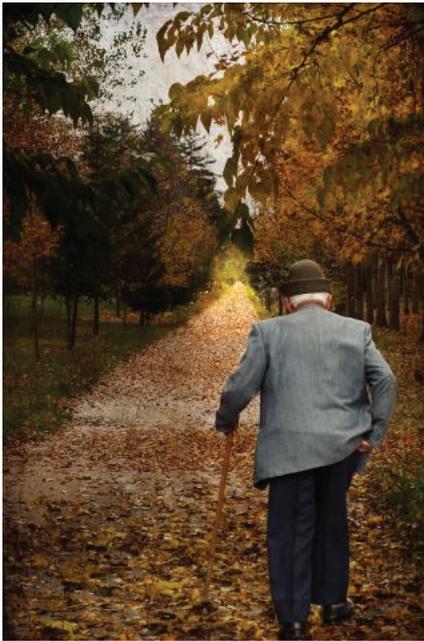


# Long-Term Care in Motion



Wisconsin's Long-Term Care Programs

# 2013 Annual Report

# Long-Term Care in Motion - 2013 Annual Report

## Contents

A Message from Brian Shoup.....	3
Introduction .....	4
2013 Family Care Program Activities .....	5
2013 IRIS Program Activities.....	6
Demographics and Service Highlights.....	8
Enrollment by Program.....	8
Enrollment by Target Group .....	8
Target Group by Program .....	9
Enrollment by Age.....	10
Age by Program.....	10
Current Living Situation .....	12
Service Expenditures by Program .....	13
Self-Directed Services (SDS) by Program .....	14
Employment.....	14
Program Results .....	16
Influenza and Pneumonia Vaccinations.....	16
Member Satisfaction Survey Results .....	16
Family Care Member Stories.....	18
IRIS Participant Stories.....	22
Appendices.....	25
Appendix 1: Glossary .....	25
Appendix 2: Map of Long-Term Care Programs in Wisconsin .....	27
Appendix 3: Examples of Wisconsin’s Long-Term Care Program Services.....	28
Appendix 4: Links for More Information .....	29



## Family Care Program Values

**CHOICE** – Give people better choices about the services and supports available to meet their needs.

**ACCESS** – Improve people’s access to services.

**QUALITY** – Improve the overall quality of the long-term care system by focusing on achieving people’s health and social outcomes.

**COST-EFFECTIVENESS** – Create a cost-effective long-term care system for the future.

## IRIS Program Values

**INCLUDE** – Wisconsin frail elders, adults with physical disabilities and adults with intellectual/developmental disabilities with long-term care needs who are Medicaid eligible are included and stay connected to their communities.

**RESPECT** – Participants choose their living setting, their relationships, their work and their participation in the community.

**SELF-DIRECT** – IRIS is a self-directed long-term care option. The participant manages an Individual Services and Supports Plan within an individual budget and the guidelines of allowable supports and services to meet his or her long-term care needs. The participant has the flexibility to design a cost-effective service plan.



### A Message from Brian Shoup

Welcome to the 2013 annual report on Wisconsin's Medicaid-funded long-term care programs for adults. These programs, administered by the Wisconsin Department of Health Services' Division of Long Term Care, are:

- Family Care,
- Family Care Partnership,
- Program of All-Inclusive Care for the Elderly (PACE), and
- Include, Respect, I Self-Direct (IRIS).

The Wisconsin Department of Health Services has led a transformation of the state's long-term care system over the past three decades. This increased the availability of cost-effective community supports and services, which decreased the use of costly nursing home services. The Family Care, Partnership, PACE and IRIS program options accomplished this transformation.

In December 2013, the Department completed its analysis on the future of publicly funded, community-based long-term care in Wisconsin. The analysis recognized that the growth in the aging population over the next 25 years requires a cost-effective system to manage limited public resources to ensure that the needs of Wisconsin's most vulnerable citizens are addressed.

Critical to the Department's success is the promotion of:

- The wise use of personal resources to delay entry into publicly funded supports;
- Healthy aging and achieving the best health possible for people with complex needs; and
- Coordinated, community-based supports that help people maintain better health and independence.

The Department's analysis shows that the implementation of the Family Care and IRIS programs is the most effective strategy to meet the needs of Wisconsin's residents. Further, implementing these programs statewide will eliminate waiting lists for 1,600 people in fifteen counties while reducing the growth of state spending by \$34.7 million over the coming ten years.

I look forward to continuing to work with all stakeholders—consumers, counties, tribes, providers and advocates—to ensure frail elders and people with disabilities have access to quality, cost-effective long-term care services.

Brian Shoup, Administrator  
Division of Long Term Care

## Long-Term Care in Motion - 2013 Annual Report

### Introduction

In 2013, about 57,700 frail elders and adults with physical, developmental or intellectual disabilities received long-term care services from Wisconsin's Medicaid long-term care (LTC) programs at some point during the year. These programs are Family Care, Family Care Partnership (Partnership), PACE (Program of All-Inclusive Care for the Elderly) and IRIS (Include, Respect, I Self-Direct).

The Wisconsin Department of Health Services (DHS) began Family Care in 2000 to help improve its long-term care system. IRIS began in 2008 as an option for people who wanted to self-direct all of their long-term care services. At the end of 2013, Family Care and IRIS were available in 57 of Wisconsin's 72 counties. See appendix 2 for a map of long-term care programs in Wisconsin.

The Department's long-term care programs help people stay in their own home or other non-institutional setting whenever possible. Most people enrolled in Family Care, Partnership, PACE and IRIS live in their own home or other community setting. This allows them to have more power over their lives and be more involved with their communities. They can decide when to do certain things, such as when to wake up and eat meals, and how to organize their daily activities.

#### Family Care, Partnership and PACE

DHS contracts with Managed Care Organizations (MCOs) to operate Family Care, Partnership and PACE. These are voluntary programs where eligible people can choose to enroll and become members of an MCO. MCOs provide or coordinate cost-effective and flexible services tailored to each member's needs.

DHS provides the MCO with a monthly payment for each member. The MCO uses these funds to provide and coordinate services for all of its members. One of the goals of Family Care is to provide the right service, in the right amount, at the right time, and in the right setting.

Care managers work with members to identify their needs, strengths and preferences. Together, they identify the resources available and develop a care plan that may include help from family, friends and neighbors. When this help is not available, the MCO will purchase necessary services.

Members may also choose to self-direct some of their long-term care by choosing who will provide their services or when to receive certain services. Members who self-direct their services still have access to their care teams for help.

Family Care MCOs do not provide primary health care services such as regular medical checkups or acute care such as hospital stays. Members receive these services through Medicaid or Medicare. The Partnership and PACE programs cover all of the long-term care services in Family Care, plus primary and acute care, and prescription drugs. The difference between Partnership and PACE is that PACE is only for people age 55 or older who live in Milwaukee or Waukesha County.

## Long-Term Care in Motion - 2013 Annual Report

### **IRIS (Include, Respect, I Self-Direct)**

IRIS is a program in which participants self-direct their care plan and services within an individual budget. People who want to direct all of their long-term care services can choose to enroll in, and become, an IRIS participant.

In IRIS, participants manage their own support and service plan and work with an IRIS Consultant to create a plan within an individual budget. The budget is used toward the cost of allowable long-term care supports, services and goods. Participants are responsible for managing their long-term care supports within the established budget.

Participants may hire their own workers directly, or purchase goods and services from an agency. They choose the services necessary to meet their long-term care needs, and decide whom they will hire to provide supports or where to purchase those services. IRIS does not include any Medicaid services including primary and acute care, prescriptions or home health care. These services are available through Medicaid or Medicare.

The IRIS Fiscal Employer Agents (FEA) handles bill paying and accounting. The participant hires workers directly, and the FEA completes background checks on providers, processes timesheets, generates paychecks and handles payroll taxes.

## **2013 Family Care Program Activities**

### **Performance Improvement Projects**

In 2013, MCOs carried out projects to improve care and outcomes for Family Care, Partnership and PACE members. DHS and the federal Centers for Medicare and Medicaid Services (CMS) require MCOs to complete quality improvement projects. Some of the 2013 improvement projects were clinical in nature, such as reducing cardiovascular disease for members with hypertension and diabetes. Other projects focused on non-medical aspects of care and outcomes, such as increasing the use of self-directed supports. While some projects result in a reduction in costs by preventing unnecessary hospitalizations or medical care, others affect the social and psychological well-being of members. Some of the other improvement projects focused on:

- Decreasing risk of falls;
- Reducing hospital readmissions within 30 days of a hospital discharge; and
- Improving the coordination of care transitions from acute care to community living settings.

