

**PEONIES Member Interviews**

**State Fiscal Year 2012**

**FINAL REPORT**

Report prepared for the Wisconsin Department of Health Services  
Office of Family Care Expansion

by

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September 2012



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We wish to thank our colleagues at MetaStar, who coordinated the interviews with the MCOs and conducted the interviews with the members. We also wish to thank the staff at the MCOs who assisted in scheduling the interviews. Most importantly, we thank the many members of Family Care, Family Care Partnership, and their family members who participated in these interviews, and who graciously shared so much of their lives with us.

## EXECUTIVE SUMMARY

During SFY2012, interviews were conducted with 549 members of Wisconsin's Long Term care programs, including Family Care (FC), Family Care Partnership (FCP), and IRIS. Interviews were conducted using the state's approved method for identifying personal experience (quality of life) outcomes, known as PEONIES (Personal Experience Outcomes iNtegrated Interview and Evaluation System). Data were analyzed and reports provided back to the managed care organizations (MCOs), for use in quality improvement activities. This report summarizes the findings across the state, and compares the quality of life experiences of people served by the different Long Term care programs. It also compares the quality of life experiences of people in different target population groups: people with developmental disabilities (DD), people with physical disabilities (PD), and people who are eligible as a result of age-related impairments (frail elders, FE).

### Key Performance Indicators

PEONIES provides extensive data on the types of outcomes that are important to people, the status of those outcomes with regard to achievement and support, and the types and sources of supports that are needed by individuals. Two key performance indicators provide a high-level overview of quality of life.

*The percent of outcomes that are achieved or in progress.* This indicator shows the success of individuals in having the quality of life desired. Outcomes that are achieved are those that are exactly as the individual desires, e.g., "I want to continue living with my parents in this house." Outcomes that are in progress also represent a positive situation, e.g., "I want to keep going to school to learn to be a car mechanic."

- In SFY2012, 82% of outcomes were achieved or in progress.
- Members of IRIS were more likely to report that outcomes were achieved or in progress (87%) than was the case in FC (81%) or FCP (78%).
- People with physical disabilities were less likely to report that outcomes were achieved or in progress (77%) than were people with developmental disabilities (85%) or frail elders (86%).
- The most frequent reason that outcomes were not achieved or in progress is that they were new, i.e., they had not been identified previously as desired outcomes.

*The percent of outcomes that are fully supported.* This indicator reports on how well outcomes are being supported. Any given outcome may require one or more supports to maintain or make progress toward the desired goal. Outcomes are "fully supported" only when all necessary supports are available, adequate, and acceptable, as reported by the member or member's proxy. Outcomes that are not fully supported may be partially supported, and may even be achieved; however, without full support, they are at risk. For example, a member who is living where desired in a private home may be at risk of entering a nursing home if the necessary supports for personal care are inadequate, even if supports for transportation and meals are available, and adequate, and acceptable.

- In SFY2012, 85% of all outcomes were fully supported.

- Outcomes were more likely to be described as fully supported by IRIS members (89%) than by FC (85%) or FCP (82%) members.
- People with physical disabilities were less likely (79%) to have outcomes fully supported than were people with developmental disabilities (88%) or frail elders (90%).

### Other Key Findings

- PEONIES identifies outcomes in twelve distinct quality of life domains or outcome areas. Not all outcome areas are equally important, and members may not identify outcomes in all twelve areas. The achievement and support of outcomes may differ by domain.
- The outcome areas that were important to the greatest share of members were those related to living where and with whom ones desires; having relationships with family and friends; working or doing other things that are personally meaningful; and having the best possible health.
- Outcomes related to deciding how to spend one's day, having privacy, feeling safe, and being free from abuse and neglect had the highest rates of support. Outcomes related to employment, health, having a preferred living arrangement, and working or doing other meaningful activities were the least well supported.
- The outcomes that were the most likely to be described as achieved or in progress were those related to making decisions about supports and services, making decisions about how to spend one's day, and having privacy. Outcomes that were the least likely to be achieved or in progress were those related to being employed, working or doing other meaningful activities, having desired interpersonal relationships, and being involved in one's communities. Often, those outcomes that were least likely to be achieved or in progress were the most likely to be described as new.

The types and sources of support that members described varied only slightly by Long Term Care program or by population.

- The most frequently reported types of supports needed included transportation, IADL assistance, ADL assistance, and health services.
- The most frequent source of support were described as the members themselves, followed by their families. Residential care providers also were frequent sources of support for people with developmental disabilities and for frail elders.

While SFY2012 marks the first year in which PEONIES interviews were conducted for all FC and FCP MCOs and for IRIS, PEONIES data are available from prior years, for some FC and FCP MCOs. These data offer a basis for comparison. Results indicate that the overall rates of outcome support and outcome achievement/progress have been fairly stable since SFY2009.

### Conclusions and Recommendations

Results from the first statewide collection of PEONIES data indicate areas of strength. The majority of desired quality of life outcomes are achieved or in progress, and are being supported. Broadly speaking, this is true across Long Term Care programs and across populations. Some consistent differences, however, indicate areas of particular strength and opportunities for improvement.

- *Improve discussion of outcomes in FC and FCP programs.* IRIS participants have more outcomes achieved or in progress than do members in the FCP/FC programs, by a statistically significant margin. To a large extent, this results from the lower rate of new outcomes identified by IRIS members. Due to the nature of the IRIS program, participants or those close to them may identify outcomes on an on-going basis without waiting for a team planning meeting to occur. Perhaps due to this constancy and consistency in goal setting (outcome identification), fewer outcomes are categorized as “new”. Although FC/FCP programs are different in design and structure, care managers in these programs may wish to provide members with more opportunity to discuss and identify the outcomes that are important to them. Doing so does not need to be part of a formal team meeting, but can occur through informal means during check-in calls or visits by any team member. This is part of natural relationship building with members, and also is a way to ascertain desired outcomes on an on-going basis.
- *Improve support of outcomes for people with physical disabilities.* People with physical disabilities were less likely than members of the other target groups to report that their outcomes were achieved/in progress and that outcomes were fully supported. Further investigation would need to be done to determine the reason for these differences. We speculate that this finding may result from the unique characteristics of this population (PD), including health concerns, age, or the availability of natural supports. Regardless of the reasons for these findings, they suggest an opportunity to improve the support of outcomes for people with physical disabilities, to reduce the observed disparities and to assure that people with physical disabilities have appropriate and necessary supports.
- *Assure adequate support for members and their families.* Individuals most frequently named themselves as a source of support, followed by their families, as a means to meet their desired outcomes. The majority of the time, members and their families felt up to the task (i.e., adequate) and were glad to do so (i.e., were acceptable). Care managers and independent consultants may want to work with members and families to assure that they are able to continue the levels of support on an on-going basis, to reduce the risk of “burnout” and subsequent need for suddenly increased formal supports. Efforts to provide supplemental supports, including respite services, can assist with this. Such efforts can enable members to continue to receive support from their preferred sources (self and family), and also would appear on its face to be a cost-effective approach to support.
- *Implement PEONIES within long term care programs.* The PEONIES interview process identifies quality of life measures from the perspective of long-term care recipients. Obtaining information for a representative sample by long term care program, population group, and for individual MCOs is a valuable, but non-trivial undertaking. By design, PEONIES can be used by care managers to support care planning activities. The use of PEONIES in this way could help reduce the number of new outcomes, especially in FC and FCP programs, and has the potential to improve support and achievement of outcomes. Further, if PEONIES were used in this way and data reported in a standardized way to DHS, performance indicators could be measured on an on-going basis. External quality review could validate the indicators that result from data collected by care managers, and focus efforts on supporting MCOs in their quality improvement activities. Such an approach could increase efficiency, and would be consistent with other types of quality assurance activities in long term care settings.

## **A. BACKGROUND AND PURPOSE OF INTERVIEWS**

The Quality Compliance Review (QCR) of the Family Care Managed Care Organizations (MCOs) is a mandatory External Quality Review (EQR) activity utilized to determine whether the Family Care and Family Care Partnership Managed Care Organizations (MCOs) comply with Federal Medicaid Managed Care Regulations and the contract between the Wisconsin Department of Health Services (DHS) and the MCOs. One method of discovery, related to compliance evaluation, is conducting interviews with members of the MCOs. The purpose of the Member Outcome Interviews is to provide data about the quality of life of members of Wisconsin's MCOs and how well person-centered quality of life is being supported.

In Wisconsin, person-centered quality of life is assessed using the Personal Experience Outcomes iNtegrated Interview and Evaluation System (PEONIES) approach. PEONIES was developed by staff at the University of Wisconsin – Madison's Center for Health Systems Research and Analysis (CHSRA), and is designed for use both in external quality review and care planning. PEONIES uses semi-structured interviews that identify person-specific desired outcomes, and information about the achievement and support of these outcomes. A standardized approach is used to convert the individualized information into aggregate measures of outcome achievement and support at the organizational level. PEONIES has been tested and the resultant measures found to be reliable and valid for quality measurement, when used by well-trained staff.

During the state fiscal year 2012, staff from MetaStar, Wisconsin's External Quality Review Organization, conducted PEONIES interviews with members of all Family Care (FC) and Family Care Partnership (FCP) MCOs. In addition, MetaStar conducted interviews with members of IRIS, Wisconsin's self-directed supports alternative to FC and FCP. Interviewers were trained by CHSRA staff, and received on-going oversight and support from CHSRA staff throughout the year. Data from the interviews were provided to CHSRA for analysis. CHSRA staff prepared reports for each MCO, which were provided to the DHS Office of Family Care Expansion for distribution to the MCOs.

