

3-2013

Providing Long Term Services & Supports to People with Impaired Decision-Making Capacity: Results of Data Analysis and Interviews Examining Needs and Characteristics of Persons with Impaired Decision-Making Capacity in Maine.

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Griffin E, Olsen L, Fralich J. Providing Long Term Services & Supports to People with Impaired Decision-Making Capacity: Results of Data Analysis and Interviews Examining Needs and Characteristics of Persons with Impaired Decision-Making Capacity in Maine. Portland, ME: University of Southern Maine, Muskie School of Public Service; March, 2013.

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March 2013

MUSKIE SCHOOL OF PUBLIC SERVICE



UNIVERSITY OF
SOUTHERN MAINE

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Acknowledgments

Acknowledgments

We would like to thank the following people who generously made the time to be interviewed. This document attempts to reflect the insight and expertise they shared with us.

Goold Health Systems

Lorraine Lachapelle, Director
Community Assessment Programs

Maine Long-Term Care Ombudsman Program

Brenda Gallant, Executive Director
Pam Marshall, Program Manager

Elders Independence of Maine

Betsy Sawyer-Manter, Executive Director
Gretchen Zeh-Higgins, Care Coordination Manager

Alzheimer's Association, Maine Chapter

Laurie Trenholm, Executive Director
Lisa Corson, Helpline Coordinator

Alpha One

Betsy Grass, Southern Regional Manager

Maine Legal Services for the Elderly

Denis Culley, Staff Attorney

Catholic Charities Maine

Don Harden, Program Director
Independent Support Services

Maine Department of Health and Human Services

Rick Mooers
Adult Protective Services

The authors would also like to acknowledge with gratitude the role of Vanessa Bell, a former employee at the Muskie School. Vanessa's passion for the rights of persons with disabilities was the driving force behind this project. She participated in conceptualizing the project, designing the study, and conducting interviews, before leaving the Muskie School to follow her passion by starting her own business.

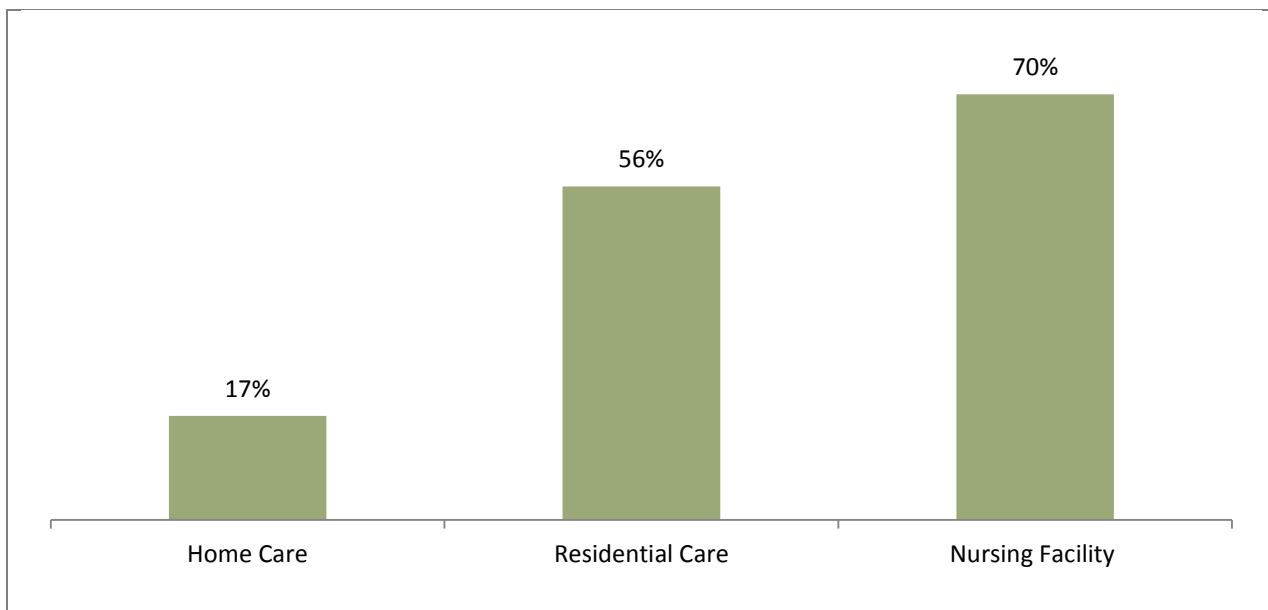
Introduction

Many of the ethical, legal and common sense principles underpinning our society are built on the assumption that each individual is an autonomous agent, with the responsibility and the authority to make his or her own decisions. For example, in normal circumstances, a health care provider cannot decide what treatment to provide a patient without first obtaining that patient's informed consent. An adult daughter cannot decide it is time for her elderly father to sell his house, if her father is able to make that decision for himself.

However, when an individual's ability to make decisions is impaired because of dementia, intellectual disability, brain injury, mental illness or another condition, respect for individual autonomy has to be balanced against the need to protect an individual from harm or exploitation.

