LONG TERM CARE
SOCIAL WORKERS OF IOWA

FALL CONFERENCE 2025

The Plex at Christ Community ~ Ames, Iowa
Friday, October 24, 2025

The Long-Term Care Ombudsman Program: Putting Rights First
Melanie Kempf, SLTCO

Dementia Friends Iowa
Diana Crosswait, Dementia Friends Iowa

Advancing Cognitive Care: Tools & Resources for Better Outcomes
Anne O'Rear, Broadlawns Medical Center Memory Clinic

Alzheimer's: Awareness, Caregiving & Research
Erica Eikren, Alzheimer's Association

The Partnership for Community Integration: Iowa's Money Follows the Person Program ~ Lindsey Robertson & Gina Makarios, MFP

AGENDA
Friday, October 24, 2025

8:30 a.m.	Announcements
8:30 - 10:00 a.m.	*Residents' Rights & OSLTC Ombudsman – Kempf*
10:00 - 10:15 a.m.	Break
10:15 - 11:15 a.m.	*Dementia Friends Iowa – Crosswait*
11:15 - 12:15 p.m.	*Advancing Cognitive Care – O'Rear*
12:15 - 1:00 p.m.	Lunch
1:00 - 2:00 p.m.	*Alzheimer's: Awareness, Caregiving & Research – Eikren*
2:00 - 2:15 p.m.	Break
2:15 - 3:15 p.m.	*The Money Follows the Person – Robertson & Makarios*
3:15 p.m.	Evaluations and Adjournment

This program complies with the Iowa Board of Social Worker Examiners Rules for Continuing Education, meeting 5.5 general continuing education contact hours.

LTCSWI FALL CONFERENCE 2025

The Plex at Christ Community ~ Ames, Iowa

October 24, 2025

WORKSHOP GOALS AND OBJECTIVES

The Long-Term Care Ombudsman Program: Putting Rights First

Learn about Iowa's Office of the State Long-Term Care Ombudsman Program, including role and scope. Review rules and regulations that pertain to rights of those in long-term care facilities and of Medicaid managed care members in Iowa. Discuss real-life scenarios and learn about ways to put individuals and their rights first in a highly regulated industry.

Dementia Friends Iowa

Increase understanding and reduce stigma of dementia. Give participants skills to help someone with dementia. Describe dementia and know the most common type of dementia. Understand 5 key messages about dementia. Learn how to effectively communicate with a person living with dementia. Learn about available community resources.

Advancing Cognitive Care: Tools and Resources for Better Outcomes

Alzheimer's: Awareness, Caregiving and Research

This presentation covers information about the Alzheimer's Association resources, support services and how to get involved in the cause. Learn about the latest treatments available for the disease, how they work, who may be a candidate for the treatment and information regarding access and availability. Gain a better understanding around how dementia affects communication, including tips for communicating well with family, friends and healthcare professionals. Learn how behavior changes for those with dementia and how they are a form of communication, identify non-medical approaches to behaviors and recognize when additional help is needed.

The Partnership for Community Integration: Iowa's Money Follows the Person Program

Participants will learn the fundamental goals and structure of the MFP program, including how it helps individuals transition from institutional settings to community-based care. Attendees will gain insight into the specific services offered through the MFP program and how it supports individuals' independence, choice, and quality of life. Participants will understand the role of various stakeholders in the success of MFP and the continued development of community-based long-term care options.

About Our Presenters...

Melanie Kempf serves as the Program Manager for Quality and Process Improvement at the Iowa Office of the State Long-Term Care Ombudsman where she works closely with the State Long-Term Care Ombudsman to coordinate statewide priorities and provide support to Iowa's nine local ombudsmen. These professionals, along with dedicated volunteers, serve as the on-the-ground advocates in long-term care facilities—offering information, assistance, and a strong voice for residents across the state.

Diana Crosswait is a long-time Ames resident who enjoys advocating for her 91-year-old mother living with Alzheimer's, and helping others on the caregiving journey. She is a volunteer (Champion) with Dementia Friends Iowa.

Anne O'Rear holds a Bachelor of Science in Gerontology, as well as certifications in Care Management, Dementia Care, and Activity and Program Planning. She brings 12 years of healthcare experience and over 18 years of personal and professional experience in dementia care to her role as Dementia Community Care Specialist for the Broadlawns Memory Clinic. Anne is committed to enhancing the lives of individuals living with dementia and their care partners through education, support, and community partnerships.

Erica Eikren is certified as a Dementia Friend and is an active advocate for families with a dementia journey like her own. She is a resource for those with Alzheimer's and all other Dementias in her role as Program Manager for the Iowa Chapter of the Alzheimer's Association. She supports research funding and legislation that positively impacts those living with the disease and their caregivers. She also serves as a media spokesperson, acts as a support group facilitator for caregivers and provides educational programming. .

Lindsey Robertson, Lindsey Robertson is the Project Director for Iowa's nationally recognized Money Follows the Person (MFP) program. She was first introduced to MFP while working in an institutional setting, then had the opportunity to engage with the program in her capacity as a volunteer legal guardian, and she was fortunate to join MFP and facilitate transitions as a Transition Specialist. She is passionate about person-centered planning and she is grateful to have the opportunity to live this passion through MFP's work.

Gina Makarios, works as a Transition Specialist for Iowa's Money Follows the Person program. Gina has served in a variety of social service roles in 5 states throughout her 25-year career. She found her way to the IDD and TBI populations ten years ago, where she found her true passion. Gina has been described as a tenacious advocate for the people she serves. MFP is the perfect vessel by which Gina can support people to live their best life in their community of choice.

The Long-Term Care Ombudsman Program: Putting Rights First

Melanie Kempf, Program Manager, Quality and Process Improvement

October 24, 2025

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Our Mission

Office of the State Long-Term Care Ombudsman

To offer advocacy, support choices, and resolve concerns on behalf of individuals living in long-term care facilities and for Medicaid managed care members who receive services in a long-term care facility or under one of Iowa's Home and Community-Based Services (HCBS) waivers.

Volunteer Ombudsman Program

To empower volunteers to make a positive difference in the lives of individuals in long-term care through advocacy that enhances residents' rights, safety, and wellbeing.

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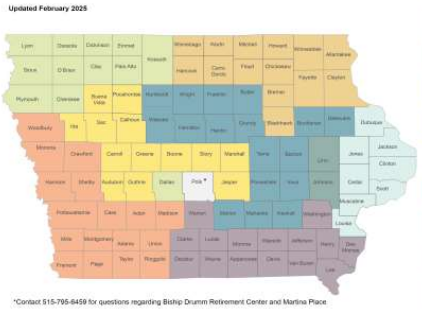
State Long-Term Care Ombudsman Regions Map

Updated February 2025



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Kim Cooper
563-210-7439

*Contact 515-795-6459 for questions regarding Bishop Drumm Retirement Center and Martina Place

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What does the Long-Term Care Ombudsman Program (LTCOP) do?

- Advocates for residents of nursing homes, board and care homes, assisted living facilities, Residential Care Facilities, and Medicaid Managed Care members who receive HCBS (Home and Community Based) Waivers.
- Works to resolve problems individual residents face and to effect change at the local, state, and national levels to improve quality of care.
- Supports the overall responsibility to help residents, family members, and others to understand residents' rights and to support residents in exercising their rights guaranteed by law.

