1. Estimated cost of the 4 scenarios
2. Data gaps to explore
3. Additional considerations

The bottom line is that delivering Residential Services to SLS members that would quality for Residential Services using the Needs Based Assessment is the most expensive cost associated with consolidation. Full waiver redesign (in Scenario 4) is the costliest with both adding new innovative services and removing service limits in behavioral and transportation categories. Stakeholder questions:

1. Bob got clarification on where a numeric figure could be found.
2. Charlene got clarification that the SLS members included members on the waiting list for the DD waiver, also that 74% of these SLS members were estimated to meet the criteria for receiving Residential Services.

Identified data gaps and areas to explore:

1. HCPF lacks data on self-direction which could result in threatening the accuracy of future cost projections. And there is no current historical data in Colorado or nationally for self-direction in Residential Services.
2. IDD waiver consolidation complements other OCL initiatives such as the LTSS Assessment Tool, Conflict-Free Case Management and the HCBS Settings Final Rule which work in tandem with one another.
3. Washington state includes some data in their algorithm that Colorado does not collect. Exceptional behavioral health support needs are felt to be not well captured by the Colorado SIS.
4. The algorithm for Needs-Based Criteria does not include some caregiver factors. The Department recently implemented there are new caregiver capacity criteria for emergency enrollment into the DD waiver that could be a match for more caregiver factors, in the Needs-Based Criteria.
5. The Needs Based Criteria needs to be refined. Some consider the Needs Based Criteria too generous; some consider it too restrictive.

Additional considerations:

1. Initially some people presumed that there would be offsetting costs from some DD members who would not choose to continue Residential Services, but that has not proved to be true. So, resulting high estimated costs could prove not fiscally sustainable annually.
2. Bolton's Cost Model is only a starting point, from which to build to other steps.

Case Studies and Refining Needs Based Criteria – Fall 2019

- Build from the Phase 1 Case Studies and determine a small sample
- Recruit volunteers to participate in real life examples for fifteen case studies
- Identify missing elements in the Needs-Based Criteria

- Paint a picture of the impact on quality of life for members

Areas of Missing Elements

1. Exceptional behavioral or medical support needs
2. Caregiver capacity issues
3. Living arrangements -frequency and intensity of support needs
4. Medical devices or treatments needed. Bolton identified that Colorado does not collect data on this unless in the SIS 3a.
5. Technology gaps which could promote independence and more self-sufficiency

In Phase I, a HCPF contractor aggregated a representative random sample of case studies on 432 people in the DD and SLS waivers and the waiting list. Now we want to do a much smaller sample of real-life case studies to refine the Needs-Based Criteria and how this would affect people's quality of life and what services they would put together.

1. Jessica: Does Washington state define needing residential supports and needing access to residential supports, because this comprises such a big cost and need for funding? Lori explained that Washington has 2 IDD waivers, one called the "Community Protection" Waiver which is specifically for people who need direct on-site 24/7 supervision and residential supports and one waiver that provides access to 24/7. Bolton used the algorithm from the one similar to our DD Waiver which provides access to 24/7 up to and including on-site support and supervision. Lori responded that in Colorado, speaking generally, Support Levels 4 through 7 are needing actual on-site 24/7 services, while Support Levels 1 and 2 are more needing access to 24/7 services.
2. Carol: So, I understand these to be estimates so far. In SLS, people use up their SPAL for other services so they do not have funding for, like Personal Care. So, in Bolton, this now accounts for the high cost estimate as there is no limit on the use of Personal Care. When Bolton chose to remove some service limits, why not the Day Program service limit of 4800 hours? Lori: HCPF did not ask Bolton to cost model removing the day habilitation 4800-hour limit. But we could use Bolton data and the Cost Modeling tool to adjust and estimate the cost of removing that 4800-hour limit.
3. Carol: How is it that people on Support Level 5 would not qualify for daily support needs? Lori: yes, that seems strange. Candace: Another reason for additional case studies would be to see if people on Support Levels 5, 6, and 7 really don't meet the support needs criteria, or if something was missed, so we need to do some more digging.
4. Pat: Bolton says they use summary data provided by HCPF. Is there anything we can examine in depth? Lori: Bolton did get individual PHI data. For the report, they summarized data into non-identifying information, but their Excel spreadsheets have PHI, birthdates, Medicaid IDs and other member identifying info in them.

