

Annual Report



2014



Long-Term Care in Motion

Wisconsin's Long-Term Care Programs



Long-Term Care in Motion - 2014 Annual Report

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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.



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Introduction

In 2014, nearly 62,000 frail elders and adults with physical, developmental, or intellectual disabilities received long-term care services from Wisconsin's Medicaid long-term care 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.

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 adults 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.

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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 ForwardHealth care 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) handle 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.

2014 Family Care Program Activities

Performance Improvement Projects

In 2014, eight MCOs conducted 18 performance improvement projects. DHS and the federal Centers for Medicare and Medicaid Services (CMS) require MCOs to work on performance improvement projects every year. MCOs developed projects based on an assessment of member needs. MCO project activities included:

- Participating in the CMS Million Hearts Campaign—a national initiative to prevent heart attacks and strokes. Three MCOs focused on monitoring blood pressure and medication treatment for members with cardiovascular disease, hypertension, and diabetes.
- Partnering with the Wisconsin Medical Society and its Honoring Choices initiative to promote end-of-life care planning.
- Expanding the use of vitamin D supplements. An MCO has shown consistent results that connect vitamin D use with a decrease in the rate of falls. The results applied to members age 65 and older, who lived in a community-based residence.
- Increasing member satisfaction by timely response to member contacts.
- Increasing behavior support planning for members. This decreased the need for restrictive measures and the number of psychiatric admissions. As a result, one MCO is creating a team to provide ongoing behavioral supports to community providers.

External Quality Reviews

DHS contracts with a federally required External Quality Review Organization (EQRO) to evaluate the quality of each MCO. In 2014, the EQRO was MetaStar, Inc. MetaStar reviewed

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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, 2013, to June 30, 2014.

Key MetaStar Quality Findings—July 1, 2013, to June 30, 2014:

- One additional MCO met 100 percent of the federal quality compliance standards. As a result, four MCOs have achieved full compliance.
- Three other MCOs improved their compliance rates to 90 percent or higher.
- Seven of eight MCOs achieved full compliance with standards related to member rights.
- Across all MCOs, the rate of compliance with all standards improved over the past three years—from 81 percent in 2011-2012 to 95 percent in 2013-2014.
- MCOs consistently demonstrated their ability to address members' needs and include members and their supports in care planning and decision-making.

Members with Behavioral Health Needs

Mental and behavioral health is a very important part of a person's overall health and well-being, and his or her ability to live independently. The Department is committed to improving its long-term care system so that people with the most challenging behaviors can have more stability in the community.

Some Family Care members with intellectual or developmental disabilities and complex behaviors have had extended stays at institutions for mental disease, state centers, and intermediate care facilities for individuals with intellectual disabilities. These situations have resulted in increased tension between key stakeholders due to conflicting needs and resources.

To address these challenges, DHS created the Complex Behaviors Workgroup, which included county representatives, residential providers, MCOs, and DHS staff.

In 2014, the workgroup developed the following products:

- A database where MCOs can enter a de-identified member profile for a person for whom they are having difficulty finding a home in the community. MCOs and providers receive an alert each time a profile is added. This allows MCOs and providers to see who is in need of placement statewide. The provider or MCO then contacts the placing agency to learn more and discuss whether they could work together to develop a successful community home for the member.
- Transition flow sheets that lay out the role of each stakeholder when transitioning a member with complex behaviors from an institution to a community setting.
- A best practices guide for the restrictive measures application process. This group made great strides in streamlining processes by inviting each MCO's restrictive measures lead to participate.

In addition to the above, the workgroup improved understanding, communication, and collaboration among all of the stakeholders. Together, they have a shared commitment to take ownership of the need to ensure stable and safe community placements for Family Care members who are in an institution, or who are at risk of institutionalization.

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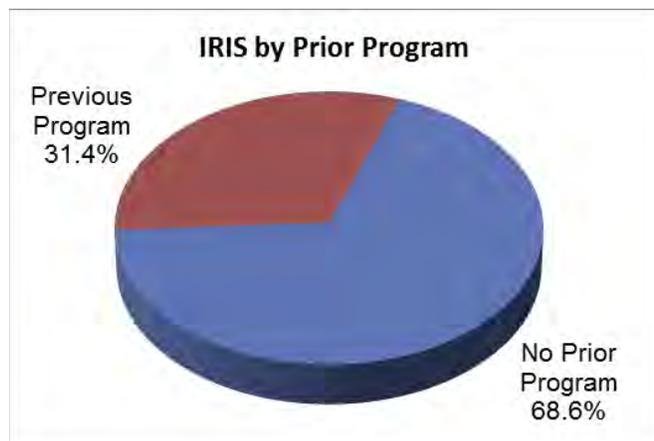
Bringing Family Care and IRIS to Northeast Wisconsin

On April 21, 2014, Governor Scott Walker announced the implementation of Family Care and IRIS to the following counties in northeast Wisconsin: Brown, Door, Kewaunee, Marinette, Menominee, Oconto, and Shawano. Through a request for proposal process, DHS awarded contracts to Care Wisconsin and Lakeland Care District to begin Family Care enrollment in 2015. By the end of 2015, Family Care and IRIS will be available in 64 of Wisconsin's 72 counties. (See appendix 2 for a map of long-term care programs in Wisconsin.)

2014 IRIS Program Activities

The IRIS program enrollment grew by 1,873 participants during 2014. At the end of 2013, there were 9,670 participants, and by the close of 2014, enrollment reached 11,543 participants, supported by 275 IRIS consultants.

Statistics concerning the prior program participation of IRIS participants remained consistent between 2013 and 2014. Slightly less than 69 percent of people who joined IRIS were not previously enrolled in a long-term care program. Only 31 percent came from another long-term care program, such as Family Care (18.5%) or the children's long-term support waiver (6.3%).



IRIS Self-Directed Personal Care Program

IRIS participants choosing to self-direct their personal care services continued to grow in 2014. The IRIS Self-Directed Personal Care program grew from 3,072 participants at the end of 2013, to 4,408 participants at the end of 2014.

Self-Directing Services/Employer Authority

IRIS participants can exercise employer authority and serve as the employer of record. This is one of the cornerstones of the IRIS program. At the end of 2014, IRIS participants employed 13,923 people as their caregivers. Participant-hired workers provided supportive home care, respite, and IRIS self-directed personal care.

IRIS Self-Directed Information Technology System

During 2014, DHS continued developing the DHS-owned centralized data system. DHS anticipates the system will streamline functionality, centralize communication, and improve data accuracy. IRIS participants will be able to access their own records within the system, and make changes to their services in future versions of the system. Development will continue in 2015, with implementation of the new system by June 2015.

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IRIS Quality Improvement Program

The IRIS program has a quality management team consisting of a team lead and four quality specialists. This team is responsible for building, implementing, and monitoring the IRIS program's quality management systems and activities. These systems and activities include systems to identify, monitor, and collect data regarding:

- Critical incident reporting.
- Fraud allegation review and assessment.
- Budget amendments and one-time expenses.
- Notices of action and appeals.
- Compliance with federal and state standards and contract requirements.
- Quality improvement projects to address systems issues.