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Specifics

- Identifies, investigates and resolves complaints
- Ensures that residents have regular and timely access to ombudsman services
- Educates residents, family and facility staff
- Advocates for changes to improve residents' quality of life and care
- Represents resident interests before governmental agencies
- Provides technical support for the development of resident and family councils
- Provides information to the public
- Analyzes, comments on, and recommends changes in laws and regulations

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What does the LTCOP do?

- Recruit, train, orientate, and manage volunteer ombudsmen.
  - Volunteers:
    - Become certified Representatives of the Office.
    - Receive comprehensive training, resources, and continuing support from OSLTCO staff.
    - May carry out visits, administrative tasks, or special projects.
    - Can help ensure care is delivered in a respectful, dignified manner to meet an individual's needs and provide a support system for individuals in long-term care facilities.

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Who does the LTCOP represent?

- Individuals, regardless of age, living in long-term care facilities
- Facilities must provide LTCOP with access to residents
- LTCOP takes action at the direction of the resident.
- LTCOP do not advocate for illegal activities.
- LTCOP do not represent individuals who reside in ICF/PMI, RCF/ID, ICF/ID facilities.

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When might someone call the LTCOP? (1)

- To work through the concerns if a resident feels the facility is not resolving their issue.
- To address systemic issues like call light response time, poor housekeeping, or cold/poor quality food.
- If a resident is given a 30-day notice stating they need to leave the facility.
- If a resident feels their rights are not being honored.
- If the management is not responding to a grievance they presented.

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When might someone call the LTCOP? (2)

- To understand the role of substitute decision makers, such as power of attorney, guardian and/or conservator.
- To receive information about managed care rights, responsibilities, and grievance and appeal processes.
- To learn about information available to choose a long-term care facility or Medicaid managed care organization.
- To learn about or apply to become a volunteer ombudsman.

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Resident Rights (1)

*Title 42 Code of Federal Regulations 483.10

- Right to a Dignified Existence
- Right to Self-Determination
- Right to be Fully Informed of:
  - The type of care to be provided, and risks and benefits of proposed treatments
  - Changes to the plan of care, or in medical or health status
  - Rules and regulations, including a written copy of resident's rights
  - Contact information for the long-term care ombudsman program and the state survey agency
  - State survey reports and the nurse facility's plan of correction
  - Written notice before a change in room or roommate
  - Notices and information in a language or manner he/she understands

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Case Example: Dignity Concerns

During a routine visit to a long-term care facility, the LLTCO noted odors throughout, dignity concerns with a resident lying in bed with only a brief and socks on with the door and window blinds open, oxygen canisters not properly stored, catheter bags exposed, trash piling up and food on the floor in resident rooms. In addition, no resident names were on the doors and a high percentage of agency staffing were being utilized in the building. Items were blocking an exit door, there were housekeeping concerns, lengthy call light response time, and staff arguing in resident areas. During this visit, residents expressed that staff gave them medications with their bare hands and would pick medication up off the floor and give it to them.

The LLTCO was able to make subsequent visits to the facility to follow up on these concerns and assist residents in bringing up new concerns regarding lack of showers/bathing at least 2 times weekly. The LLTCO communicated with facility staff during visits to work towards resolution for residents to improve their quality of care.

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Resident Rights (2)

- Right to Raise Grievances
- Right of Access to:
  - Individuals, services, community members and activities inside and outside the facility
  - Visitors of his or her choosing, at any time, and the right to refuse visitors
  - Personal and medical records
  - His or her personal physician and representatives from the state survey agency and long-term care ombudsman program
  - Assistance if sensory impairment exists
  - Participate in social, religious, and community activities

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Case Examples: Visitation

A nursing home resident has several grown children. Two of the sons have not spoken to each other in years. One of the sons serves as POA for the medical and financial matters for his mother and has instructed the staff not to allow the other son to visit his mother. The resident wants to see all of her children, including the son who the brother has tried to restrict.

The daughter of a resident works the night shift at a local factory and wants to visit her mother on her way to work. She can only visit at 9:00 p.m. and the staff has informed her that visiting hours are over at 8:00 p.m. The resident is very upset that her daughter cannot visit at 9:00 p.m. The resident resides in a private room.

What should the facility do?

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Resident Rights (3)

- Rights Regarding Financial Affairs
- Right to Privacy
- Rights during Discharge/Transfer
  - Right to appeal the proposed transfer or discharge and not be discharged while an appeal is pending
  - Receive a 30-day written notice of discharge or transfer that includes: the reason; the effective date; the location going to; appeal rights and process for filing an appeal; and the name and contact information for the long-term care ombudsman
  - Preparation and orientation to ensure safe and orderly transfer or discharge
  - Notice of the right to return to the facility after hospitalization or therapeutic leave

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Case Example: Discharge Attempt

A resident has lived in the facility for 4 years and her son has recently quit paying her bill. She owes the facility approximately $50,000 and has the funds to pay. The son will no longer return phone calls to the administrator. The administrator approaches the resident on Friday afternoon and informs her that she must leave by Monday afternoon.

What should the resident do?

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Tenant Rights (1)

*Iowa Administrative Code 481.67.3 (231B, 231C, 231D)

- To be treated with consideration, respect, and full recognition of personal dignity and autonomy.
- To receive care, treatment and services which are adequate and appropriate.
- To receive respect and privacy in the tenant's medical care program Personal and medical records shall be confidential, and the written consent of the tenant shall be obtained for the records' release to any individual, including family members, except as needed in case of the tenant's transfer to a health care facility or as required by law or a third-party payment contract.

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Tenant Rights (2)

- To be free from mental and physical abuse.
- To receive from the manager and staff of the program a reasonable response to all requests.
- To associate and communicate privately and without restriction with persons and groups of the tenant's choice, including the tenant advocate, on the tenant's initiative or on the initiative of the persons or groups at any reasonable hour.
- To manage the tenant's own financial affairs unless a tenant's legal representative has been appointed for the purpose of managing the tenant's financial affairs.

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Tenant Rights (3)

- To present grievances and recommend changes in program policies and services, personally or through other persons or in combination with others, to the programs staff or person in charge without fear of reprisal, restraint, interference, coercion, or discrimination.
- To be free from restraints.

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Case Example: Changes Recommended

- Tenants in an ALP were unhappy with the quality of their meals. The meals were supplied from an outside agency who delivered the lunch and supper meal each day. ALP tenants felt that no one was listening to their concerns about the poor quality of their meals. With permission, the Ombudsman reached out to the company supplying the meal and facilitated a tenant meeting for tenants to air their concerns to the provider. A plan was put in place and a follow-up meeting occurred the following month with the food provider. The meal provider outlined their menu changes (as suggested by the tenants) and quality control measures they intended to take to resolve the concerns.
- The meal provider asked the tenants to provide feedback the following month after their changes were implemented. The tenants were happy with the improvements that were made.

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Member Rights (1)

*Title 42 Code of Federal Regulations 483.100, 438.206-438.210

- To receive timely, appropriate, and accessible medical care.
- To obtain a second opinion regarding a medical diagnosis.
- To choose the provider of your choice from the providers available with your MCO.
- To change your MCO as allowed by program policy.