### **External Quality Reviews**

DHS contracts with a federally required External Quality Review Organization (EQRO) to evaluate the quality of each MCO. In 2013, the EQRO was MetaStar, Inc. MetaStar reviewed MCO systems and processes in many important areas affecting the care of Family Care, Partnership and PACE members. MetaStar conducted the annual review from July 1, 2012, to June 30, 2013.

## Long-Term Care in Motion - 2013 Annual Report

Key MetaStar Quality Findings – July 1, 2012, to June 30, 2013:

- Three MCOs met 100% of the federal quality compliance standards.
- Three other MCOs improved their rates of compliance to 90% or greater.
- Across all MCOs, the rate of compliance with all standards improved from 80.7% to 90.5%.
- Compliance with standards that relate to member rights reached 95.8%.
- MCOs consistently demonstrated their ability to address members' needs and include members and their supports in care planning and decision-making.

### Self-Directed Supports Option

In 2013, DHS worked with MCOs to develop a manual to promote successful use of self-directed supports (SDS) in Family Care, Partnership and PACE. This manual is a best practice guide for care management staff that assist members who choose to self-direct some of their long-term care services. The manual helps care managers to learn:

- The ways in which members can direct their own services and supports;
- Strategies for assuring member health and safety; and
- The process for calculating budgets for purchase of self-directed services and supports.

### Program Transition

The MCO that served an 11-county area in northwestern Wisconsin stopped operating the Family Care program on December 31, 2013. All members successfully transitioned to either a new MCO, IRIS or to another Medicaid program.

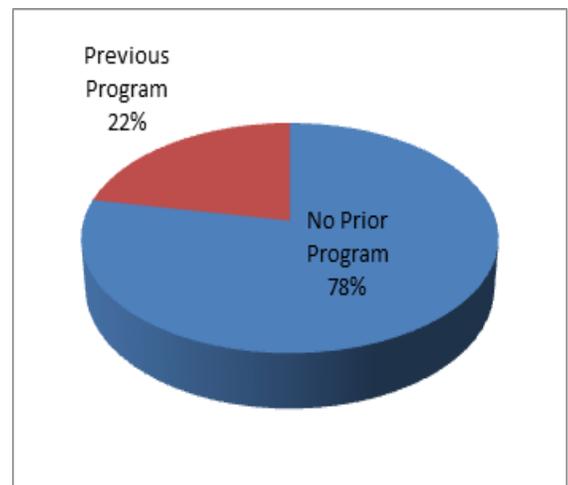
## 2013 IRIS Program Activities

The IRIS program enrollment grew by 2,215 participants during 2013. At the end of 2012, there were 7,455 participants, and by the close of 2013, enrollment reached 9,670 participants. At the close of 2013, there were 280 IRIS Consultants supporting the 9,670 IRIS participants.

Statistics concerning the prior program participation of IRIS participants remained consistent between 2012 and 2013. Just over 78% of people who joined IRIS were not previously enrolled in a long-term care program. Only 22% came from another long-term care program, such as Family Care (16.1%) or the Children's Long-Term Support Waiver (4.9%).

### IRIS Self-Directed Personal Care Program

IRIS participants choosing to self-direct their personal care services continued to grow in 2013. The IRIS Self-Directed Personal Care program grew from 1,657 participants at the end of 2012, to 3,072 participants at the end of 2013.



## Long-Term Care in Motion - 2013 Annual Report

### Self-Directing Services/Employer Authority

IRIS participants serve as the employer of record which is one of the cornerstones of the IRIS program. By the end of 2013, IRIS participants directly employed 14,191 people as their caregivers. Some of the services these employees provided were supportive home care, respite and IRIS self-directed personal care.

### IRIS Self-Directed Information Technology System (ISITS)

During 2013, DHS completed procurement through a Request for Proposal for a centralized data system to be owned by DHS and used by all IRIS partner agencies. Anticipated benefits of this centralized data system include streamlined functionality, centralized communication and improved data accuracy. IRIS participants will be able to access their records within the ISITS system. Development will take place in 2014 and 2015, with implementation of the new system occurring in the third quarter of 2015.

### IRIS Quality Improvement Program

The IRIS program has a formal system in place to manage program quality. This includes:

- Identification of system trends and issues through the analysis of data and participant feedback;
- Data collection and analysis to show evidence of compliance with federal and state standards and contract requirements; and
- Implementation of quality improvement projects to address systems issues.

### Other Key IRIS Accomplishments in 2013:

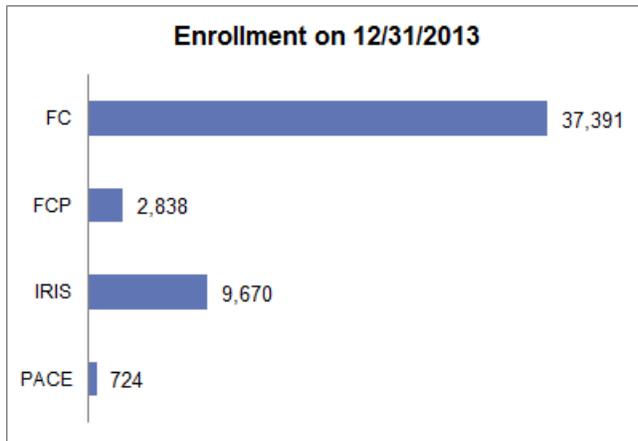
- Developed and implemented work instructions and an online system to address and resolve allegations of fraud.
- Reviewed 663 participant records for compliance with the CMS assurances and contract compliance.
- Developed and implemented a structured process including work instructions and an online system to track and ensure resolution of all critical incidents.
- Developed and implemented a more robust mortality review process to review each participant death.
- Continued work on a comprehensive IRIS policy manual and IRIS work instructions manual.
- Developed and implemented a structured method for the IRIS Consultant Agency and Fiscal Employer Agent to submit quality management plans including an approval process and tracking mechanism.
- Partnered with MetaStar, Inc. to establish a complaint and grievances process including a hotline for participants to call to obtain assistance.
- Began development of participant education materials on key topics such as participant rights and responsibilities, fraud prevention and critical incident reporting.



## Demographics and Service Highlights

### Enrollment by Program

- At the end of 2013, 50,623 people were enrolled in the Family Care (FC), Family Care Partnership (FCP), PACE and IRIS programs.
- About three-quarters (74%) of all enrollees were in Family Care. IRIS was the next largest program (19%), followed by Partnership (6%), then PACE (1%).



### Enrollment by Target Group

**Eligible Target Groups:** To enroll in Family Care, Partnership, PACE or IRIS, people must have certain complex conditions and need for help with daily activities. Only people in the following 'target groups' are eligible to enroll:

- Frail elders, age 65 and older, who have serious and long-lasting physical health problems or dementia that significantly limits their ability to care for themselves;
- Adults with physical disabilities who have a physical condition that significantly limits their ability to care for themselves; and
- Adults with developmental or intellectual disabilities who have the onset of developmental or intellectual disabilities before the age of 22, and may have cognitive functioning that limits their ability to care for themselves. The person must have limitations in at least three of the following areas: learning, use of language, self-direction, mobility, self-care (bathing, dressing, eating, toileting or mobility), or the ability to live independently without help from another person.

**Reporting Change:** For the 2013 annual report, DHS used a different method to assign members and participants to a target group. DHS made this change in order to be consistent with financial reporting for Family Care, Partnership and PACE. Previously all people age 65 or older were reported in the frail elderly target group.

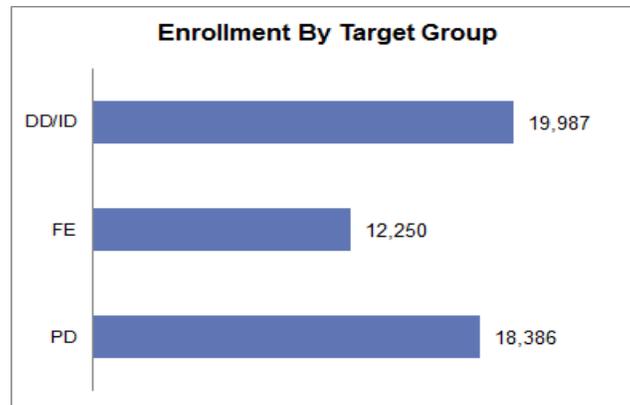
For this report, people were reported in the target group related to their disability with developmental disability being first in the hierarchy. For example, a person who has both a developmental/intellectual disability (DD/ID) and a physical disability, and is age 65 or older, is

## Long-Term Care in Motion - 2013 Annual Report

in the DD/ID target group. In previous annual reports, this person would have been in the frail elder target group. This method significantly changed the count of people in each target group.