5. Pat: We should be able to see the scales and subscales and the decision tree. Also, Bolton used the SIS and some subset of the SIS even though the SIS is planned to be replaced in Colorado. All of that should be able to be seen by families. Lori: page 14 of 33 shows the exact SIS scores used. In Table 3, the decision tree talks about the type of supports in each of those SIS activities and that determines if it is daily support time.
6. Pat: If we have not captured all the components of the Washington algorithm, then it is faulty. Lori: This is just the best comparable approach that we have, just not a separate assessment for behavioral support needs like WA has, so we want to refine that further.
7. Pat: How does the new SIS fit into this work? Lori: the new tool determines Level of Care and which waiver a person qualifies for. We need this Needs-based Criteria to determine if a person qualifies for Residential Habilitation in the DD waiver. So, this works in tandem with the new assessment tool.
8. Pat: A big problem is that Bolton cut 10% from the person's PAR data in figuring costs. Lori: Bolton found a middle ground by combining PAR data and claims data to give a more actual picture of a person's needs because utilization does not accurately reflect a person's need, due to lack of providers, etc.
9. Pat: What does 90% of PAR, mean?
10. Bob: Line 5; Page 7. Candace: This is just an estimate. Even when services in the PAR are available, not everybody uses them, so Bolton estimated a 90% utilization rate.
11. Pat: It is not acceptable after a team determines an individual's needs, then to only use 90% of those needs instead of figuring out why all the needs are not being met. And the reference to "90% of utilization data" is on page 22.
Candace: We hope case studies can get to why people are not using what is in their PAR.
12. Pat: We feel very strongly about consumer-direction. This needs to be considered again as a model or a pilot.
13. Bob explained that families would use 40+ hours of day services and more providers would be available if the day services unit limit could be raised from 24 hours per week. Lori confirmed that Bolton did the cost modeling scenarios with no changes in day service limits.
14. Bob is very concerned about significant numbers of people as they become available to move from the SLS waiver to the DD waiver, and now will be subject to the Needs-Based Criteria and deemed ineligible for Residential Services. It is scary and feels dangerous that when I die, my son might not be entitled to Residential Services, place-based services. Candace acknowledged the fear, but said if the need is there, the service is available. If the need is not there, they do not receive Residential Services.
15. Carol and Lori found a current regulation that says you must require access to 24-hour supervision to access the DD waiver. Candace: We can all admit that there have been a number of individuals who have not always been appropriately assessed. There have been a number of individuals receiving

services who probably should not have qualified in the first place. If someone can live independently, but in five years they need 24/7 services, then they can receive those services.

16. Bob: There is no way to measure accurately. It is an imperfect system. There is some case manager resistance to justifiable SIS reassessments. Coming up with a solution is not as easy as creating an algorithm. Candace: Correct. This model is not ready yet. We need all of you to help us to get the best product possible.
17. Charlene: The SIS has been legislated away and should not now be any basis for this project. It is crazy to assume that 24% of members on SLS will not need 24/7 services. It is wrong to take data from another state. We are creating more mystery with the Needs-Based Criteria. We are cut off from most of the data in the Bolton project, with no transparency or data sharing. It is also offensive to me, planning for only fifteen case studies in a complex issue like this.
18. Maureen Welch: Instead of bureaucratic answers, we need HCPF to give us accurate information, more open engagement and leadership from the top.
19. Gerrie: First, I formally ask HCPF internal budget staff to cost out the day program 4800-hour limit, so that advocates can ask the Spring 2020 legislature to eliminate this limit from the waiver. Second, to convene a meeting to address how Bolton's Individual Support Plan Budget (ISPB) would work and how it differs from a SPAL. Third, to continue meetings on negotiating ongoing items between HCPF and the public.

Next Steps:

Candace discussed the next steps

- Bolton's estimated funding of waiver redesign in its entirety at one time will have a large fiscal impact
- Original legislation had no funding for implementing the waiver or its benefits
- Forecasts are for an economic downturn
- We must consider these forecasts
- HCPF would like to work with stakeholders on other potential ideas moving forward even if no funding is in Governor's budget or from the general assembly
- How would the group like to proceed if the project is fully funding, partially funded, or not funded.
- After Candace presented next steps, she opened the topic for discussion. We need a plan to move forward no matter the scenario.
- One idea – Incremental Steps and Alignment
Use the developed Service Coverage Standards as a guide for alignment across all HCBS waivers to simplify and streamline the HCBS system and build provider capacity. Having one definition for Personal Care to go into all LTSS waivers, is one example.
- Other ideas?

- Carol: In the HCPF timeline document, waiver redesign was to be completed in 2021. Completion of Conflict-Free Case Management and the new assessment tool might delay submission of waiver redesign.
- Alicia noted that if the Department is not yet in compliance with the Final Settings Rule, there would still exist an option to submit an amendment to the DD waiver, but not a whole new waiver.
- Maureen: I'd like to see visionary leadership and optimism with easy-to-read tools available. Can we come together instead of being divided and avoid fear tactics?
- Candace: Agreed that we do need to meet some more. What should the next topics be? Tasia: maybe use the Co-Chair process to gather ideas.
 - Carol: Next, we should do Parking Lot issues.
 - Bob: Live edits to the existing Service Coverage Standards; case studies; consumer-direction.
 - Pat: Dittoed Bob. Also, maybe brainstorm how to make waiver redesign more cost effective. Instead of caps on services, have an overall budget without any specific caps. Lastly, we are trusting you, the Department, with our feedback for our family members who need the most help.
 - Charlene: We need this group's Guiding Principle, such as we need to sync up with the new Assessment Tool. I can add other Principles and other people can also think about what they should be.
- Tasia: Maybe that is for the agenda for the next meeting. Tasia then closed the meeting at 3:05.

Respectfully submitted,
Gerrie Frohne, family member