This report summarizes the findings across all of the MCOs and IRIS. As such, it highlights the types of outcomes that are important to members, the status of those outcomes with respect to achievement, and how well those outcomes were supported in the last year. It also provides insight into the relative experiences of people served by the three different programs (FC, FCP, IRIS) and the experiences of people by key population groups: people with developmental disabilities (DD), people with physical disabilities (PD), and people who experience frailty associated with aging (frail elders, FE).

## **B. METHODOLOGY**

Details of the methodology used for selecting the sample, conducting the interviews, and analyzing the data are provided in Appendix A. We briefly describe the methodology here.

- The sample was selected to permit comparisons across the three Long Term Care programs, and across the three target population groups. This resulted in a final sample of 549 people across the state. These included 187 members of FC, 178 members of FCP, and 184

members of IRIS. By population group, the sample included 191 people with developmental disabilities, 186 people with physical disabilities, and 172 frail elders.

- PEONIES data are collected through a semi-structured interview process that is designed to identify the personal experience outcomes most important to the member, the current status of those outcomes (achieved, in progress, new, other), and to identify the support for those outcomes.
- Interviews were conducted with the member, whenever possible. In some cases, proxy respondents – family members, staff, friends, or others familiar with the member – provided information in addition to the member; and in a few cases, a proxy was the sole source of information. In all cases, proxies were instructed to present information that would best represent the member’s view.
- Two key performance indicators were measured:
- *the percent of outcomes that are fully supported*: all supports needed for the specific outcome are available, adequate, and acceptable to the member. This indicator excludes from the denominator any outcomes that the member describes as “new,” as it is not reasonable to expect that such outcomes will be fully supported
- *the percent of outcomes that are achieved or in progress*: as reported by the member, outcomes are achieved, meaning the situation is as the member desires, or the member is making progress toward the outcome.
- Data also are reported on the types of supports needed and the sources of those supports, whether provided by the Long Term care program or through some other means.
- Details about the results by the 12 quality of life domains (defined in Appendix A) are discussed in the text, with detailed tables given in Appendix B.

## C. FINDINGS

We begin by describing the sample of members interviewed, and findings overall (Section C1.) In Section C2, we describe how these findings differ across the Long Term Care programs (FC, FCP, and IRIS), and in Section C3, we describe how they differ by population group (DD, PD, and FE). We also compare findings for SFY12 to previous time periods (Section C4). Results are presented at an aggregate level, with differences by outcome area discussed in the text. Detailed tables with results by outcome area are presented in Appendix B, with appropriate references in the text. Tables with numbers beginning “B” are found in Appendix B.

### C1. Overview

Summary measures of the two key performance indicators are shown in Table 1. Overall, 85% of outcomes were fully supported, and 82% were achieved or in progress. These key performance indicators varied by outcome area (see detail in Table B1).

- Employment-related outcomes were both the least likely to be supported (69%) and the least likely to be achieved or in progress (57%).
- Outcomes with the greatest rates of support were in areas related to deciding how to spend one’s day (95%) and having privacy (93%). These areas also were the most likely to be achieved or in progress (91% and 90%, respectively).
- Outcomes related to having privacy, feeling safe, and being free from abuse and neglect also had high rates of support (each at 93%).

**Table 1. Key Performance Indicators Overall**

Measure	
Percent of outcomes fully supported	85%
Percent of outcomes achieved or in progress	82%

Note: Percent of outcomes fully supported excludes new outcomes, which are not expected to be fully supported.

Not all members identified outcomes in all areas. On average, members identified seven (7) outcomes. Areas in which the members were most likely to report one or more outcomes (see Table B2) were:

- Deciding where and with whom to live (99%)
- Having relationships with family and friends (88%)
- Working or doing other things that are meaningful (88%)
- Having the best possible health (87%).

Members were least likely to identify outcomes in areas related to stability (25%), being respected and treated fairly (32%), having privacy (31%), and being free from abuse and neglect (10%). These are areas in which members who have never experienced a lack of the condition simply take the presence of these things (i.e., stability, respect, privacy, freedom from abuse and neglect) as givens, and so do not articulate specific outcomes.

In the following sections, we identify how these key findings vary by Long Term Care program (Section C2) and by population group (Section C3).

## **C2. Key Findings by Long Term Care Program**

### Key Performance Indicator #1: Percent of Outcomes that are Fully Supported

The percent of all outcomes that were fully supported (all necessary supports available, and adequate, and acceptable to the member) ranged from a low of 82% in the Family Care Partnership program to a high of 89% for outcomes identified by members of IRIS (Table 2). The difference across programs was statistically significant. However, this range is fairly narrow and may not be of substantive significance. Table B3 shows the detail of support by outcome domain. This helps to examine whether different Long Term care programs are more or less successful at supporting particular types of outcomes. With two exceptions, there were no statistically significant differences in the support of outcomes by domain.

- Members of FCP were less likely to have support of outcomes related to deciding how to spend their days than were members of FC or IRIS. Nonetheless, the rate of support at FCP still was relatively high, at 88%.

- Members of FCP also were less likely to have full support of outcomes related to privacy (82%) than were members of FC (93%) or IRIS (97%).

The reasons why outcomes are not fully supported are shown in Table 3. Members at IRIS were less likely than others to describe supports as being unacceptable or inadequate. Members at FCP were more likely than others to describe reports as being unavailable.

**Table 2. Percent of Outcomes Fully Supported by Long Term Care Program**

Outcome Area	Family Care	Family Care Partnership	IRIS	Stat. Signif.
TOTAL	85%	82%	89%	***

Note: Excludes outcomes described as new. Statistical significance was tested by ANOVA.  
\*\*\*p<.001

**Table 3. Reasons Outcomes are Not Supported by Long Term Care Program**

Support of Outcomes	FC	FCP	IRIS	Statistical Significance
Number of Outcomes	1100	1029	1265	
Supported (%)	85%	82%	89%	***
Supports Not In Place (%)	6	8	6	*
Supports Inadequate (%)	8	8	5	*
Supports Unacceptable (%)	6	7	3	***

Notes: Results do not sum to 100%, as outcomes may be unsupported for multiple reasons. Excludes new outcomes. Statistical significance of differences between programs is tested using ANOVA. \* p<.05; \*\* p<.01; \*\*\* p<.001.

### Key Performance Indicator #2: Percent of Outcomes that are Achieved or In Progress

The percent of outcomes that were either achieved or in progress ranged from a low of 78% for members of the Family Care Partnership programs to a high of 87% for members of IRIS (Table 4). This difference was statistically significant, and the variation was large enough to also appear to be of substantive significance. The status of outcomes as achieved or in progress varied by outcome area (see detail in Table B4).

- In most outcome areas, there were no differences by Long Term Care program.
- Members of IRIS were the most likely to report that outcomes related to making decisions about supports and services, and making decisions about how to spend their days, were achieved or in progress.
- Members of IRIS also were the most likely to report that outcomes related to being treated respectfully and fairly were achieved or in progress.
- Members of FCP were the least likely to report achievement or support of outcomes related to being involved in their communities.

This key performance indicator combines achievement and progress into a single measure, as both achievement and progress are considered to be positive situations. Figure 1 illustrates the contribution of achievement of progress to the key performance indicator.

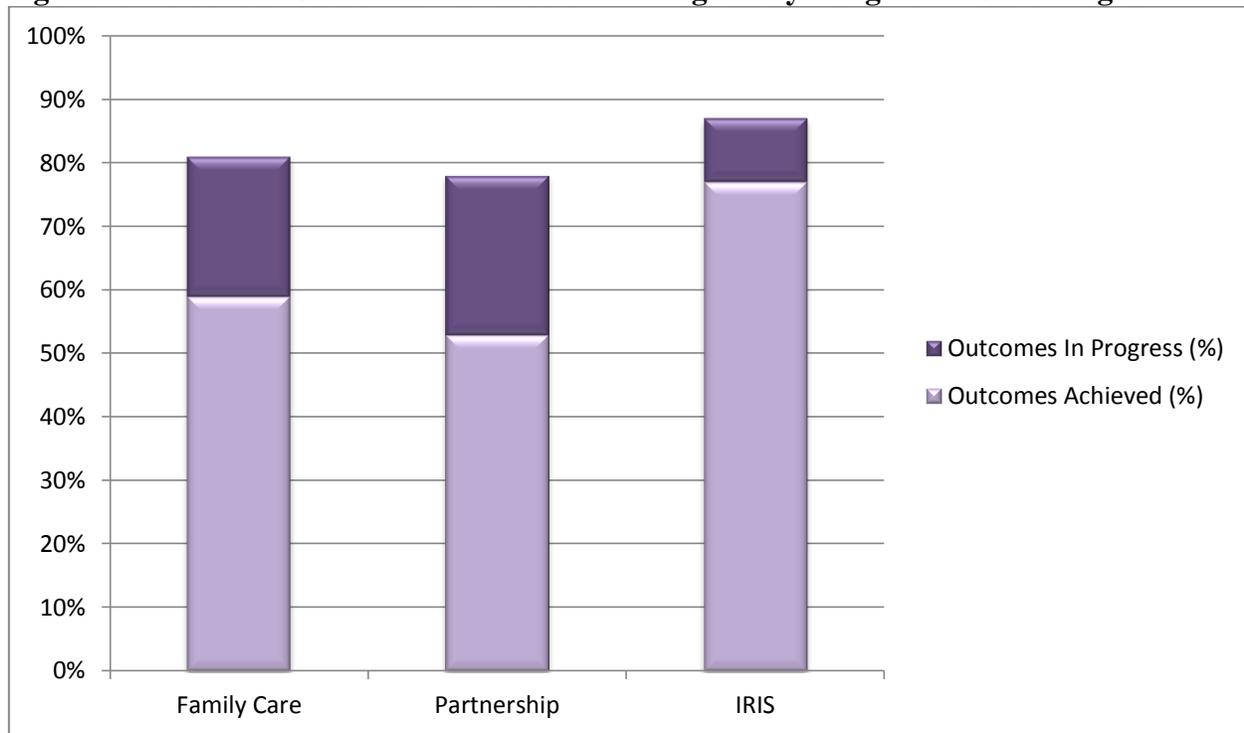
- FC and FCP members have similar rates of outcomes that are achieved or in progress, but at FCP a greater share of the outcomes are described as in progress.
- There are higher rates of outcomes achieved or in progress at IRIS.
- For IRIS members, a much greater share of outcomes are achieved than in progress than is the case for members of FC and FCP.

