



Memorandum

Date: June 30, 2017

To: Lori Thompson, Sarah Hoerle, and Leah Pogoriler, Colorado Department of Health Care Policy and Financing

From: Erika Robbins, The Lewin Group

Re: Colorado HCBS Individuals, Families and Advocates Survey Summary Report Update

Cc: Kristen Rice, The Lewin Group

The 2014 CMS Final Rule for Medicaid funded Home and Community Based Services (HCBS Final Rule) marks an opportunity to build a truly person-centered service delivery system that supports older adults and people with disabilities. Implementation of the rule will help thousands of Colorado's older adults and people with disabilities to enjoy the full promise of community living by prioritizing the quality of each individual's experience.

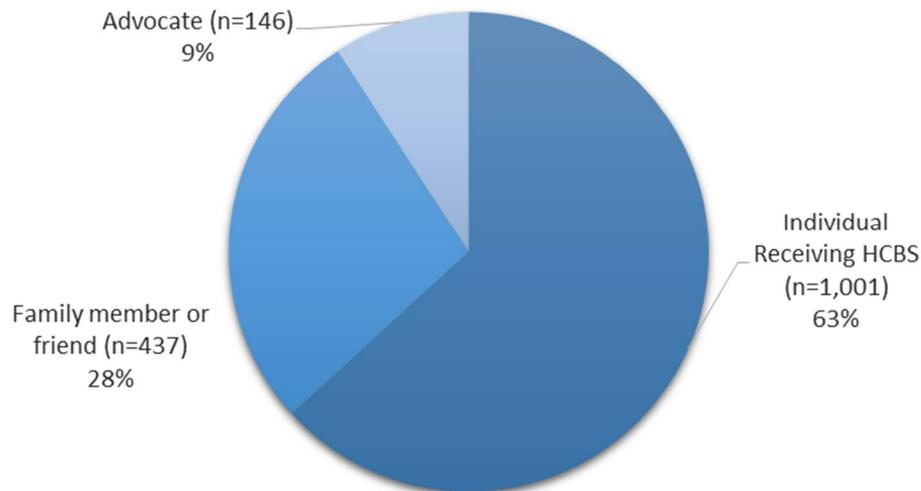
Under contract with the Colorado Department of Health Care Policy and Financing (HCPF), the Lewin Group designed a survey to assess the experience of individuals receiving Medicaid HCBS in the context of the HCBS Final Rule. The survey instrument included questions tailored for each of three key audiences - individuals receiving Medicaid HCBS, their family members and friends, and their advocates.

HCPF first distributed the survey from July 2015 through April 2016 through an email list serve with instructions that the survey could be printed and mailed or submitted through a link on the HCPF website. This outreach effort returned 66 responses. In April 2016, HCPF began fielding the survey to its provider network, instructing providers participating in site visits to notify individuals, families, and advocates living or receiving services at their settings of the availability of the survey. In early 2017, HCPF staff attended meetings with case management entities, providers, and other stakeholder and advocate groups; at these meetings, HCPF staff described the availability of the survey and encouraged stakeholders to take it as often as they liked. The survey was hosted online by Lewin. Paper copies and a web link to the survey were available on the [HCPF HCBS Final Rule website](#) under Site-Specific Assessments and for each of the visited providers.

This memo summarizes the responses received to the survey from each audience, and provides recommendations and potential next steps for HCPF as it continues its compliance activities related to the HCBS Final Rule.

As of June 26, 2017, Lewin received 1,584 responses to the survey from individuals receiving services, family members and friends, and advocates. The majority of responses (63.2%) came from individuals receiving HCBS, with a significant portion of responses coming from family members and friends of individuals receiving HCBS (27.6%). The full composition of survey responses is found in **Exhibit 1**.

Exhibit 1: Survey Response Composition



The memo includes six sections: one for high-level findings, one for each category of respondents, one for additional findings, and one for recommendations and next steps.

Section 1 – High-Level Findings

Residential Settings

The most commonly-cited areas where providers appear to perform well according to individuals receiving HCBS services in residential settings (n=754) were:

- The perception that homes are in the community among other homes, apartments, and businesses;
- Access to individuals' rooms and common areas of the home; and
- Individuals' ability to keep their belongings safe in their home.