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Member Rights (2)

- To appeal a decision that you do not agree with.
- To be treated with respect and dignity.
- To be treated without discrimination in regard to race, color, national origin, sex, sexual orientation, gender identity, religion, age, disability, political belief or veteran status.
- To participate in decisions regarding your health care, including the right to refuse treatment.

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Member Rights (3)

- To present grievances and recommend changes in program policies and services, personally or through other persons or in combination with others, to the programs staff or person in charge without fear of reprisal, restraint, interference, coercion, or discrimination
- To be free from restraints

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Case Examples: Managed Care

- Beth's transportation provider was late to pick her up many times in one month. When Beth talked with the driver, she was told there were too many people to take places, and she would just have to deal with being late. Beth's MCO did not ensure her services were received on time, and the provider was rude. Beth submits a grievance to her MCO.
- John receives care in his home to help him remain independent. A home health aide visits John three times weekly to assist with bathing and personal care. John gets a letter from his MCO saying that his home health aide will be visiting only one time every week instead. John submits an appeal with his MCO.

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Ongoing Initiatives

- Individual and Systemic Advocacy
- Resident and Family Council Support Meetings
- Quarterly Town Halls
- Volunteer Ombudsman Recruitment
- Community Engagement

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Contact Information
Office of the State Long-Term Care Ombudsman
866-236-1430
SLtco@hhs.iowa.gov
Website: https://hhs.iowa.gov/health-prevention/aging-services/ltcombudsman
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LONG-TERM CARE OMBUDSMAN

Mission: To empower and enhance the lives of residents in long-term care facilities by seeking resolution of issues and advocating for resident rights.

The long-term care ombudsman advocates for rights and the wishes of residents in long-term care facilities by investigating complaints, seeking resolution to problems, and providing advocacy with the goal of enhancing quality of life. All services are free and confidential.

WHAT CONCERNS DOES A LONG-TERM CARE OMBUDSMAN ADDRESS?

Violation of resident rights

Poor quality of care

Improper transfer/discharge

Any resident concern about quality of life

WHEN TO CALL THE OMBUDSMAN

- → To ask for assistance resolving a concern or to learn about self-advocacy
- → To inquire about resident rights
- → To clarify state or federal regulations and facility policies
- → To understand the role of substitute decision makers, such as power of attorney, guardian and/or conservator
- → To obtain assistance with the involuntary discharge of a resident or the facility closure process

Reach out to your long-term care ombudsman at

866-236-1430

RESIDENT RIGHTS

Resident rights are guaranteed by the federal Nursing Home Reform Law of 1987, which requires nursing facilities to promote and protect the rights of each resident and places a strong emphasis on individual dignity and self-determination.

KNOW YOUR RIGHTS!

Residents of long-term care facilities are entitled to many rights. These include, but are not limited to:

Honoring dignity, respect, and privacy

Managing one's own finances

Ensuring information remains confidential

Participating in the care planning process and making informed decisions about treatment

Making independent choices, such as when to go to bed, when to get up and what to eat

Receiving advance notice of a transfer or discharge

Choosing visitors

Enjoying individual interests

Remaining free from chemical and physical restraints, abuse, discrimination and neglect

Expressing grievances without fear of retaliation

Being fully informed about rights, services and costs prior to admission

To learn more about resident rights, reach out to your long-term care ombudsman at

866-236-1430

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Sexual Expression in Long-Term Care

The Iowa Office of the State Long-Term Care Ombudsman (OSLTCO) plays an integral role in advocating for the rights of individuals living in long-term care, including nursing facilities, assisted living programs and residential care facilities. Freedom of sexual expression has proven a sensitive and sometimes controversial topic, particularly when cognitive capacity is in question.

Under federal law, those in long-term care are afforded multiple rights, many of which are relevant to sexual expression and include, but are not limited to, the rights to privacy, confidentiality, dignity and respect, self-determination, visitors, and freedom from abuse. The OSLTCO supports every person in developing maximum self-reliance and independence regarding consensual sexual activity and strives to preserve these rights by promoting attitudes of awareness and acceptance.

Consensual Sexual Expression

Anyone in a long-term care facility who maintains cognitive capacity to consent should be afforded the same rights to privacy, respect, and freedom to sexual expression as they would if they were living in the community.

Determinations of capacity to consent depend on the context of the issue, and one determination does not necessarily apply to all decisions made by an individual.

Capacity on its most basic level means that a person has the ability to understand potential consequences and choose a course of action for a given situation. Decisions of capacity to consent to sexual activity must balance considerations of safety and autonomy, and capacity determinations must be consistent with State law, if applicable.

Facility policies, procedures, and protocols should identify when, how, and by whom determinations of capacity to consent to sexual contact will be made and where this documentation will be recorded. Because cognitive functioning may change, a facility should continue to monitor and re-evaluate capacity to consent over time, as needed, based on an individual's physical, mental and psychosocial needs.

Non-Consensual Sexual Contact

Generally, sexual contact is non-consensual if an individual either appears to want the contact to occur, but lacks the cognitive ability to consent, or does not want the contact to occur. Other examples of non-consensual sexual contact may include, but are not limited to, situations where a person is sedated, is temporarily unconscious, or is in a coma.

A facility is required to protect individuals from non-consensual sexual relations. Any time a facility has reason to suspect that a person does not wish to engage in sexual activity or may not have the capacity to consent to such relations, an investigation must be conducted.

Sexual Abuse

Any investigation of an allegation of sexual abuse must start with a determination of whether sexual activity was consensual on the part of the person(s). Apparent consent to engage in sexual activity is not valid if it is obtained from someone lacking the capacity to consent or if consent is obtained through intimidation, coercion or fear, whether it is expressed by the person or suspected by staff. Any forced, coerced or extorted sexual activity with a person who resides in long-term care, regardless of the existence of a pre-existing or current sexual relationship, is considered to be sexual abuse.

Creating Policy To Support Sexual Expression

Facilities can support the right to freedom of sexual expression for individuals in long-term care facilities by being proactive and developing formal policy to include definitions, an interdisciplinary approach, processes, assessments and education for those who live in long-term care, their representatives, and facility staff.

Resources

Scan the QR code for a list of resources, not all-inclusive, that may be utilized to help create thoughtful, person-centered discussion, policy, and response to sexual expression.

Contact the Office of the State Long-Term Care Ombudsman

Toll Free: 866-236-1430
Email Address: sltco@hhs.iowa.gov
Mailing Address: 321 E 12th St., Des Moines, IA 50319

Dementia Friends Iowa

A Dementia Friendly America initiative

Session Workbook

Adapted from Dementia Friends Minnesota and with permission of
Dementia Friends, Alzheimer's Society, London UK. | Rev. 04/15/2025

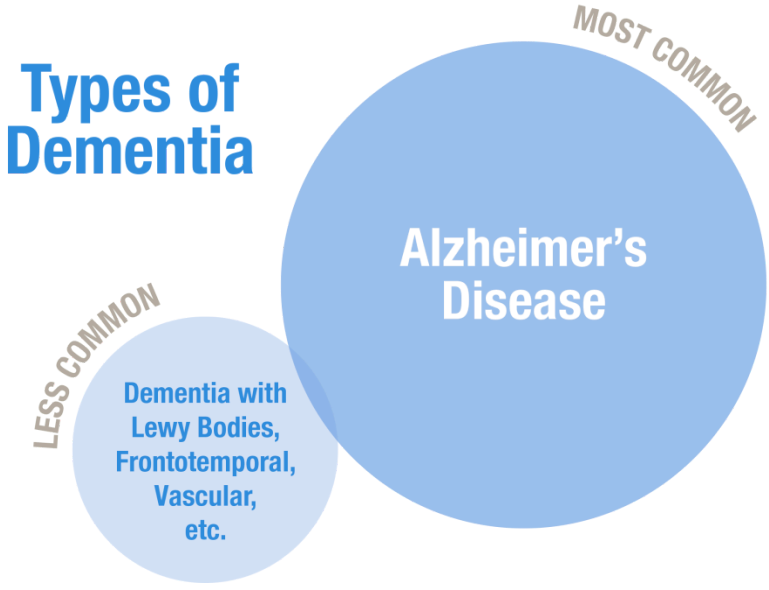
What is Dementia Friends?