Decision-making capacity has important implications for Maine's long term services and supports (LTSS) system. Figure 1 shows the prevalence of impaired decision-making capacity among persons receiving LTSS in Maine in State Fiscal Year 2011; 17 percent of people receiving home care services, 56 percent of people receiving residential care services and 70 percent of nursing facility residents have either moderate or severely impaired decision-making capacity.¹

Figure 1. Percent of Service Recipients with Impaired Decision-Making by the Setting in Which They Receive Services



Notes: Nursing facility service recipients, n = 5097. Residential care service recipients, n = 3908. Home care service recipients, n = 4198.

As the number of older adults and adults with disabilities grows, the prevalence of impaired decision-making capacity is also likely to grow. In this document we focus on two issues relating to decision-making capacity:

The decision-making capacity necessary to maintain independence and live at home. Impaired decision-making capacity can impact a person's ability to live independently, if an impairment limits a person's ability to drive, manage money or medications, grocery shop, prepare meals, keep house, or perform other

¹ For the purpose of this document, we have defined "impaired decision-making capacity" to include persons who have moderately or severely impaired decision-making capacity, as determined in a clinical assessment. We have defined persons with independent decision-making capacity to include persons with independence or modified independence in decision-making capacity.

important tasks. Severe impairment can limit a person's ability to perform more basic tasks, such as eating, bathing, personal hygiene, and other activities of daily living.

It is difficult to generalize about the impact impaired decision-making capacity might have on a person's ability to live at home safely. Independence might depend on a combination of factors, including the severity and nature of the impairment, the home environment, and the level and type of support available from family or friends, or paid workers. The fact that an impairment can change over time adds to the complexity – impairment might be episodic, relating to fluctuations in an illness, such as a mental illness, or progressive, growing more severe as an illness progresses.

Because a person with a decision-making impairment is more likely to require ongoing monitoring to assure safety, persons with this kind of impairment are more likely to need oversight and supervision – services often provided by a residential or nursing facility. As Maine's population ages, and the number of people with impaired decision-making capacity grows, it will be important to find less expensive alternatives to residential and nursing facility care. Family members, informal caregivers, and direct care workers make it possible for people with impaired decision-making capacity to live successfully at home. As the disease progresses, the need for supervision and support increases and the ability to live at home, particularly alone or without support, becomes more challenging.

This document:

- Reviews the prevalence of impaired decision-making capacity among adults and older adults receiving publicly funded home care services and supports in Maine, the characteristics of this population group, and the caregivers caring for persons with impaired decision-making capacity.
- Reports on interviews with providers describing their ideas for helping people with impaired decision-making capacity live in the community longer.

The decision-making capacity to provide informed consent. Older adults and adults with disabilities are often faced with important decisions about the services and supports they need. Some of these decisions are health care decisions about the kind of treatment they should have and who should provide it. In addition, many people are also faced with personal decisions about who to allow into their homes to provide personal assistance. In some cases, an individual with a high level of need may have to choose between remaining at home or moving into a residential setting or nursing facility. LTSS providers are responsible for recognizing when decision-making ability might or might not be impaired and navigating the challenging emotional, ethical and legal issues that arise when decisions about care need to be made.

This document:

- Reviews the legal status of persons receiving long term services and supports in Maine, including the presence of a guardian or a Power of Attorney, among those with impaired decision-making capacity across settings.
- Reports on interviews with providers, describing kinds of issues they encounter as they serve persons with impaired or deteriorating decision-making capacity.

Methodology

Data Analysis

Data Sources

We used the following data sources to identify characteristics of persons with impaired decision-making capacity in Maine's LTSS system:

Characteristics of Persons Receiving Home Care: Medical Eligibility Determination assessment data MeCare FY2011 (N=4198). Persons seeking long term services and supports are assessed for functional eligibility for various publicly funded programs using the state's Medical Eligibility Determination (MED) assessment. RN assessors visit the person to assess their need for in-home or institutional support. The MED assessment includes data on the amount of help people need with activities of daily living, behavioral health, cognitive status, short and long term memory and degree of impaired decision making.

Characteristics of Persons Receiving Residential Care Services: MDS RCA Roster 9/15/2011 (N=3908). People in residential care settings in Maine are assessed upon admission to a facility and annually thereafter to determine their needs, goals and service plans. Like the MDS assessment instrument in nursing facilities, the MDS RCA includes data on the amount of help people need with activities of daily living, behavioral health, cognitive status, short and long-term memory and degree of impaired decision-making. Other demographic information is also captured.

Characteristics of Persons Receiving Nursing Facility Services: MDS Roster 9/15/2010 (N=5104). People in nursing facilities in Maine are assessed upon admission to a nursing facility, and on a quarterly basis thereafter to determine their needs, goals and service plans. Like the MDS assessment instrument for residential care facilities, the MDS includes data on the amount of help people need with activities of daily living, behavioral health, cognitive status, short and long-term memory and degree of impaired decision-making. Other demographic information is also captured.

The definitions and codes used in the MED assessment instrument and the MDS and MDS RCA are consistent for many of the data elements allowing for cross site comparisons on items such as decision-making capacity.