Other Accomplishments

Other key IRIS Program accomplishments in 2014 include:

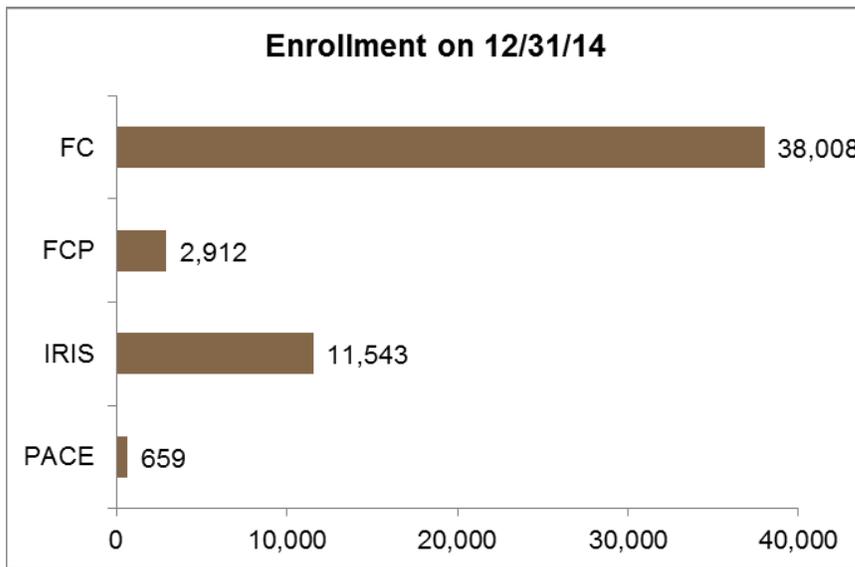
- Building an electronic system to simplify the budget amendment and one-time expense request process. Now the participant does not have to wait as long to get more funding when needed.
- Improving versions of current fraud and critical incident reporting systems to collect better information.
- Reviewing 693 participant records for compliance with the CMS assurances, best practices, and contract requirements.
- Building a system to calculate record review results and track the remediation process.
- Increasing the duties of the Mortality Review Committee to review abuse and neglect reports as well as death reports.
- Continuing work on a comprehensive IRIS policy manual and work instructions manual.
- Partnering with the IRIS Consultant Agency (ICA), the Fiscal Employer Agent, and MetaStar, Inc. to build a system to improve communication on the state fair hearing process from the beginning to the end.
- Continuing development of participant education materials on key topics such as:
 - How to request a budget amendment or one-time expense.
 - Complaints and grievances.
 - Notices of action and appeals.
 - Conflict of interest.
 - The IRIS Self-Directed Personal Care program.

Demographics and Service Highlights

Report note: Due to rounding, the sum of percentages may not equal 100 percent.

Enrollment by Program

- At the end of 2014, 53,122 people were enrolled in Family Care (FC), Family Care Partnership (FCP), PACE, and IRIS.
- Just under three-quarters (72%) of all enrollees were in Family Care. IRIS was the next largest program (22%), 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 groups¹ are eligible to enroll:

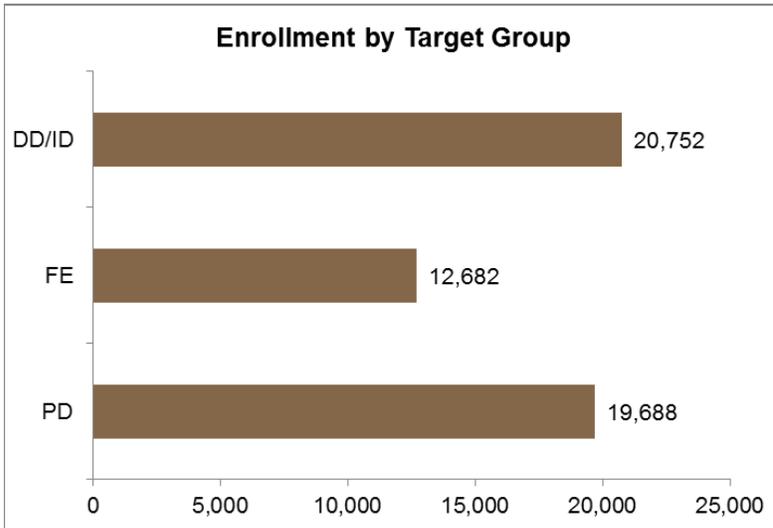
- Frail elders, age 65 and older, who have serious and long-lasting physical health problems or dementia that significantly limits their ability to care for themselves.
- Adults with physical disabilities who have a physical condition that significantly limits their ability to care for themselves.
- 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.

¹ Individuals are assigned to a target group based on the hierarchy used for financial reporting, which maintains the assignment to the developmental or physical disability target group regardless of the age of the person. The hierarchy for someone with multiple target groups is developmental disability, physical disability, and frail elderly.

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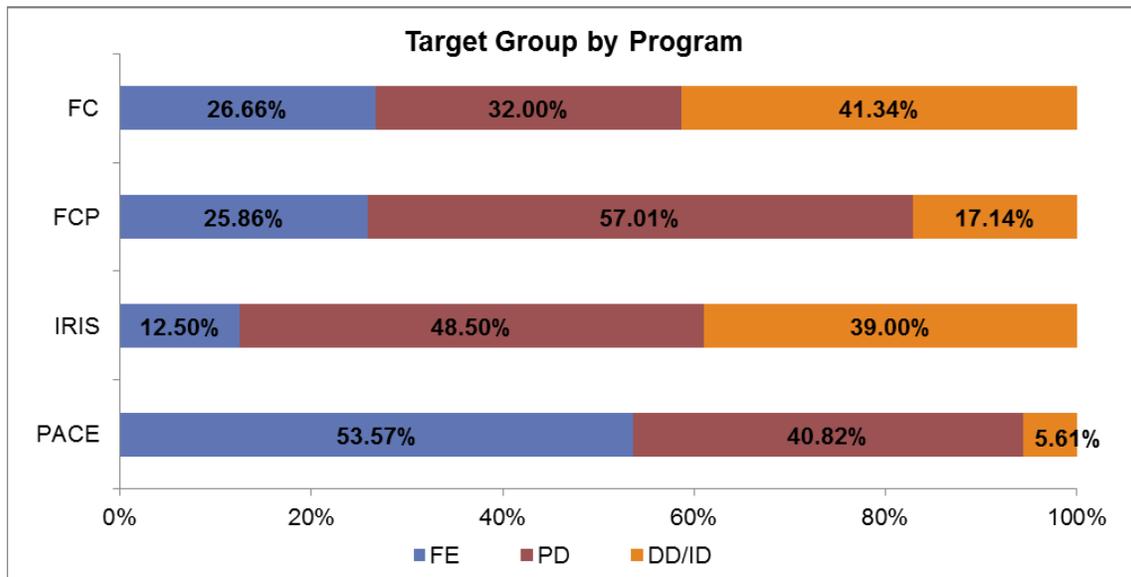
In 2014:

- The largest group of enrollees (39%) were individuals with a developmental or intellectual disability (DD/ID).
- A slightly smaller group of enrollees (37%) were individuals with a physical disability.
- Just under one-fourth (24%) of all enrollees in the long-term care programs were frail elders.



