

# LONG-TERM CARE IN MOTION

## Wisconsin's Long-Term Care Programs



Wisconsin Department of Health Services  
Division of Long-Term Care  
P.O. Box 7851  
Madison, Wisconsin 53707-7851  
[dhs.wisconsin.gov/LTCare](http://dhs.wisconsin.gov/LTCare)  
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**Annual Report**

## Values of Family Care

**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.

## Values of IRIS

**INCLUDE** – Wisconsin elders, adults with physical disabilities and adults with developmental disabilities who are Medicaid eligible are included in communities across Wisconsin. IRIS can help participants remain connected to others.

**RESPECT** – You choose where you live, the relationships you build, your work, and your participation in your community.

**I SELF-DIRECT** – IRIS is a self-directed long-term care option in which you use an individual budget allocation to help meet your long-term care needs.

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## Introduction

In 2012, about 53,500 frail elders and adults with physical, developmental or intellectual disabilities received long-term care services from Wisconsin's Medicaid (MA) long-term care (LTC) programs at some point during the year. These programs are Family Care and IRIS (Include, Respect, I Self-Direct).

IRIS is a program in which participants self-direct their care plan and services within an individual budget. The Family Care programs (Family Care, Family Care-Partnership, and PACE) work with members to develop individualized care plans and provide or coordinate services.

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. DHS collaborated with consumers, providers, and advocates to develop these publicly funded programs.

Family Care and IRIS are based on the belief that all people – including frail elders and people with disabilities – should be able to live at home with the supports they need and participate in communities that value their contributions.

The programs help individuals stay in their own homes or other non-institutional settings whenever possible. Most people in Family Care and IRIS live in their own homes or other community settings. This allows people 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.



## What is Family Care?



DHS contracts with Managed Care Organizations (MCOs) to operate Wisconsin's three managed long-term care programs:

- Family Care
- Family Care Partnership
- PACE

These are voluntary programs where eligible individuals can choose to enroll and become members of an MCO. MCOs provide or coordinate cost-effective and flexible services tailored to each individual's needs.

DHS provides the MCO with a monthly payment for each member. The MCO uses these funds to provide individually planned services for all of its members.

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 their 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 medications and acute care such as hospital stays. Members receive these services through Medicaid or Medicare.

The Partnership and PACE (Program of All-Inclusive Care for the Elderly) programs cover all of the long-term care services in Family Care, plus primary and acute care, and prescription drugs. The difference between these two programs is that PACE is only for people age 55 or older who live in Milwaukee or Waukesha County.



## What is IRIS? (Include, Respect, I Self-Direct)



Individuals who want to direct all of their long-term care services can choose to enroll in and become an IRIS participant.

In IRIS, participants are in charge of 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 long-term care supports, services,

and goods. Participants are responsible for managing within their budget.

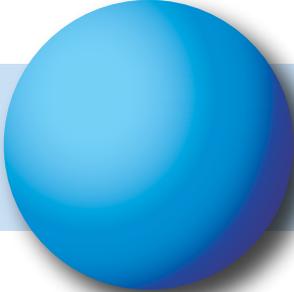
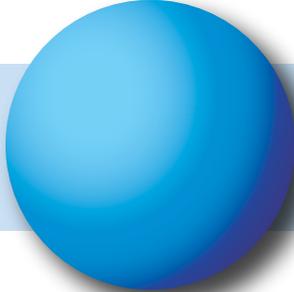
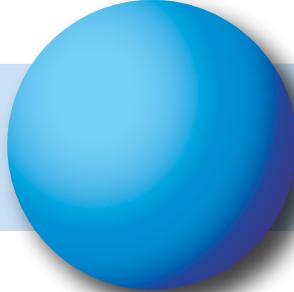
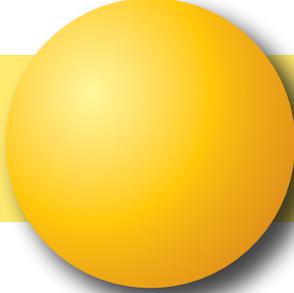
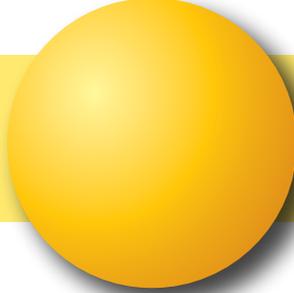
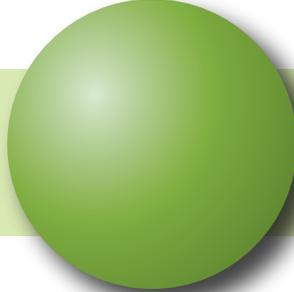
Participants may hire their own workers directly, or purchase goods and services from an agency. They choose the services necessary to meet their long-term care needs, and decide whom they will hire to provide supports or where to purchase those services. IRIS does not include long-term care Medicaid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

The IRIS Financial Services Agency (FSA) handles bill paying and accounting. The participant hires workers directly, and the FSA completes background checks on providers, processes timesheets, generates paychecks and handles payroll taxes.