Definition of Terms

Decision-Making Capacity

A number of conditions can influence decision-making capacity, including conditions that impair short-term or long-term memory, concentration, planning, and judgment and other cognitive functions. For some, the need is life long, starting at birth, with an intellectual disability for example. For others an impairment may be acquired later in life, the result of illness, injury or other factors. People with dementia are often identified as a particularly vulnerable group. Persons who experience a stroke or have certain chronic health conditions may also experience impaired decision-making capacity that impacts their ability to make decisions.

To measure impaired decision-making, this brief relies on MED/MDS assessment data that measures skills for daily decision-making.

Using the standard assessment tool for people who are accessing home and community based services in Maine, nurses assess the decision-making ability of people at home. Decision-making capacity is scored on a scale of 0 to 3. People who are considered independent or moderately independent in decision-making score a 0 or 1. People whose decision-making capacity is considered moderately impaired or severely impaired are scored as a 2 or 3. For purposes of this discussion, we examine people with impaired decision-making (score of 2 or 3) regardless of whether they have dementia or not.

Independent in Decision-Making: includes people who scored a 0 (independent) or 1 (modified independence) in daily decision-making.

Impaired Decision-Making: includes people who scored a 2 (moderately impaired) or 3 (severely impaired).

Hierarchy of Decision-Making Support

As part of the assessment process, people are asked whether they have a legal guardian, a health care proxy or durable power of attorney, or have no legal guardian or health care proxy. Some people may have both a legal guardian and a health care proxy or durable POA. For purposes of this analysis, we created a hierarchy and placed people in one of the following groups, with anyone having a legal guardian being placed in that category first:

- Legal Guardian
- Health Care Proxy – Durable Health POA
- No guardian or health care proxy

Interviews

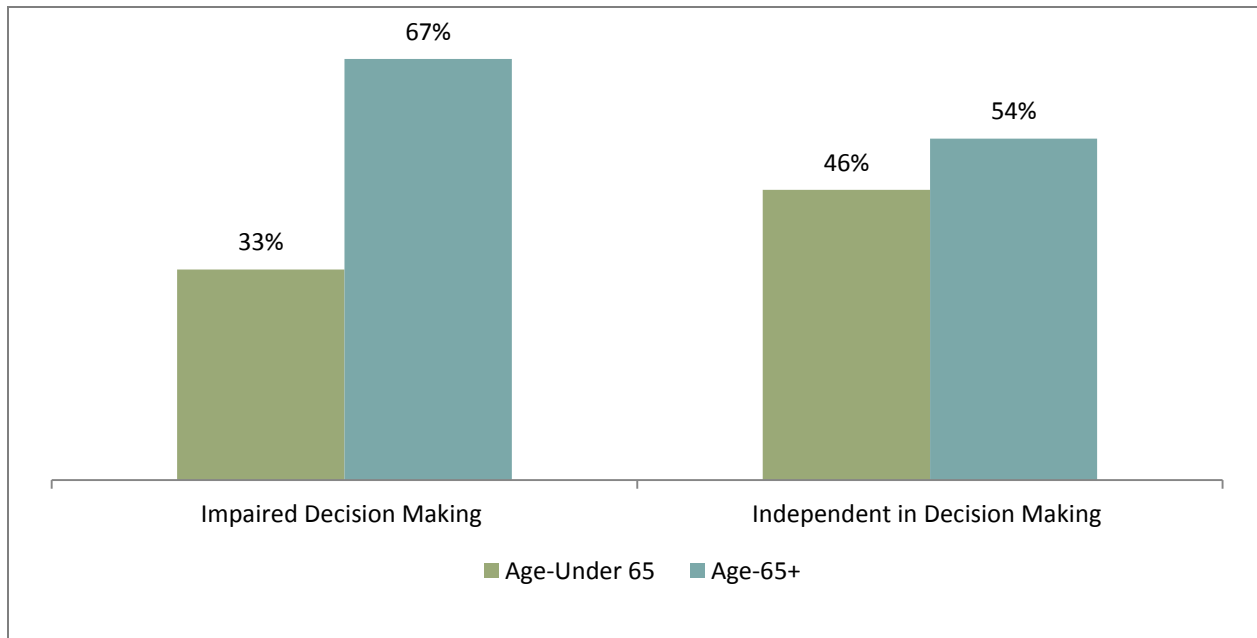
We interviewed providers and advocates to better understand the experience of providing services to persons with impaired decision-making capacity. These interviews were conducted May and June 2012.

Impaired Decision-Making Capacity and Living at Home

This section provides an overview of the characteristics of persons receiving home care services who have impaired decision-making capacity and the supports they receive from informal caregivers. We also report on interviews with providers and advocates.