Target Group by Program

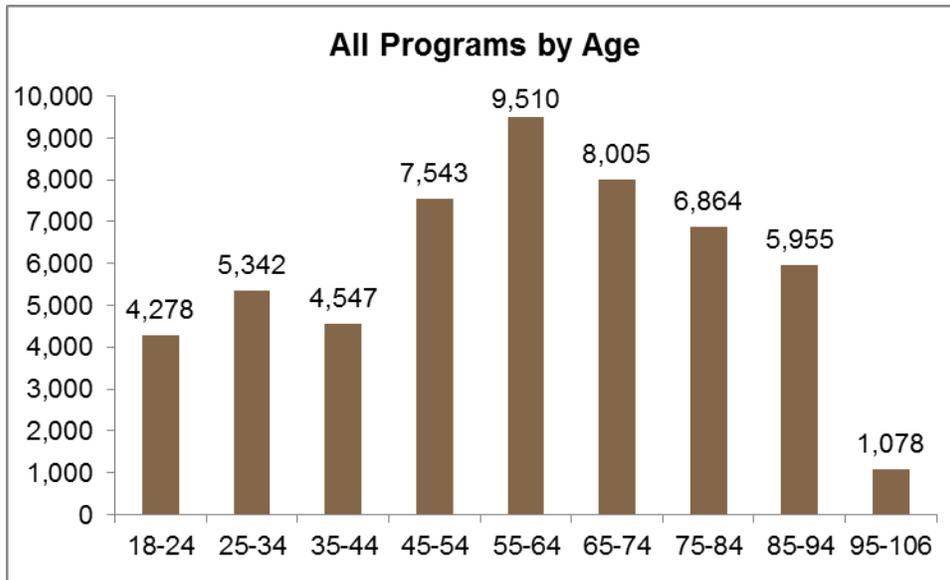
- PACE had the highest percentage of frail elders (54%). This is due in part to PACE eligibility beginning at age 55. Family Care and Partnership had almost the same percentage of frail elder members (27% and 26%, respectively), and IRIS had the smallest percentage of frail elder members (13%).
- Partnership (57%) and IRIS (49%) had the highest proportion of people with physical disabilities.
- Family Care and IRIS had similar percentages of people with developmental or intellectual disabilities (41% and 39%, respectively).



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Enrollment by Age

- In 2014, people in Family Care and IRIS were between 18 and 106 years old.
- A little more than 41 percent of the people were age 65 and older.



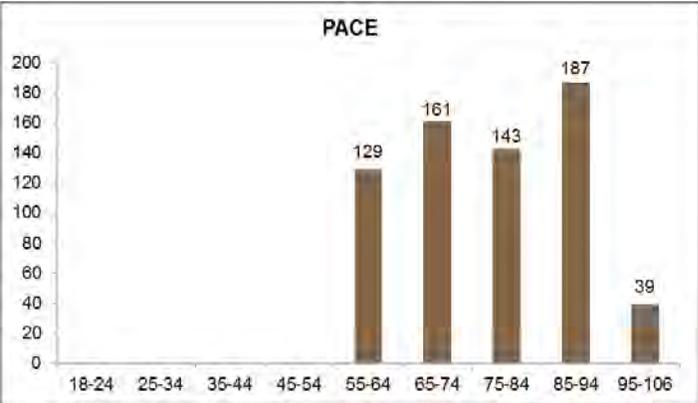
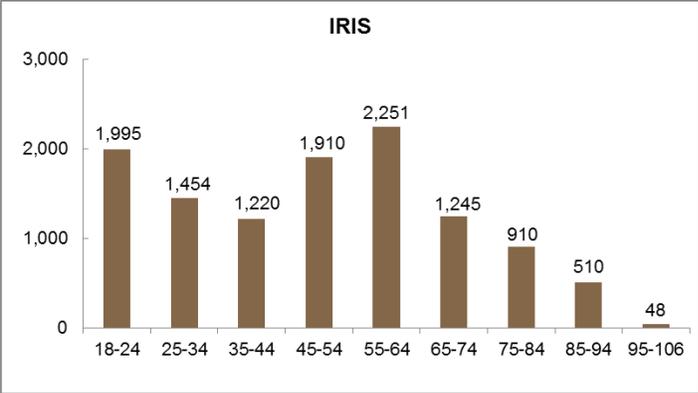
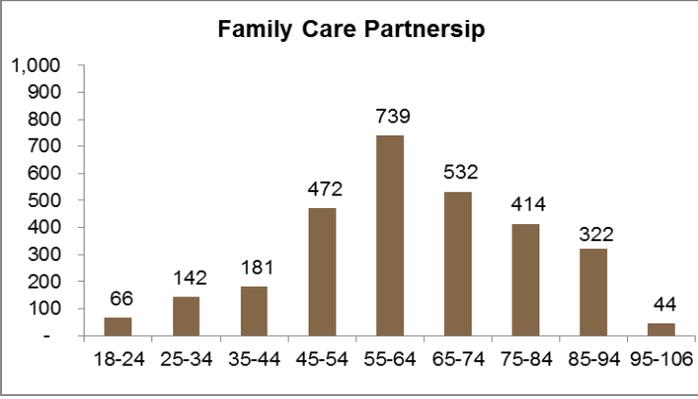
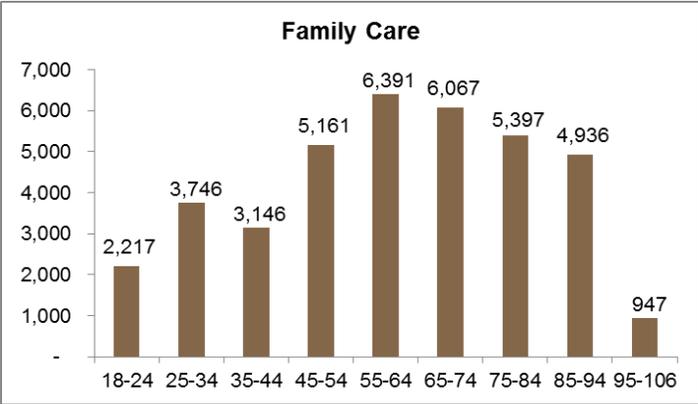
Age by Program

- The average age of individuals varies by program as shown in the table below.

Program	Average Age
FC	61
FCP	63
IRIS	48
PACE	77

- Family Care and Partnership had a similar distribution of members across age groups, peaking with the 55-64 age group.
- IRIS generally had younger enrollees than Family Care or Partnership. Less than one-quarter (24%) of IRIS participants were age 65 and older.
- PACE had a higher percentage of elderly enrollees than any other program. More than 80 percent of PACE members were age 65 and older.
- The following charts show the number of individuals in each age category by program.

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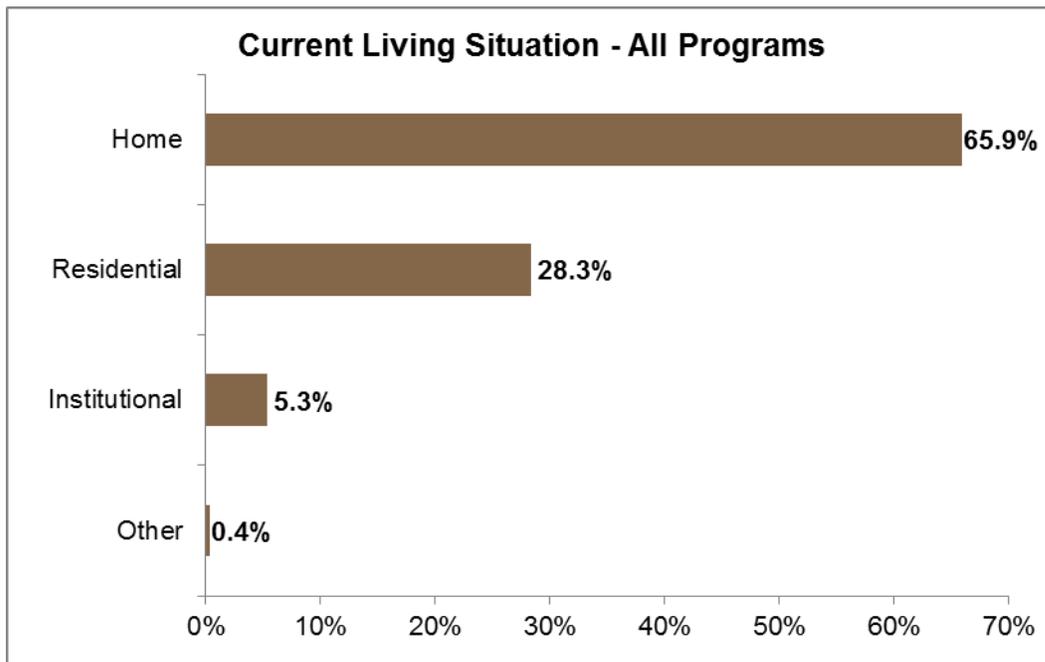


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Current Living Situation

All Programs

- In 2014, almost two-thirds (66%) of all members and participants lived in a home setting.
- Nearly all (over 95%) IRIS participants lived at home. Most Family Care, Partnership, and PACE members lived in a home setting as well.
- Overall, 96 percent of people living at home identified home as their preferred living setting.
- Less than 6 percent of people across all programs lived in an institutional setting.