# Examples of Wisconsin's LTC Program Services

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

	<b>IRIS</b>	<b>Family Care</b>	<b>Partnership/PACE</b>
<b>MA Waiver Services</b> Supportive Home Care Home Modifications Home-Delivered Meals Lifeline Assisted Living Employment			
<b>MA LTC Card Services</b> Home Health Medical Supplies Nursing Home Personal Care Mental Health Alcohol or Other Drug Treatment	Accessed Through Medicare or Medicaid Card		
<b>Acute and Primary Medicare or MA</b> Emergency Room Visit Hospitalization Doctor Visits Lab Tests Prescription Drugs Dental Care	Accessed Through Medicare or Medicaid Card	Accessed Through Medicare or Medicaid Card	



## Who Can Enroll?

To enroll in Family Care or IRIS, individuals must be at least 18 years old, financially eligible for Medicaid, have certain health conditions and need help with daily activities. Only people in the following three ‘target groups’ are eligible to enroll:

- **Frail elders** are 65 and older who have serious and long-lasting physical health problems or dementia that significantly limits their ability to care for themselves. Common conditions are diabetes, disabling arthritis, heart failure, cancer, Alzheimer’s disease or the effects of a stroke.
- **Adults with physical disabilities** have a physical condition that significantly limits their ability to care for themselves. Example conditions include amputations, paralysis, multiple sclerosis, lung disease and brain injuries.
- **Adults with developmental or intellectual disabilities** 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, etc.), or the ability to live independently without help from another person.

## Want to find out if you are eligible for Family Care or IRIS?

Contact your local Aging and Disability Resource Center (ADRC). ADRCs are places to get information and help with finding services and applying for benefits. For ADRC information, go to:

[www.dhs.wisconsin.gov/adrc](http://www.dhs.wisconsin.gov/adrc)



## 2012 Program Highlights - Family Care and IRIS

### Program Initiatives

In order to meet the future long-term care needs of Wisconsin's residents in the coming years, it is essential that the Department design long-term care programs to be cost-effective. In 2012, DHS consulted with consumers, family members, advocates, MCOs, ADRCs, providers, tribes and other experts about ideas to improve Wisconsin's long-term care programs. DHS then developed a package of reforms and savings measures to help make the programs sustainable on an ongoing basis while keeping consistent with the interests of current and future program participants. Program improvements included:

### Supporting Integrated Community Living:

Most people want to live in their own home in the community among family and friends. These settings provide people with more control over their lives and the opportunity to be more involved with their communities. In 2012, DHS issued program policy stating that the person's own home, whether owned or rented, is the most integrated setting.

The IRIS program limited the use of restrictive residential settings (including 3-4 bed Adult Family Homes, Community-Based Residential Facilities, Residential Care Apartment Complexes, and assisted living facilities) to short-term utilization. DHS will complete the implementation of this policy in 2014.

### Promoting Natural Supports:

Family Care and IRIS increased the focus on fully supporting individuals as members of their communities rather than solely on

care provision. MCO care managers and IRIS Consultants talk with individuals about their strengths and resources. Needed services then are built on, rather than replacing, the assistance the individual gets from family, friends, faith connections and the community. This helps people to maintain these important relationships and assures the use of public dollars to areas where needed. This includes helping people to make connections with all community resources, as well as develop new informal resources and connections.

### Improving Program Administration and Reducing Costs:

In 2012, DHS worked to improve the efficiency and cost-effectiveness of program operations. For example, DHS:

- Improved the process MCOs use for approving a member's services. The process reinforces cost-effectiveness, and encourages members to self-direct their services in Family Care.
- Increased the flexibility for MCOs in assigning care management staff.
- Improved the operation and management of the IRIS program.
- Strengthened the IRIS program to better support choice, self-determination and more cost-effective options.
- Aligned IRIS budget allocations to improve consistency with Family Care.
- Added Area Lead Consultants to IRIS to provide guidance and leadership to Consultants in the field and assistance in resolving difficult situations for participants.
- Created a new office in DHS to provide oversight and direction for the IRIS program.

## Family Care Program Activities

### Medication Management and Falls Prevention

In 2012, MCOs implemented projects to avoid unnecessary hospitalizations, emergency room (ER) visits and nursing home placements for its members. Identifying potential health problems early on may prevent the need for an ER visit, hospital stay or nursing home admission. This helps to reduce the amount of money spent on primary, acute and long-term care services. The projects focused on:

#### Managing Medications:

Making sure members take their medications properly contributes to overall wellness and decreases preventable events. In 2012, DHS and MCOs designed a process to ensure member take their medications as prescribed and decrease errors in dispensing medications. MCOs began identifying members who could benefit from medication management services.

#### Preventing Falls:

In 2012-13, five MCOs did performance improvement projects related to falls prevention. Projects included evidence-based exercise programs and nutritional interventions. After MCOs identify effective ways to prevent falls, they develop guidelines and implement quality improvement strategies for members.

### External Reviews

DHS contracts with an External Quality Review Organization (EQRO) called MetaStar to evaluate the quality of each MCO. Federal rules require an EQRO process for managed care. MetaStar reviews MCO systems and processes in several areas. The annual review conducted from July 1,



2011 to June 30, 2012, found that MCO administrative systems, processes and tools provided:

- Care management practices that are member-centered and show respect for the rights of members.
- Sufficient qualified providers to provide access to all services in the benefit package.
- A basis to measure and improve quality of care, effectiveness of quality assessments and performance improvement programs.
- Accurate performance measures data.
- Assurance of member health and safety.
- Support for care management practices. MetaStar noted that MCOs made progress in some key areas; however, there are further opportunities to improve care management systems and practices.
- Compliance with DHS reporting requirements. Results indicated areas of strength, as well as opportunities for improvement in this area.