Dementia Friends is a global movement developed by the Alzheimer's Society in the United Kingdom and now underway in the United States. It has been active in Iowa since 2021. The Dementia Friendly Iowa initiative of Northeast Iowa Area Agency on Aging supports the Dementia Friends movement in Iowa.

The goal is to help everyone in a community understand five key messages about dementia, how it affects people, and how we each can make a difference in the lives of people living with the disease. People with dementia need to be understood and supported in their communities. You can help by becoming a Dementia Friend.

Dementia: What You Should Know

Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer's disease is the most common type of dementia and accounts for 60 to 80% of cases. Other types of dementia include Lewy Body dementia (LBD), Frontotemporal, Vascular, and many more. The different types of dementia are caused by different biological changes in the brain. They all cause a similar set of symptoms, but they each may have different characteristics.



Learn more about the differences between the common types of dementia:
www.nia.nih.gov/health/infographics/understanding-different-types-dementia

Typical Aging vs. Dementia

	Typical Aging	10 Early Signs and Symptoms
1.	Sometimes forgetting names or appointments but remembering them later	Memory loss that disrupts daily life
2.	Making occasional errors when balancing a checkbook	Challenges in planning or solving problems such as following a recipe
3.	Needing occasional help to use the settings on a microwave or to record a TV show	Difficulty completing familiar tasks at home, at work or at leisure
4.	Confused about the day of the week but recalling it later; needing extra assistance navigating to new locations	Confusion with time or place
5.	Vision changes related to cataracts	Trouble understanding visual images and spatial relationships
6.	Sometimes having trouble finding the right word	New problems with words in speaking or writing; struggles with word-finding
7.	Misplacing things from time to time and retracing steps to find them	Misplacing items and losing the ability to retrace steps
8.	Making a bad decision once in a while	Decreased or poor judgment
9.	Sometimes feeling weary of work, family and social obligations	Withdrawal from work or social activities
10.	Occasionally becoming irritable when a routine is disrupted or feeling stressed with responsibilities	Drastic changes in mood and personality

Source: 10 Early Signs and Symptoms of Alzheimer's
www.alz.org/10-signs-symptoms-alzheimers-dementia.asp

Diagnosis & Awareness of Symptoms

If you or someone you know shows signs of dementia, the first step towards getting a diagnosis is by talking to a primary care provider. Many doctors will perform a cognitive screening. Depending on the results, the doctor may make a referral to a neurologist for further testing and brain scans.

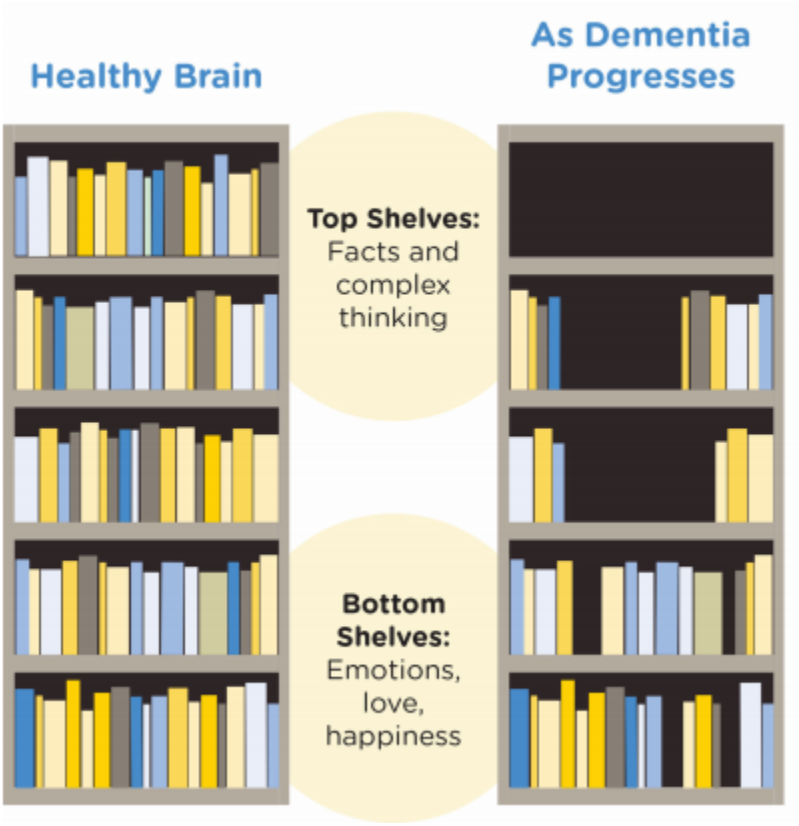
Related to knowing the common signs of dementia, it is important to note that in some cases, individuals may not have the ability to recognize or acknowledge their cognitive or thinking changes. This is called **anosognosia.** This is why it is important for family, friends and community members to be aware of the signs and symptoms of dementia, so you may offer support even if an individual is unaware they are experiencing cognitive changes.

Five Key Messages

1. **Dementia is not a typical part of the aging process.** Not everyone who grows old will develop dementia.
2. **Dementia is caused by diseases of the brain.** The most common is Alzheimer's disease.
3. **Dementia is not just about memory problems.** It can affect thinking, communication, doing everyday tasks, and more.
4. **It is possible to have a good quality of life with dementia.**
5. **There's more to the person than the dementia.** People with dementia are a valuable part of the community.

Bookcase Story

Imagine the brain is represented by a bookcase. Each book inside the bookcase represents something we store in our brains. For example, each book represents memories, facts, complex thinking skills, and more.

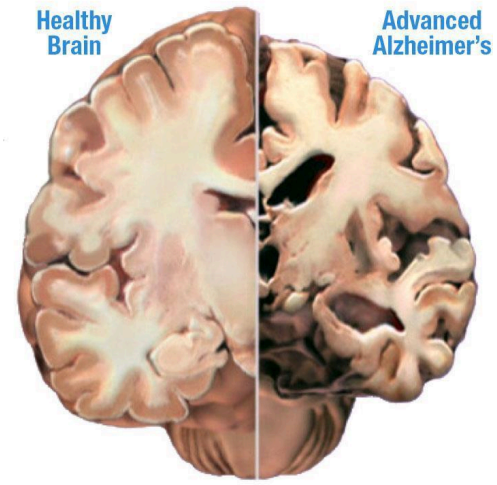


On the top shelves, we store short-term memories, facts, and complex thinking skills. Books on the top shelves may include memories of what we ate for breakfast today, how to use our new smart phone, how to drive to our friend's new house, and more. On the bottom shelves, emotions, feelings, long-term emotional memories, and deeply rooted values are stored. Feelings like love, happiness, frustration and sensing respect reside here.