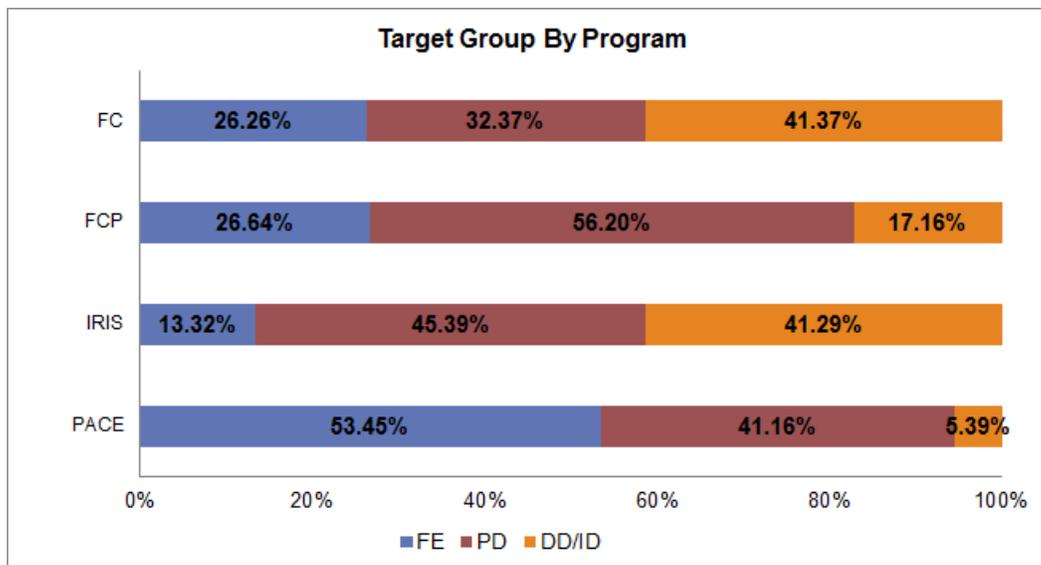
In 2013:

- Approximately 24% of all people enrolled in Family Care, Partnership, PACE and IRIS were frail elders (FE).
- About a third (36%) of the people had a physical disability (PD).
- The remaining people (39%) had a developmental or intellectual disability (DD/ID).



### Target Group by Program

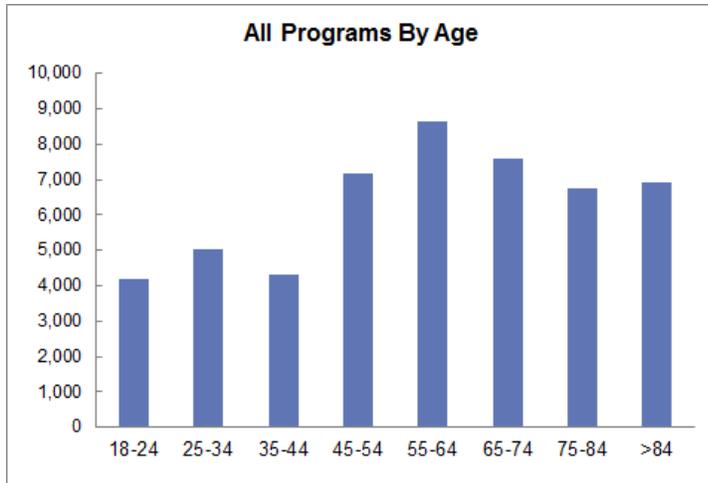
- Each program serves all three target groups. The proportion of these groups varies by program.
- PACE had the highest percentage of frail elders (53.5%). This is partly because PACE eligibility begins at age 55.
- FC and IRIS had about the same percentage of people with developmental or intellectual disabilities (41.4% and 41.3% respectively).
- FC and Partnership had almost the same percentage of frail elder members (26.3% and 26.6% respectively).
- This is the first year in which people with physical disabilities compromised the largest share (45.4%) of the IRIS population.



## Long-Term Care in Motion - 2013 Annual Report

### Enrollment by Age

- In 2013, people enrolled in Family Care and IRIS were between 18-107 years old.
- Approximately 42% were 65 or older.



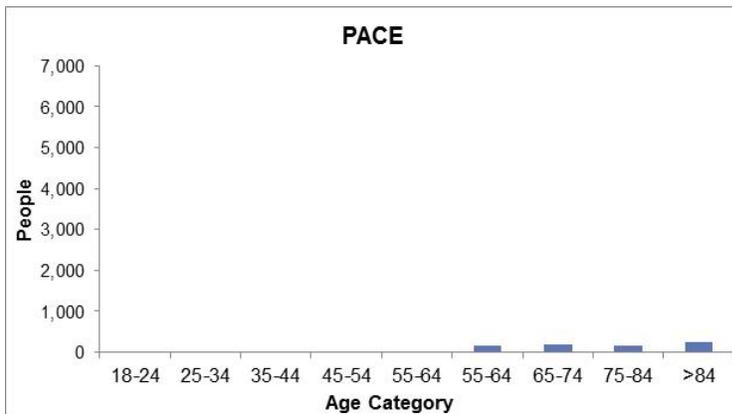
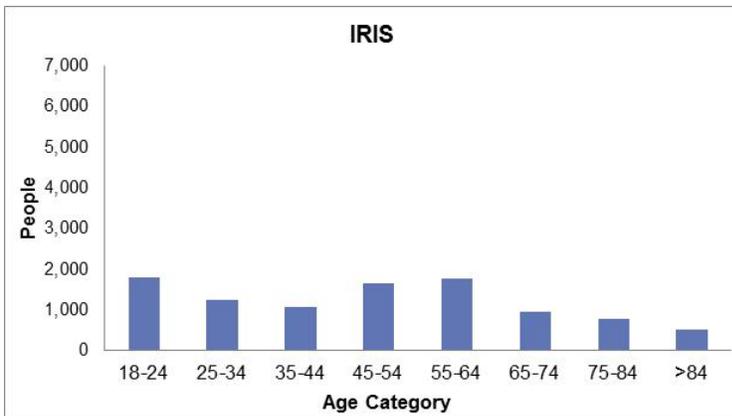
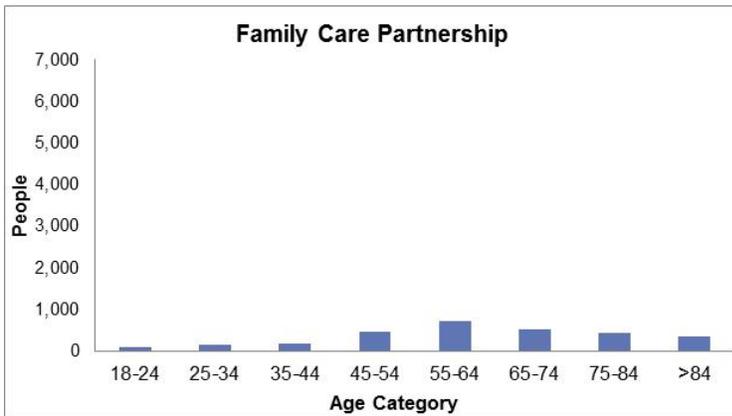
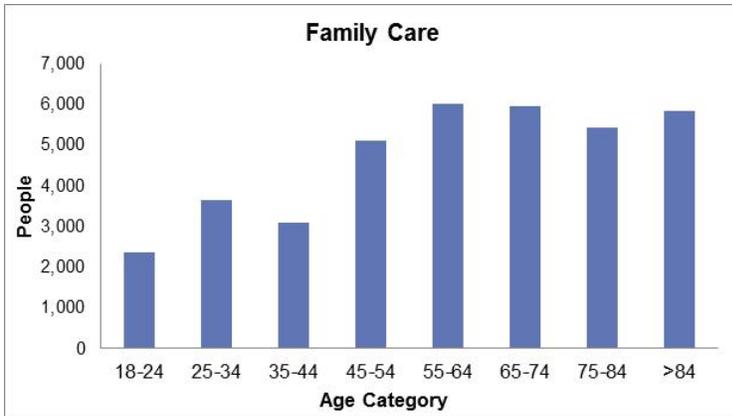
### Age by Program

- The average age of participants and members varies by program as shown in the table below.