**Table 4. Percent of Outcomes Achieved or In Progress by Long Term Care Program**

Outcome Area	Family Care	Family Care Partnership	IRIS	Statistical Significance
<b>TOTAL</b>	81%	78%	87%	***

Percentages are based on number of outcomes identified, not number of individuals. Significant differences are identified using ANOVA. \*\*\* p<.001

**Figure 1. Percent of Outcomes Achieved or In Progress by Long Term Care Program**



### Percent of Outcomes that are New

One reason that outcomes may not be achieved or in progress is that they are “new” outcomes (Table 5). Having new outcomes is not necessarily a bad thing, and may be a very good thing. New outcomes may result from a change in health (e.g., “My doctor just told me I have diabetes, and I want to learn how to live with it better.”), a change in life circumstance (e.g., “I want to get a job in the criminal justice field now that I finished my degree”), or simply a new desire (e.g., “I’d like to join a bowling league, so that I can meet new people”). Desiring new outcomes is a part of life. Having new outcomes may indicate a positive engagement with life. However, a large number of new outcomes may indicate that people are not being given the opportunity to talk about the things that are important to them, or not being supported to recognize options and opportunities.

- Overall, members of IRIS reported fewer new outcomes (9%) than did members of FC or FCP (14% and 13%, respectively), a difference that is statistically significant.
- Members of IRIS were significantly less likely than members of FC or FCP to identify new outcomes related to control over their supports and services, or control over how they spend their day (see detail in Table B5). This may reflect the unique nature of IRIS as a self-directed program.
- Members of IRIS also were less likely to identify new outcomes related to being treated respectfully and having privacy.
- Members of FCP were more likely than others to identify new outcomes related to community involvement. Nearly one-quarter (23%) of FCP members’ outcomes related to community involvement were described as new.

**Table 5. Percent of Outcomes That Are New by Long Term Care Program**

Outcome Area	Family Care	Family Care Partnership	IRIS	Statistical Significance
<b>TOTAL</b>	14%	13%	9%	***

Note: Significant differences are identified using ANOVA. \*\*\* p<.001

These key performance indicators show at a broad level how well members are achieving outcomes, and how well those outcomes are being supported. One question that might be asked is whether the outcomes that are important to members are the same across programs. Some outcomes may be more difficult to support or achieve than others. Health outcomes, for example, may be very difficult to achieve and may never be fully achieved. Consider, for example, a person who lives with chronic pain. Such a person might have an outcome of being pain free. That may be difficult to achieve, but the person might be able to reduce or better manage their pain, in which case the outcome might be described as being in progress. Whether or not a complete remission of pain is possible, the outcome could be fully supported.

Types of Outcomes that are Important to People

PEONIES organizes personal experience outcomes, the specific things that individuals identify as important aspects of their quality of life (e.g., “I want to live with my best friend, Bob, in an apartment that is close to my job”) into twelve quality of life domains, also called “outcome areas” (e.g., “I decide where and with whom I live”). At any given time, some domains of quality of life may be more important to people than others (see Table B6 for detail).

- IRIS members are more likely than members of FC or FCP to identify outcomes related to control of supports and services, and control over how they spend their time. This is consistent with the focus of IRIS on self-directed supports.
- People in IRIS also are more likely than those in other programs to identify outcomes related to being respected and treated fairly, and having privacy.
- People in IRIS are less likely than those in Family Care and Family Care Partnership to identify outcomes related to feeling safe.
- Members of FC are the most likely to identify employment outcomes (37%), while members of FCP are the least likely to do so (24%).
- Outcome areas in which few people identified outcomes included being free from abuse and neglect (9-10% of members), stability (about 24% across programs) and having privacy (less than 30% for members of Family Care and Family Care Partnership; 41% for members of IRIS).

Most Frequently Needed Types and Sources of Support

Members were asked about the types and sources of support needed for each outcome identified. Table 6 shows the types of support most often reported by members, by Long Term Care program.

- Across programs, the most frequently needed type of support was transportation, which was needed to support about one-quarter of all outcomes.
- Support for activities of daily living (ADLs, including such things as bathing, dressing, and using the toilet) and instrumental activities of daily living (IADLs, such as preparing meals, cleaning, and managing finances) were the next most often needed types of support.
- Other frequently needed supports were health related services, social supports, communication, and support coordination.
- Support coordination was reported more frequently by IRIS members than others, a difference that was statistically significant.

**Table 6. Most Frequently Needed Types of Support by Program**

Type of Support	Family Care (N=1142)	Family Care Partnership (N=1084)	IRIS (N=1299)
Transportation	26%	26%	25%
Activities of daily living (ADL)	22%	20%	17%
Instrumental activities of daily living (IADL)	21%	21%	16%
Health related services	14%	16%	16%
Social supports	14%	14%	15%
Communication	11%	15%	12%
Support coordination	8%	7%	12%

Notes: N refers to the total number of outcomes identified by members. Data indicate the percentage of outcomes for which members reported needed the specific type of support. Any given outcome may require multiple types of support. Only the most frequently reported types of support are shown.

Table 7 shows the most frequently reported sources of support by program. While similar sources of support were reported in each of the programs, some differences were observed in the relative importance of these sources.

- Across all programs, members reported that they themselves were the most frequently used source of support for outcomes. This was true for nearly half of the outcomes in FC and FCP, and for 61% of the outcomes in IRIS.
- Family members also were a significant source of support for all outcomes, supporting more than one-third (36%) of outcomes in IRIS and over a quarter of outcomes in FC and FCP.
- Residential care providers were frequent sources of support for members of FC and FCP, but much less so for members of IRIS.
- Members of FCP reported that the MCO was a common source of support (17% of outcomes). Members of FC and IRIS were much less likely to identify the Long Term Care program as a source of support.

**Table 7. Most Frequently Reported Sources of Support by Program**

Source of Support	Family Care (N=1142)	Family Care Partnership (N=1084)	IRIS (N=1299)
Self	48%	49%	61%
Family	29%	25%	36%
Residential care provider	22%	15%	3%
MCO/IRIS	8%	17%	5%

Notes: N refers to the total number of outcomes identified by members. Data indicate the percentage of outcomes for which members reported using the specific source of support. Any given outcome may require multiple sources of support. Only the most frequently reported sources of support are shown.

### **C3. Key Findings by Population Group**

In this section, we present findings by population group, regardless of the program in which they are enrolled. There is no reason to expect that the quality of the experiences of different populations should differ overall, but it may be reasonable to expect that the specific outcome areas will hold different meaning and importance to these populations, as they differ by underlying health and disability issues, and by stage of life.

#### Key Performance Indicator #1: Percent of Outcomes that are Fully Supported

Overall, people with physical disabilities were least likely to report that their desired outcomes were fully supported (79%), while elders were the most likely to report that outcomes were fully supported (90%). These differences were statistically significant (Table 8). The likelihood that outcomes were fully supported differed by the outcome area (see detail in Table B7).

- In all cases where differences were statistically significant, people with physical disabilities were less likely than the other population groups to have support for their desired outcomes. This was true for outcomes related to living where and with whom one desires, working or doing other meaningful activities, being involved in one's community, having the best possible health, and feeling safe.
- People with developmental disabilities and frail elders reported very similar levels of support for outcomes in nearly all outcome areas.
- People with developmental disabilities were much less likely than frail elders to report support for outcomes related to being treated fairly and respectfully. While this difference was not statistically significant, it approach significance ( $p < .10$ ), and is a large enough absolute difference to warrant attention.

Table 9 shows the reasons why outcomes were not fully supported. People with physical disabilities reported that 10% of necessary supports were not in place, and 10% were inadequate to the task. Inadequacy may indicate either a quantitative lack (e.g., person needs transportation to work 5 days a week, but only has transportation 3 days a week), or a lack of technical adequacy (e.g., a person who desires a reduction in pain is using a medication that is not working adequately).

**Table 8. Percent of Outcomes Fully Supported by Population Group**

Outcome Area	DD (N=1221)	PD (N=1137)	FE (N=1036)	Statistica l
TOTAL	88%	79%	90%	***

Note: Excludes outcomes described as new. Statistical significance was tested by ANOVA.  
\*\*\*p<.001

**Table 9. Reasons Outcomes are Not Supported by Population Group**

Support of Outcomes	DD	PD	FE	Statistical Significance
Number of Outcomes	1221	1137	1036	
Supported (%)	88	79	90	***
Supports Not In Place (%)	5	10	4	***
Supports Inadequate (%)	6	10	4	***
Supports Unacceptable (%)	5	7	3	***

Notes: Results do not sum to 100%, as outcomes may be unsupported for multiple reasons. Excludes new outcomes. Statistical significance of differences between programs is tested using ANOVA. \* p<.05; \*\* p<.01; \*\*\* p<.001.