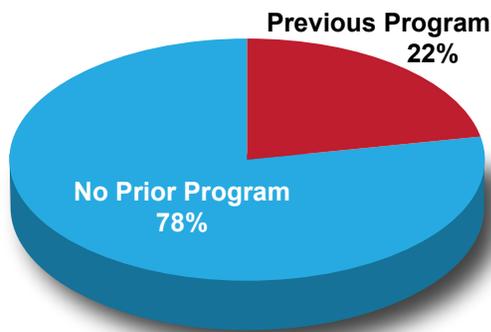
### Program Transition

On December 31, 2012, an MCO that served a five-county area in western Wisconsin stopped operating the Family Care and Partnership programs. All members were successfully transitioned either to a new MCO, IRIS or to another Medicaid program.

## IRIS Program Activities

### Program Growth

The IRIS program continued to grow in 2012. At the beginning of the year there were 5,081 participants and by the end of the year enrollment reached 7,455 participants. The number of IRIS Consultants also increased along with the growth in enrollment.



About 78% of people who joined IRIS were not previously enrolled in a long-term care program meaning that only 22% of IRIS participants came from another long-term care program, such as Family Care or the Children's Long-Term Support Waivers.

Participants who self-directed their personal care services nearly doubled again in 2012. The IRIS Self-Directed Personal Care program grew from 881 participants at the end of 2011 to 1,657 participants at the end of 2012. Part of this growth is likely due to participants' growing confidence in their abilities to self-direct their services and manage their own employees.

### Quality Improvement Projects

In 2012, DHS observed results of several IRIS improvement projects that began in 2011:

- Saw a decrease in the percentage of participants for whom the period of time from referral to start date exceeded 62

days (2011 averaged 31.8% while 2012 averaged 10.1%). This is an improvement of 21.7 percentage points.

- Of the 5,081 people enrolled in IRIS as of December 31, 2011, 32.6% had completed an assessment indicating their current employment status. Of those with an assessment, 19.4% indicated they were currently employed. Of the 7,455 individuals enrolled in IRIS on December 31, 2012, 82.2% had completed an assessment indicating their current employment status. Of those with an assessment, 16.9% indicated they were currently employed.

The number of IRIS participants with employment continues to increase, but is increasing at a lower rate than new participants are joining the program. This is why there was a decrease in the percent employed even though there are more participants employed at the end of 2011 versus the end of 2012.

### Employer Authority

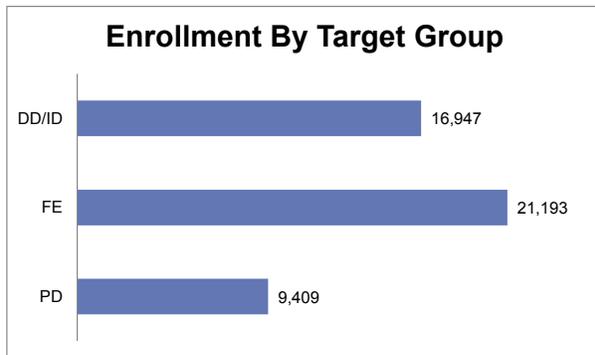
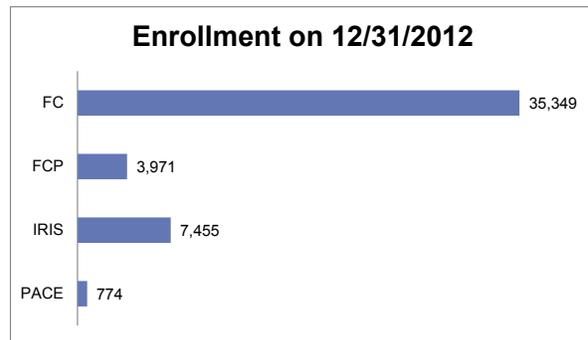
A key goal of Wisconsin's self-directed long-term care programs is to give people more choice and control over who provides their services by employing their own workers. By the end of 2012, IRIS participants employed 9,853 individuals as caregivers. On average, each participant employed 1.34 workers. Most workers provided supportive home care services.



## Demographics and Service Highlights

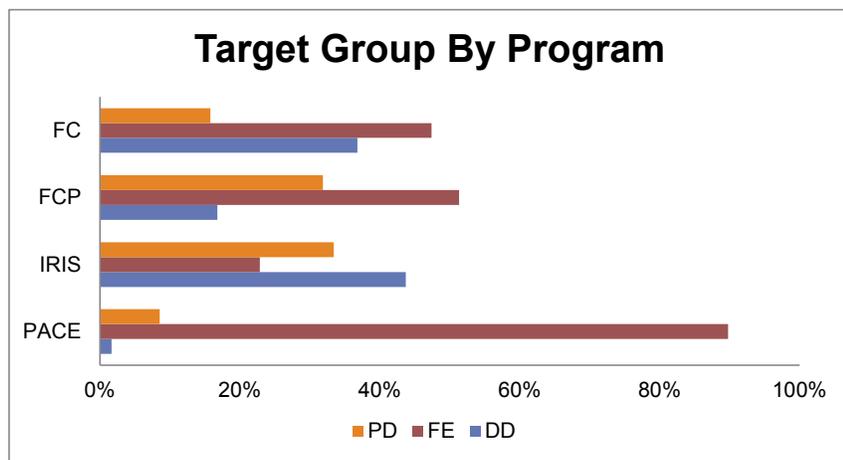
### Enrollment by Program

- At the end of 2012, 47,549 people were enrolled in Family Care and IRIS.
- About three-quarters (74%) of all enrollees were in Family Care (FC). IRIS was the next largest program (16%), followed by Family Care Partnership (FCP) (8%), and then PACE (2%).