Program	Average Age
FC	61
FCP	63
IRIS	49
PACE	76

- Family Care and Partnership had a similar distribution of members across age groups.
- The IRIS program had younger enrollees than Family Care or Partnership. Only 23% of IRIS participants were age 65 or older.
- PACE had a higher percentage of elderly members than any other program. More than 77% of PACE members were age 65 and older.
- The charts on the following page show the number of people in each age category by program.

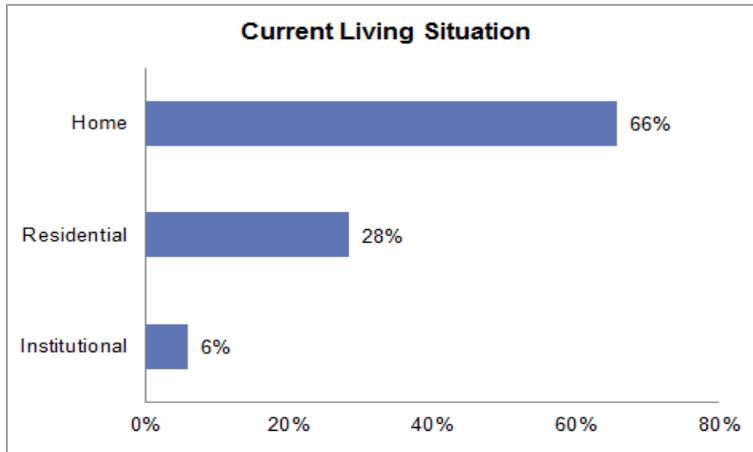
## Long-Term Care in Motion - 2013 Annual Report



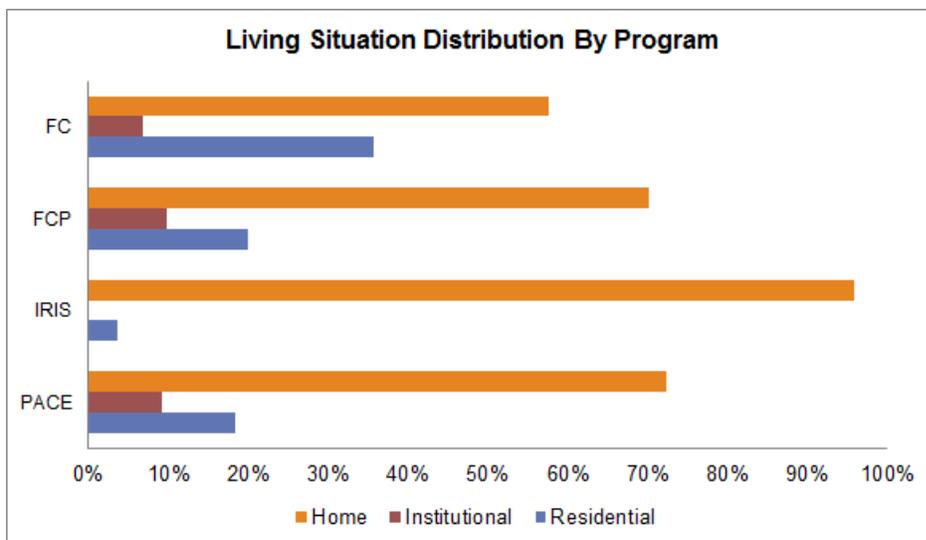
## Long-Term Care in Motion - 2013 Annual Report

### Current Living Situation

- In 2013, almost 66% of the people enrolled in Family Care and IRIS lived in a home setting.
- Nearly all (96%) IRIS participants lived at home. Most Family Care, Partnership and PACE members lived at home as well.
- Overall, 94% of the people living at home identified home as their preferred living setting.
- Only 27% of the people in an institutional setting said this was their preferred setting.



- Sometimes it is not safe for people to remain in their own home and they may move to a residential setting where they can get additional support, such as an Adult Family Home, Community-Based Residential Facility or Residential Care Apartment Complex.
- About a third (28%) of the people in Wisconsin's long-term care programs lived in one of these residential settings.
- Family Care members were more likely to live in a residential setting.
- When people live in an institutional setting like a nursing home or an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID), they can remain enrolled in Family Care, Partnership or PACE, but not IRIS.
- Partnership had the highest percentage of members that lived in an institutional setting (10%), followed by PACE (9%) and Family Care (7%).



## Long-Term Care in Motion - 2013 Annual Report

### ***Service Expenditures by Program***

In calendar year 2013, total expenditures for services purchased for Family Care, Partnership, PACE and IRIS were approximately \$1.6 billion. The table below shows total expenditures by program.

Program	Total Expenditure for Services (millions)
Family Care	\$1,217
Partnership and PACE	\$207
IRIS	\$210
<b>Total</b>	<b>\$1,633</b>

The services that account for the greatest proportion of spending for each program are shown below. The percentages do not include care management services. Totals may differ from the sum of programs or services due to rounding.

Family Care Services	Percentage of Total Expenditures
Residential Services	52%
Supportive Home Care/Personal Care	18%
Nursing Home and Intermediate Care Facilities	13%
Adult Day Activities	6%
Vocational Services	4%
Transportation	3%
Other	4%
<b>Total</b>	<b>100%</b>

Care management accounts for 13% of total service expenditures.

Partnership and PACE	Percentage of Total Expenditures
Long-Term Care Services	
Residential Services	15%
Nursing Home and Intermediate Care Facilities	10%
Supportive Home Care/Personal Care	9%
Transportation	4%
Adult Day Activities	3%
Medical Equipment and Supplies	3%
Other (LTC)	7%
Primary & Acute Care Services	
Inpatient Hospital	15%
Medications (Pharmacy)	13%
Office or Outpatient Assessments	5%
Other (Acute and Primary)	17%
<b>Total</b>	<b>100%</b>

Care Management accounts for 10% of total service expenditures.

## Long-Term Care in Motion - 2013 Annual Report

IRIS Services	Percentage of Total Expenditures
Supportive Home Care	56%
Self-Directed Personal Care*	18%
Residential Services	8%
Adult Day Activities	5%
Transportation	4%
Respite	4%
Other	5%
<b>Total</b>	<b>100%</b>

\*IRIS Self-Directed Personal Care is a service available to IRIS participants who are eligible to self-direct their personal care. This service is provided under a 1915(j) Self-Directed Personal Assistance Services State Plan Amendment.

### ***Self-Directed Services (SDS) by Program***

Members of Family Care, Partnership and PACE programs may choose to self-direct one, or more, of their long-term care services. Members choose the level they want to participate in SDS and the amount of support they need. The MCO continues to manage any service the member does not choose to self-direct. In IRIS, participants self-direct all of their long-term care services and schedule all of their providers. Regardless of the program, members and participants manage their services within an established budget. The following table shows the percentage of members that self-directed at least one service during 2013.

- All (100%) participants enrolled in IRIS self-directed at least one service during 2013.
- Family Care and Partnership each had nearly 20% of members who self-directed at least one service during 2013.
- About 6% of PACE members self-directed at least one service during 2013.

Program	Percentage of Member Self-Directed Services
Family Care	17%
Family Care Partnership	19%
IRIS	100%
PACE	6%
Overall Total (Including IRIS)	32%
Overall Total (Excluding IRIS)	17%

### ***Employment***

DHS is committed to integrated employment outcomes for all people with disabilities and has prioritized its resources and activities to achieve this outcome. The Department's goal is to increase the integrated, community-based employment rate for working age people with disabilities.

## Long-Term Care in Motion - 2013 Annual Report

Integrated employment, at a competitive wage, offers people economic security, as well as the respect and dignity associated with employment. The Department's efforts focused on increasing integrated employment, providing people with long-term care needs access to a full range of employment choices and outcomes, and giving people opportunities to participate fully in their community.

In October 2013, DHS collected the following data about working age people (18-64 years of age) enrolled in Family Care, Partnership and IRIS.

- **Family Care/Partnership:**

There were 22,105 working age people enrolled in Family Care and Partnership.

- Of these people, 6,425 (29%) worked in an integrated employment setting<sup>1</sup>, a facility-based setting<sup>2</sup> or in a group/enclave setting.<sup>3</sup>
- 1,856 people were in integrated employment.
- 4,805 people were in facility-based employment.
- 313 people were in group/enclave employment.
- 549 people worked in more than one setting, such as in integrated employment in the morning and in a facility-based setting in the afternoon.

- **IRIS:**

There were 7,913 working age people enrolled in IRIS.

- Of these people, 988 (12%) worked in an integrated employment setting<sup>1</sup>, a facility-based setting<sup>2</sup> or in a group/enclave setting.<sup>3</sup>
- 410 people were in integrated employment.
- 562 people were in facility-based employment.
- 61 people were in group/enclave employment.
- 45 people worked in more than one setting, such as in integrated employment in the morning and a facility-based setting in the afternoon.