Demographic Characteristics

Figure 2. Percent of People with Impaired Decision-Making Capacity by Age

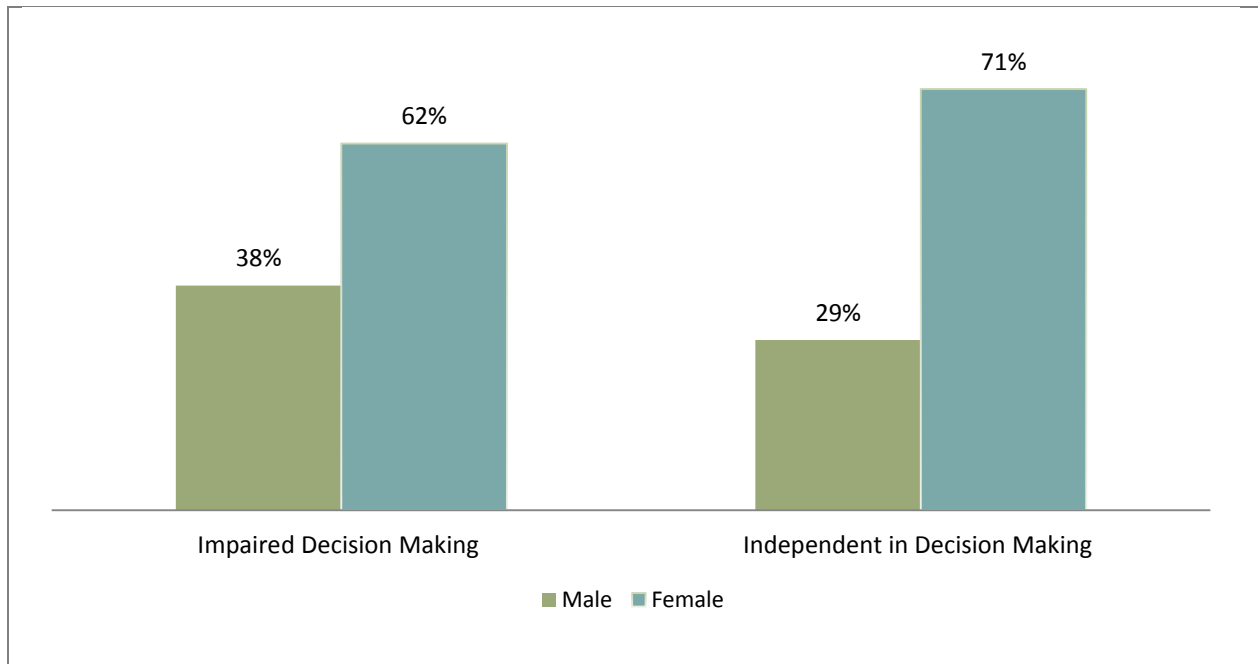


Medical Eligibility Determination Assessment Data MeCare FY2011. Independent Decision-Making n = 3469; Impaired Decision-Making n = 729.

Age

Among persons receiving home care services, people with impaired decision-making are more likely to be older: in 2011, 67% of those with impaired decision-making receiving services at home (N= 729) were older (age 65 and up) compared to 54% of those who were independent in decision-making (N= 3469).

Figure 3. Percent of People with Impaired Decision-Making Capacity by Gender

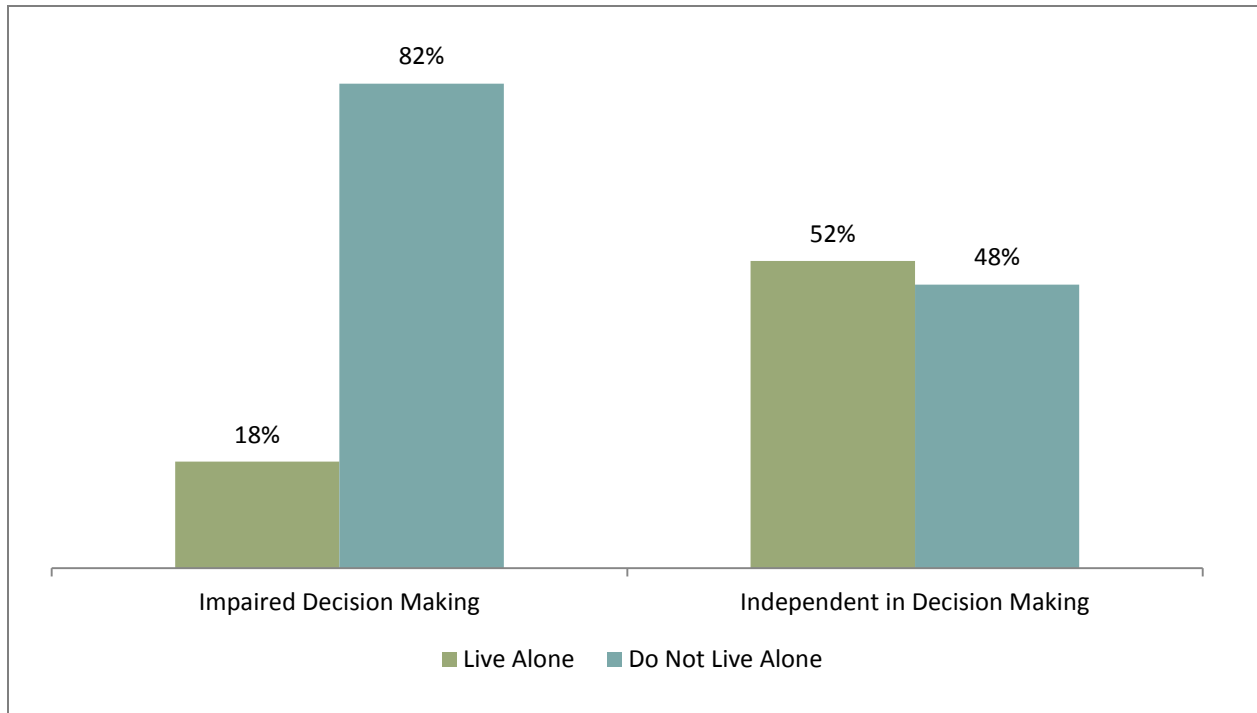


Medical Eligibility Determination Assessment Data MeCare FY2011. Independent Decision-Making n = 3469; Impaired Decision-Making n = 729.