- Just under half (45%) of all people enrolled were frail elders (FE).
- About a third of the people enrolled (36%) had a developmental or intellectual disability (DD/ID).
- The remaining people enrolled (20%) had a physical disability (PD).

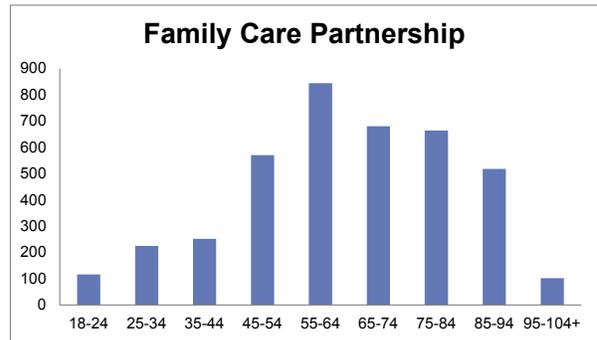
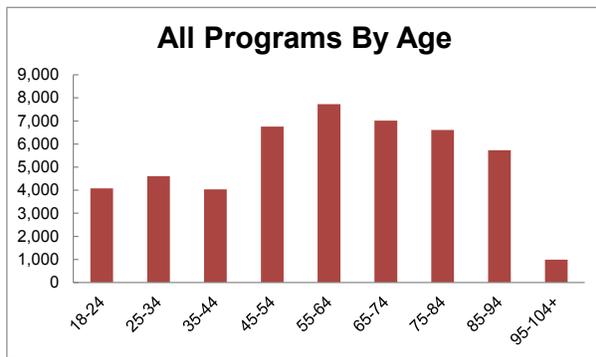
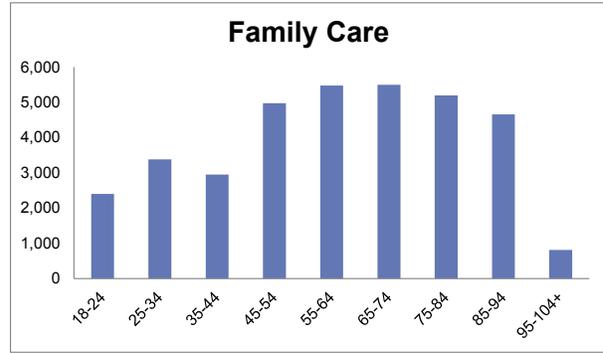
- Each program serves all three target groups. The proportion of these groups varies by program.
- PACE had the highest percentage of frail elders (90%). This is due in part to PACE eligibility beginning at age 55.



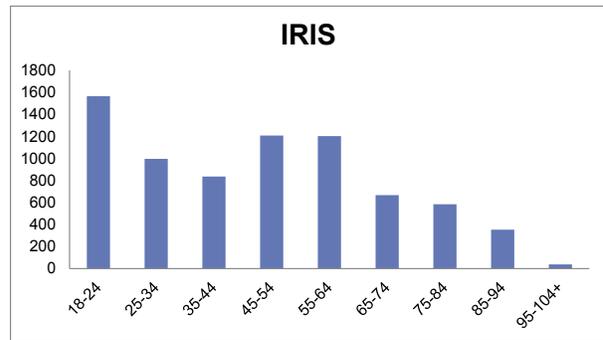
- IRIS had the highest percentage of participants with developmental or intellectual disabilities (44%).
- IRIS and Partnership had almost the same percentage of members with a physical disability (33% and 32% respectively).
- About half (45%) of Family Care and Partnership members were frail elders.

### Enrollment by Age

- In 2012, people in Family Care and IRIS were between 18-107 years old.
- Just under half (43%) were 65 and older.
- IRIS had a higher percentage of younger enrollees than Family Care or Partnership. Only 22% of IRIS participants were age 65 and older.
- PACE had a higher percentage of elderly members than any other program.



Program	Average Age
Family Care	60
Partnership	64
IRIS	47
PACE	76



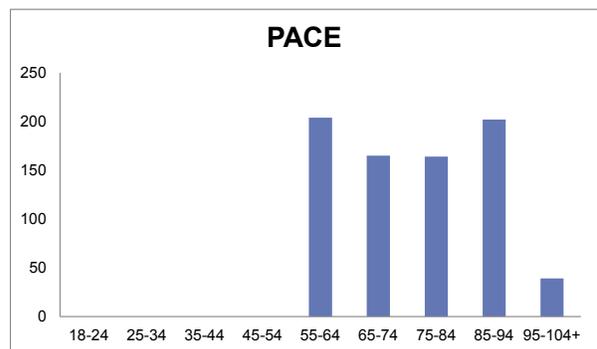
### Age by Program

The average age of individuals varies by program.

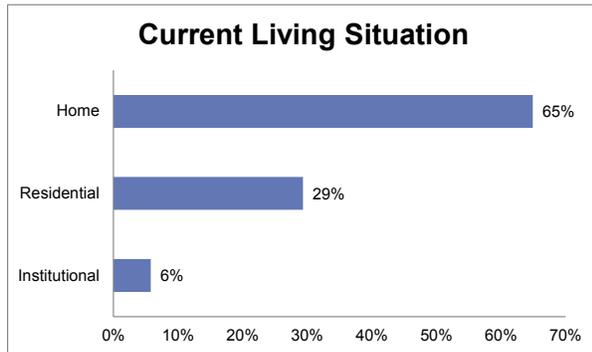
IRIS has younger enrollees than Family Care or Partnership. Only 23% of IRIS participants are age 65 and older.