When dementia impacts the brain and rocks the bookcase, the books on the top shelf begin to fall out first. People living with dementia may not remember what they ate for breakfast, or that they must pay for items at the drugstore, or that someone came to visit this morning. For most people with dementia, the top or outer part of the brain is often damaged first, which is where these skills are stored.

As dementia continues to rock the bookcase, the books on the lower shelves representing emotions, feelings, and long-term emotional memories often stay for a much longer time. Many of these functions are in the lower or inner part of the brain, which is the instinct area of the brain.

The bookcase story helps us explain why different skills and memories may be more accessible as dementia progresses. The main takeaway with this analogy is to understand that we can still connect to the bottom bookshelves as dementia progresses. People living with dementia may not remember our name or forget that we visited them five minutes after, but we can still help them feel positive emotions in the moment by connecting to the bottom bookshelves. They may lose the ability to control emotions, but emotions and feelings are still present.



Everyday Task Activity

Write a step-by-step instruction list to complete a task you do daily or often. Make sure someone reading your list could follow the instructions successfully to complete the task.

There are many steps to remember, and dementia could make everyday tasks more difficult.

Communication Tips

Consider these tips when communicating with a person with dementia.

Treat the person with dignity and respect. Avoid talking past the person as if he or she isn't there.

Be aware of your feelings. Your tone of voice may communicate your attitude. Use positive, friendly facial expressions.

Be patient and supportive. Let the person know that you are listening and trying to understand. Show that you care about what he or she is saying and be careful not to interrupt.

Offer comfort and reassurance. If he or she is having trouble communicating, reassure them that it's okay and encourage the person to continue.

Avoid criticizing or correcting. Don't tell the person what he or she is saying is incorrect. Instead, listen and try to find the meaning in what is being said.

Avoid arguing. If the person says something you don't agree with, let it be. Arguing usually only makes things worse and often increases agitation for the person with dementia.

Offer a guess. If the person uses the wrong word or cannot find a word, try guessing the right word. If you understand what the person means, finding the right word may not be necessary.

Encourage nonverbal communication. If you don't understand what is being said, ask the person to point or gesture.

Conversation Tips

When approaching the person with dementia and starting a conversation:

- Come from the front, identify yourself, and keep good eye contact. If the person is seated or reclined, go down to that level.
- Call the person by their preferred name to get his or her attention.
- Use short, simple phrases and repeat information as needed. Ask only one question at a time.
- Patiently wait for a response while the person takes time to process what you said.
- Speak slowly and clearly. Use a gentle and relaxed tone.

During the conversation:

- Provide a cue rather than a command. For example, say “The checkout is right over here,” instead of saying, “You need to go through the checkout now.”
- Avoid confusing and vague statements about something you want the person to do. Instead, speak directly: “Please come here. Your coffee is ready.” Name an object or place. For example, rather than “Here it is,” say “Here is your hat.”
- Turn negatives into positives. Instead of saying, “Don't go there,” say, “Let’s go here.”
- Avoid quizzing. Reminiscing may be healthy, but avoid asking, “Do you remember when?” Instead, you can provide a prompt such as, “I remember when…”
- Try using written notes or pictures as reminders.

Instead of this...	You could say...
You need to go through the checkout now.	The checkout is right over here.
Come over. It’s ready.	Please come here. Your coffee is ready.
Don’t go there.	Let’s go here.
Do you remember when…?	I remember when…

Turn Your Understanding into Action

As a Dementia Friend, I will… (choose an action)

- Get in touch and staying in touch with someone I know living with dementia
- Say “living with dementia” instead of “suffering with dementia”
- Carry out a personal action (such as being more patient when out in my community)
- Initiate dementia friendly changes or practices within my business/organization
- Contact a community resource to seek out assistance for myself, someone living with dementia, or a family caregiver I know
- Share the information I learned today with someone who might benefit
- Support or start dementia friendly community initiative in my town
- Become a Dementia Friends Champion or tell others to become Dementia Friends
- Anything else - what can you do?

Keeping Your Brain Healthy As You Age

Because there is no cure for dementia (at this time), it is essential to embrace healthy brain habits that research suggests may reduce the risk of dementia. The following potentially modifiable risk factors have been identified as research-supported risk reduction practices. **While these activities can help reduce the risk of dementia, it is not completely preventable. Genetics can also play a role. It is never someone’s fault if they develop dementia!**

1. Pursue higher levels of education and never stop learning.
2. Monitor and treat any hearing or vision loss.
3. Protect your head from brain injuries.
4. Keep your heart healthy and manage high blood pressure.
5. Limit alcohol consumption.
6. Attain and maintain a healthy body weight.
7. Quit smoking or vaping and the use of tobacco.
8. Treat and manage depression.
9. Build friendships and stay socially connected.
10. Develop and maintain a physical activity schedule.
11. Treat and manage diabetes.
12. Reduce exposure to air pollution.
13. Build healthy sleep habits.

Iowa Dementia Resources List

Alzheimer's Association

- **1-800-272-3900 | www.alz.org**
- Supports people with all types of dementia, not just Alzheimer's Disease
- Hosts support groups/education for people living with dementia and caregivers
- Provides care consultations, referrals, information, and individual meetings
- Walks client through legal/financial planning, future living preferences, etc
- Local support group listing: https://www.alz.org/iowa

Area Agencies on Aging & Lifelong Links

- **866-468-7887 | https://lifelonglinks.org/**
- Home & phone visits to equip client with strategies to safely age in home
- Potentially able to offer funding for homemaker, transportation, respite care, etc
- Family care consultations and referrals to other local resources; support groups

Dementia Friendly Iowa / Dementia Friends

- **319-239-2902 | www.dementiafriendlyiowa.org**
- Provides education for the community about dementia (Dementia Friends and Dementia Friendly Business trainings); builds dementia friendly communities
- Opportunity to volunteer as an advocate through community education
- Topic-by-topic Dementia Resource Guide available

Dependent Adult Protective Services

- **1-800-362-2178 (toll-free, 24 hours a day, 7 days a week)**
- Report abuse, neglect, exploitation, or self-neglect of a dependent adult
- If a person is in imminent danger, call 911

Iowa Department of Health & Human Services

- **Iowa Aging Services** | Supports the Long-Term Care Ombudsman program, Managed Care Ombudsman program, Retired & Senior Volunteer Program (RSVP), Area Agencies on Aging, and more.
- **Iowa Alzheimer's and Related Dementias Program** | Public health and healthy brain initiative; educational information available. https://bit.ly/HHSAlzheimersAndOtherDementias

The Association for Frontotemporal Degeneration (AFTD)

- 1-866-507-7222 | **https://www.theaftd.org/iowa/**
- Specific to FTD dementia; reliable information, valuable resources, essential support, and opportunities to make a difference. Support groups available throughout the state.