The most commonly-identified compliance issues by individuals were:

- Staff not providing information about public transportation, such as buses or taxis;
- Choice of whether or not to live in a home where roommates were already living;
- Selection of roommates or housemates who are not family members; and
- Ability to schedule their appointments/outings at their convenience as opposed to the convenience of the paid staff in the home.

The most commonly-cited areas where providers appear to perform well according to families and friends of individuals receiving HCBS services in residential settings (n=324) were:

- The perception that homes are in the community among other homes, apartments, and business; and
- Individuals are able to go where they want in their home, such as their bedroom or the kitchen.

The most commonly-identified compliance issues according to families and friends were:

- Staff not providing information about public transportation, such as buses and taxis;
- Choice of roommates or housemates;
- Ability to leave their home when they want; and
- Ability to schedule their appointments/outings at their convenience as opposed to the paid staff at their home.

The most commonly-cited areas where providers appear to perform well according to advocates of individuals receiving HCBS services in residential settings were:

- Homes are part of the community; and
- Individuals are able to control their money.

The most commonly-identified compliance issues according to advocates were:

- Individuals do not control their schedules;
- Interactions are limited to other individuals receiving services and paid staff; and
- Choice of roommates.

Non-residential Settings

Across non-residential settings, the most commonly-cited areas where providers appear to perform well according to individuals receiving services (n=831) were:

- The provision of support needed to be successful in a volunteer position, paid job, or day program;
- Job or day program present in the community with other private homes or businesses; and
- The provision of support to seek a volunteer opportunity or paid job, and to participate in a day program in the community.

The most commonly-identified compliance issues by individuals were:

- The provision of support to give input on work schedules, break/lunch times, and work benefits; and
- The provision of support needed to negotiate work hours.

The most commonly-cited areas where providers appear to perform well according to families and friends of individuals receiving HCBS services in non-residential settings (n=158) were:

- Job or day program present in the community with other private homes or businesses;

- The provision of support needed to be successful in a volunteer position, paid job, or day program; and
- The provision of support needed to negotiate work hours.

The most commonly-identified compliance issues according to friends and families were:

- The provision of support to give input on work schedules, break/lunch times, and work benefits; and
- The provision of support to seek a volunteer opportunity or paid job, and to participate in a day program in the community.

The most commonly-cited areas where providers appear to perform well according to advocates of individuals receiving HCBS services in non-residential settings were:

- Activities are age-appropriate; and
- Settings are part of the community.

The most commonly-identified compliance issues were:

- Individuals do not have the choice to pursue interests; and
- Interactions are limited to individuals and paid staff.

The following sections provide more detail by respondent category.

Section 2 – Individuals Receiving HCBS

Survey Respondents

Individuals receiving HCBS completed the survey 1,001 times. (Because individuals were able to take the survey as often as they liked, there may have been fewer than 1,001 individual respondents.) Of this group, 75.4% receive services in their homes. A large majority, 86.6%, receive services where they work, as seen in **Exhibit 2**.

Exhibit 2: Services Received by Individuals Completing the Survey

Question	Yes	No	Total
Do you receive Medicaid-funded services where you live?	75.4% (n=754)	24.6% (n=247)	1,001
Do you receive Medicaid-funded services where you work?	86.6% (n=831)	13.4% (n=129)	960

The majority of questions for individuals receiving HCBS were multiple choice, with answer options of:

- Yes - indicating the individual *does* have the aspect of choice and/or community access at issue

- No - indicating the individual *does not* have the aspect of choice and/or community access at issue
- Does not apply - the question doesn't apply to the individual's services

Responses of “yes” tend to indicate setting-level compliance with the HCBS Final Rule, while responses of “no” tend to indicate a compliance issue at the setting. Not every survey respondent answered every survey question. Thus, some questions have fewer answers than others.

Characteristics of the Home

The survey asked 19 questions related to choice and community access in services received in residential settings. Seventeen (17) of these questions received responses of “yes” at a rate of 50% or higher, indicating that respondents have choice and/or community access in these areas.

For each question listed below, over 90% of respondents replied “yes.”

1. Is your home in the community among other homes and apartments or businesses?
2. Do you have access to your room and the common areas in your home?
3. Can you keep your things safe in your home?

Exhibit 3 below details the frequencies for each question in this section.