Key Performance Indicator #2: Percent of Outcomes that are Achieved or In Progress

People with physical disabilities had the fewest outcomes that were achieved or in progress, at a rate of 77%. (Table 10). People with developmental disabilities and elders had similar rates of outcomes that were achieved or in progress (85% and 86%, respectively). As shown in Figure 2, frail elders were somewhat less likely to report outcomes in progress, and more likely to report that outcomes were fully achieved. People with physical disabilities were slightly more likely than were people with developmental disabilities to report that outcomes were in progress than fully achieved.

Population groups varied in the likelihood that outcomes that were achieved or in progress by outcome area (see detail in Table B8).

- In all outcome areas in which there were significant differences by population group, people with physical disabilities were less likely than others to report that outcomes were achieved or in progress.
- The types of outcome that were most likely to be achieved or in progress for people with physical disabilities were those related to deciding how they spend their day (90%) and having privacy (92%).
- For people with developmental disabilities, the outcomes that were most likely to be achieved or in progress were those related to making decisions about supports and services (91%), deciding how to spend one's day (93%), and feeling safe (92%).
- Frail elders reported that the outcomes most likely to be achieved or in progress were related to deciding where and with whom to live (90%), making decisions about supports and services (93%), having privacy (93%), feeling safe (93%), and being free from abuse and neglect (92%).
- For all population groups, employment outcomes were the least likely to be achieved or in progress. However, the absolute rate of achievement or progress of employment outcomes varied dramatically by outcome group, from 72% for people with developmental disabilities to only 33% for frail elders.
- Other areas with low rates of achievement or progress differed by population group. In addition to employment-related outcomes, people with developmental disabilities reported low rates of achievement/progress for outcomes related to being free from abuse and neglect (77%). People with physical disabilities reported low rates for outcomes related to doing meaningful activities, including work (66%) and being involved in their communities (68%). Frail elders also reported low rates of achievement/progress for outcomes related to doing meaningful activities (77%).

### Percent of Outcomes that are New

One reason that outcomes may not be achieved or in progress is because they are new. As discussed previously, some rate of new outcomes is a positive sign of engagement, while a large number may indicate inadequate attention to particular types of outcomes.

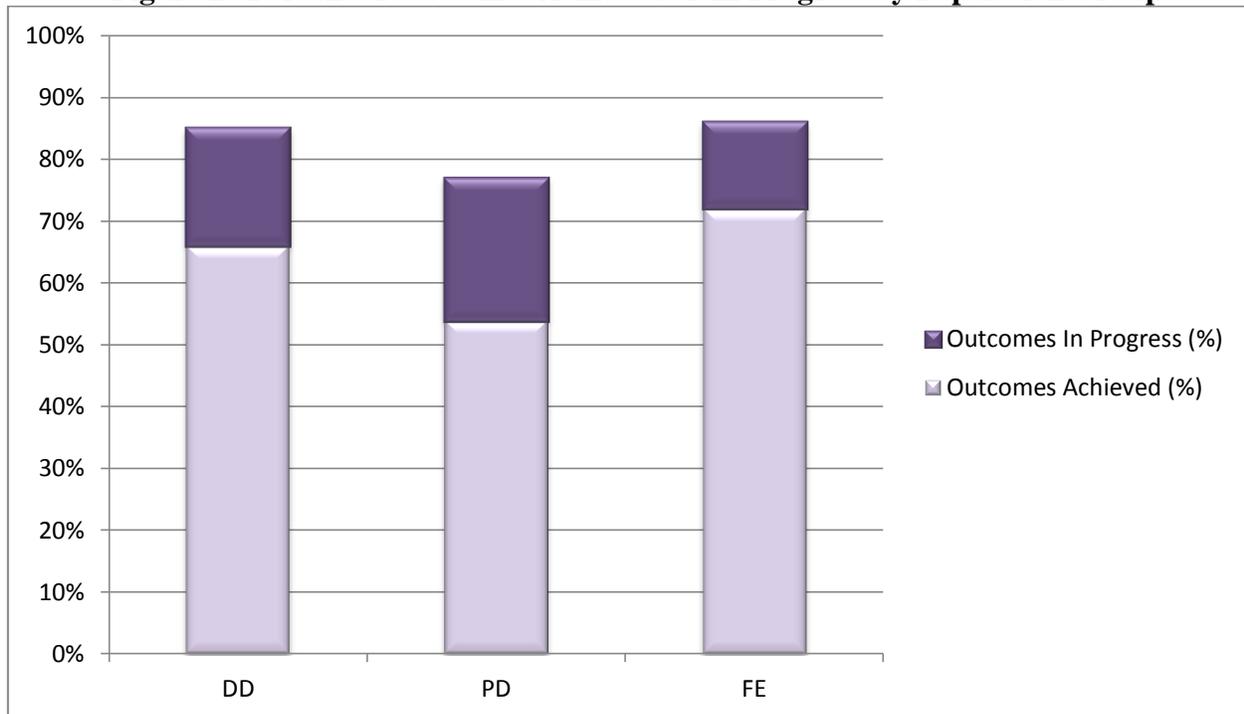
- Overall, people with physical disabilities were more likely than others to describe outcomes as being new (Table 11). This pattern also was observed in each outcome area where differences among populations were statistically significant (see detail in Table B9).
- People with developmental disabilities were most likely to describe outcomes as new that were related to being free from abuse and neglect (23%), employment (21%), and being treated respectfully (20%).
- People with physical disabilities were most likely to describe outcomes related to employment (29%), community involvement (26%), and stability (24%) as new.
- Frail elders, like the other two groups, also were most likely to identify employment outcomes as being new (31%).

**Table 10. Percent of Outcomes Achieved or In Progress by Population Group**

Outcome Area	PD	DD	FE	Statistical Significance
<b>TOTAL</b>	85%	77%	86%	***

Percentages are based on number of outcomes identified, not number of individuals. Significant differences are identified using ANOVA. \*\*\* p<.001

**Figure 2. Percent of Outcomes Achieved or In Progress by Population Group**



**Table 11. Percent of Outcomes That Are New by Population Group**

Outcome Area	DD	PD	FE	Statistical Significance
<b>TOTAL</b>	11%	16%	8%	***

Note: Percentages are based on the number of outcomes identified. Tests of significant differences are done using ANOVA. \*\*\* p<.001

## Types of Outcomes that are Important to People

There is no reason to expect that the relative importance of different outcome areas will vary by the population. Results are generally consistent with this (see detail in Table B10). In most cases, there are no significant differences in the percent of the population that reports having one or more desired outcome in each area. However, some differences were observed.

- Nearly everyone identified one or more outcomes related to living situation.
- The largest difference is found in the percent of people who identify one or more outcomes related to health. The vast majority (95%) of people with physical disabilities have one or more health-related outcomes, whereas this is true for many fewer people with developmental disabilities (81%). The nature of physical disabilities may imply a greater number of health problems, so that this difference is not surprising. Members of the other two population groups (DD, FE) may have fairly stable health, so that their priorities are placed elsewhere.
- Elders are less likely to identify outcomes related to working or doing other things that are important to them. This is a difficult finding to understand. While it is reasonable to believe that elders may be less likely to want to work – retirement is an expected part of life – this area also captures other activities that may be important to people, such as volunteer activities and hobbies, both of which may be important to people at any age.
- People with developmental disabilities are more likely than either of the other population groups to describe outcomes related to community involvement. This may reflect a common experience of people with developmental disabilities who often receive services throughout their lives that emphasize community involvement.
- Elders are less likely than either of the other population groups to report outcomes related to stability. This finding is consistent with the greater rate of outcomes being achieved and fewer new outcomes that was discussed previously in this report.
- People with physical disabilities were the most likely to identify outcomes related to being treated with respect and fairness (39%). The other two groups reported similarly lower rates of outcomes in this domain (27-28%).

## Most Frequently Needed Types and Sources of Support

Table 12 shows the most frequently needed types of support reported by each population group.

- Transportation was among the most frequently needed support for all population groups, but especially so for people with developmental disabilities. Nearly one-third (32%) of the outcomes they identified required transportation.
- Need for assistance with IADLs and ADLs also was reported frequently by each population group. This was especially true for frail elders. ADL assistance was their most frequent need, reported for nearly one-quarter of all outcomes.

Assistance with these types of support can come from a variety of sources (Table 13).

- The most frequent sources of support, for all population groups, come from the members themselves and from their families.
- People with developmental disabilities and frail elders also often receive support from residential care providers.

- Roughly 10% of individual reported that the Long Term care program was a source of support.

**Table 12. Most Frequently Needed Types of Support by Population Group**

Type of Support	DD (N=1256)	PD (N=1188)	FE (N=1081)
Transportation	32%	24%	21%
Instrumental activities of daily living (IADL)	19%	19%	20%
Social supports	16%	11%	17%
Activities of daily living (ADL)	15%	19%	24%
Health related services	13%	17%	15%
Communication	13%	13%	13%
Support coordination	10%	10%	8%

Notes: N refers to the total number of outcomes identified by members. Data indicate the percentage of outcomes for which members reported needed the specific type of support. Any given outcome may require multiple types of support. Only the most frequently reported types of support are shown.