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<sup>1</sup> **Integrated Employment** – Competitive employment in community businesses with co-workers who do not have disabilities. This includes supported employment.

<sup>2</sup> **Facility-Based Employment** – Services that are provided in a facility to develop general, non-job-task-specific skills, which are designed to create a path to integrated employment. These services are expected to occur over a defined period of time with six-month progress reports.

<sup>3</sup> **Group/Enclave Employment** – Paid work in small group settings (2-8 workers with disabilities) such as work crews or enclaves that occur in community businesses. Typically, the vocational provider (e.g., community rehabilitation facility/supported employment provider) pays the worker's wages.

## Program Results

### *Influenza and Pneumonia Vaccinations*

The MCOs encourage members to receive appropriate vaccinations. This is because influenza and pneumonia can lead to health complications, hospitalization, and sometimes death. Each MCO monitors members' immunization status.

The following table shows the percentage of members in 2013 that were vaccinated against influenza or pneumonia<sup>4</sup>.

Program	Influenza	Pneumonia
Family Care	70%	80%
Partnership	74%	82%
PACE	89%	96%

### *Member Satisfaction Survey Results*

The MCOs survey members each year to determine their level of satisfaction. The survey questions ask members to respond with one of five choices:

- Always
- Most of the Time
- Sometimes
- Almost Never
- Never

In 2013, Family Care members reported the highest percentage of "Always" and "Most of the Time" responses, followed by Partnership members. PACE members had the lowest percentage of "Always" and "Most of the Time" responses.

Combining "Always" and "Most of the Time" responses, the top two scoring questions were:

- I feel comfortable asking my nurse questions (98%).
- I am happy with the quality of services I receive (95%).

Combining "Always" and "Most of the Time" responses, the two lowest scoring questions were:

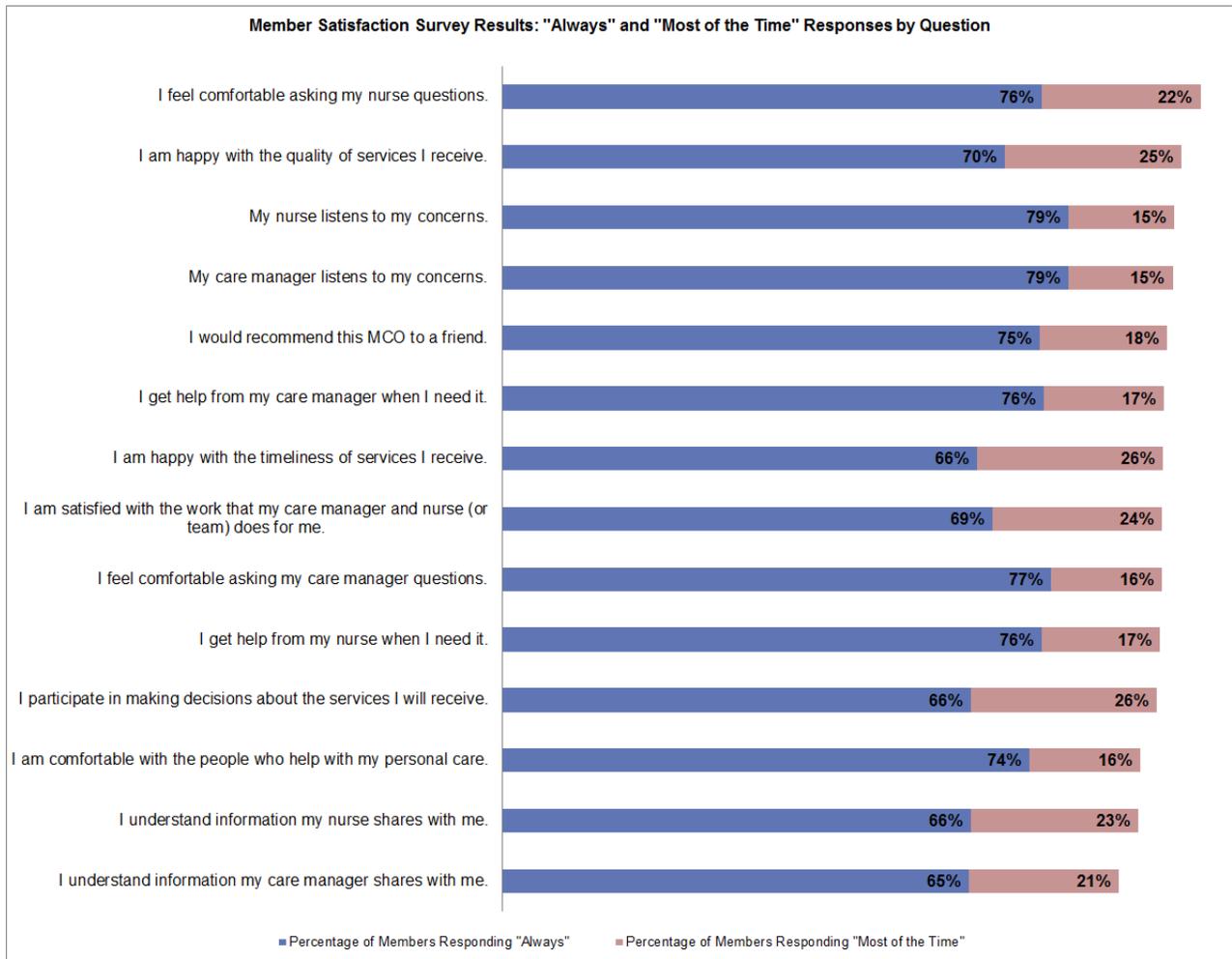
- I understand information my care manager shares with me (86%).
- I understand information my nurse shares with me (89%).

Three-quarters (75%) of respondents indicated they would "Always" recommend their program to a friend, and an additional 18% indicated they would recommend their program "Most of the Time."

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<sup>4</sup> Pneumococcal vaccination is only measured for members age 65 and over.

## Long-Term Care in Motion - 2013 Annual Report



## Family Care Member Stories

### Noreen's Story

When Noreen joined the PACE program in 2008, the 64-year-old described her life as “a mess.” She had been battling the chronic illnesses of depression and anxiety. Her insurance company referred her to many different health professionals at a variety of locations – there simply was no coordination of her care.



When she enrolled in PACE, a team of professionals worked with Noreen and her family to identify her health and life goals, and developed a plan to manage her chronic illnesses and achieve her goals. The coordinated care she receives through the PACE program changed her life. Says Noreen, “...everything comes together. It’s all under one roof, and I know I am getting good care.”

Noreen has gone from needing help to becoming the helper. She now provides support to four elderly residents in the apartment building where she lives. Serving as their companion, she spends time with them doing everything from helping them read their mail to praying with them.

Noreen is active in the community doing volunteer work and serves on her MCO’s appeals committee. “Noreen has dealt with a lot, and has handled the challenges so well,” said her PACE program social worker. “By coordinating her care, we were able to realize significant cost savings, and at the same time, improve the quality of the healthcare she receives. It’s a win-win all around.”

### Josh's Story

It is important that people have meaningful activities to do during the day. When a person’s day is filled with meaningful activities, life is usually more rewarding. For some people with disabilities, days can sometimes be spent in activities that don’t match their skills or interests.

Josh, a 26-year-old with cerebral palsy, found himself in such a position. Spending three days a week in an adult day center wasn’t a good match for his needs, and it caused him to act out at home and become upset with his personal care workers.

His personal care workers looked for ways Josh could be more involved in his community. They contacted a number of local volunteer and other organizations and set up regular activities for Josh.

## Long-Term Care in Motion - 2013 Annual Report



Josh's life is now filled with activities he enjoys. One day a week, he serves as a greeter at a local frozen yogurt shop. His bright smile and warm welcome make customers feel at home as they enter the store. On Fridays, he works as a greeter at a craft store. This job taps into Josh's natural artistic interests and talent. People say they like seeing him and even stop by just to see how he is doing.

On another day, he puts both his art and social skills to use serving as a companion at a hospital. He works with a woman who is deaf and they paint together. Josh communicates with her on a tablet computer.

Josh also keeps busy painting and doing other crafts. For example, he decorated jars for a local fair and donated some of his profits to a park project.

His mom Tammy says finding activities that are meaningful for Josh have made all the difference in the world. She says his attitude has shifted and everyday he is excited to contribute to the community. "He has a sense of responsibility and [is] happier than he's been before," she says. "Now when he gets up in the morning, there's a real sense that he's getting ready for the day."