Gender

While people receiving home care are more likely to be female, the ratio of male to female increases for persons with impaired decision-making capacity, relative to persons with independent decision-making capacity: among persons with impaired decision-making capacity, 38 percent were male compared to 29 percent for persons with independent decision-making capacity.

Figure 4. Percent with Impaired Decision-Making Capacity Who Live Alone or With Someone Else

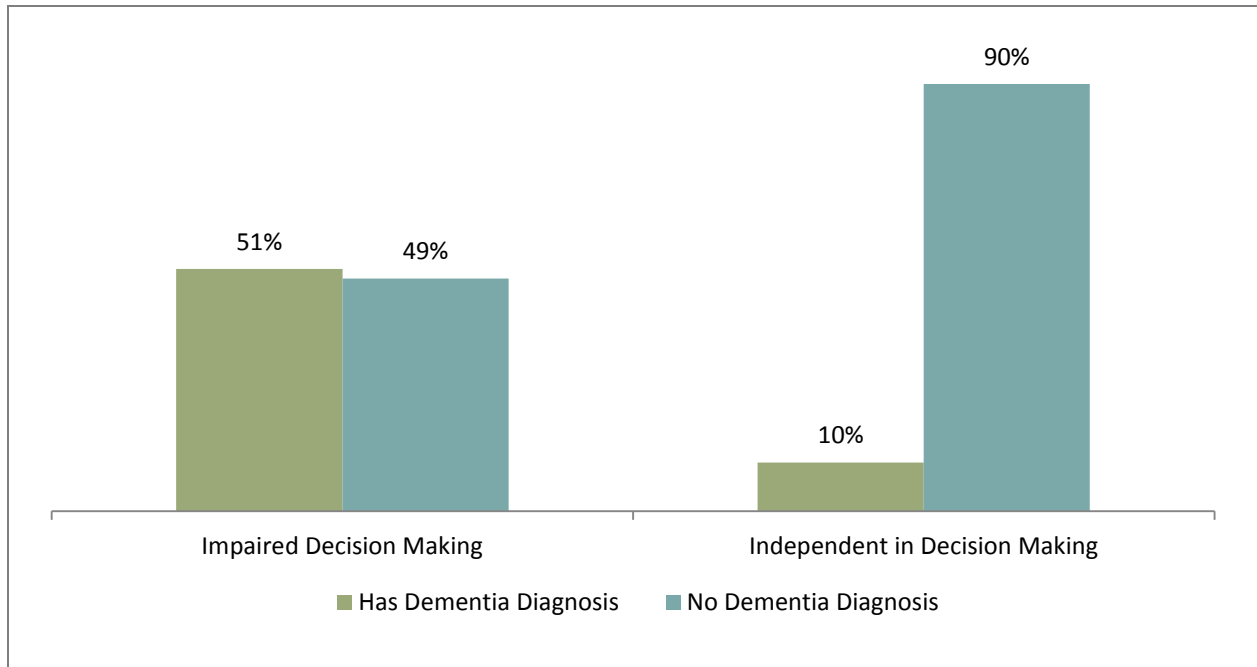


Medical Eligibility Determination Assessment Data MeCare FY2011. Independent Decision-Making n = 3469; Impaired Decision-Making n = 729.

Living Alone

The majority of those with impaired decision-making capacity live with someone else: only 18% live alone (n = 131).

Figure 5. Dementia Diagnosis Among Persons with and without Impaired Decision-Making Capacity