PACE has a higher percentage of elderly members than any other program.

The following charts show the number of individuals in each age category by program.



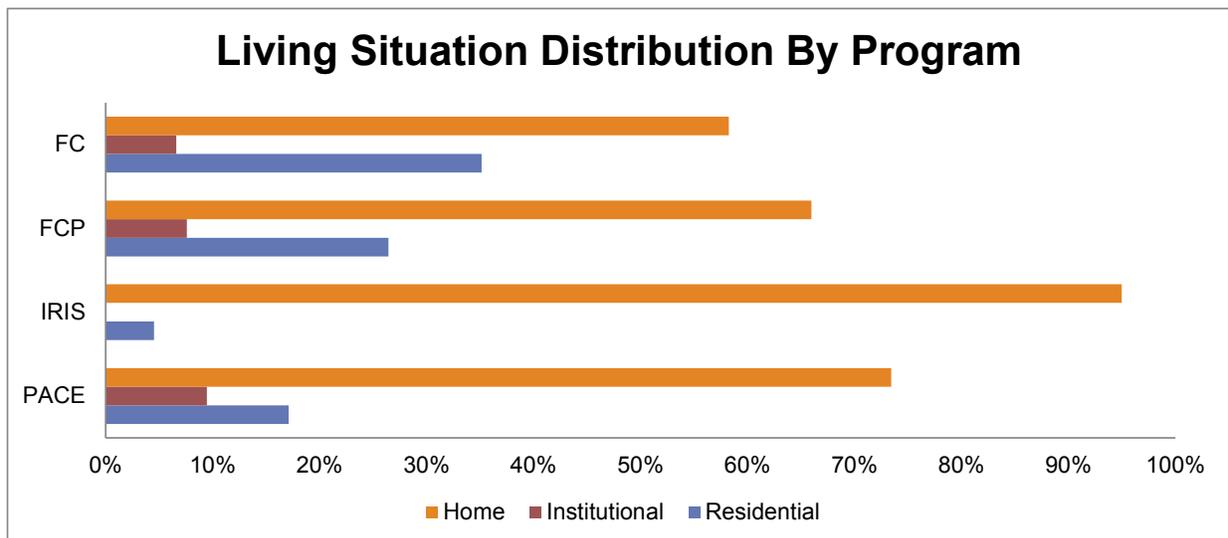
## Living Situation



- In 2012, almost two-thirds (65%) of the people enrolled in Family Care and IRIS lived in a home setting.
- Nearly all (95%) IRIS participants lived at home. Most Family Care, Partnership and PACE members lived at home as well.
- Overall, 94% of people living at home identify home as their preferred living setting.
- Sometimes it is not safe for people to remain in their own homes and they may move to a setting where they can get 24/7 care, such as an Adult Family Home,

Community-Based Residential Facility or Residential Care Apartment Complex.

- About a third (29%) of the people in Wisconsin's long-term care programs lived in such a residential setting.
- Of those, 73% said this was their preferred setting.
- Family Care members were the most likely to live in a residential setting.
- When people live in an institutional setting like a nursing home or an Immediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID), they can be enrolled in Family Care, Partnership or PACE, but not IRIS.
  - Six percent (6%) of the people in Family Care, Partnership and PACE lived in an institutional setting.
  - PACE serves only people age 55 and older, and had the highest percentage of members that lived in an institutional setting (9%), followed by Partnership (8%) and Family Care (7%).
  - Only 28% of the members in an institutional setting said this was their preferred setting.



## Service Expenditures

In calendar year 2012, total expenditures for services purchased for Family Care, Partnership, PACE and IRIS were just under \$1.6 billion.

Family Care and IRIS data are from the Department's encounter reporting system. Partnership and PACE data are from annual MCO financial summaries. The table below shows total expenditures.

Program	Total Expenditure for Services (millions)
Family Care	\$1,141
Partnership & PACE	\$290
IRIS	\$158
Total	\$1,589

The top six services account for around 90% of each program's total service spending. These services are shown below by program.

The percentages do not include care management services.

### Family Care

Service	Percent of Total Expenditure
Residential	51%
Supportive Home/ Personal Care	19%
Nursing Home and Intermediate Care Facilities	12%
Adult Day Activities	6%
Vocational	5%
Transportation	3%
Other	4%
Total	100%

Care Management accounts for 13% of total service expenditures.

## Partnership and PACE

Service	Percent of Total Expenditure
<b>Long-Term Care Services</b>	
Residential	19%
Nursing Home and Intermediate Care Facilities	11%
Supportive Home/ Personal Care	8%
Transportation	3%
Medical Equipment and Supplies	2%
Adult Day Activities	2%
Other (LTC)	9%
<b>Acute &amp; Primary Care Services</b>	
Inpatient Hospital	14%
Medications (Pharmacy)	13%
Office or Outpatient Assessments	5%
Other	14%
Total	100%

Care Management accounts for 12% of total service expenditures.

### IRIS

Service	Percent of Total Expenditure
Supportive Home Care	57%
Self-Directed Personal Care*	15%
Residential	8%
Adult Day Activities	6%
Vocational Services	4%
Transportation	4%
Other	6%
Total	100%

\*IRIS Self-Directed Personal Care (SDPC) 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.

## Employment

DHS is committed to integrated employment outcomes for all people with disabilities and has prioritized its resources and activities toward that end. The DHS goal is to increase the integrated, community-based employment rate for working age people with disabilities.