Exhibit 3: Survey Responses among Individuals Receiving HCBS, Residential

Final Rule Component	Question	Yes	No	N/A
Integration	Is your home in the community among other homes and apartments or businesses?	94.0%	3.8%	2.2%
Integration	Do you or your guardian decide how to spend your money?	88.1%	7.1%	4.8%
Integration	Do you know about activities that happen outside of your home (for example, a fair, movies, music event)?	82.6%	11.7%	5.8%
Integration	Do you have friends and relationships with persons other than paid staff, family, or other individuals receiving services?	73.8%	22.4%	3.7%
Integration	Does the staff at your home provide information about public transportation such as buses or taxis?	51.6%	13.7%	24.7%
Choice	Did you have a say in where you were going to live?	72.6%	14.5%	12.9%
Choice	Did you choose to live in a home where roommates were already living?	36.0%	20.6%	43.4%
Choice	If you have roommates or housemates who are not family members, did you choose them?	25.0%	32.4%	42.6%
Independence	Do have access to your room and the common areas in your home?	94.3%	1.9%	3.8%
Independence	Can you have visitors when you want to?	89.6%	6.5%	3.9%
Independence	Can you eat when you want to (barring any diet restrictions)?	88.8%	6.8%	4.4%

Final Rule Component	Question	Yes	No	N/A
Independence	Can you talk on the phone when you want to?	85.7%	5.3%	9.0%
Independence	Can you generally go where you want outside of your home, such as to lunch, stores, or religious settings?	79.9%	12.4%	7.8%
Independence	Are you generally able to schedule your appointments/outings at your convenience as opposed to the convenience of the paid staff at your home?	50.8%	32.5%	16.7%
Rights	Can you keep your things safe in your home?	92.0%	1.8%	6.1%
Rights	Do the staff in your home treat you with respect?	88.3%	2.2%	9.5%
Rights	Do the staff in your home respect your privacy?	86.7%	2.4%	10.9%
Rights	Do the staff in your home respect your choices?	85.3%	3.2%	11.5%
Rights	Can you leave your home when you want to?	69.6%	19.9%	10.6%

In addition, participants were asked how often they interact with their neighbors. Responses were fairly evenly distributed with 22% reporting multiple times per week, 13% reporting once a week, 18% reporting a few times a month, 23% reporting rarely, and 22% reporting never.

From this data, it appears that individuals' most significant concerns are in the following areas:

1. Staff do not provide information about public transportation such as buses or taxis;
2. Choice of whether or not to live in a home where roommates were already living;
3. Selection of roommates or housemates who are not family members; and
4. Ability to schedule their appointments/outings at their convenience as opposed to the convenience of the paid staff at the home.

Characteristics of the Workplace

The survey asked five questions related to choice and community access in services received in non-residential, workplace settings. The survey did not ask about other types of day settings, such as supported community connections or other day programs (the next version of the survey will cover such programs). Each of these questions received responses of "yes" at a rate of 50% or higher, indicating that respondents have choice and/or community access in these areas. **Exhibit 4** below details the frequencies for each question in this section.

Exhibit 4: Survey Responses among Individuals Receiving HCBS, Nonresidential

Final Rule Component	Question	Yes	No	N/A
Integration	In general, do you feel you have the supports you need to be successful in your volunteer position, paid job, or day program?	92.0%	2.4%	5.5%

Final Rule Component	Question	Yes	No	N/A
Integration	Is your job or day program in the community with other private homes or businesses?	88.2%	5.1%	6.7%
Independence	Do you have the support to give input on your work schedule, break/lunch times and benefits at your job?	69.9%	7.4%	22.7%
Choice	Do you feel you have the support to seek a volunteer opportunity, paid job, or participate in a day program in the community?	84.8%	4.8%	10.4%
Rights	Do you feel like you work enough hours during the week? If not, do you feel you have the supports to negotiate your work hours?	65.0%	7.8%	27.2%

From this data, it appears that individuals’ most significant concerns are in the following areas:

1. Working enough hours during the week and/or having the supports to negotiate their work hours; and
2. Support to give input on their work schedule, break/lunch times and benefits at their job.

Perhaps most important of these questions is whether individuals feel they have “the support to seek a volunteer opportunity, paid job, or participate in a day program in the community.” Without such support, many individuals would likely not engage in these activities and achieve community integration, and 84.8% of respondents indicated they did have this support. In addition, 88.2% of respondents reported that their job or day program was in fact in the community, near private homes and businesses. While the Colorado Department of Public Health & Environment (CDPHE) is conducting site visits to verify that HCBS settings are in fact supporting community integration, this question indicates that the majority of people receiving employment support believe the employment setting is integrated in the community.