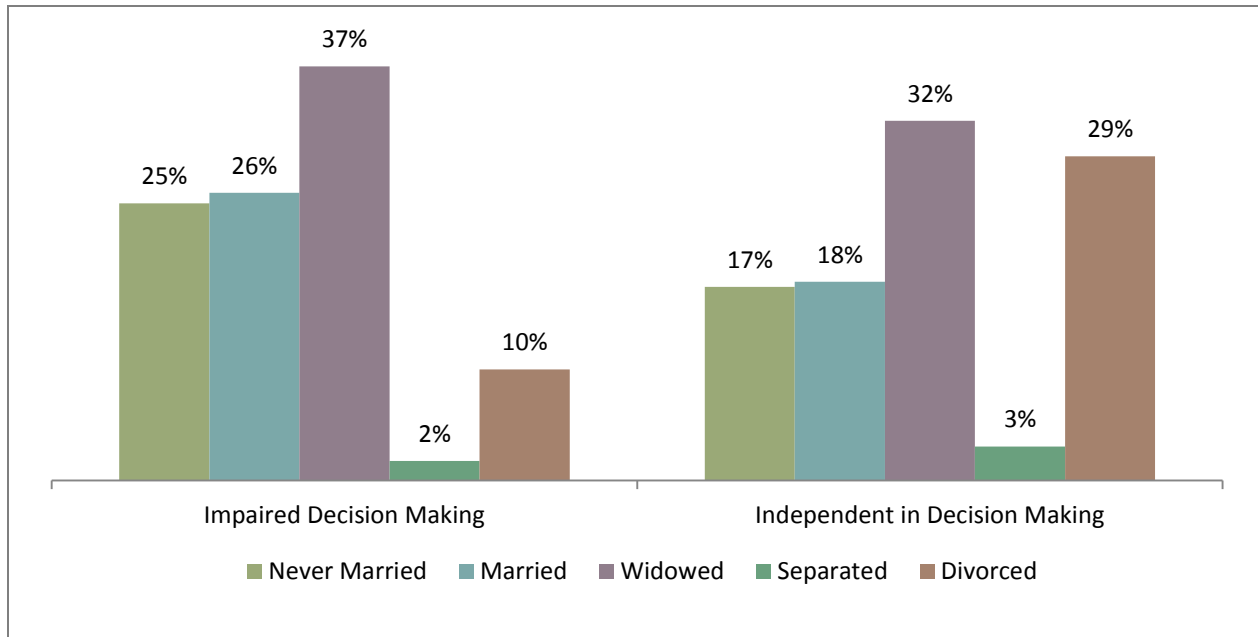


Medical Eligibility Determination Assessment Data MeCare FY2011. Independent Decision-Making n = 3469; Impaired Decision-Making n = 729.

Dementia

Just over half of those with impaired decision-making capacity have a dementia diagnosis, including both Alzheimer's and dementia other than Alzheimer's. Almost half of those with impaired decision making capacity have no dementia diagnosis, highlighting the need for decision making and caregiver support for all persons with impaired decision making capacity, not just those with Alzheimer's or another dementia.

Figure 6. Marital Status of Persons with and without Impaired Decision-Making Capacity



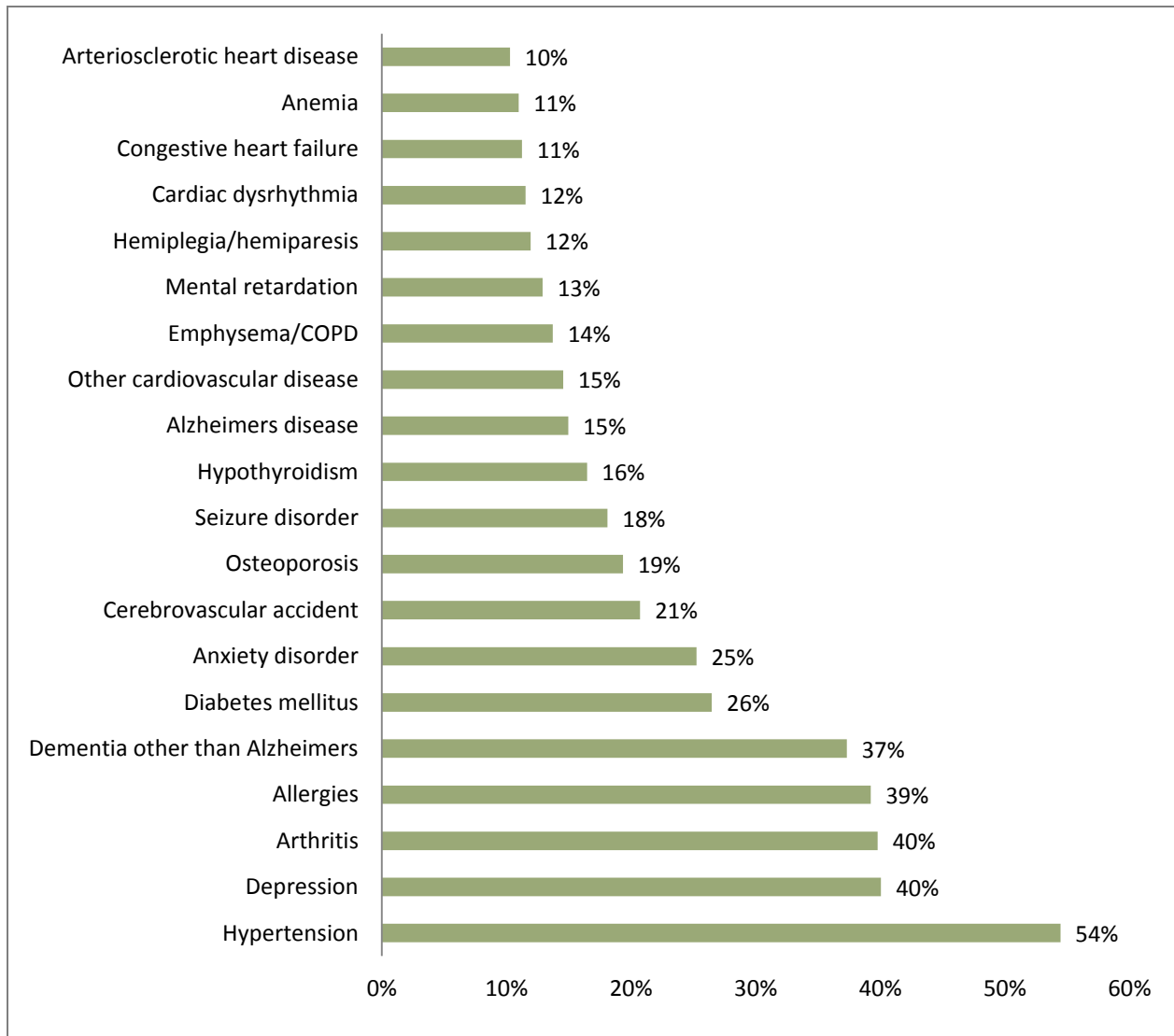
Medical Eligibility Determination Assessment Data MeCare FY2011. Independent Decision-Making n = 3469; Impaired Decision-Making n = 729.