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

In October 2012, DHS collected the following data about working age people (18-64 years of age) enrolled in Family Care, Partnership or IRIS.

### Family Care/Partnership:

There were 20,647 working age people enrolled in Family Care/Partnership.

- Of these people, 6,516 (32%) worked in an integrated employment setting, a facility-based setting or in a group/enclave setting.
- 1,800 people were in integrated employment.
- 4,950 people were in facility-based employment.
- 306 people were in group/enclave employment.
- 540 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 5,124 working age people enrolled in IRIS.

- Of these people, 758 (15%) worked in an integrated employment setting, a facility-based setting or in a group/enclave setting.
- 247 people were in integrated employment.
- 461 people were in facility-based employment.
- 65 people were in group/enclave employment.
- 15 worked in more than one setting, such as in integrated employment in the morning and a facility-based setting in the afternoon.



## Program Results

### Influenza and Pneumonia Vaccinations

Family Care encourages members to receive appropriate vaccinations. This is 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 that received an influenza or pneumonia vaccination during 2012.

Program	Influenza	Pneumonia
Family Care	71%	77%
Partnership and PACE	82%	92%

### Member Satisfaction Survey Results

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

- Always
- Almost always
- Sometimes
- Hardly ever
- Never

In 2012, Family Care members reported the highest percentage of 'Always' responses, followed by the Partnership members. PACE members had the lowest percentage of 'Always' responses.

The top two scoring questions were:

- My nurse listens to my concerns (77% 'Always').
- My care manager listens to my concerns (76% 'Always').

The two lowest scoring questions were:

- I participate in making decisions about the services I receive (61% 'Always').
- I am happy with the timeliness of the services I receive (59% 'Always').

Nearly three-quarters (72%) of respondents indicated that they would 'always' recommend their program to a friend.

#### Percentage of Members Responding "Always"



## Supporting Personal Experience Outcomes

An important goal of Wisconsin's long-term care programs is that services and supports help people with long-term care needs have the quality of life they want as stated in the following outcome statements:

- I am involved in deciding where and with whom I live.
- I make decisions regarding my supports and services.
- I decide how I spend my day.
- I have relationships with family and friends I care about.
- I do things that are important to me.
- I am involved in my community.
- My life is stable.
- I am respected and treated fairly.
- I have privacy.
- I have the best possible health.
- I feel safe.
- I am free from abuse and neglect

Between July 2011 and June 2012, interviews were conducted with 549 people enrolled in Family Care, Partnership and IRIS or their representatives. During the interviews, people identify the goals and outcomes that are important to them and assess whether the program is working to address their goals and desired outcomes. People also report how well the program supports their outcomes and goals.

### Outcomes Achieved or In Progress

This indicator shows the percent of people who are having the quality of life they desire. Outcomes that are achieved are those that relate to the person's desires. For example, "I want to continue living with my parents in this house." Outcomes that are in progress also represent a positive situation. For



example, "I want to keep going to school to learn to be a car mechanic."

- As reported by members and participants, 82% of outcomes were achieved, or in progress.
- IRIS had the highest rate of outcomes that were achieved, or in progress at 87%, compared to Family Care (81%) and Partnership (78%).
- People with physical disabilities were less likely to report that outcomes were achieved or in progress (77%) than were frail elders (86%) or people with developmental/intellectual disabilities (85%).

### Outcomes Fully Supported

This indicator reports on how well the Family Care and IRIS programs support a person's outcomes. An outcome may require one or more supports to maintain or make progress toward the person's desired goal. Outcomes are "fully supported" only when all needed supports are available and acceptable to the person.

- As reported by members and participants, 85% of all outcomes were fully supported.
- IRIS had the highest rate of support for outcomes (89%), compared to Family Care (85%) and Partnership (82%).
- People with physical disabilities were less likely (79%) to have outcomes fully supported than were frail elders (90%) or people with developmental/intellectual disabilities (88%).

## Family Care Member Profiles

### Eleanor's Story

Eleanor was an 88-year-old elderly woman with Alzheimer's/dementia. She lived with her husband, Robert, who was her primary caretaker. Eleanor had been placed into a nursing home and then an assisted living setting prior to enrolling in Family Care.

In the facilities, without her husband, Eleanor would become upset, yelling out, and at times was physically aggressive. She was lost without her husband at her side in these unfamiliar surroundings and she would frantically search for him.

When Eleanor returned home, Family Care set up her services and daily care providers, and obtained equipment and supplies to supplement the care her husband and family provided. This allowed Eleanor to be with her husband, safe at home. Just having him in her sight, and being in her own home, put Eleanor at ease. Her dementia

was progressing quickly; Family Care increased her supports to include respite and hospice services.

Everyone involved worked together to best support Eleanor, her husband, and her family, while keeping her in her home until her passing only a few months later. Without Family Care, Eleanor would have likely been in a facility; alone, afraid and searching for her soul mate of 66+ years. With Family Care, her final days were spent reading the newspaper and her personally-written poetry, while smiling toward the recliner next to hers, where her loving husband smiled back from behind his book. Eleanor gently slipped away in her sleep in her own bed during her morning nap. Peaceful, comfortable and feeling the love of her family around her.

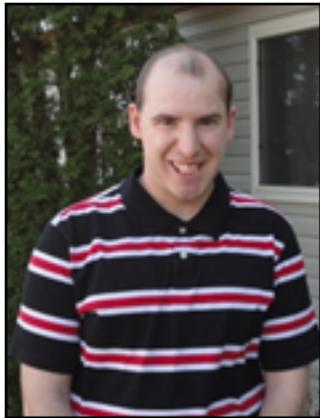
Family Care is not just about the wheelchair or ride it can provide, it's about that smile and look in Eleanor's eyes that said she was happy being where she wanted to be.