**Table 13. Most Frequently Reported Sources of Support by Population Group**

Source of Support	DD (N=1256)	PD (N=1188)	FE (N=1081)
Self	47%	59%	54%
Family	35%	24%	32%
Residential care provider	15%	7%	16%
MCO/IRIS	8%	11%	9%

Notes: N refers to the total number of outcomes identified by members. Data indicate the percentage of outcomes for which members reported using the specific source of support. Any given outcome may require multiple sources of support. Only the most frequently reported sources of support are shown.

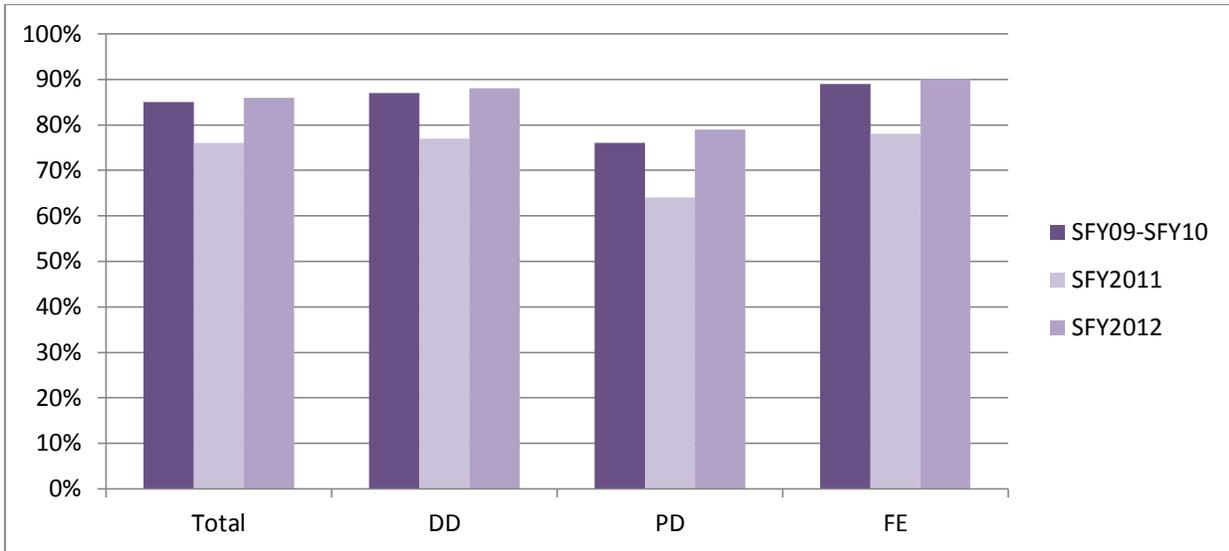
#### C4. Trends over Time

PEONIES data have been collected in Wisconsin for several years now, for various purposes. In SFY2009-2010, data were collected for members of some FC and FCP MCOs, as part of validation activities. IN SFY2011, PEONIES interviews were again collected in some FC and FCP MCOs for purposes of piloting the scheduling, interview, and reporting process as part of external quality review. This is the first year that data have been collected for IRIS members. The sample selection process in each period has differed, to meet the demands of the specific goals for that time period. Despite these differences, it is useful to examine trends over time. The trends over time, in total and by population group, are shown in Figure 3 for the percent of outcomes supported and Figure 4 for the percent of outcomes that are achieved or in progress.

- The percent of outcomes that are supported has been essentially unchanged over the last four fiscal years, with a slight dip in the middle time period. This trend is seen in all population groups (Figure 3).

- The percent of outcomes that are achieved or in progress has been essentially unchanged over the last four fiscal years (Figure 4).

**Figure 3. Percent of Outcomes that are Fully Supported by Population Group and State Fiscal Year**



**Figure 4. Percent of Outcomes Achieved or In Progress by Population Group and State Fiscal Year**



## **D. CONCLUSIONS AND RECOMMENDATIONS**

### Discussion

As part of its SFY2012 Quality Compliance Review activities, interviews were conducted with 549 members of Family Care (FC) and Family Care Partnership (FCP) MCOs, and IRIS-to produce comparisons of performance across target populations and programs. PEONIES interviews were conducted with 187 members of FC, 178 members of FCP, and 184 members of IRIS. By population group, the sample included 191 people with developmental disabilities, 186 people with physical disabilities, and 172 frail elders. This distribution was representative of the overall membership of people receiving services through the Family Care, Partnership and IRIS programs in which the interviews were conducted. In approximately one-third of interviews, information was provided with the assistance of a person knowledgeable about the member (i.e., a proxy).

With few exceptions, each person discussed all of the twelve personal experience outcome areas. This discussion could result in the identification of none, one or more unique outcomes in each of the twelve outcome areas, depending on the individual. On average, each individual identified 7 unique outcomes. These outcomes were not equally distributed among the different outcome areas. Nearly everyone (99%) had one or more outcomes related to their living situation, while very few (10%) identified outcomes related to being free from abuse and restraint.

In terms of the two key performance measures, the majority of outcomes were fully supported across target groups and program types (85%) and fully achieved or in progress (82%) across target group and program type. When an outcome was not achieved, the predominant reason for it not being so, was because it was “new”. Of specific interest, IRIS was found to have the most fully supported, achieved outcomes and the lowest number of “new” outcomes. By target group, people with physical disabilities had the lowest rates of outcomes being fully supported, and achieved. They also had the highest number of outcomes which were described as “new”.

Outcome areas with the lowest rates of support included employment, deciding where and with whom to live, and health. Outcomes least likely to be achieved were those related to having relationships, employment, and doing other meaningful things. Examining the supports in these areas and addressing any deficiencies may very well increase the rate of achievement in these areas.

PEONIES interviewers asked members about the types of supports they required to attain their outcomes as well as the sources of those supports. The most frequent types of support needed were transportation, followed by IADL and ADL assistance and health related services. The main source of supports was from the members themselves or their families. Other frequent sources of supports included residential care providers and the MCOs.

### Recommendations

Results from the first statewide collection of PEONIES data indicate areas of strength. The majority of desired quality of life outcomes are achieved or in progress, and are being supported. Broadly speaking, this is true across Long Term Care programs and across populations. Some

consistent differences, however, indicate areas of particular strength and opportunities for improvement.

- *Improve discussion of outcomes in FC and FCP programs.* IRIS participants have more outcomes achieved or in progress than do members in the FCP/FC programs, by a statistically significant margin. To a large extent, this results from the lower rate of new outcomes identified by IRIS members. Due to the nature of the IRIS program, participants or those close to them may identify outcomes on an on-going basis without waiting for a team planning meeting to occur. Perhaps due to this constancy and consistency in goal setting (outcome identification), fewer outcomes are categorized as “new”. Although FC/FCP programs are different in design and structure, care managers in these programs may wish to provide members with more opportunity to discuss and identify the outcomes that are important to them. Doing so does not need to be part of a formal team meeting, but can occur through informal means during check-in calls or visits by any team member. This is part of natural relationship building with members, and also is a way to ascertain desired outcomes on an on-going basis.
- *Improve support of outcomes for people with physical disabilities.* People with physical disabilities were less likely than members of the other target groups to report that their outcomes were achieved/in progress and that outcomes were fully supported. Further investigation would need to be done to determine the reason for these differences. We speculate that this finding may result from the unique characteristics of this population (PD), including health concerns, age, or the availability of natural supports. Regardless of the reasons for these findings, they suggest an opportunity to improve the support of outcomes for people with physical disabilities, to reduce the observed disparities and to assure that people with physical disabilities have appropriate and necessary supports.
- *Assure adequate support for members and their families.* Individuals most frequently named themselves as a source of support, followed by their families, as a means to meet their desired outcomes. The majority of the time, members and their families felt up to the task (i.e., adequate) and were glad to do so (i.e., were acceptable). Care managers and independent consultants may want to work with members and families to assure that they are able to continue the levels of support on an on-going basis, to reduce the risk of “burnout” and subsequent need for suddenly increased formal supports. Efforts to provide supplemental supports, including respite services, can assist with this. Such efforts can enable members to continue to receive support from their preferred sources (self and family), and also would appear on its face to be a cost-effective approach to support.
- *Implement PEONIES within long term care programs.* The PEONIES interview process identifies quality of life measures from the perspective of long-term care recipients. Obtaining information for a representative sample by long term care program, population group, and for individual MCOs is a valuable, but non-trivial undertaking. By design, PEONIES can be used by care managers to support care planning activities. The use of PEONIES in this way could help reduce the number of new outcomes, especially in FC and FCP programs, and has the potential to improve support and achievement of outcomes. Further, if PEONIES were used in this way and data reported in a standardized way to DHS, performance indicators could be measures on an on-going basis. External quality review could validate the indicators that result from data collected by care managers, and focus efforts on supporting MCOs in their quality improvement activities. Such an

approach could increase efficiency, and would be consistent with other types of quality assurance activities in Long Term Care settings.

## APPENDIX A: METHODS

This appendix contains technical details of the method, including sample selection, interview processes, and measure calculation.

### Sample selection

The sample of members interviewed in SFY2012 was designed to permit statistical comparisons of the three programs – Family Care (FC), Family Care Partnership (FCP), and IRIS – as well as comparisons of the experiences of the three target populations – people with physical disabilities (PD), people with developmental disabilities (DD), and frail elders (FE). The sample was not designed to provide a representative sample for any individual managed care organization (MCO), nor was it designed to permit statistical comparisons among MCOs. Doing so would have required a significantly larger total sample, and was beyond the scope of available resources.