Section 3 – Family Members and Friends

Survey Respondents

Family members and friends completed the survey 437 times. Of this group, 75.7% have a family member or friend who receives Medicaid-funded services in their home. In addition, 47.2% have a family or friend who receives Medicaid-funded services where they work, as seen in **Exhibit 5**.

Exhibit 5: Services Received by Family Members and Friends of Survey Respondents

Question	Yes	No	Total
Does your family member or friend receive Medicaid-funded services where they live?	75.7% 324	24.3% 104	428
Does your family member or friend receive Medicaid-funded services where they work?	47.2% 158	52.8% 177	335

Compared to the responses from individuals receiving services, these responses cover proportionately fewer settings where people work. This may be a result of how the survey was distributed, and family members and friends may have been more likely to receive the survey from individuals receiving services at home than at work.

The majority of questions for individuals receiving HCBS were multiple choice, with answer options of:

- Yes - indicating the family member or friend believes the individual *does* have the aspect of choice and/or community access at issue
- No - indicating the family member or friend believes the individual *does not* have the aspect of choice and/or community access at issue
- Does not apply - the question doesn't apply to the individual's services

Responses of “yes” tend to indicate setting-level compliance with the HCBS Final Rule, while responses of “no” tend to indicate a compliance issue at the setting. Not every survey respondent answered every survey question. Thus, some questions have fewer answers than others.

Characteristics of the Home

The survey asked 18 questions related to choice and community access in services received in residential settings. Of the 17 questions with a “yes” or “no” response, a majority of respondents replied “yes” to 13 of these questions, indicating that their family or friend receiving services did have choice and/or community access.

For each question listed below, over 90% of respondents replied “yes.”

1. Is their home located in the community among other private residences or retail businesses?
2. Can they go where they want in their home, such as their bedroom or the kitchen?

Exhibit 6 below details the frequencies for each question in this section.

Exhibit 6: Survey Responses from Family/Friends of Individuals Receiving HCBS, Residential

Final Rule Component	Question	Yes	No	N/A
Integration	Is their home located in the community among other private residences or retail businesses?	95.1%	2.0%	2.9%
Integration	Do they or their guardian decide how to spend their money?	88.5%	9.0%	2.5%
Integration	Do they know about activities that happen outside of their home (for example, a fair, movies, music event)?	81.6%	7.0%	11.5%
Integration	Do they have friends and relationships with persons other than paid staff, family, and other people receiving services?	72.1%	21.3%	6.6%
Choice	Did they have a say in where they were going to live?	67.1%	12.8%	20.2%

Final Rule Component	Question	Yes	No	N/A
Integration	Does their home provide information about public transportation, such as buses and taxis?	41.0%	10.2%	48.8%
Choice	Did they choose to live in a home where roommates were already living?	20.6%	22.6%	56.8%
Choice	If they have roommates or housemates who are not family members, did they choose them?	12.8%	26.3%	60.9%
Independence	Can they go where they want in their home, such as their bedroom or the kitchen?	94.5%	2.1%	3.4%
Independence	Can they have visitors when they want to?	84.8%	3.8%	11.4%
Independence	Can they eat when they want to?	78.9%	13.9%	7.2%
Independence	Can they talk on the phone when they want to?	70.9%	4.6%	24.5%
Independence	Can they generally go where they want outside of their home, such as out to lunch, shopping, or attend a church?	70.5%	12.7%	16.9%
Independence	Can they leave their home when they want to?	50.6%	24.1%	25.3%
Independence	Are they generally able to schedule their appointments/outings at their convenience as opposed to the paid staff at their home?	38.8%	35.0%	26.2%
Rights	Can they keep their things safe in their home?	89.0%	4.2%	6.8%
Rights	Are the staff in their home nice to them?	75.0%	3.0%	22.0%

In addition, families and guardians were asked how often their family members or friends interact with their neighbors. Responses were less evenly distributed than individuals' response with 29% reporting multiple times per week, 6% reporting once a week, 21% reporting a few times a month, 19% reporting rarely, 8% reporting never, 2% reporting that they do not have neighbors, and 15% unsure.