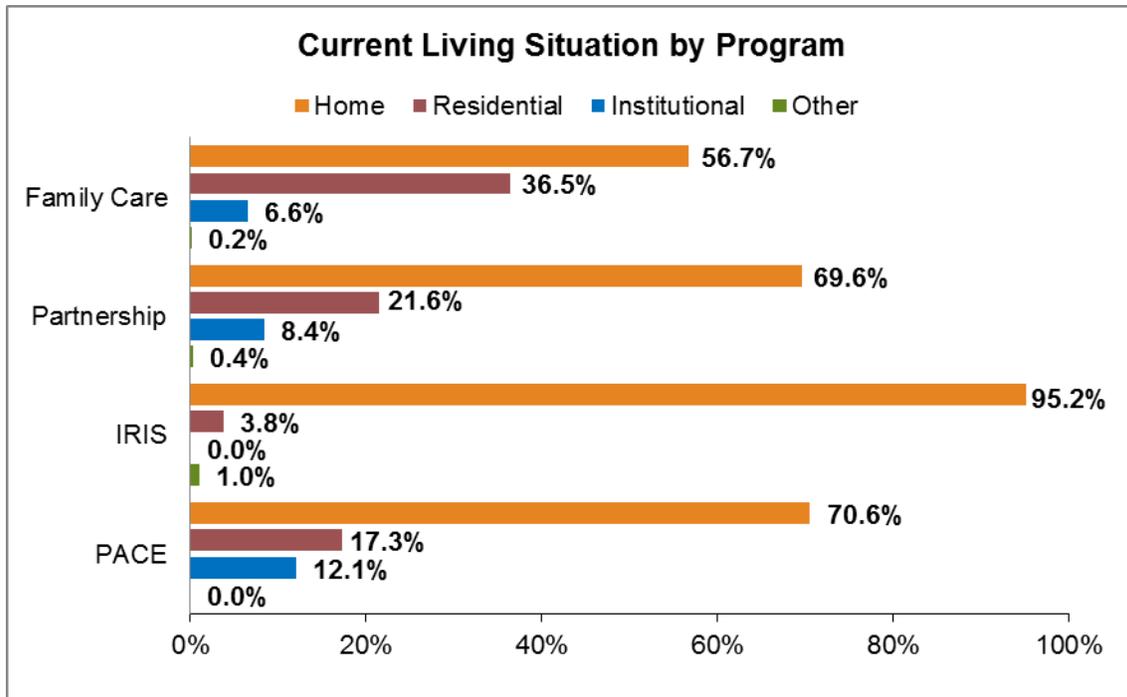


By Program

- Sometimes it is not safe for people to remain in their own home. They may move to a residential setting where they can receive additional support, such as an adult family home, community-based residential facility, or residential care apartment complex.
- Over a quarter (28%) of the people in Wisconsin's long-term care programs lived in a residential setting.
- Of those living in a residential setting, 73 percent said this was their preferred living situation.

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- Family Care members were the most likely to live in a residential setting (37%).
- When people live in an institutional setting, like a nursing home or an immediate care facility for individuals with intellectual disabilities, they can enroll in Family Care, Partnership, or PACE, but not IRIS.
- PACE had the highest percentage of members who lived in an institution or a setting categorized as “other” (12.1%), followed by Partnership (8.8%), and Family Care (6.8%).
- Only 30 percent of the members in an institutional setting said it was their preferred setting.



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Service Expenditures by Program

In calendar year 2014, total expenditures for services purchased for Family Care, Partnership, PACE, and IRIS were approximately \$1.7 billion. The table below shows total expenditures by program.

Program	Total Expenditure for Services (millions)
Family Care	\$1,263
Partnership and PACE	\$232
IRIS	\$265
Total	\$1,760

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	53%
Supportive Home Care/Personal Care	18%
Nursing Home and Intermediate Care Facilities	13%
Adult Day Activities	6%
Vocational Services	3%
Transportation	4%
Other	4%
Total	100%

Care management accounts for 13% of total service expenditures.

Partnership and PACE	Percentage of Total Expenditures
Long-Term Care Services (LTC)	
Residential Services	16%
Nursing Home and Intermediate Care Facilities	12%
Supportive Home Care/Personal Care	9%
Transportation	4%
Adult Day Activities	3%
Medical Equipment and Supplies	3%
Other (LTC)	6%
Primary and Acute Care Services	
Inpatient Hospital	16%
Medications (Pharmacy)	14%
Office or Outpatient Assessments	5%
Other (Acute and Primary)	13%
Total	100%

Care Management accounts for 13% of total service expenditures.

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IRIS Services	Percentage of Total Expenditures
Supportive Home Care	55%
Self-Directed Personal Care*	22%
Residential Services	7%
Adult Day Activities	5%
Transportation	4%
Respite	4%
Other	4%
Total	100%

*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.

- Across all programs, 36 percent of enrollees self-directed at least one service during 2014.
- All participants (100%) enrolled in IRIS self-directed at least one service during 2014.
- Nearly one in five Family Care members self-directed at least one service during 2014, while 24 percent of Partnership members, and 5 percent of PACE members, self-directed at least one service.

Program	Percentage of Member Self-Directed Services
Family Care	20%
Family Care Partnership	24%
PACE	5%
IRIS	100%
Overall Total (Including IRIS)	36%
Overall Total (Excluding IRIS)	20%

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.

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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 2014, DHS collected the following data about working-age people (18-64 years of age) enrolled in Family Care, Partnership, PACE, and IRIS.

- **Family Care, Partnership, and PACE:**

There were 22,643 working age people (18-64) enrolled in Family Care, Partnership, and PACE.

- Of these people, 7,476 (33%) had employment in an integrated employment setting², a facility-based setting³, or in a small group-supported employment setting.⁴
- 2,086 people were in integrated employment.
- 4,838 people were in facility-based employment.
- 328 people were in small group supported employment.
- 224 people worked in another type of setting, or an unknown setting.

- **IRIS:**

There were 8,817 working age people (18-64) enrolled in IRIS.

- Of these people, 1,400 (16%) completed an employment assessment indicating they worked in an integrated employment setting¹, a facility-based setting², or in a group/enclave setting.³
- 847 people were in integrated employment.
- 561 people were in facility-based employment.
- 68 people were in small group-supported employment.
- 75 people worked in more than one setting, such as in integrated employment in the morning, and a facility-based setting in the afternoon.

² **Integrated Employment:** Competitive employment in community businesses with co-workers who do not have disabilities. This includes supported employment.

³ **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.

⁴ **Group/Enclave Employment:** Paid work in small group settings (two to eight 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

Family Care encourages members to receive appropriate vaccinations, because influenza and pneumonia can lead to health complications, hospitalization, and sometimes death. MCOs monitor their members' immunization status.

The following table shows the percentage of members who received an influenza or pneumonia⁵ vaccination during 2014.

Program	Influenza	Pneumonia
Family Care	72%	82%
Partnership	72%	89%
PACE	92%	96%

Member Satisfaction Survey Results

MCOs survey members each year to determine their level of satisfaction. The survey questions ask members to respond on a variety of topics, two of which are illustrated in the graphs on pages 19-20.