THE PARTNERSHIP FOR COMMUNITY INTEGRATION

Iowa's Money Follows the Person (MFP) Program

October 24, 2025

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Objectives

- Participants will learn the fundamental goals and structure of the MFP initiative, including how it helps individuals transition from institutional settings to community-based care.
- Attendees will gain insight into the specific services offered through the MFP program and how it supports individuals' independence, choice, and quality of life.
- Participants will understand the role of various stakeholders in the success of MFP and the continued development of community-based long-term care options.

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Who We Are

- Transition Specialists & Supervisors
- Behavior Support Specialists & Supervisor
- Employment Specialists
- Housing Specialist
- Data and Quality Analyst
- Program Coordinator
- Administrative Services Coordinator
- Project Director

This program is supported by the Centers for Medicare & Medicaid Services (CMS) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $134,572,913.00 with 100 percent funded by CMS/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CMS/HHS, or the U.S. Government.

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Philosophy

People with disabilities of any age should have choices about how and where to get quality services.

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MFP is Nationwide

- 43 states and territories have MFP programs
  - Iowa is often a resource to other MFP programs
- Each MFP program is unique – no two operate the same way

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Program Goals

- Increase the use of home and community-based services (HCBS) and reduce the use of institutionally-based services
- Eliminate barriers in State law, State Medicaid plans, and State budgets that restrict the use of Medicaid funds to let people get long-term care in the settings of their choice
- Strengthen the ability of Medicaid programs to provide HCBS to people who choose to transition out of institutions
- Put procedures in place to provide quality assurance and improvement of HCBS

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MFP in Iowa - Vision

Assist people in transitioning to independent settings in the community of their choice, where they will receive the enhanced services and support, they need to pursue their personal goals and to achieve a high quality of life.

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MFP in Iowa

- Part of the State's larger strategy to rebalance its systems of long-term support.
  - The driver for the strategy is the primary value the State of Iowa places on choice.

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Program Success

- 99% remain in the community at the end of the MFP Demonstration Year
  - *As of the Semiannual Report to CMS for 01/01/2025-06/30/2025*
- #3 in the country for IDD transitions
  - Source: https://clpc.ucsf.edu/publications/evidence-impact-money-follows-person-program (July 2019)
- In 2022, Iowa was recognized as one of six Best Practice States identified by Mathematica

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MFP Guiding Principles (slide 1 of 9)

1. MFP participant preferences and choices will be respected.

This includes:

- the decision whether or not to transition to community living
- the composition of the transition planning team
- preferences regarding the community and residence
- roommates (if any)
- service providers
- employment or other meaningful daytime activities.

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MFP Guiding Principles (slide 2 of 9)

2. All Medicaid-eligible individuals who:

- Have resided in ICF/IDs, Nursing Facilities, PMICs, or inpatient hospitalization settings
- For at least 60 consecutive days and
- Would meet criteria for the ID or BI Waiver
- Eligible for MFP services and are assumed capable of successful transition to community living.

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MFP Guiding Principles (slide 3 of 9)

3. Continuity in transition assistance and supports will be provided by a single transition specialist who will, in most instances, work with the MFP participant from initial contact to the close of the Demonstration Year.

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MFP Guiding Principles (slide 4 of 9)

4. Involvement of the participants' parents, guardians or legal representatives in transition planning, including such key decisions as the choice of residence and service providers, will be encouraged.

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MFP Guiding Principles (slide 5 of 9)

5. Planning and service coordination will be carried out by an Interdisciplinary Team (IDT) capable of and responsible for

- understanding all barriers to successful community living faced by a participant
- identifying the full range of service and support needs
- providing the participant with a choice of providers to meet those needs

The transition specialist assumes responsibility for

- working with the participant to identify and recruit members of the IDT
- scheduling planning meetings
- ensuring that the transition plan developed by the IDT provides for an orderly transition, for the health and safety of the participant at all times, and for full participation in community life

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MFP Guiding Principles (slide 6 of 9)

6. All MFP participants can elect to participate in the Consumer Choices Option (CCO).

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MFP Guiding Principles (slide 7 of 9)

7. Full community participation for MFP participants must include meaningful daytime activities. A high priority will be placed on the creation of satisfying employment options for participants in the community of their choice.

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MFP Guiding Principles (slide 8 of 9)

8. MFP participants will enjoy the same health safety and rights protections as HCBS Waiver participants.

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MFP Guiding Principles (slide 9 of 9)

9. The MFP demonstration is subject to HCBS quality assurance requirements.

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Lessons Learned

Needs vary and bring unique challenges to community living.

Therefore, six themes were identified in supporting people in transitioning to living in the community.

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Lesson One

- Individuals need intensive transition coordination and ongoing support through the transition process.

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Lesson Two

- Individuals need Transition Specialists to work with them while they are in a facility to develop a transition plan.

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Lesson Three

- Individuals need a Transition Specialist to provide on-going monitoring and support during the first year, including at least monthly face-to-face visits.

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Lesson Four

- Transition Specialists only carry a caseload of people in the transition process.

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Lesson Five

- Training for direct support professionals prior to the individual's transition and ongoing on-site consultations and behavioral plan development are essential.

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Lesson Six

- Securing employment opportunities and support to seek those opportunities can be challenging.

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What Does MFP Offer?

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Transition Coordination Services

- A person-centered process for individuals transitioning from a Qualifying Facility to a Qualified Residence in the home or community-based setting of their choice with the supports and services that meet their needs and preferences via:
  - Transition Planning Assistance
  - Transition Monitoring and Case Management
  - Conducting social marketing and outreach
  - Work with community providers to build capacity

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Behavioral Support Services (slide 1 of 2)

Supports MFP participants who have complex behavioral health needs to move to and/or maintain living in the community through:

- Functional behavioral assessment
- Behavioral Support Plans (BSPs)
  - Development
  - Training
  - Maintenance and revisions
- Data collection and monitoring

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Behavioral Support Services (slide 2 of 2)

To meet the needs of people with complex behaviors:

- Collaborative partnerships with other behavior support entities (i.e., PPSS, ITABS, etc.)
- Educational training to build the capacity of providers:
  - Positive Behavior Supports (PBS)
    - 1 day training
    - 2-day train-the-trainer training
  - Safety Care
  - Other training topics as requested that align with the scope of the role

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Employment Support Services

- Supports those interested in working to locate employment opportunities in their community of choice through
  - Vocational planning
  - Resume building
  - Data collection and monitoring
  - Employment support training
  - Connections with collaborative partners
- Outreach activities
- Provides technical assistance to partner agencies and organizations to build capacity

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Housing Support Services

- Supports MFP participants with:
  - locating housing
  - applying for rent and/or utility assistance
  - coordinating home modification projects
  - support to address challenges in maintaining living arrangements (related to housing-specific challenges)
- Outreach activities to overcome barriers
- Collaborative partnerships with other housing-related entities

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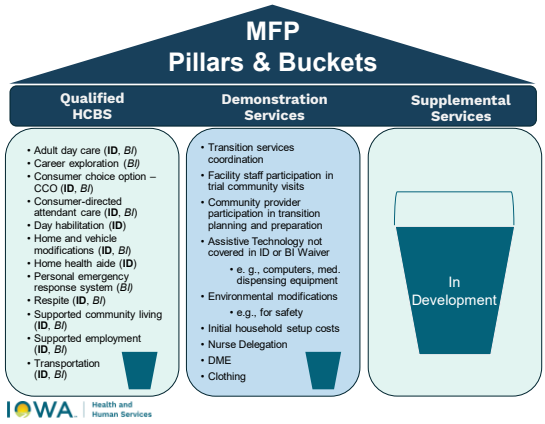

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Qualified HCBS

- The Medicaid service package(s) that the state will make available to an MFP participant wen they move to a community-based residence.
- Can be comprised of any Medicaid home and community-based state plan services and HCBS waiver program services.