Interestingly, two of the above questions (the 1st and 3rd questions in the "Integration" category) also had a "yes" response of 80% or more from individuals receiving HCBS. This is particularly important for the question addressing community location, and suggests that both individuals and their family and friends perceive residential services to take place in locations integrated within the community.

In addition, 88.5% of respondents indicated that their family member or friend and/or their guardians have control over their money, which is a similar to the response to the same question asked of individual's receiving services (88.1%).

From this data, it appears that family members and friends' most significant concerns are in the following areas:

1. Staff does not provide information about public transportation, such as buses and taxis.
2. Choice of roommates or housemates.

3. Ability to leave their home when they want.
4. Ability to schedule their appointments/outings at their convenience as opposed to the paid staff at their home.

Similar to the responses from individuals receiving HCBS, family members and friends indicated that there may be opportunity for improvement in terms of roommate choice. Although, it is important to know that over 58% of family members and friends indicated roommate issues do not apply to the person they know who receives HCBS.

The responses from family members and friends also mirrored the individual response results in the area of scheduling appointments and outings. About 38.8% of family members and friends indicated that the person they know is able to schedule outings at their convenience, although 35.0% reported that appointments are scheduled more at the convenience of paid staff.

While many of the response trends from family members and friends are similar to those among individuals receiving services, there are some variances worth considering. For example, almost 70% of individuals indicated they can leave their home when they want to while just 50.6% of family members and friends indicated this characteristic. Similarly, 85.7% of individuals reported being able to talk on the phone when they want, compared to 70.9% of family members and friends.

Characteristics of the Workplace

The survey asked five questions related to choice and community access in services received in nonresidential, workplace settings. A majority of respondents replied “yes” to each of these questions, indicating that they did have choice and/or community access. **Exhibit 7** below details the frequencies for each question in this section.

Exhibit 7: Survey Responses from Family/Friends of Individuals Receiving HCBS, Nonresidential

Final Rule Component	Question	Yes	No	N/A
Integration	Is their job or day program in the community with other private homes or businesses?	90.0%	6.7%	3.3%
Integration	In general, do they feel they have the supports needed to be successful in their volunteer position, paid job, or day program?	91.3%	3.3%	5.3%
Independence	Do they have support to give input on their work schedule, break/lunch times, and benefits at their job?	64.7%	10.0%	25.3%
Choice	Do they feel they have the support to seek a volunteer opportunity, paid job, or participate in a day program in the community?	66.7%	12.0%	21.3%
Rights	Do they feel they work enough hours in a week? If not, do they have the support to negotiate their hours?	80.0%	5.3%	14.7%

From this data, it appears that family members and friends’ most significant concerns are in the following areas:

1. Support to give input on their work schedule, break/lunch times, and benefits at their job.
2. Support to seek a volunteer opportunity, paid job, or participate in a day program in the community.

Similar to how individuals receiving HCBS responded, family members and friends indicated that the person they know has the “supports needed to be successful in their volunteer position, paid job, or day program.” Over 90% of respondents indicated this, and 90.0% reported that the job and/or day program the person they know attends is in the community, furthering the perception that HCBS in Colorado is integrated in the community.

Fewer respondents indicated that their family member or friend has support to give input on their schedule and benefits (64.7%) and/or their number of hours worked (80.0%).

Section 4 – Advocates

Survey Respondents

The survey also collected information from advocates to identify potential settings that may be noncompliant with the HCBS Final Rule. Self-identified advocates completed the survey 146 times, and of these, 44 responses indicated at least one setting that may be noncompliant. Respondents to this section were given a checklist of characteristics of potential noncompliance and were asked to note which characteristics apply to each setting they reported. Of the 44 responses that indicated a setting is noncompliant, some responses endorsed items from the checklist of characteristics of potential noncompliance issues, and some did not.

Characteristics of the Home

Among advocates providing information related to services received in the home, the most common characteristic of potential noncompliance is that individuals do not control their own schedule, which is similar to responses received from individuals receiving services and their family members and friends. In addition, six respondents each indicated potential limits to roommate choice and limited interaction with individuals that are not other residents of the home or paid staff.

Exhibit 8 below details the frequencies for each question in this section.