- In 2014, 87 percent of Family Care members rated their supports and services, and the help they received from their care team, as “Excellent” or “Very Good.”
- Of Partnership members, 85 percent rated their supports and services as “Excellent” or “Very Good,” and 83 percent rated the help they receive as “Excellent” or “Very Good.”
- PACE members had similar combined percentages of “Excellent” or “Very Good” responses to those questions. However, PACE members were more likely to have rated their supports and services, and the help they received, as “Very Good” instead of “Excellent.”

The survey asked members to respond to another set of questions with one of four choices: “Always,” “Usually,” “Sometimes,” and “Never.”

Combining “Always” and “Usually” responses, the top two scoring questions were:

- How often does your care team treat you with courtesy and respect? (96%)
- How often does your care team listen carefully to you? (94%)

Combining “Always” and “Usually” responses, the two lowest scoring questions were:

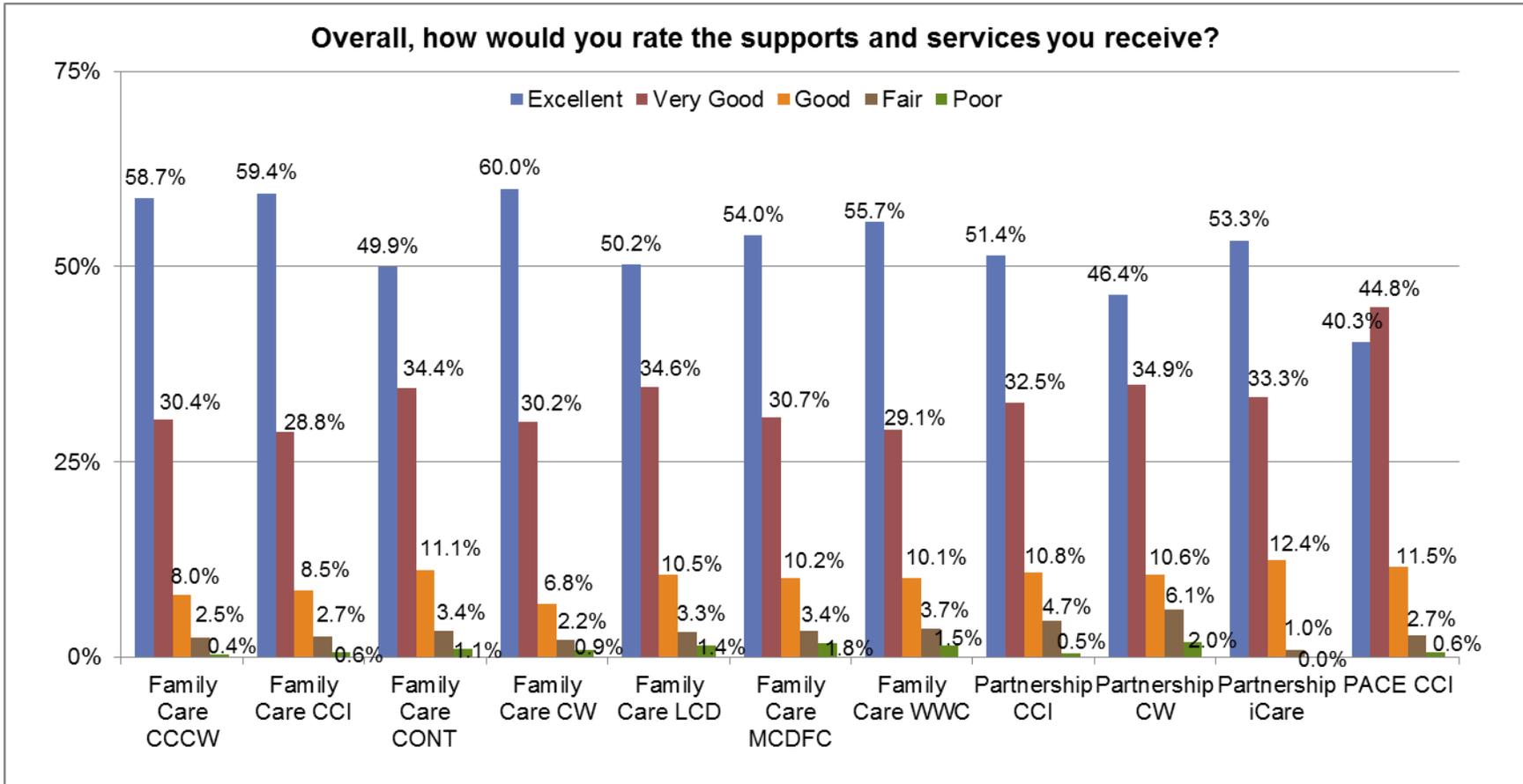
- How often do you get the help you need from your care team? (86%)
- How often do the people who help you with your personal care treat you with courtesy and respect? (87%)

⁵ Pneumonia vaccination is only measured for members age 65 and over.

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- Regarding care plans, 87% of respondents said their plan included “All” or “Most” of the things that are important to them.
- Nearly 70 percent of respondents indicated they would “Definitely” recommend their MCO to their friends and family, and an additional 26 percent indicated they would “Probably” recommend their MCO.
- On a scale of 0 to 10, with 10 being the best, nearly 48 percent of respondents rated their MCO as a “10,” and over four out of five respondents (81%) gave their MCO an 8, 9, or 10. Less than 4 percent rated their MCO with a number less than “5.”

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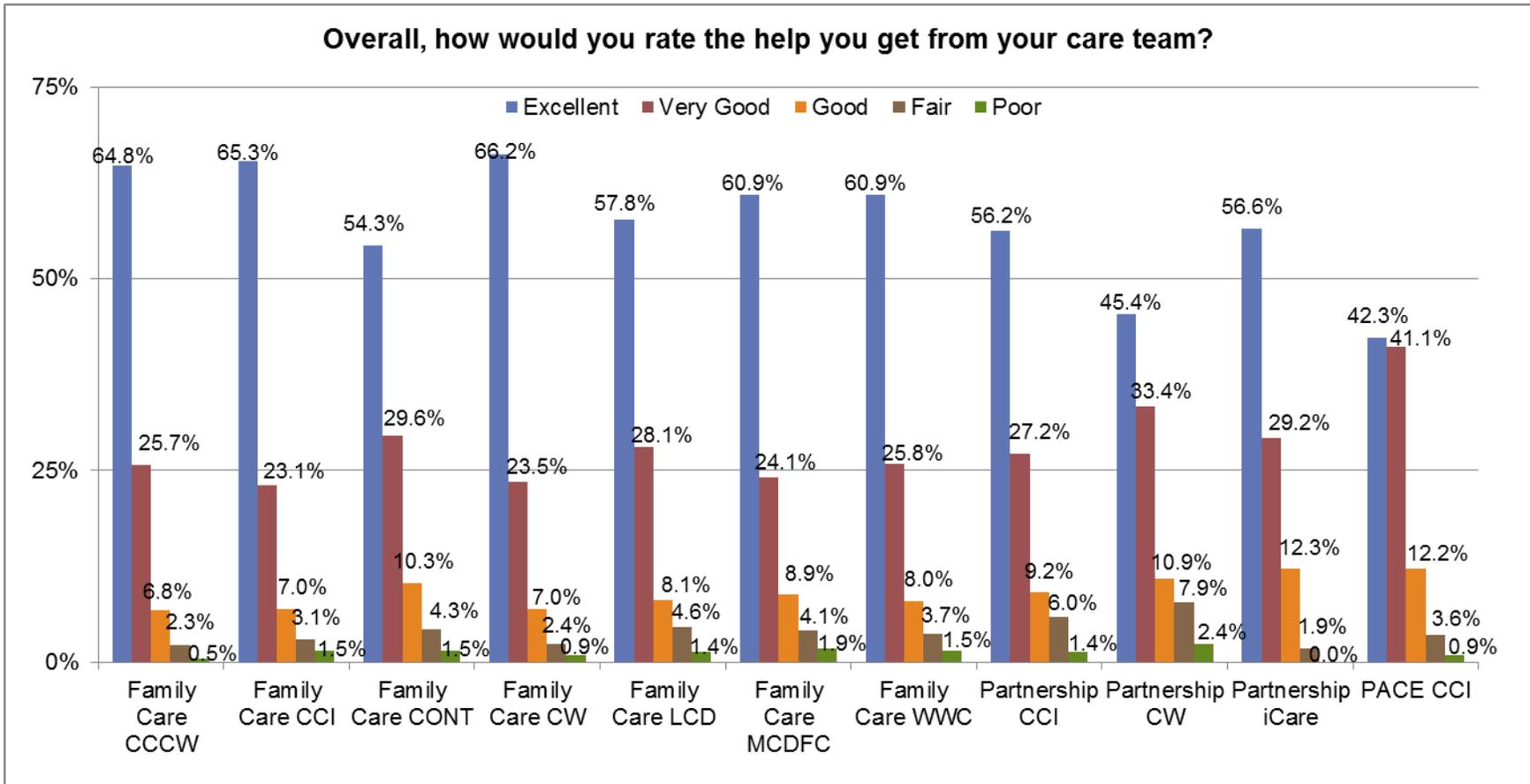