Since he began taking part in activities that are a better fit for his skills and interests, his attitude and days are much more joyful. "I would not have believed three months ago that this would be Josh's life today. I see a huge transformation in his attitude, maturity level and overall sense of responsibility," says Tammy.

"It's incredible the number of people that are giving him these opportunities and I sincerely hope that he will set a precedent for others in the community."

### **In Dave's Own Words**

My name is Dave and due to a car accident, I am a quadriplegic and I'm paralyzed from the shoulders down. Post-accident I went five years without a program. I was on a waiting list. Medicare and Medicaid would have paid for me to go into a nursing home, but not to stay at home. Being in a nursing home would have triggered major depression for me.

My transition to Family Care went smoothly. I have been with Family Care for almost four years now. Prior to Family Care, my wife and I had to pay out-of-pocket for the ramp I use to get in and out of the house, wider doors, an elevator to my "man cave" in the basement, a shower room, incontinent supplies, bathroom equipment and a lift for my van.

## Long-Term Care in Motion - 2013 Annual Report



Family Care supports me in living a good life, in my home with my wife. Our house has a revolving door with friends and family. Being able to live at home allows me to be outside and be my own person. I can keep my own schedule.

My wife is able to be paid for taking care of me through Family Care's self-directed supports option. The Family Care program isn't just about making it easier

for the member, it is also about making it easier for the caregiver... in this case, my wife... because without a caregiver I would be in a nursing home.

Family Care provides the supports I need to be independent. For example, my care team helped me get a standing frame, which puts me in a standing position for bone strengthening and helps me with overall body functioning. I also have a machine for foot and arm pedaling that helps with range of motion. Family Care also provides mileage reimbursement for long and short medical-related trips, incontinent supplies, and repairs on equipment and my wheelchair. We are working with my care team to arrange for respite care so my wife can have a break.

We do live a good life. The program is helping me live this new adventure.

### Brandon's Story

Brandon is a 24-year-old man living in rural northern Wisconsin. Brandon loves music, especially country music. While not a musician himself, Brandon very much wanted to get involved in the "music scene." As a recent high school graduate, Brandon was also looking for ways to get out of the house during the day and keep busy in the community.

With the help of Family Care funding, Brandon began working with an area service provider to find a way to share his love and knowledge of music with the local community. He worked with his staff to build a relationship with a local college radio station, and now hosts his own radio show once a month.

Through this program, Brandon has made a name for himself in the community. He has had the opportunity to interview some of his favorite artists on the air, and has



## Long-Term Care in Motion - 2013 Annual Report

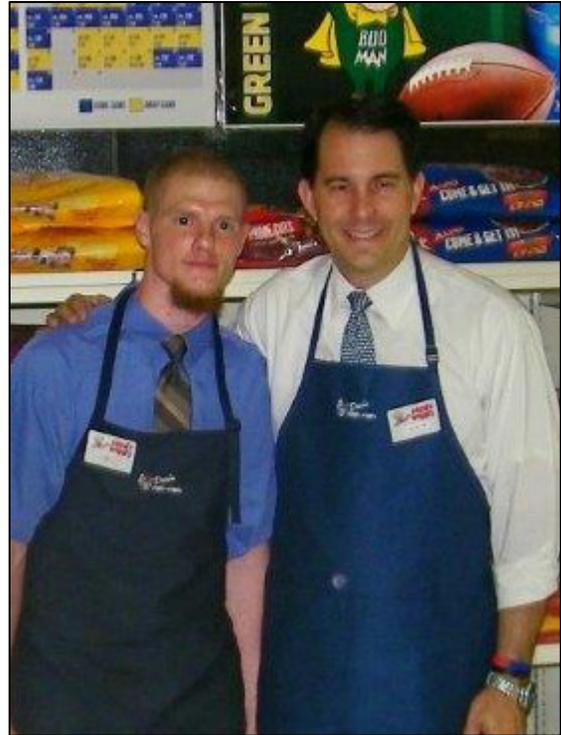
expanded his own work opportunities in the community by selling advertising space for the radio station. He also used his radio program as a platform to discuss his experience with Autism and to promote the independence of people with different abilities in his local community.

The public can learn more about Brandon and stream previous episodes of his show at [www.wrnclp.org/category/the-brandon-hanson-show](http://www.wrnclp.org/category/the-brandon-hanson-show).

### Lee: Take Your Legislator to Work

Governor Scott Walker paid a visit to Drew's Piggly Wiggly in Merrill, Wisconsin, as a part of the *Better Bottom Line* initiative and the annual Take Your Legislator to Work Campaign, organized by the Wisconsin Board for People with Developmental Disabilities. During this visit, Governor Walker worked side-by-side with Lee, a Drew's Piggly Wiggly employee, during his shift.

"Drew's Piggly Wiggly recognizes that individuals of all abilities are an asset in the workplace environment," Governor Walker said. "I'm thrilled I had the opportunity to be here with Lee and work with him today bagging groceries and stocking shelves. I was able to witness first-hand the positive impact that hiring employees with disabilities has on the employee and community as a whole. In providing the training and resources necessary, individuals with disabilities are able to work in their communities at a competitive wage, gaining confidence as well as marketable skills."



Story and photo credit: Office of the Governor [press release, 8/21/2014]. <http://walker.wi.gov>.

The year of *A Better Bottom Line* initiative is aimed at overcoming obstacles to employment for people with disabilities. According to the Bureau of Labor Statistics, the nationwide unemployment rate of people with a disability was 13.2 percent in 2013, which is higher than the 7.1 percent unemployment rate for people without a disability.



## IRIS Participant Stories

### Barbara's Story



Barbara is a lively woman living in Waukesha County. In her own words, IRIS is, “helping me live independently to the best of my ability.” Although there were some twists on her road back to independence, she is finally living a stable, healthy life.

Barbara lived in a log cabin in the country for many years, taking care of her flowers and helping on a farm. When her health declined, she began to plan for a different life.

Barbara praises her IRIS Consultant and the rest of her support network for motivating her to get out into the community. When Barbara first joined IRIS, she had hardly unpacked anything in her new apartment, as she was missing her cabin.

After her first visit with her IRIS Consultant, she realized that she wanted to “stop feeling sorry for herself and start her life again.” She called her IRIS Consultant later that evening to thank her for inspiring her to start her new life.

Now, Barbara's apartment is decorated with new things, as well as old things from her cabin. She has even started a flowerbed outside of her apartment. She has the help she needs to maintain a very social life.

Though getting around can be a struggle physically, Barbara loves getting out into the community, especially the local library, where she is a member of a book club. “The library has walkers, large print books, all kinds of people to talk with about a book or the newest things that went up on the wall... that's one of the first places [to go] if you want to get more connected to the community, go to the library.” She also likes to volunteer at a nursing home and chat with people at the local grocery store.

Barbara shared a great story of her having fun at the grocery store: “There was a woman who worked there that pulled out bubble wrap and she popped a couple, so I asked, can I pop a couple? And then another girl came over and I said, let's step on them! Everybody was laughing and smiling. When I can make someone smile or laugh, I'm the one that gets better from it! So it's the little things like that that I like to do.” Her community connections and fascination with people keep her busy.

When Barbara isn't out making people laugh in the community, she's at home relaxing with her dog and cat. Her infectious smile and great optimism keep her excited and ready for the future. Barbara's last piece of advice is, “We are all caring survivors, and we have all survived

## Long-Term Care in Motion - 2013 Annual Report

something. Care for yourself in the best way that you can. Your caring will help you in a positive way and then you can be caring to the world around you.” Barbara shows that you can have a positive impact on the community no matter what obstacles appear to be in your way.

### Jake’s Story

Downtown Menomonie, home of the University of Wisconsin-Stout, recently received a creative makeover. Local artists decorated the dull-looking traffic signal boxes around town. Jacob (Jake) was one of the artists. Coining his style, “Bare Hands Abstract Art,” he uses his hands and a palette of many colors to bring his ideas to life on canvas and other surfaces. Jake and his team of supporters work hard to find as many chances as possible for him to contribute to his community through his art, while also providing the services he needs to stay healthy and safe.



Jake painting a traffic signal box in downtown Menomonie.

Jake’s mom and his IRIS Consultant helped him submit his proposal to paint some of the traffic boxes in town. They knew there would be competition since so many young artists graduate from the University of Wisconsin-Stout every year, but the hard work would be worth it. Jake was one of the local artists selected and he began painting soon after.