Based on the resultant total sample size, we identified the number of members of each target population to be selected at each MCO. Sample sizes by MCO were created to share the burden in relatively equal ways across MCO and to approximate the target population distribution by MCO, to the extent possible.

Members were selected at random at each MCO from among people who had been members for at least six months. The sample was chosen to obtain the desired number of members in each of the three target populations: PD, DD, and FE. The number desired from each population was intended to support statewide representativeness of the populations, and not to be representative of the population of the MCO.

In each MCO, the sample was drawn from a subset of counties or organizational hubs selected to maximize the share of membership represented by the sample. Enrollment dates and residency status of the random sample were verified in DHS' ForwardHealth interchange system and Long Term Care Function Screen (LTC FS) system. Additional information was obtained from the MCO, as needed.

The initial sample included approximately twice as many individuals as were needed for the final sample. This was done to accommodate refusals. The complete initial sample was provided to the MCO staff for recruitment, along with a script to use in the recruitment process. An MCO staff member called the individuals on the list to invite them to participate. The recruitment script was used to explain the purpose of the interview to the members. Individuals were asked if they were willing to participate. Individuals who agreed to take part in the interviews had an interview time scheduled. Those who did not agree were “replaced” by others from the initial sample list who belonged in the same target population. The MCO staff called as many people from the initial sample list as was needed to schedule the correct number of interviews with people from each target population.

All interviews were done voluntarily and with permission of legal decision-makers, i.e. guardians, when applicable. The sample was selected without regard for cognitive or communication abilities or living situation. When necessary, interviews were scheduled to include proxy respondents or others who could assist an individual to participate in the interview. Interviews were conducted in the settings preferred by the members.

More interviews than were necessary were scheduled, in order to accommodate last-minute cancellations. Additional interviews also were scheduled as needed to maintain the minimum sample and comparable distribution across target populations for the statewide sample.

### Interview team

PEONIES interviews were conducted by MetaStar, the State's External Quality Review Organization. The member outcome interview team is comprised of registered nurses, licensed social workers, and other degreed professionals with extensive experience working with people with developmental disabilities, people with physical disabilities, and elders. All interviewers were trained to use the DHS-approved member interview process, PEONIES, and were certified as interviewers by staff at CHSRA, the developers of PEONIES. The PEONIES approach uses person-centered interviews to identify the outcomes (goals) desired by members, assess the status of those outcomes, identify supports and services needed to assist members in maintaining outcomes that currently are achieved or to make progress toward outcomes not yet achieved, and assess the extent to which the necessary supports and services are in place and functioning.

Interviews were conducted with the member whenever possible. In some situations, interviews included one or more proxy respondents who either assisted the individual to participate in the interview or who responded on behalf of the individual. Interviewers confirmed information from proxies with the individual member to the extent possible. Proxy respondents were selected on the basis of their knowledge of the member and were not necessarily the legal decision-maker.

### Measures

The PEONIES measures address 12 quality of life domains that reflect the following issues:

- Living in a preferred setting and with whom one prefers;
- Making one's own decisions about supports and services;
- Deciding one's own daily schedule;
- Maintaining personal relationships with people one cares about;
- Working or doing other activities that give meaning and purpose to life;
- Being involved in the community in the ways that one prefers;
- Being treated with respect and fairness;
- Having stability and predictability in one's life;
- Having the amount and type of privacy one prefers;
- Being comfortable with one's health situation;
- Feeling safe; and
- Feeling free from abuse and neglect.

The PEONIES interviews generate highly individualized member information. Information from these interviews was provided from all interviewers to CHSRA; staff at CHSRA used the data to calculate aggregate PEONIES measures, including:

- Two key performance indicators: (1) the percent of outcomes that are fully supported, and (2) the percent of outcomes that are achieved or in progress
- The share of members who have one or more desired outcomes in each domain
- The total number of outcomes identified in each domain
- Reasons why outcomes are not fully supported (supports not in place, supports not adequate, supports not acceptable)

Each of the measures described above is reported overall, by Long Term care program, and by population. In addition, each measure is reported separately for each quality of life domain. Employment-related outcomes are included among those reported in the fifth domain (“I work or do other things that are important to me”) but also are reported separately as a subset of that domain, due to their policy importance.

Measures of outcomes achievement are based on the members’ descriptions of each outcome as achieved or not. “Achieved” outcomes describe aspects of life that are as the individual wishes them to be. When outcomes are not currently achieved, members are asked to describe the reason why this is not the case. Reasons are coded as “in progress,” “new,” “on hold,” and “legal/other.”

Outcomes that are “in progress,” describe situations that are not yet as the member wishes, but action is underway to achieve the desired goal. For example, a person may wish to live in a different location and be in the process of searching for a new home.

For the purposes of this report, “new” outcomes are ones that the member identified during the interview and which the member has not previously identified or reported to anyone at the MCO or the member’s team as a desired goal. For example, a person may realize during the course of the interview that the current living situation has worked well for many years but is no longer the best situation given changes in life circumstances. It is up to the member to determine whether or not an outcome is new.

Some outcomes may be on “hold,” with the agreement of the member, as other things are given priority. For example, a member may wish to move to a new location but only after finding a new job. In this case, the desired outcome of “move to a new location” is put on hold pending successful completion of the job search.

Legal reasons for not achieving an outcome refer specifically to court orders or similar legal barriers. For example, a person may wish to live in a different situation but be required to live in the current situation by court order. Other reasons for not achieving outcomes most often refer to disagreements between members and family members or guardians over the value and safety of a desired outcome. Regardless of legal barriers and interpersonal disagreements it is important to acknowledge and understand the outcomes that are desired by the member. Further, both legal barriers and disagreements with family and/or guardians need not be the end of the road. Knowing the outcomes desired by the member may simply be the start of a conversation.

Members describe the types of services and supports needed for each outcome and the status of the necessary services and supports. In the case of outcomes currently being achieved, the questions concern supports needed to maintain the current situation. In the case of outcomes not yet achieved, the questions concern supports needed to make progress toward that outcome.

Supports and services include things provided by and/or coordinated by the MCO (e.g., transportation services, medical supplies, supportive home care), people and actions provided under the MCO (e.g., care manager, referrals to other resources), supports from family and friends (e.g., assistance with transportation, cooking, emotional support, advocacy), resources from other organizations (e.g., social service organizations, community groups, religious groups), and the member's own skills and actions (e.g., self-advocacy, motivation).

Members are asked whether each of the supports/services that they identify as necessary to an outcome is (a) available to them, (b) adequate, and (c) acceptable. "Available" means that the member has been connected to the necessary support or service (e.g., member has transportation to get to and from work). "Adequacy" includes whether there is adequate quantity of the support to do what is needed (e.g., member works three days a week, but has transportation only two days per week) and whether the support is sufficient to the task (e.g., whether an approach to pain management is achieving the desired result). "Acceptability" concerns whether the member is satisfied with the quality of the support or service (e.g., the transportation is on time).

An outcome is "fully supported" only when all of the necessary services and supports are in place, adequate, and acceptable, as reported by the individual. While outcomes may be achieved even when not fully supported, the lack of full support may place the outcome at risk. For example, a person may achieve the desired outcome of living in their own home, but without full support (e.g., assistance with housecleaning, snow removal, cooking) the person may be at risk of needing to leave that home for a less desired situation. The inclusion in the measure of supports outside of those for which the MCO is directly responsible recognizes the importance of MCO staff understanding the full picture for its members. It is important for MCO staff to be aware of all the supports a member may need to achieve or maintain a desired outcome, even when the MCO is not directly responsible for coordination or providing some of those supports.

In addition to the basic measures described here, CHSRA staff conducted qualitative analyses of the types and sources of supports that members said were needed. The types and sources of support were coded into a discrete number of categories, and frequencies reported. These data show the sorts of support that members need, and the variety of sources from which they may obtain the necessary support. The coding schemas are shown in Tables A1 (Types of Support) and A2 (Sources of Support).

**Table A1. Coding Types Of Supports Needed**

Type of Support	Description	Examples Of Words And Phrases Included In The Category
ADL assistance (ADL)	<p>Assistance provided with activities of daily living: bathing, dressing, eating, toileting, transferring, and mobility.</p> <p>Mobility includes assistance with walking or assistance with using a wheelchair.</p> <p>Assistance may be from another person or from a piece of equipment. An individual also may perform ADLs independently (in which case the “self” is the source of this type of support).</p>	<p>ADLs; bathing; cares; food cut; PC; mobility; wheelchair; ambulation; shower; transfer; wheelchair (when help needed to use it)</p>
Communication/ communication assistance (COMM)	<p>Includes both direct and assisted/facilitated communication. May include interpreter services, use of machines to facilitate communication, assistance of another to facilitate communication, or communication by the member without any assistance.</p>	<p>Communication; interpreter; talk to (a given person); write; letters; sign; typing; privacy (when related to communication)</p>
Durable Medical Equipment/ Supplies (DME)	<p>Durable medical equipment and supplies, designed to assist with care or support function.</p>	<p>Lifeline; PERS; AFO; assistive device; head protection; walker; wheelchair</p>
Employment or employment assistance (EMPLOY)	<p>Includes supports related to obtaining or maintaining employment. Employment includes any work for pay. It does not require any minimum hours of work, or any specific type of employment situation.</p>	<p>Help with application; marketing; work; training; job coach or supervision; sheltered workshops</p>
Equipment, not DME (EQUIP)	<p>Includes equipment and supplies needed to support an activity, when those objects are not included in DME. Such items may support social interactions and recreation.</p>	<p>Computer; play station; iPod; telephone (when what is needed is the piece of equipment, not the help to use it); art supplies; exercise equipment</p>
Financial resources (MONEY)	<p>Includes money needed to support a desired outcome.</p> <p>This type of support is about the need for financial resources, not the management of those resources (which is an IADL).</p>	<p>Expenses; financial; funding; money</p>
Health related services (HRS)	<p>Activities related to maintenance and improvement of health. Such supports may include exercise, skilled medical care, skilled therapies, and other health care interventions when done by or under the direction of a medical professional.</p> <p>Note that some activities (e.g., diet, exercise) may be coded as HRS when done with medical direction, but coded differently when not under medical direction.</p>	<p>Pain management; nursing; physician; medical services; second opinion; radiation; medical care; exercise; dental; strengthening</p>