Legend

CCCW: Community Care Connections of Wisconsin
 CCI: Community Care, Inc.
 CONT: ContinuUs
 CW: Care Wisconsin

LCD: Lakeland Care District
 MCDFC: Milwaukee County Department of Family Care
 WWC: Western Wisconsin Cares
 iCare: Independent Care Health Plan

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Legend

CCCW: Community Care Connections of Wisconsin
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 WWC: Western Wisconsin Cares
 iCare: Independent Care Health Plan



Family Care Member Stories

Brent's Story

Brent is like most 22-year-old young men. He has a job and lives in a home with three roommates. This is the way his mom, Lisa, always saw it for him. She always wanted Brent, who is legally blind, to have options that allowed him to live his life independently as an adult. It took a lot of perseverance to get to this point and now it is paying off.

“He’s an independent young person. He likes living with his roommates, and likes to visit his parents every once in a while, but also likes to go back home again,” she says. “He’s doing the things a 22-year-old should be doing.”

Brent, a member of the Family Care program, and his family began working with his care team before he was out of high school to find an apartment where he could live independently. Lisa says his care team was very goal-oriented in their plans for Brent. They wanted to find the right place for him to live, and that meant finding the right fit.

Brent also continued to work with career classes through the high school, including job sampling and very short-term job trials. He tried a number of different jobs for a few weeks, but they were not always a good fit for Brent’s skills and abilities, and he had a hard time learning them in such a short time. He also received orientation and mobility training, and help with navigating through town, using taxis, getting in and out of buildings, and learning about necessary adaptations to the workplace.

More recently, he was able to complete a longer job trial at a local hotel, for more than two months, more than once a week. He had worked there once for a shorter trial while he was in high school and remembered some of the people he worked with. Trying the job for an extended amount of time gave him a chance to learn the job, and the physical layout of the hotel, so that he could get around easily.

After his trial, the hotel offered Brent a permanent position and he now works there part-time three days a week. He mops the floors, cleans, takes out the trash, and helps the maintenance workers and others. He enjoys his job and Lisa says it makes him feel important and a part of the community. She says his employer told Brent they feel the work he does is important too. Having him



Brent with his first paycheck.

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there makes it easier on the other employees. For example, a coworker who had a sore leg told Brent her leg didn't hurt as bad anymore because he was able to help with some of her work.

"It was really nice to see how supportive and accommodating everybody was," Lisa says about a time when she observed Brent at work.

Brent is also excited about the job and the paycheck he is now earning. Lisa took a picture of him with his first paycheck, which he says he plans on saving. He may use it to visit family in Minnesota, or maybe see a game in Chicago, since he's a Bears and White Sox fan.

"It's really nice. I know what needs to be done," Brent says of the job.

Lisa says she continues to see growth in him. One day when they didn't need the taxi that gives Brent rides to and from work, Lisa wasn't sure how to cancel it. She said she was so proud when he took the phone from her and did it himself, knowing who to call, and speaking clearly so they could understand.

Lisa hopes other businesses will continue thinking of ways they can have individuals with disabilities get involved in the workplace. She says it takes some creative thinking, but there are a lot of benefits for the business and for the worker. "It's a big unknown, but it's worth giving it a shot," she says.

Lance's Story

Lance enjoyed riding his motorcycle more than anything. He loved the sense of freedom and independence he got from riding on the open road, and he found spending time outside invigorating, according to his girlfriend Denise.

But his rides came to an end in an instant when a motorcycle accident left Lance physically, mentally, and emotionally broken. After the accident, he spent six months in the hospital and another year in a rehabilitation facility healing his body.

Unable to care for himself or to simply get around, Lance was frustrated and angry. He contemplated giving up on life. The depth of the hurt and despair he felt is hard to imagine.



Lance

At this most critical point, Lance was introduced to the Partnership program. With Denise by his side, Lance worked with his care team to regain the independence and freedom he had lost. His care team helped coordinate his enrollment in occupational and speech therapy classes and set

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him up with special aquatic classes. He learned to use adaptive equipment to overcome physical limitations, and worked relentlessly to gain strength and confidence.

Lance's story demonstrates the power of the human spirit and what can be accomplished when caring people work together toward a common goal.

Genesis' Story

Genesis, 21, and her parents, Victoria and Ildefonso, live in a house on a winding street in Milwaukee. Genesis is a member of the Partnership program, which provides long-term care, as well as acute and primary care.

Genesis was diagnosed with epilepsy at the age of three and has mild intellectual disability. Having attended her high school's special education program, Genesis has since transitioned from her classes and lives with her parents, where her father took on the responsibility of providing full-time care.

Originally from Puerto Rico, Victoria and Ildefonso moved to the United States in 2001 and do not speak English. Through the Partnership program, the parents receive free Spanish translation services to ensure they understand all of the services available in Partnership, and to maintain consistent communication in caring for Genesis.

When describing Genesis' care manager, Victoria stated, "She helps a lot, she coordinates a lot, is always willing, and when I leave a message, she always gets back to me."

Genesis' care manager referred her to Columbia St. Mary's for physical and occupational therapy sessions. When Genesis' safety helmet didn't fit, her care manager arranged to obtain a new one.

Genesis' care manager proved instrumental in ensuring she remained active by helping her enroll in recreational programs, where she could participate in crafts, pool activities, and field trips to the zoo and museum. Victoria indicated that Genesis is very much into crafts, loves to go shopping, and is always occupied with something.



Genesis and her parents

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Victoria also expressed how pleased she was with Partnership's services, especially monitoring Genesis' medications. Victoria described a visit to a doctor where she believed Genesis' physician was not listening to her concerns regarding a medication that was affecting Genesis' liver. On her next appointment, Karen, Genesis' Partnership team nurse, accompanied her where it was agreed that the doctor would reduce the dosage and then discontinue using it.

"She went with me and he listened. That's why I give thanks to Karen, and she is going with me on my next appointment," Victoria exclaimed.