## James' Journey to Happiness

In a well-kept apartment building located in a northern Wisconsin neighborhood, 25-year-old James has found a life of happiness and independence.

After five years of living in an Adult Family Home, with the help of his care team, he moved into his own apartment. One of his goals has been to live independently, and his care team was very proud to have helped him accomplish his goal.



James has thrived since moving into his apartment. He likes to be active in the community. He likes to walk in the park, ride his bike around town, and enjoys playing softball in the summer. In addition to his active lifestyle, James is a

weather watcher for a local television channel. He has an outdoor weather system, which includes a thermometer and a rain gauge. He calls in once a day to report the weather in his area.

James does most of his own cleaning, laundry and cooking. His daily routine includes making his bed, showering and brushing his teeth.

There are signs on the wall to remind him of some of the rules. His caregiver helps him with his household chores and takes him grocery shopping. James likes to clip coupons to save money on the items he uses regularly. He has a representative payee to help him manage his money and he shares his living expenses with his roommate.

Reaching his goal of living independently has been a huge accomplishment for this outgoing and kind-hearted young man. It has been a long

journey filled with a lot of learning and hard work, and it has been truly worth the effort. James wears a mood ring, which is almost always dark blue in color, showing he is very happy.

## Leslie's Story

Family Care promotes independence and self-determination for all members. That may mean something different for each member, depending on the individual's strengths, needs, and personal preferences. For Leslie, it meant an opportunity to change everything about the way she lived.

Leslie is a young woman with cerebral palsy, an intellectual disability, depression and obsessive-compulsive disorder (OCD). After she turned 18, she moved out of her family's home and lived in several residential settings until she was about 30 years old.



Leslie's family decided that the residential facility she was living in did not provide the care they expected. Her care team explained how the Family Care self-directed support (SDS) option might work well for Leslie.

Her family decided to use SDS and with the help of her mother and sisters, as well as support from her care team, Leslie hired her own personal care and supportive home care staff. Today she is living in her own apartment and has more control over her life. She is doing things for herself that she had never done before. For example, she is able to shower independently and assist with meals and clean up, not to mention the many other household chores she completes with pride. Leslie and her family could not be happier.

## Roger's Ride to Independence – A Care Manager's Perspective

I have been Roger's care manager for three years. He is a kind-hearted man with a wonderful personality and sense of humor. Roger has a developmental disability but that does not keep him down. He has always been a



hard worker striving to do his best and willing to do extra. It has always been his goal to lead a productive life and become an integral part of society.

Roger worked at a pre-vocational site for many years and has struggled to “make ends meet.” In 2011, he registered with the State of Wisconsin's Division of Vocational Rehabilitation (DVR) and began to receive services. Roger wanted to work for a local transportation company and asked if I would go with him to talk to the owner. Roger approached the owner to let him know he was interested in driving for him. The owner was willing to hire Roger. I explained supported employment services through DVR. The owner

contacted the local DVR office and supported employment was set up. Roger was hired to work 20 hours a week at Bob's Medical Transport. Roger did well with only minimal assistance from the supported employment specialist.

Roger continues to work as a driver for Bob's Medical Transport. His employer is very happy with his work. He has an excellent work record. He treats clients with respect and kindness. It is Roger's goal to work full time for Bob's Medical Transport.

## Stephen's Story

Stephen's story is about the power of hard work and determination. He had been living in a nursing home due to a surgery that he knew would leave him paralyzed from the waist down. When he first enrolled in Family Care, he told his care team that his main goal was to live in his own apartment.

Stephen was persistent in physical therapy and he eventually was able to move to an Adult Family Home. He continued his therapy after he moved, and eventually he was able to stand with a walker and was almost independent with transfers. As he built his strength and independence, he started participating in 5K wheelchair races. Throughout it all, Stephen remained committed to his goal of living in his own apartment.

With the help of Family Care, Stephen researched public housing options and filled out rental applications. Finally, after years of hard work and determination, he got the good news – he had been approved for his own apartment. In three short years, Stephen went from being in a nursing home and using a wheelchair, to living in his own apartment, and being able to walk a few steps.

## IRIS Member Profiles

### John, Newell and Todd

John, Newell and Todd are roommates living together in Neenah, Wisconsin. One of the best features of their house is the room they call the “man cave,” which includes a couple of comfy chairs pointed directly at a television. It sends the message that this is definitely a “guys” place!



John

The men work together to do household chores such as mowing the lawn, shoveling snow, going to the store, and shopping for their own groceries. Since they all have unique hobbies and interests, they each like to do their own things, but sometimes decide to attend events or visit places together.

Todd, John, and Newell use their IRIS funds to purchase the individual services that they need to meet their long term care needs. They each control when and how their services are delivered.

Connie, who helps to coordinate services, observes that this is the first time she worked with people who are their own bosses. It changes the focus from other places she has worked.

Todd is happy and comfortable in his home and really enjoys relaxing in his favorite chair. “Todd’s life is here,” says his mother, Alice. Both parents like to talk about how Todd’s world will remain stable, even if something happens to them, because of all the planning and work that went into creating the life he has now. They describe how Todd’s home acts as a launching pad for everything else that he does. Their advice for people who want to find homes of their own and learn more about community living is “Take it step-by-step.”