Marital Status

Of those with impaired decision-making capacity living at home, only 26 percent are currently married, 37 percent are widowed, and 25 percent have never been married.

Health and Other Conditions

Figure 7. Top Twenty Chronic Conditions for Those with Impaired Decision-Making

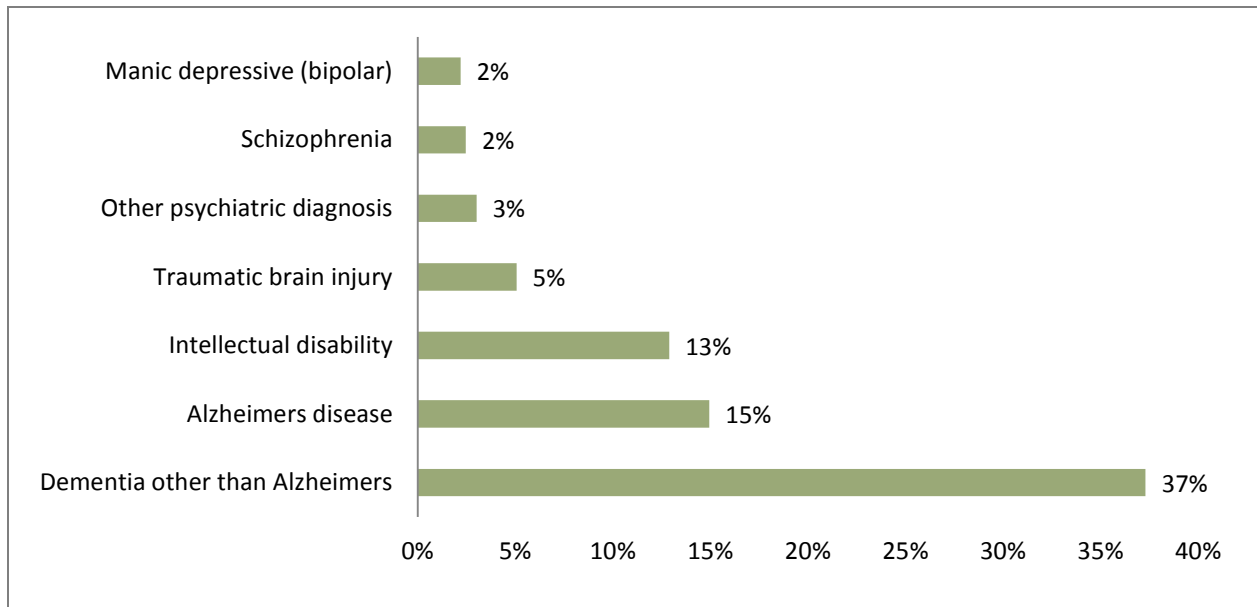


Medical Eligibility Determination Assessment Data MeCare FY2011; n = 729.

Chronic Conditions

Figure 7 identifies the top twenty chronic conditions among those with impaired decision-making capacity. Many people living at home with impaired decision-making capacity also have one or more chronic illnesses. Chronic conditions often require medical management to prevent deteriorating health status and unnecessary utilization of hospital and other services.