Jesse's Story

At age 93, Jesse has overcome many barriers and has much to be proud of in his life. He lived through the Great Depression, served in the U.S. military, raised a family, and had a successful career. Jesse has always prided himself on being involved in his community, whether as an active member of his church, teaching classes at the local senior center, serving on the Red Cross board, or helping people through his other volunteer activities.

When he was in his 50s, Jesse began to face health problems. He's had heart attacks, strokes, degenerative joint disease, and skin cancer. Carpal tunnel surgery left him without the use of two fingers. Despite some physical limits, Jesse is thankful to live each day as it comes. He is able to dress himself, make himself small meals, manage his finances, and make his own decisions about his life.

Through the Family Care program, he receives assistance with bathing, cleaning, running errands, and meal preparation. He has someone come over to help him set up his medications for the week. He also has a lifeline in case of an emergency. Being a member of the Family Care program has allowed Jesse to continue to live independently in his home, where he has resided for the past 55 years.



Jesse standing in front of his artwork.

Jesse is happy he has the support to continue to live independently with his cat, "Boy." Jesse believes the Family Care program has been a great support to his life. He feels his care team listens to him, and addresses his concerns, as they work together to meet his outcomes. Jesse is grateful for the assistance and support he receives at home from his caregivers, family, friends, and neighbors. He finds comfort in knowing his team is only a phone call away. Jesse says he feels blessed to have such a strong support system.

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Jerry's Story

Jerry was like most young adults—he sought freedom and independence. So, at the age of 18 with no plans or destination in mind, he moved out of his parents' home, and for the next 30 years, drifted from house to house, never staying longer than a few nights at a time.

Throughout the three decades of couch surfing, friends and family continually worried about his health and safety. Complicating an already difficult situation, Jerry has an intellectual disability and suffers from a seizure disorder.

The people Jerry was closest to repeatedly asked him to stay in their homes on a more permanent basis, but Jerry—citing he didn't want to become an annoyance or lose his sense of independence—always turned down the offers. Jerry somehow survived this rugged and dangerous existence for 30 years before he was introduced to Family Care at the age of 48.

Jerry's care team supported and guided him in developing personal goals and a plan that would start Jerry down the path to true independence. The team worked with him to find a place of his own—his greatest dream—that was clean, comfortable, and safe, and close to family and resources.

Finally home, Jerry achieved the independence and freedom he sought for so long. Along with that came a greater sense of personal achievement and satisfaction. Plus, the people who love and care about him have peace of mind knowing that Jerry is safe at home.



Jerry



IRIS Participant Stories

Kate's Story

Kate is a social butterfly living in northcentral Wisconsin. With her effortless outgoing personality, Kate has found that one of her passions is enjoying time with the people around her. Kate says, "I like to help in the community, because it makes it more fun when I give back." She is socially active by using her experience and athletic background to stay involved with many sports teams and organizations.

Kate is a member of the Lions Club and serves as Lion Tamer for the club. She loves her responsibilities there, and she is greatly valued by the members of the club. She shares, "They like my help, it makes a big difference that I help them." Her Lions Club meets every first and third Monday of the month, and works through a large agenda of business items while enjoying social time and dinner. Kate likes planning the events, which help community members.



Kate in her role as "Lion Tamer."

One of Kate's other big roles in the community is being team manager for the local high school's girls basketball team. For the last 17 years, she has helped the team fight for conference and state championships. Kate says, "It's a fun and active group," and she shares that she continues to manage the team, "so I can get out of the house more, I go to practice every day, and when it's game time, I go with them on the bus." Her positive attitude is an inspiration to the whole team.

After her duties as the Lion Tamer and basketball manager, Kate finds time to go to her local fitness center and help her friend coach water aerobics, in addition to swimming on her own for fitness. She's also in three bowling leagues and holds a part-time job. Kate reminds her friends and family that staying busy, exercising, and eating healthy, make a big difference in your daily life. Though staying active can be a lot of work, Kate feels proud to be counted on for so many things in her community.

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Elizabeth's Story

My name is Elizabeth. I enjoy going to the UW-Whitewater and what they have to offer, like accommodations for students with disabilities. They inspired me to spread my wings and fly, and in a couple years, I'm going to graduate with my degree in Communications and Public Relations. I've enjoyed meeting other students with disabilities, but also students without disabilities. These experiences empowered me to see what else is out there, which has given me a lot of confidence and independence.

I also enjoy doing things out of school like swimming, singing, and hanging out with friends. I especially love swimming because it makes me feel free; when I'm in the water, I don't have to worry about anything. I am part of the swim team (the J-Hawks) here at UW-Whitewater. My training with them is helping me get ready to hopefully be on team USA for the Paralympics in 2016. This past summer I also have enjoyed running triathlons. I love the sport because you get to run, bike, and swim, all in one. Dare2tri has given me the confidence and tools to be able to compete in triathlons.

I enjoy trying new things and finding what's out there. I always tell people that even if you have a disability, don't let it hold you back. Anything's possible! You might have to find it, and there are tons of things out there we can do, like everything everyone else is doing. For instance, I took a summer trip to Yellowstone with UW-Whitewater for a Biology class. I never thought I would be able to experience an opportunity like that. I met new friends and experienced a lot of things. I don't want my disability to hold me back, and never say never!

Emily's Story

My name is Emily and I'm from southeastern Wisconsin. I go to the UW-Whitewater and I think getting a higher education helps you later on in life. Going to college can help you find jobs and



Emily and Elizabeth

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I want to show others that people with disabilities can also go to college just like everybody else.

It's a challenge to go to college, but it's also a fun experience. You get to meet people and be active in the community. I like to play sports because I've gotten to meet a lot of my friends playing wheelchair basketball in Chicago. I always like to smile on the court and I made lifetime friends that way. For example, I still talk to one of my friends at school who got me into basketball. I also like to go to sports camp in summer because I like to go waterskiing and learning about different sports and just to be out of the house for a week!



Appendices

Appendix 1: Glossary

Adult Family Home (AFH): A type of residential setting. One- to 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- to four-bed AFHs are places where three to 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.

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 handle 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.

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Long-Term Care: 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), the Community Integration Program (CIP) for adults, and the children's long-term support waiver programs.

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.

Ombudsman: A person who investigates reported concerns and helps members and participants resolve issues.