This isn’t the first time this Wisconsin resident shared his art in his community. The Mayo Clinic in Menomonie, as well as a couple other locations in town, proudly display his work on their walls. Jake’s art has even been featured on a line of women’s handbags, which are sold at two stores in the area.

Jake also reaches beyond his local community, presenting his art and connecting with others at events such as the annual Self-Determination Conference. He has gained nationwide attention on news stations in Wisconsin, Texas, New Mexico, New York and many others. Though Jake speaks few words, his art communicates the importance of sharing our gifts with others.

As if his community and nationwide recognition wasn’t enough to get his whole family excited, President Barack Obama also sent Jake a letter of appreciation. The President wrote, “I am continually inspired by young people like you who rise above challenges to give back and make a difference, and your example reflects the very best of the country.” His mother Tina is proud of his accomplishments, and continues to support his artistry through maintaining his website, [www.jakesprints.webs.com](http://www.jakesprints.webs.com), and coming up with new ways to share his art.

## Long-Term Care in Motion - 2013 Annual Report

Jake has successfully made his hobby into a way to communicate and participate in his community with the support he needs. His story shows that everyone can find something they are passionate about and share it with others to create strong community connections.

### Kelly's Story

Kelly lives in the Fox Cities area with in-home support. As a survivor of a rare illness that caused brain trauma more than 15 years ago, Kelly has experienced many different living situations and long-term care programs. Kelly was a bit skeptical about IRIS when she first learned about the possibility of self-directing her supports, but once she was enrolled in the program, she couldn't believe the authority and independence that she finally had. "I have a say in my care and in my life, what I can do with it, and who cares for me," says Kelly. With IRIS making it possible for her supports to live with her, Kelly has been in her own apartment for the past few years.



Kelly is looking toward her future and making an effort to share her experiences in attempt to impact the outlook of people with illnesses or disabilities. Kelly's caregivers encourage her to reach these goals and assist her to get out into the community through helping her transfer to her wheelchair and driving her to events in her area. She has begun attending more conferences in her community to learn more about programs and resources and to share her story with others.

Kelly's contributions to the community would not be possible without her wonderful team of caregivers and friends. Kelly is the proud godmother of her main caregiver's son, who visits at least once a week. As a result of the care and love she receives, Kelly has access to the community. She loves going to her favorite sushi restaurant, places to play darts, and events where she can meet others.

For Kelly, IRIS gives her independence, which means in her words, "being able to do the little things on my own, and that's a big deal." Kelly's story inspires us all to "never give up" and to live life to the fullest.



## Appendices

### **Appendix 1: Glossary**

**Adult Family Home (AFH)** – A type of residential setting. One-two bed AFHs are places in which the operator provides care, treatment, support, or services above the level of room and board for up to two adults. Three-four bed AFHs are places where three-four adults who are not related to the operator reside and receive care, treatment or services above the level of room and board and that may include up to seven hours of nursing care per resident per week.

**Aging and Disability Resource Center (ADRC)** – ADRCs are the first place to go with aging and disability questions. ADRCs offer information and advice and help people apply for programs like Family Care and IRIS. To find an ADRC, visit [www.dhs.wisconsin.gov/adrc](http://www.dhs.wisconsin.gov/adrc).

**Care Manager** – Every Family Care, Partnership and PACE member has a care manager. Care managers help members identify their goals and the long-term care services they need to work toward those goals. The care manager is part of the member's team along with a nurse and others the member wants included. The care team authorizes, coordinates and monitors the member's services.

**Community-Based Residential Facility (CBRF)** – CBRFs are a type of residential setting where five or more unrelated people live together in a community setting. Residents receive care, supervision, support services, and up to three hours of nursing care per week if needed.

**Family Care (FC)** – A Medicaid managed long-term care program for frail elders, adults with developmental or intellectual disabilities, and adults with physical disabilities.

**Family Care Partnership (FCP)** – A Medicare and Medicaid program that provides long-term care services, plus acute and primary care and prescription drugs.

**Fiscal Employer Agents (FEA)** – The agencies that handles bill paying and accounting for IRIS participants. The FEA helps participants monitor their spending and they can also provide employer services on behalf of participants, including processing timesheets, generating paychecks and handling payroll taxes.

**Institution/Institutional Setting** – Includes nursing homes, state centers for people with intellectual disabilities, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IID), and institutions for mental disease.

**IRIS (Include, Respect, I Self-Direct)** – Wisconsin's self-directed supports program for older people and adults with disabilities. IRIS participants manage their support and service plan. They use a monthly budget to buy long-term care services, supports, and goods. Participants decide who will provide their services and when and where they will be provided. Allowable services are defined for all participants.

## Long-Term Care in Motion - 2013 Annual Report

**Long-Term Care (LTC)** – Services a person needs due to having infirmities of aging, a disability or a chronic health condition. Long-term care services include help with bathing, dressing, eating and going to work. Long-term care can be provided at home, in residential settings and institutional settings.

**Long-Term Care Program** – Family Care, Partnership, PACE and IRIS are some of Wisconsin’s long-term care programs. Other long-term care programs in Wisconsin include the Community Options Program (COP) and the Community Integration Program (CIP).

**Managed Care Organization (MCO)** – The organizations that operate Family Care, Partnership and PACE. MCOs must authorize services before the member receives care, and members must get their services from a provider in the MCO’s network.

**Medicaid** – A health insurance program that provides coverage for lower-income people, families, the elderly, and people with disabilities. Medicaid is also known as “Medical Assistance,” “MA,” and “Title 19.” The federal and state governments fund Medicaid. To enroll in Family Care, Partnership, PACE or IRIS, individuals must be eligible for Medicaid.

**Medicare** – The federal health insurance program for people age 65 or older, people with end-stage renal disease (permanent kidney failure requiring dialysis or kidney transplant), and some younger people with disabilities. Different parts of Medicare cover specific services. Partnership and PACE are Medicare and Medicaid programs.

**PACE (Program of All-Inclusive Care for the Elderly)** – PACE is like Partnership but is only available for people age 55 or older who live in Milwaukee or Waukesha County.

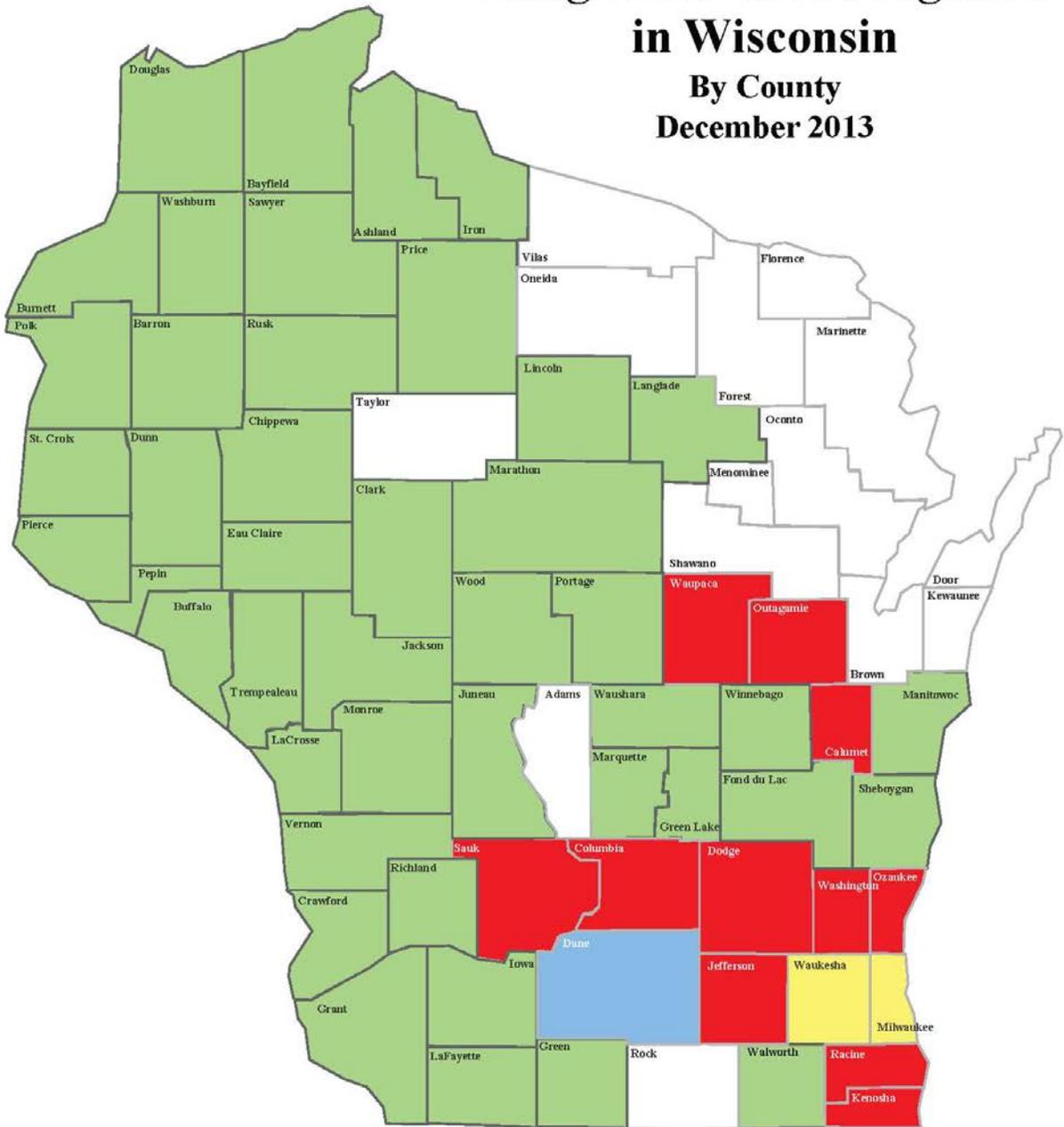
**Residential Care Apartment Complex (RCAC)** – A type of residential living setting. RCACs are independent apartment units where five or more adults reside in their own living unit. Services include up to 28 hours per week of supportive care, personal care, and nursing services.