Exhibit 8: Survey Responses from Advocates for Individuals Receiving HCBS, Residential

Characteristic	Response indicating non-compliance
Individuals do not control their own schedules.	70.0%
Interactions are limited to individuals and paid staff.	60.0%
Individuals cannot choose roommates.	60.0%
Individuals cannot engage in the community.	50.0%

Characteristic	Response indicating non-compliance
Individuals do not have privacy.	50.0%
Individuals cannot access every part of the home.	40.0%
Individuals cannot leave the home if they choose.	40.0%
Individuals do not have legal protections and rights.	40.0%
Individuals cannot have visitors when they want.	40.0%
Individuals cannot decorate the home how they choose.	30.0%
Individuals cannot eat when they want.	30.0%
It's not part of the community.	20.0%
Individuals do not control their money.	20.0%

Characteristics of the Workplace

Among advocates providing information related to services received in non-residential settings, the most commonly cited issues were that individuals do not have the choice to pursue interests and that individuals' interactions are limited to other individuals receiving services at the setting and paid staff.

Exhibit 9 below details the frequencies for each question in this section.

Exhibit 9: Survey Responses by Advocates for Individuals Receiving HCBS, Nonresidential

Characteristic	Response indicating non-compliance
Individuals do not have the choice to pursue interests.	80.0%
Interactions are limited to individuals and paid staff.	70.0%
Individuals cannot choose whether they want to work and where.	50.0%
Individuals are paid sub-minimum wage.	50.0%
Individuals do not have input on hours and schedules.	50.0%
Individuals do not receive supports to hold a job or volunteer in the community.	40.0%
Activities are not age appropriate.	30.0%
It's not part of the community.	30.0%

Section 5 – Additional Findings

Respondents could elect to specify the address where they or their family member or friend received HCBS. 63.2% of survey responses (n=1,001) specified at least one complete address for a residential setting and 62.2% (n=986) specified at least one complete address for a non-residential setting.

Respondents could write in additional information in text boxes. The Department is reviewing this additional information, but in order to protect respondents' anonymity and potential personal health information, it is not planning to publish it.

Section 6 - Recommendations and Next Steps

The survey responses received to date suggest that the majority of individuals receiving HCBS and their family members and friends perceive HCBS to include choice, rights, independence and community integration. HCPF could consider further distributing the survey across the state to receive additional feedback and confirm the responses included in this report.

Almost one-third of individuals receiving HCBS indicated that they do not have the ability to schedule appointments and outings at their own convenience but rather at that of paid staff. Family and friend respondents cited the same concern. These results suggest a restriction of both choice and access to the community, and could be addressed through updated guidance to providers indicating that individuals should have the ability to schedule outings at their convenience without restrictions from staff, and that staff should actively support individuals to access public transportation and community activities on their own.

Variances between individuals' and family and friends' responses to questions about the ability to leave the home and talk on the phone when desired could suggest that family members and friends may not be fully aware of the lived experience of their family or friend receiving services; to address this issue, HCPF could continue its efforts towards Person-Centered planning and Person-Centered approaches to ensure that individuals are able to express their views more fully. Another interpretation of the variances is that individuals are not as informed of their rights or willing to speak up when their rights are being violated; to address this issue, HCPF could do more work to inform individuals of their rights and ways to speak up about their concerns.

Based on these data, there are some areas where HCPF could consider taking steps to improve services and/or increase the level of community integration in both residential and nonresidential. These areas include:

- Choice of Roommates Through Roommate Matching;
- Control of Scheduling Appointments/Outings;
- Ability to Go Out In The Community With Supports; and
- Input to Hours, Schedules and Benefits.

These areas should continue to be part of HCPF's and CDPHE's ongoing compliance, remediation, and technical assistance work with providers. In addition, HCPF could consider

developing resources and/or training materials for individuals, family members and friends, and/or employers that increase choice and input to how services are received.

The low response from advocates suggests that HCPF could consider additional and targeted outreach to the advocacy community to ensure that their input and insights are fully considered in the state's compliance activities. This could include the survey and may also incorporate other methods of collecting feedback, including meetings and interviews.

Finally, HCPF could consider using the setting address and provider names provided by respondents, in combination with other information it has about providers and settings, to determine whether additional site visits or other forms of technical assistance are warranted at particular settings. If the survey is further distributed, HCPF could consider including provider name as a collected item to more directly connect responses to specific providers.