John and Newell first met each other in nursery school. Growing up, they drifted apart and went to different public schools. Now, later in life, they have reunited as roommates.

Since moving into his new place, John says he has been very happy and especially likes making his own decisions. He has a job he likes, but says it is nice to come home after a day of work and relax in a place that he loves.

His mom, Rosie, says it is important that his place look and feel like a home. Since John grew up in a busy house with several brothers and sisters, he appreciates having two other roommates who help create an active household.



Newell



Todd

When asked what advice she would give to others who were interested in community living, John's mom smiled sweetly and said, "Go for it!"

Newell and his mom looked for a good place to live for a long time and talked to lots of people before meeting Todd's parents.

Newell feels that moving in with Todd and John was the right way to go and says he is very happy. His mother, Marian, says that it was important for Newell to stay involved with the community he knows and for her to live near her son.

The parents of all three men say they wanted their sons to live where they are happy and could have a good life without parents being around all the time (although they joke that the guys do telephone quite often). Having their own place makes it easier for Todd, John, and Newell to spend time in their community, building relationships and doing the things they enjoy.

## LeAnn's Story

LeAnn is a vivacious young woman who enjoys deer hunting, shopping at the mall, and giving back to her community. She volunteers her time by working with several physical therapy students at the local technical college,

and wrapping donated gifts to give to others during the holidays.

She chose to enroll in the IRIS program because she liked how IRIS Consultants highlight the many different possibilities available to her through self-direction; but she feels that the best part of IRIS is in choosing the people she wants to work with her.

Her biggest goal right now is to become physically strong enough to attend a technical school in Eau Claire. She gets up every day to exercise, and says that the workers she hired with her IRIS funds provide the support she needs at home so she can focus on achieving her dream.

LeAnn also has her sights set on getting her driver's license, so she can attend classes and expand on the work she does helping others.

When asked about her IRIS Consultant, LeAnn smiles and says, "She's very informative; I like her a lot." LeAnn loves how her IRIS Consultant is always ready to share ideas and suggestions. "IRIS is awesome."



## Ralph's Story

Ralph is an avid outdoorsman living in Ladysmith with his wife, Jo. More than eleven years ago, he lost his eyesight due to unforeseen complications during a lower back operation. Though his life had changed, he felt that being inactive and “sitting all day” would be the worst thing he could do.



Drawing inspiration from his love of the outdoors, Ralph decided to create and sell items made from deer antlers and diamond willow branches. To get started, he spoke with Wisconsin's Division of Vocational Rehabilitation (DVR). They helped him get his first tools and connected him with someone who taught him a few beginning techniques.

Ralph founded “Ralph's Rack Shack,” to sell the items that he makes, such as hat racks, cup holders, shelves, and walking sticks. He utilizes IRIS funds to help meet his transportation needs and provide the care he uses at home, so he can continue working and pursuing his dream.



Ralph with a handful of his antler zipper pulls

This hunter's greatest happiness comes from giving back to others. While he makes plenty of antler zipper-pulls to sell, he also gives away many thousands to children with terminal-illness through “Shed of Hope,” a non-profit organization he started a few years ago.

Ralph likes how his work keeps his mind and body occupied. “It helps you mentally and physically,” he says with a smile. “As long as I can make a few dollars and keep going, I'll be happy.”

## 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 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.

**Employment Training Services** – Training, instruction and placement services to help people get and keep jobs.

**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.

**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 includes the Family Care Partnership program and PACE.

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

**Financial Services Agency (FSA)** – The agency that handles bill paying and accounting for IRIS participants. The FSA 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.

**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.

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

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

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

**IRIS Area Lead Consultant** – Area Leads are assigned to oversee a team of IRIS Consultants and IRIS Consultant Supervisors. They are responsible for providing guidance and leadership to Consultants in the field and resolving difficult situations for participants.

**IRIS Consultant** – A trained individual who provides ongoing assistance to IRIS participants. IRIS Consultants help develop and implement the participant’s support and service plan. They also provide resources and give participants information to aid in decision-making.

**Long-Term Care (LTC)** – Services an individual 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).

**MA LTC Card Services** – Long-term care services someone gets using their Medicaid Forward card or through a Managed Care Organization (MCO).

**MA Waiver Services** – “Waivers” provide services so people can live in the community instead of a nursing home or other institution. The federal government waives certain rules for Medicaid when the State provides these services in the community instead of an institutional setting. Waiver services are generally non-medical services that help with daily activities.

**Managed Care** – A way to improve the quality and cost-effectiveness of care. Managed Care Organizations (MCOs) operate Family Care and they must authorize services before the member receives care. Members have to get their services from the MCO’s network of providers.

**Managed Care Organization (MCO)** – The organizations that operate the Family Care, Partnership and PACE programs.

**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 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.

**Personal Experience Outcome** – Personal experience outcomes represent what Family Care members and IRIS participants identify as important, including their goals, hopes, and dreams. One person’s outcome might be being healthy enough to enjoy visits with her grandchildren, while another person might want to be able to be independent enough to live in his own apartment.

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

**Residential Setting** – Residential care settings include adult family homes (AFHs), community based residential facility facilities (CBRFs) and residential care apartment complexes (RCACs).

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

**Supportive Home Care (SHC)** – Services that directly assist people with daily activities and personal needs. Examples of SHC services are assistance with shopping, cooking, and routine housekeeping.

**Vocational Supports** – Services to help get, maintain and succeed in meeting a person’s employment goals.