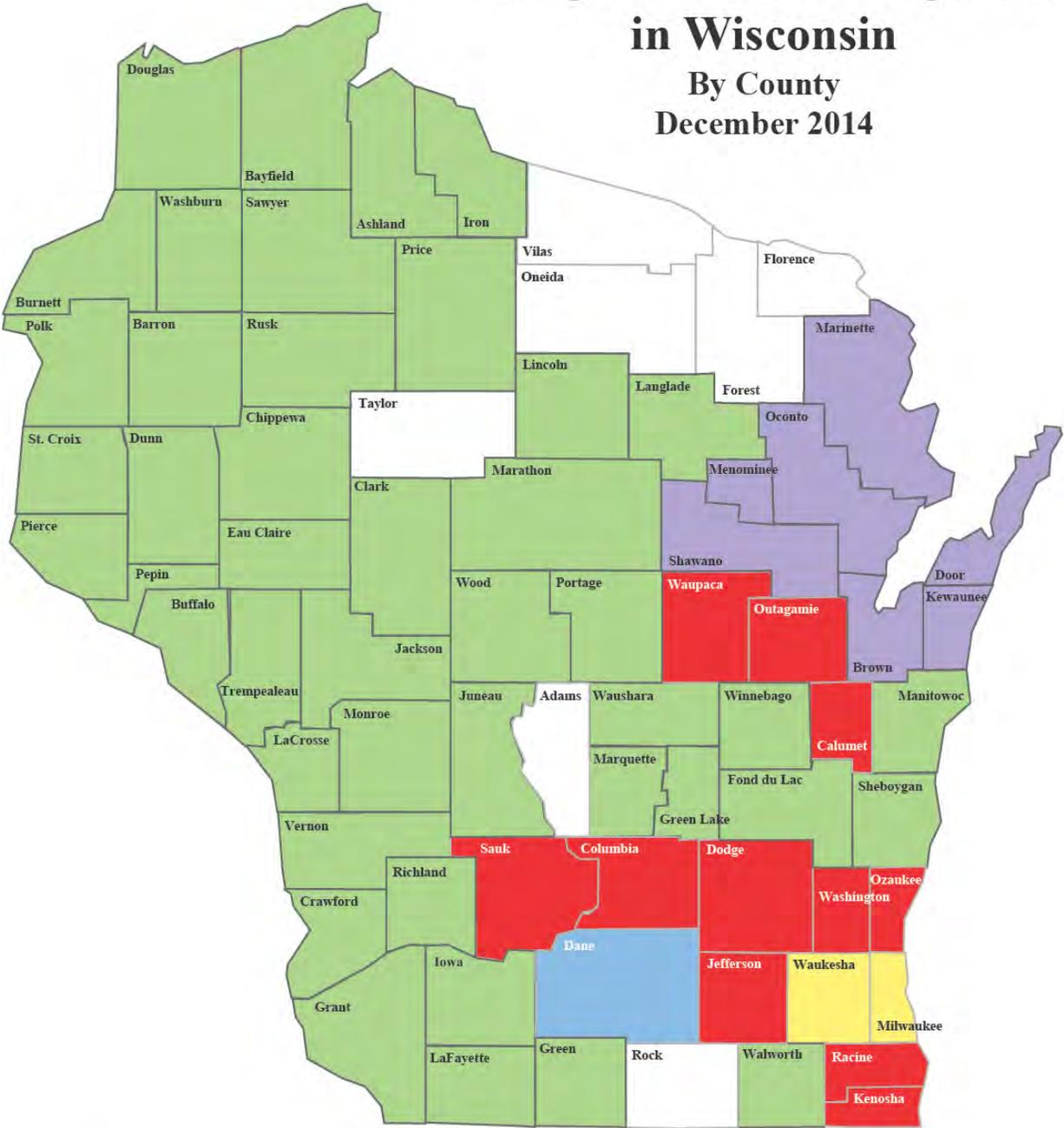
PACE (Program of All-Inclusive Care for the Elderly): PACE is like Partnership, but is only available for people age 55 or older who live in Milwaukee or Waukesha County.

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 2014

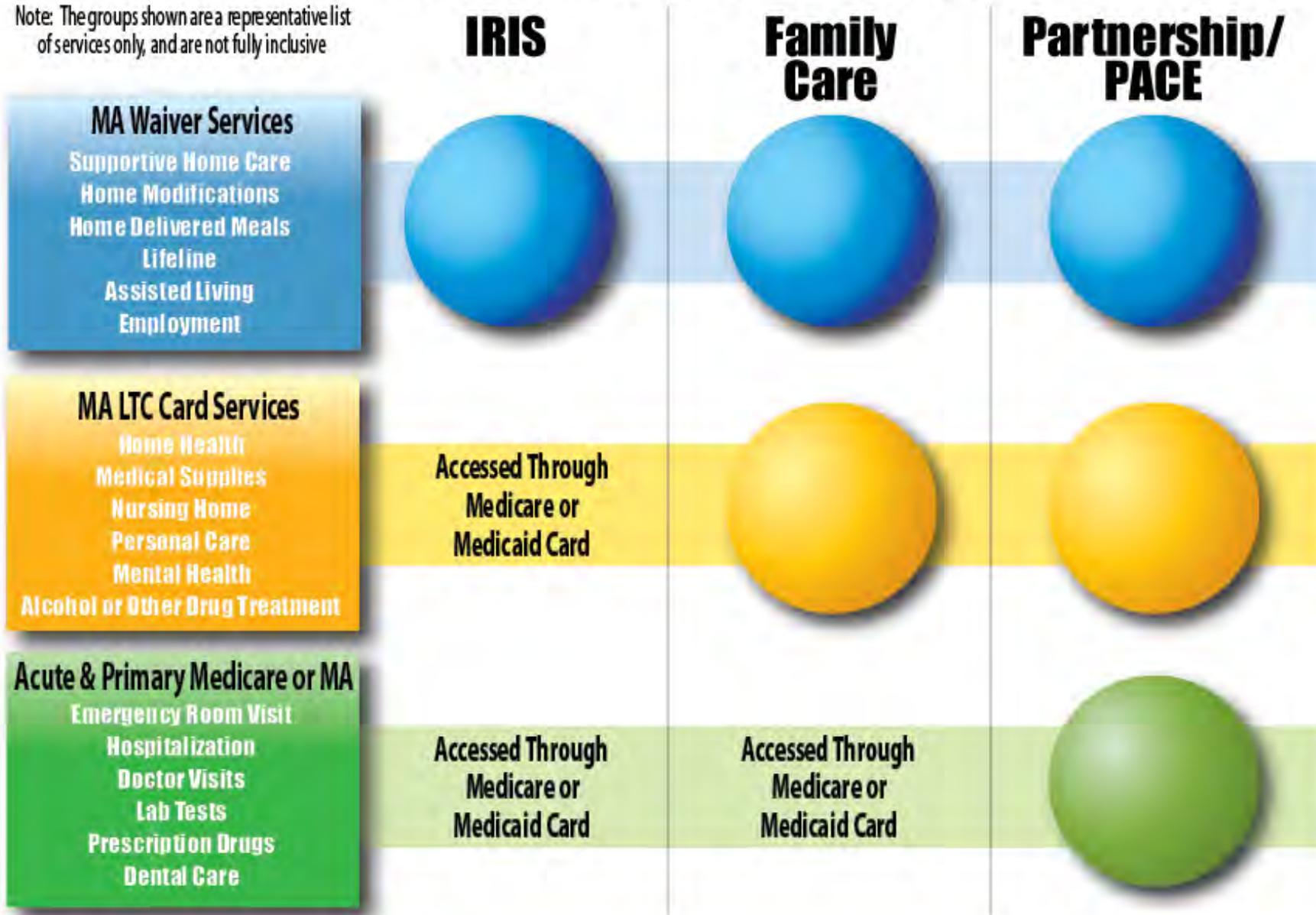


- Family Care, Partnership, PACE and IRIS
- Family Care, Partnership and IRIS
- Family Care and IRIS
- Family Care expansion pending 2015
- Other long-term care programs
- Partnership and other long-term care programs

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



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Appendix 4: Links for More Information

- Prior Annual Reports
www.dhs.wisconsin.gov/familycare/reports/index.htm
- Family Care Website:
www.dhs.wisconsin.gov/familycare
- Enrollment Data:
www.dhs.wisconsin.gov/familycare/enrollmentdata.htm
- DHS-MCO Contract:
www.dhs.wisconsin.gov/familycare/mcos/contract.htm
- MCO Contact List:
www.dhs.wisconsin.gov/familycare/mcocontacts.pdf
- Ombudsman programs for Family Care, Partnership, and PACE:
 - 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>
- IRIS Website:
www.dhs.wisconsin.gov/iris
- IRIS Policy Manual:
www.dhs.wisconsin.gov/publications/p0/p00708.pdf
- IRIS Work Instructions:
www.dhs.wisconsin.gov/publications/p0/p00708a.pdf
- Ombudsman program for IRIS, Disability Rights Wisconsin (for people between ages 18-59):
<http://www.disabilityrightswi.org>
- Aging and Disability Resource Center Website:
www.dhs.wisconsin.gov/adrc