Type of Support	Description	Examples Of Words And Phrases Included In The Category
Housing (HOUSING)	Includes both physical housing, and assistance in locating housing	Shelter; look for apartment; obtain room; apartment
IADL assistance (IADL)	<p>Assistance provided with instrumental activities of daily living: meal preparation, cleaning, home maintenance, medication management and administration; laundry; chores; managing money; using the telephone. Assistance may be from another person or from a piece of equipment. An individual may perform IADLs independently and report “self” as the source for the support</p> <p>Note that, while transportation is generally thought of as an IADL, we have treated it as a separate type of support. This reflects the frequency with which transportation is reported to be a needed support. However, we have coded any needed assistance with scheduling transportation as an IADL.</p>	Cooking; nutrition; SHC; cleaning; appointments; bills; grocery; meal prep; med reminders; medication assist; medication delivery; financial management; phone (when help needed to use it); timing of transportation;
Information (INFO)	Refers to information needed to support decision making, find sources of support, make choices, etc.	Information; resources
Interpersonal Interactions (INTERPERSONAL)	This category refers qualities of interactions with others.	Respectful treatment by others; respectful treatment of others
MCO/IRIS (MCOIRIS)	Includes any managed care organization (Family Care or Partnership) or IRIS, when identified by the individual as being the type of support required.	Family Care (FC); Partnership; IRIS; specific MCOs named
Medication (MEDS)	Includes both prescription and over-the-counter medications and supplements	Medication; medicine; vitamins; aspercreme; nicotine gum/patch
Mental health support (MH)	Any services or actions directed to assisting people in addressing mental health problems or maintaining positive mental health	Coping; psychosocial; help with problems; stabilization; therapy; counseling; treatment (when specifically for mental health)
Monitoring & Support (MONITORING)	<p>Monitoring and support from another person, primarily (but not exclusively) to assist with safety in social settings.</p> <p>This is distinct from supervision and support provided in relation to completion of specific ADLs or IADLs.</p>	24-hour supervision; monitoring; companion (when purpose is to facility safe engagement in the community)
Security (SECURITY)	Includes physical features of a building, and the presence of others, when those people or features are intended to provide the person with a sense of security and safety.	dead bolt; door lock; secure building; people around in case of trouble

Type of Support	Description	Examples Of Words And Phrases Included In The Category
Social support (SOCIAL)	Refers to supports that enable a person to engage socially with others, whether in their own home or in a community setting. Includes supports that allow a person to decide not to engage with particular individuals or in particular settings.	Conversation; recreation; visitors; family; friends; club; community; church; help with problems
Spiritual (SPIRITUAL)	Includes supports related to spiritual well-being, whether through one's self (e.g., prayer, reading holy books) or through engagement with others (e.g., meeting with clergy, attending house of worship)	Spiritual; faith; prayer; church service
Support coordination (SUPPCOORD)	Coordination and oversight of services, including self-direction and member participation in planning and oversight.	Care management; planning; arranging services; coordination; attending appointments; referral; resources
Transportation (TRANSPO)	This refers to the means of getting from one physical location to another.  Mobility within a given location (e.g., from one room to another within a residence) is coded as an ADL. Coordination of transportation is coded as an IADL.	Rides; transportation; bus; cab/taxi
Other (OTHER)	Includes any other types of services not captured in distinct categories	Maintenance; vet; organization (help organization); sitting services; decision making; appointment calendar; lose weight (when not medically supervised); training (when not clearly related to employment); advocacy

Note: The categories for monitoring, security, and interpersonal interactions were added in February 2012. Previous reports included those types of supports in the category labeled "Other."

**Table A2. Coding Sources Of Support Needed**

Source of Support	Description	Examples Of Words And Phrases Included In The Category
Community members (CommyMember)	<p>People who are members of the broader community – i.e., who are not family, friends, or paid workers.</p> <p>People who are named and also described as associated with a specific organization, e.g., “Susan – Special Olympics,” are coded as community organization, not community member.</p>	Landlord; business owner; business operator; business developer; community member; library staff; police; teacher; volunteer; clergy
Community organization (CommyOrg)	Community-based organizations such as Easter Seals, YW/YMCA, Special Olympics, religious organizations, schools, and other similar organizations. Day centers that are identified as operated by the MCO for their members are coded as MCO services, not as community organizations. Other day centers are coded as community organizations.	Church; day center; recreation department; YMCA; day centers
Dental care provider (DentalProv)	Support is provided by an individual who is in the business of providing dental care	Dentist; periodontist
DME/DMS (DME)	Support is obtained from durable medical equipment/durable medical supplies	Grab bar; chair; transfer board; walker; wheelchair; ramp; braces; ted stockings; helmet; therapy lamp; nerve stimulator
Employment Resources (EmploymentRes)	Includes organizations and individuals who are a source of support for employment.	DVR; business development; specific employer named; specific person named
Equipment, not DME (Equipment)	Tangible goods that facilitate a task, other than durable medical equipment/supplies	Computer; phone; sewing machine; van/vehicle (person’s own); fire extinguisher; cook books
Family (Family)	Support is provided by family members.	Family; brother; sister; mom; dad; parent; daughter; son; niece; aunt; specific people named
Friends (Friends)	Support is provided by friends	Friends; BF; specific people named
House (HouseApt)	Includes features of the physical dwelling that work to support the person. Examples of such features are security systems, grab bars, and walk-in showers. Also may include features of the dwelling that are included in the rent, such as cable or heat.	House; apartment; building

Source of Support	Description	Examples Of Words And Phrases Included In The Category
IDT/IC (IDT_IC)	<p>Support is provided by members of the interdisciplinary team (social worker, RN, other) or by the IRIS independent consultant.</p> <p>Note that some people may name members of the IDT/IC while others name the MCO/IRIS as the source of support. We code these based on the person's own words and description of the source of support.</p>	SW; RN; CM; specific people named
MCO/IRIS (MCO_IRIS)	<p>Support is provided as a service of the MCO or IRIS.</p> <p>Note that some people may be more specific about sources of support (e.g., a transportation services, day program, aide) that are, in fact, paid by for as a service of the MCO. In those cases, the support is coded by the source named. Sources of support are coded as the MCO/IRIS only when the person specifically describes the MCO/IRIS as the source. This approach permits us to be as specific as possible about the source of support.</p>	Family Care; agency; FC; MCO (generic or named); IRIS
Medical care provider (MedCareProv)	Supports are provided by individuals or organizations that are in the business of providing health care	MD; hospital; hospice; pharmacy; medical community; PT; doctor; specific health care organization named
Medications (Medication)	Support is obtained from medications	Medication; meds
Mental health provider (MHProv)	Any individual or organization that is used for the purpose of mental health support	Psychologist; MH; therapist; counselor; specific health care organization named
Other (Other)	Includes a variety of sources not coded to any other category. May include people, organizations, and materials.	Fundraiser; newspaper; hotel; specific people named
Pet (Pets)	Support is provided by pets or service animals	Dog; service animal
Residential care (ResCareProv)	Includes residential care facilities and the people who work in them	AFH; assisted living; staff; nursing home; specific people named
Self (Self)	The person performs the activity or provides the support on his/her own. Includes, for example, independent performance of I/ADLS, self direction of services, communication with others	Self; pray; talk to; walk

Source of Support	Description	Examples Of Words And Phrases Included In The Category
Transportation provider (TranspProv)	Supports are provided by an organization that is in the business of providing transportation	Ride; bus; cab/taxi; paratransit; drivers; specific transportation providers named
Other paid worker (PaidWorker)	Support of ADLs and IADLs is provided by paid workers who are not employees of a residential care facility in which the person resides. This may include paid workers provided by an agency, or people hired directly by the individual.	Worker; SHC; specific people named; specific agencies named
Source Unknown (NoKnownSource)	Used when the person has not yet identified a source of support, or is unaware of/unable to name the source of support	Unsure; unknown; none

## APPENDIX B: DETAILED TABLES BY OUTCOME AREA

**Table B1. Key Performance Indicators Overall and by Outcome Area**

Outcome Area		Percent of Outcomes Fully Supported	Percent of Outcomes Achieved or In Progress
<b>TOTAL</b>		<b>85%</b>	<b>82%</b>
1.	I decide where and with whom I live	80	86
2.	I make decisions regarding my supports and services	89	89
3.	I decide how I spend my day	95	91
4.	I have relationships with family and I friends I care about	83	78
5.	I work or do other things that are important to me	81	74
5a.	Employment outcomes	69	57
6.	I am involved in my community	87	79
7.	My life is stable	87	79
8.	I am respected and treated fairly	90	84
9.	I have privacy	93	90
10.	I have the best possible health	79	81
11.	I feel safe	93	87
12.	I am free from abuse and neglect	93	80