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Most Frequently Used Services

*not a comprehensive list of services available

Intellectual Disability Waiver	Brain Injury Waiver
Adult Day Care	Adult Day Care
Consumer-Directed Attendant Care (CDAC)	Career Exploration
Day Habilitation	Consumer-Directed Attendant Care (CDAC)
Home and Vehicle Modifications	Home and Vehicle Modifications
Home Health Aide	Personal Emergency Response System (PERS)
Respite	Respite
Supported Community Living (SCL)	Supported Community Living
Supported Employment	Supported Employment
Transportation	Transportation
Consumer Choices Option (CCO)	Consumer Choices Option (CCO)

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Providers

- MFP uses the same provider pool and pays the same established rates in most circumstances.

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Rates for Services

- Typically, MFP pays the Tier or other assigned rate
- MFP can pay an Enhanced Rate for services when the IDT agrees it is appropriate
  - The MCO Case Manager is part of the IDT and should be discussing this heightened rate with MCO leadership for awareness
    - Does not obligate the MCO to pay the higher rate
    - MCO must be in agreement it is appropriate for the needs and intends to evaluate the continuation past the MFP year.
- Typically, not more than 5% of people on MFP with Enhanced Rates

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What's Different About MFP?

Enhanced Services Paid During the MFP Transition Year

DEMONSTRATION SERVICES

- Transition Services Coordination
- Facility Staff Participation in Trial Community Visits
- Community provider participation in transition planning and preparation
- Assistive technology not covered in ID or BI Waiver
  - E.g., computers, med. Dispensing equipment
- Environmental modifications
  - E.g., for safety
- Nurse delegation
- Initial household set up costs
- DME
- Clothing

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Demonstration Services

Qualified HCBS

- Services that could be provided, but are not currently provided, under the state's Medicaid program.

Reasonable & Necessary

- Not available to the participant through other means and clearly specified in the participant's service plan.

Not required to continue

- Not required to continue after the conclusion of the MFP Demonstration Year or for the participant at the end of the 365-day enrollment period.

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Allowable Expenses

- Necessary to enable a person to establish a basic household that does not constitute room and board.
- All must be identified as a need and authorized in the person's plan
- Demonstration Services are furnished only to the extent that:
  - They are reasonable and necessary as determined by the IDT process
  - They are clearly identified in the individual service plan
  - The person is unable to meet such expense or when the services cannot be obtained from other sources

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Transition Services Coordination

- Services that assist with the transition of a person from a qualifying facility to a qualified residence in the community.

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Facility Staff Participation in Trial Community Visits

- Reimbursement for costs of day visits or trial overnight stays
  - The facility provider will be reimbursed for staff time and travel (mileage only) for community visits and training

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Community Provider Participation in Transition Planning and Preparation

Participate in all transition meetings, short trial visits and/or overnights, and any necessary individual-specific training

- Reimbursed for staff time and travel for such pre-transition services
- Must provide services for at least 90 days after transition and provide 30 days notification if discharge of consumer is planned
- May also train other community providers
  - i.e., employment, adult day services, etc.

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Assistive Devices
(not covered in ID or BI Waiver)

- Practical equipment products to assist persons with activities of daily living and instrumental activities of daily living to allow the person more independence

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Environmental Modifications and Equipment

- Includes modifications to the home not otherwise covered under Home and Vehicle Modification

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Nurse Delegation (slide 1 of 2)

- Services provided by a licensed registered nurse to train and oversee the procedures carried out on behalf of the individual and provide consultation.
- Determines the activity can be performed in the home or community setting and that the delegate can perform the task.

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Nurse Delegation (slide 2 of 2)

- Determines level of oversight of the care to ensure the health and safety of each participant.
  - Minimum of on-site supervisory visits every two months with the provider present.
    - More frequent visits can be provided as long as medically necessary.
- Retains accountability for their actions in the consultations, training, and management of the delegation process
  - Not accountable for the actions of the caregiver.

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Initial Household Setup Costs (Establishing Community Household)

- Funds cover the initial expenditures needed to help an individual establish a community residence
- Can be used for expenses directly related to moving

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Enhanced Durable Medical Equipment

- Equipment that can withstand repeated use
  - Is primarily and customarily used to serve a medical purpose.
  - Generally, not useful to a person in the absence of an illness.
  - Is appropriate to assist the consumer for use in the community.

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Clothing

- A one-time clothing allowance for individuals to assist with transitioning to a community setting

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Supplemental Services

Short-Term

- Services to support an MFP participant's transition that are otherwise not allowable under the Medicaid program.

Reasonable & Necessary

- Not available to the participant through other means and clearly specified in the participant's service plan.

Not required to continue

- Not required to continue after the conclusion of the MFP Demonstration Year or for the participant at the end of the 365-day enrollment period.

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In Process

- Iowa is submitting a proposal, and more details will be available at a future date.

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Accessing MFP

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Eligibility Criteria

- Medicaid eligible (with a disability determination)
- Meet criteria to qualify for eligibility and LOC for BI or ID Waiver
- Reside in a Qualifying Facility for at least **60** consecutive days
  - Intermediate Care Facility for individuals with Intellectual Disabilities (ICF/ID)
  - Nursing Facility (SNF or NF)
  - Psychiatric Medical Institutions for Children (PMIC)
  - Hospital (inpatient)

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Jack's Story

Brain Injury pathway to MFP

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Jack - age 37

- Resided in a NF after his condition progressed to a point that was beyond what his aging parents could support themselves
- Referral received by the Project Director and, after an initial eligibility review, was assigned to a Transition Specialist Supervisor (TSS)
- The TSS provided education to Jack and his legal guardian regarding the MFP program
- Jack's guardian completed consents and releases to proceed with the MFP enrollment process
- The TSS facilitated the eligibility review process with Iowa Medicaid Medical Services after receiving all necessary documents

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Jack: First Steps

- Jack was determined eligible for MFP under BI diagnostic criteria and Level of Care
- A Transition Specialist (TS) was assigned to Jack
- The TS connected with Jack's MCO case manager, who made the referral to learn more about him and how to support him best
- The TS met with Jack and his family at the NF to learn about his preferences, support needs, and goals for his return to the community

Preferences	Needs	Goals
Concerts	Routine enemas for bowel elimination	Exercise
Exercising	Accessible housing	Work

- The TS worked with the NF to identify alternatives to routine enemas (a potential barrier) that would meet his health needs

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Jack and His IDT

The IDT met to discuss Jack's wants and needs more comprehensively

- social and leisure goals
- housing preferences and supports
- adaptive equipment and DME needs
- physical health supports
- mental health needs
- risk factors to consider
- finances
- rights restrictions
- employment preferences

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Jack: Exploring Options

- TS talked with Jack about potential providers who could meet his needs and preferences in the community where he wanted to live
- An agency expressed interest in meeting him and came to visit to get to know him
- Jack met a potential host home provider who had an accessible house – they hit it off!
- The agency's director explored options with the team about ensuring the compensation rate would match Jack's support needs.
  - The IDT worked collaboratively and determined a request for an enhanced rate was appropriate.
  - This was requested by MFP and approved by Iowa Medicaid.