**Self-Direction** – A way for people to arrange, purchase and direct their own long-term care services. People who self-direct have more control and responsibility over how, when and where services are provided.



Appendix 2: Map of Long-Term Care Programs in Wisconsin

## Long Term Care Programs in Wisconsin By County December 2013

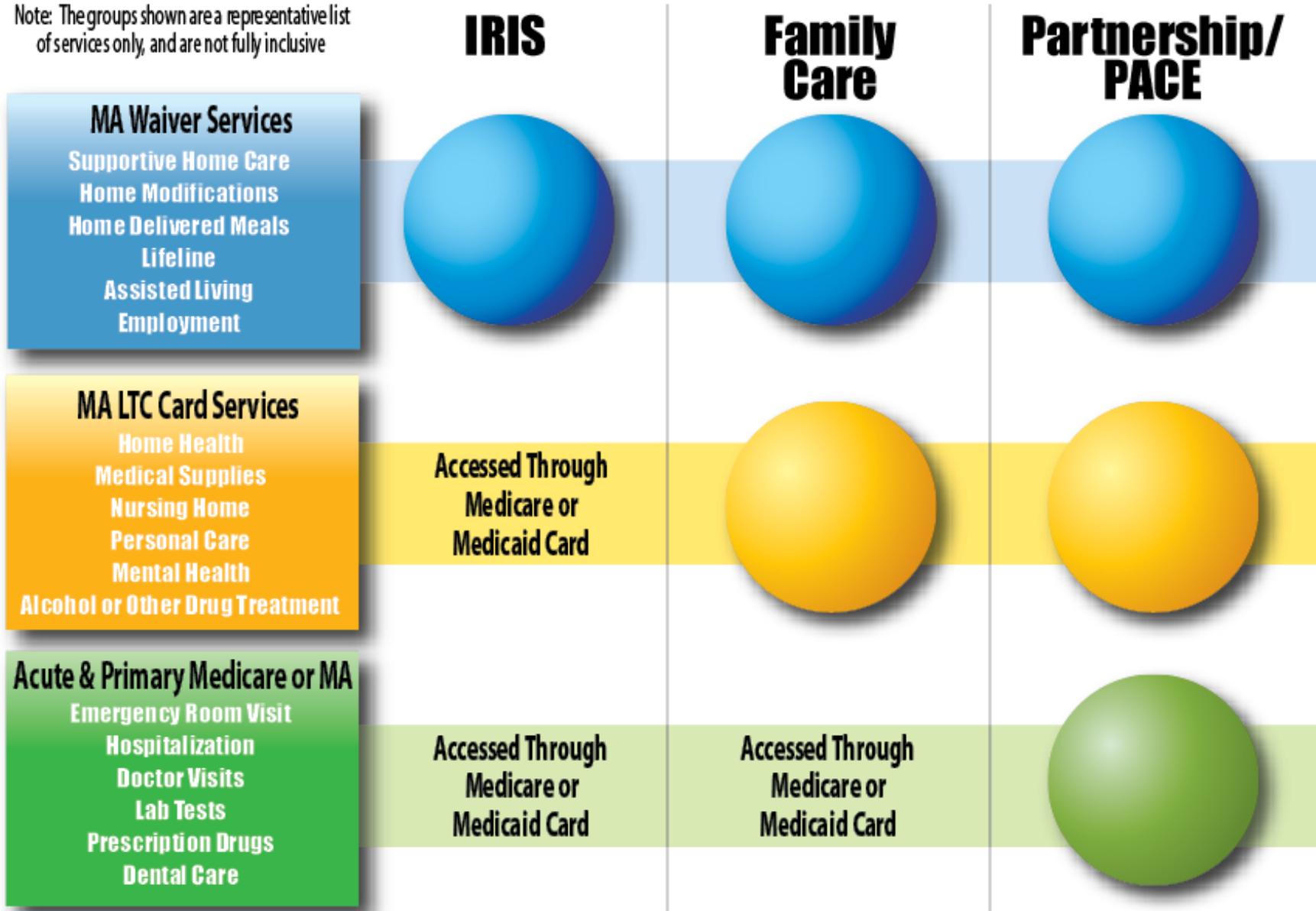


- All long-term care programs, including PACE
- Family Care, Partnership and IRIS
- Family Care and IRIS
- New Planning Consortium
- Other long-term care programs
- Partnership and other long-term care programs

Appendix 3: Examples of Wisconsin's Long-Term Care Program Services

# Examples of Wisconsin's LTC Program Services

Note: The groups shown are a representative list of services only, and are not fully inclusive



## Long-Term Care in Motion - 2013 Annual Report

### ***Appendix 4: Links for More Information***

- December 2013 Report to Committee on Finance:  
[www.dhs.wisconsin.gov/publications/p0/p00590.pdf](http://www.dhs.wisconsin.gov/publications/p0/p00590.pdf)
  
- Family Care Website:  
[www.dhs.wisconsin.gov/familycare](http://www.dhs.wisconsin.gov/familycare)
  
- DHS-MCO Contract:  
[www.dhs.wisconsin.gov/familycare/mcos/contract.htm](http://www.dhs.wisconsin.gov/familycare/mcos/contract.htm)
  
- Enrollment Data:  
[www.dhs.wisconsin.gov/familycare/enrollmentdata.htm](http://www.dhs.wisconsin.gov/familycare/enrollmentdata.htm)
  
- Family Care State Statutes:  
[www.dhs.wisconsin.gov/familycare/statefedreqs/statutes.htm](http://www.dhs.wisconsin.gov/familycare/statefedreqs/statutes.htm)
  
- Family Care Administrative Rules:  
[www.dhs.wisconsin.gov/familycare/statefedreqs/admrules11-1-00.htm](http://www.dhs.wisconsin.gov/familycare/statefedreqs/admrules11-1-00.htm)
  
- MCO Contact List:  
[www.dhs.wisconsin.gov/familycare/mcocontacts.pdf](http://www.dhs.wisconsin.gov/familycare/mcocontacts.pdf)
  
  
- IRIS Website:  
[www.dhs.wisconsin.gov/iris](http://www.dhs.wisconsin.gov/iris)
  
- IRIS Policy Manual:  
[www.dhs.wisconsin.gov/publications/p0/p00708.pdf](http://www.dhs.wisconsin.gov/publications/p0/p00708.pdf)
  
- IRIS Work Instructions:  
[www.dhs.wisconsin.gov/publications/p0/p00708a.pdf](http://www.dhs.wisconsin.gov/publications/p0/p00708a.pdf)
  
  
- Aging and Disability Resource Center Website:  
[www.dhs.wisconsin.gov/adrc](http://www.dhs.wisconsin.gov/adrc)
  
  
- Ombudsman programs for Family Care, Partnership, PACE and IRIS:
  - Disability Rights Wisconsin (for people between ages 18-59):  
<http://www.disabilityrightswi.org>
  
  - Wisconsin Board on Aging and Long Term Care (for people age 60 or older):  
<http://longtermcare.state.wi.us>