**Table B2. Percent of People Interviewed with One or More Outcomes by Outcome Area**

Outcome Area	Percent with One or More Outcomes
I decide where and with whom I live	99%
I make decisions about my supports and services	61
I decide how I spend my day	58
I have relationships with family and friends I care about	88
I work or do other things that are important to me	88
Employment outcomes	31
I am involved in my community	66
My life is stable	25
I am respected and treated fairly	32
I have privacy	31
I have the best possible health	87
I feel safe	43
I am free from abuse and neglect	10

**Table B3. Percent of Outcomes Fully Supported by Long Term Care Program and Outcome Area**

Outcome Area		Family Care	Family Care Partnership	IRIS	Stat. Signif.
TOTAL		85%	82%	89%	***
1.	I decide where and with whom I live	76%	77%	85%	ns
2.	I make decisions regarding my supports and services	90%	84%	93%	ns
3.	I decide how I spend my day	95%	88%	99%	**
4.	I have relationships with family and I friends I care about	78%	85%	87%	ns
5.	I work or do other things that are important to me	87%	77%	80%	ns
5a.	Employment outcomes	73%	67%	67%	ns
6.	I am involved in my community	90%	83%	88%	ns
7.	My life is stable	89%	88%	83%	ns
8.	I am respected and treated fairly	89%	83%	94%	ns
9.	I have privacy	93%	82%	97%	*
10.	I have the best possible health	78%	76%	84%	ns
11.	I feel safe	94%	95%	89%	ns
12.	I am free from abuse and neglect	82%	93%	100%	ns

Note: Excludes outcomes described as new. Statistical significance was tested within each outcome area by ANOVA. \* p<.05 \*\*p<.01 \*\*\*p<.001

**Table B4. Percent of Outcomes Achieved or In Progress by Long Term Care Program and Outcome Area**

Outcome Area		Family Care	Family Care Partnership	IRIS	Statistical Significance
<b>TOTAL</b>		81%	78%	87%	***
1.	I decide where and with whom I live	84	85	88	
2.	I make decisions regarding my supports and services	81	80	99	***
3.	I decide how I spend my day	87	87	97	**
76	I have relationships with family and I friends I care about	78	76	80	
5.	I work or do other things that are important to me	75	70	77	
5a.	Employment outcomes	62	47	60	
6.	I am involved in my community	81	69	87	**
7.	My life is stable	79	76	82	
8.	I am respected and treated fairly	77	77	91	*
9.	I have privacy	85	87	96	
10.	I have the best possible health	81	79	83	
11.	I feel safe	87	84	90	
12.	I am free from abuse and neglect	65	89	85	

Percentages are based on number of outcomes identified, not number of individuals. Significant differences are identified for each outcome area using ANOVA.

\* p<.05; \*\* p<.01; \*\*\* p<.001

**Table B5. Percent of Outcomes That Are New by Long Term Care Program and Outcome Area**

Outcome Area		Family Care	Family Care Partnership	IRIS	Statistical Significance
<b>TOTAL</b>		14%	13%	9%	***
1.	I decide where and with whom I live	10	8	8	
2.	I make decisions regarding my supports and services	16	11	1	***
3.	I decide how I spend my day	11	10	8	**
76	I have relationships with family and I friends I care about	16	15	14	
5.	I work or do other things that are important to me	17	16	13	
5a.	Employment outcomes	23	27	25	
6.	I am involved in my community	12	23	10	**
7.	My life is stable	21	22	16	
8.	I am respected and treated fairly	21	18	6	*
9.	I have privacy	15	8	3	*
10.	I have the best possible health	12	10	13	
11.	I feel safe	9	10	7	
12.	I am free from abuse and neglect	29	11	10	

Note: Significant differences within outcome areas are identified using ANOVA.

\* p<.05    \*\* p<.01    \*\*\* p<.001

**Table B6. Percent of Members with One or More Outcomes by Long Term Care Program and Outcome Area**

Measure	Family Care (N=187)	Family Care Partnership (N=178)	IRIS (N=184)	Statistical Significance
I decide where and with whom I live	99%	97%	99%	
I make decisions about my supports and services	49%	52%	79%	***
I decide how I spend my day	47%	53%	71%	***
I have relationships with family and friends I care about	89%	85%	88%	
I work or do other things that are important to me	87%	85%	90%	
Employment outcomes	37%	24%	31%	*
I am involved in my community	66%	69%	62%	
My life is stable	25%	24%	24%	
I am respected and treated fairly	27%	22%	45%	***
I have privacy	29%	22%	41%	***
I have the best possible health	89%	82%	88%	
I feel safe	45%	51%	32%	**
I am free from abuse and neglect	9%	10%	10%	

Note: N refers to number of members interviewed. Comparisons across programs are made using ANOVA. \* p<.05 \*\* p<.01 \*\*\* p<.001

**Table B7. Percent of Outcomes Fully Supported by Population Group and Outcome Area**

Outcome Area	DD (N=1221)	PD (N=1137)	FE (N=1036)	Statistical Significance
TOTAL	88%	79%	90%	***
1. I decide where and with whom I live	86	68	85	***
2. I make decisions regarding my supports and services	92	84	92	
3. I decide how I spend my day	95	95	96	
4. I have relationships with family and I friends I care about	84	80	84	
5. I work or do other things that are important to me	84	72	90	***
5a. Employment outcomes	78	47	75	**
6. I am involved in my community	90	77	92	**
7. My life is stable	90	81	92	
8. I am respected and treated fairly	83	90	98	
9. I have privacy	92	93	94	
10. I have the best possible health	83	70	86	**
11. I feel safe	94	87	98	*
12. I am free from abuse and neglect	94	88	100	

Note: Excludes outcomes described as new. Statistical significance was tested within each outcome area by ANOVA. \* p<.05 \*\*p<.01 \*\*\*p<.001

**Table B8. Percent of Outcomes Achieved or In Progress by Population Group and Outcome Area**

Outcome Area		DD	PD	FE	Statistical Significance
<b>TOTAL</b>		85%	77%	86%	***
1.	I decide where and with whom I live	85	84	90	
2.	I make decisions regarding my supports and services	91	84	93	
3.	I decide how I spend my day	93	90	89	
4.	I have relationships with family and I friends I care about	81	73	81	
5.	I work or do other things that are important to me	79	66	77	**
5a.	Employment outcomes	72	39	33	***
6.	I am involved in my community	85	68	82	**
7.	My life is stable	81	76	81	
8.	I am respected and treated fairly	78	86	87	
9.	I have privacy	88	92	93	
10.	I have the best possible health	86	73	87	***
11.	I feel safe	92	76	93	**
12.	I am free from abuse and neglect	77	76	92	

Percentages are based on number of outcomes identified, not number of individuals.

Significant differences are identified for each outcome area using ANOVA.

\* p<.05; \*\* p<.01; \*\*\* p<.001

**Table B9. Percent of Outcomes That Are New by Population Group and Outcome Area**

Outcome Area		DD	PD	FE	Statistical Significance
<b>TOTAL</b>		11%	16%	8%	***
1.	I decide where and with whom I live	9	10	6	
2.	I make decisions regarding my supports and services	7	11	5	
3.	I decide how I spend my day	6	8	6	
76	I have relationships with family and I friends I care about	13	20	12	
5.	I work or do other things that are important to me	15	19	12	
5a.	Employment outcomes	21	29	31	
6.	I am involved in my community	10	26	12	**
7.	My life is stable	17	24	16	
8.	I am respected and treated fairly	20	11	9	
9.	I have privacy	8	8	7	
10.	I have the best possible health	9	20	3	***
11.	I feel safe	7	15	4	*
12.	I am free from abuse and neglect	23	19	0	

Note: Percentages are based on the number of outcomes in each area, which vary. Tests of significant differences within each outcome area are done using ANOVA. \* p<.05 \*\* p<.01 \*\*\* p<.001

**Table B10. Percent of Members with One or More Outcomes by Population Group and Outcome Area**

Measure	DD	PD	FE	Statistical Significance
I decide where and with whom I live	98%	99%	99%	
I make decisions about my supports and services	59%	65%	56%	
I decide how I spend my day	61%	52%	57%	
I have relationships with family and friends I care about	89%	86%	87%	
I work or do other things that are important to me	92%	90%	80%	**
Employment outcomes	52%	31%	8%	***
I am involved in my community	72%	60%	65%	*
My life is stable	24%	31%	18%	*
I am respected and treated fairly	28%	39%	27%	*
I have privacy	35%	33%	24%	
I have the best possible health	81%	95%	83%	***
I feel safe	37%	44%	47%	
I am free from abuse and neglect	12%	11%	7%	

Note: Tests of significant differences within each outcome area are done using ANOVA. \* p<.05 \*\* p<.01 \*\*\* p<.001

## APPENDIX C: KEY PERFORMANCE INDICATORS BY MCO AND PROGRAM

**Table C1. Key Performance Indicators by Long Term Care Program and MCO, SFY2012**

Program	MCO	Percent of outcomes fully supported (excluding new outcomes)	Percent of outcomes achieved or in progress
Family Care	A	90%	76%
	B	95%	96%
	C	89%	81%
	D	81%	76%
	E	76%	84%
	F	80%	80%
	G	84%	79%
	H	77%	77%
	I	90%	72%
Family Care Partnership	J	82%	80%
	K	75%	68%
	L	89%	87%
	M	83%	80%
IRIS		89%	87%