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Jack: Transition Process

The IDT continued to meet to plan for Jack's transition.

- The MCO brought the person who would be Jack's future CBCM in to join the planning process, and they attended all planning meetings
- They worked together to develop and organize and comprehensive plan to ensure all of Jack's essential supports were in place prior to his move from the NF
  - Grab bars were installed where needed
  - A shower chair and specialized bed were purchased
  - Arrangements were made for him to continue participating in a specialty PT clinic that allowed him to exercise in ways he would otherwise not be able to
  - A plan was developed regarding how finances, bills, and shopping would occur
  - The TS made a referral to the MFP Employment Specialist who then joined the IDT and assisted Jack with connecting with resources like the Department of the Blind, Brain Injury Association, Easter Seals, and the Helen Keller Institute to support Jack with his goal to work

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Jack: The Move & Beyond

- Jack moved to his new home where everything he needed was there and waiting for him
  - IDT met six times over the course of six weeks for a total of 9 hours prior to the move
  - The TS facilitated the transition process to keep things moving by:
    - Action plans to identify who was responsible for what tasks and by when
    - Follow-ups to ensure completion of tasks identified in action plans
  - Lots of behind-the-scenes work by every IDT member.
- Two days after the move:
  - The TS visited to make sure everything was going well.
  - Address any newly identified needs that came up.
    - There were some bumps with his medications being filled by the pharmacy timely, but everything else went according to plan
- TS took monthly visits to Jack.
- Monthly IDT meetings and stayed in close communication between meetings

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Highlights of Jack's Demonstration Year

- Accommodated engagement in artwork and puzzles
- Went to:
  - the movies
  - an art festival
  - music in the park
  - fireworks
  - farmers markets
  - a casino with a friend
  - an art studio
  - an arcade bar
- watched the Hawkeyes at a sports bar and had beer
- watched many movies on his large screen TV
- got new glasses
- received a new customized wheelchair
- weaned off a medication that made him drowsy
- worked with IDT to devise plan to ensure that his sexual needs were met in a socially safe manner
- received new shoes and AFOs
- enjoyed a variety of homecooked meals which had had an active part in planning and shopping for ingredients for

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Special Circumstances

Reinstitutionalization

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Reinstitutionalization

MFP Process
If a participant is admitted to a qualifying facility for >3 days, this counts as a re-institutionalization for MFP purposes.
If >3 days but < 30 days, the participant's MFP year will be extended by the length of stay in the qualifying facility.
If > 30 days, the participant will need to be re-referred to MFP once 60 days is reached (individual then qualifies for a new demonstration year).

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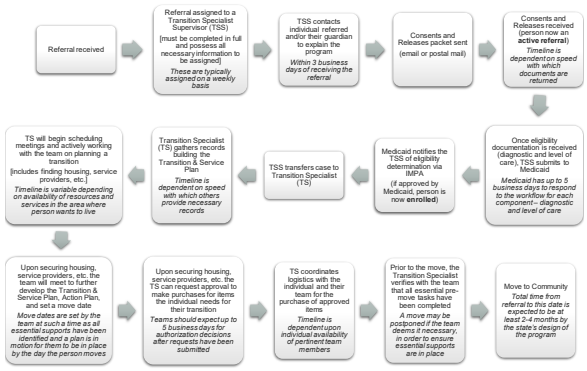

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MFP Process

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Resources for Transition Planning

- Transition Planning Guidebook

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Additional Resources

- MFP Brochure
- MFP Participant Manual

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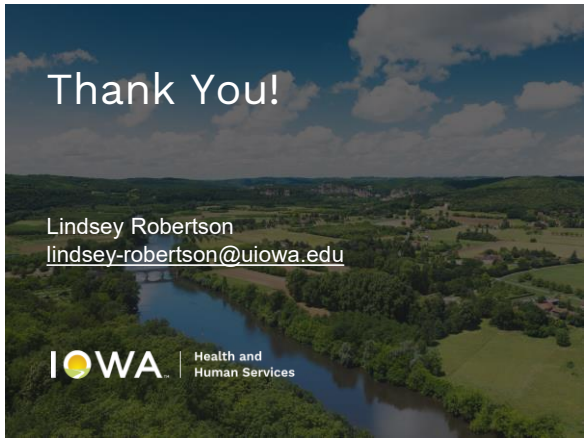

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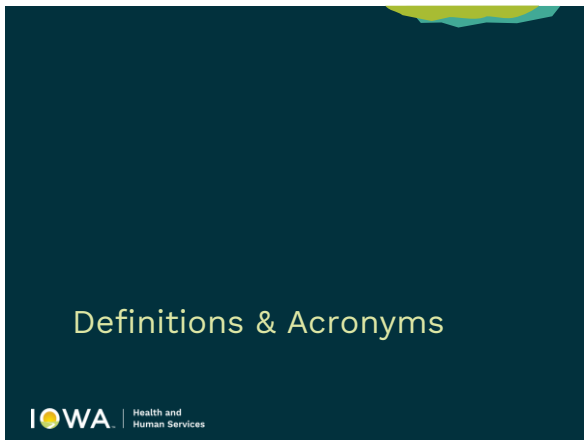

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Definitions (slide 1 of 3)

Term	Definition
IDT Meeting	• Service planning meeting held at least annually, when goal changes are needed • Identify who it consists of (grab from MCO governing documents)
Team meeting (not IDT meeting)	Team follow up meeting to check in, address acute concerns, etc.
Monthly face-to-face	Informal visit between MFP participant and Transition Specialist
Transition and Service Plan	MFP person centered planning document to support transition planning and service delivery throughout the Demonstration Year

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Definitions (slide 2 of 3)

Term	Definition
Demonstration Year	• The 365 days of services and supports, beginning the day the individual discharges from a Qualifying Facility, paid by the Money Follows the Person program
Qualifying Facility	• ICF/IDs, Nursing Facilities, PMICs, and inpatient hospital settings

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Definitions (slide 3 of 3)

Term	Definition

Qualified Residence	• As defined by section 6071(b)(6) of the DRA the term "qualified residence" means, "with respect to an eligible individual":
	  • a home owned or leased by the individual or the individual's family member;
	  • an apartment with an individual lease, with lockable access and egress, and which includes living, sleeping, bathing, and cooking areas over which the individual or the individual's family has domain and control; and
	  • a residence, in a community-based residential setting, in which no more than 4 unrelated individuals reside.

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Acronyms (slide 1 of 2)

Acronym	Details
IDT	Interdisciplinary Team
MFP	Money Follows the Person
MCO	Managed Care Organization
CM	Case Manager
TSS	Transition Specialist Supervisor
TS	Transition Specialist
PD	Project Director
FFS	Fee For Service
CSR	Continued Stay Review

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Acronyms (slide 2 of 2)

Acronym	Details
ICF/ID	Intermediate Care Facility for People with Intellectual Disabilities
NF	Nursing Facility
PMIC	Psychiatric Medical Institutes for Children
HCBS	Home and Community Based Services

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