Figure 8. Conditions Affecting Decision-Making Capacity

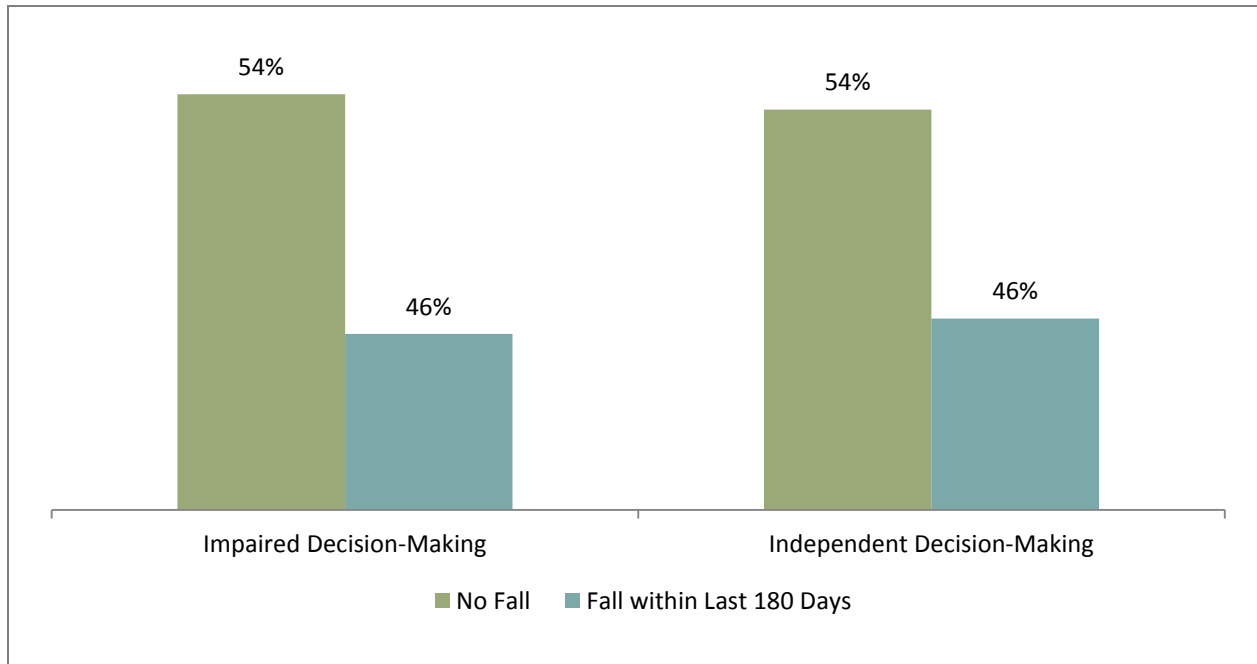


Medical Eligibility Determination Assessment Data MeCare FY2011; n = 729.

Conditions Affecting Decision-Making Capacity

Among persons receiving home care services with impaired decision-making capacity, Alzheimer’s and dementia other than Alzheimer’s are the two most prevalent conditions affecting decision-making capacity. See Figure 8. Figure 8 also presents data on the prevalence of intellectual disability, traumatic brain injury, and mental illness among those receiving home care, other conditions affecting decision-making capacity.

Figure 9. Fall within Last 180 Days by Decision-Making Capacity



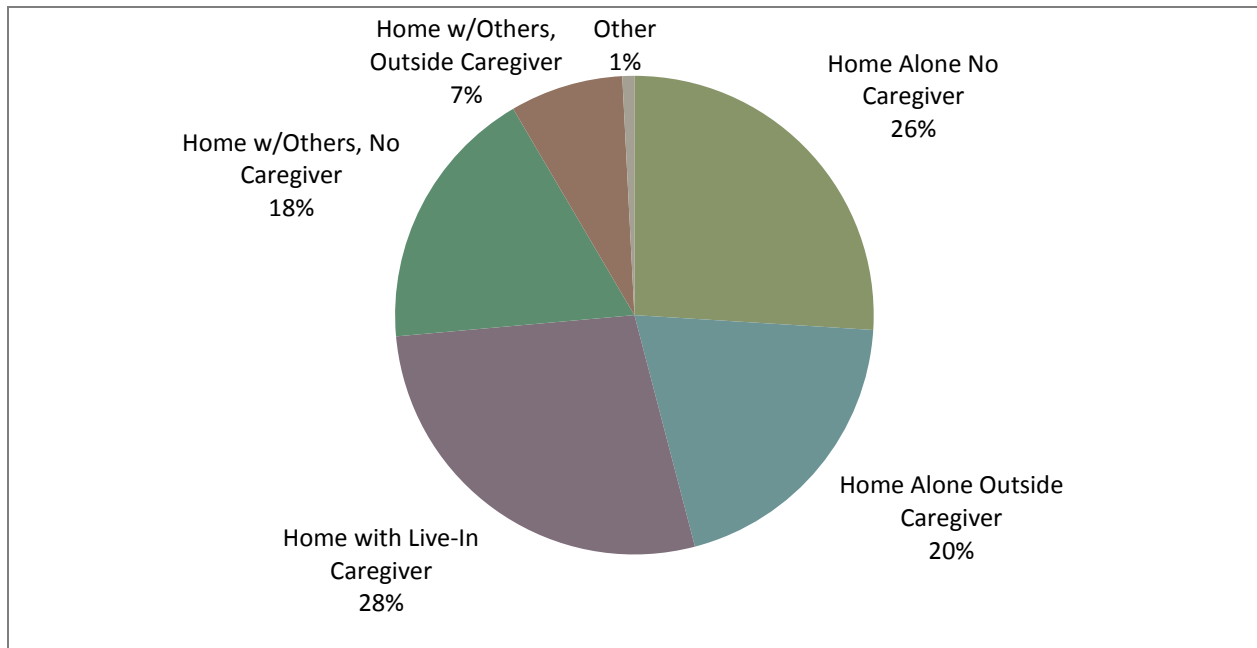
Medical Eligibility Determination Assessment Data MeCare FY2011. Independent Decision-Making n = 3469; Impaired Decision-Making n = 729.

Falls

Falling is another measure of vulnerability for older adults and persons with disabilities. Figure 9 indicates that for Maine’s home care service users, persons with impaired decision-making capacity do not experience a greater likelihood of falling than persons with independent decision-making capacity.

Caregiver Characteristics

Figure 10. Caregiver Support for All Home-Care Participants

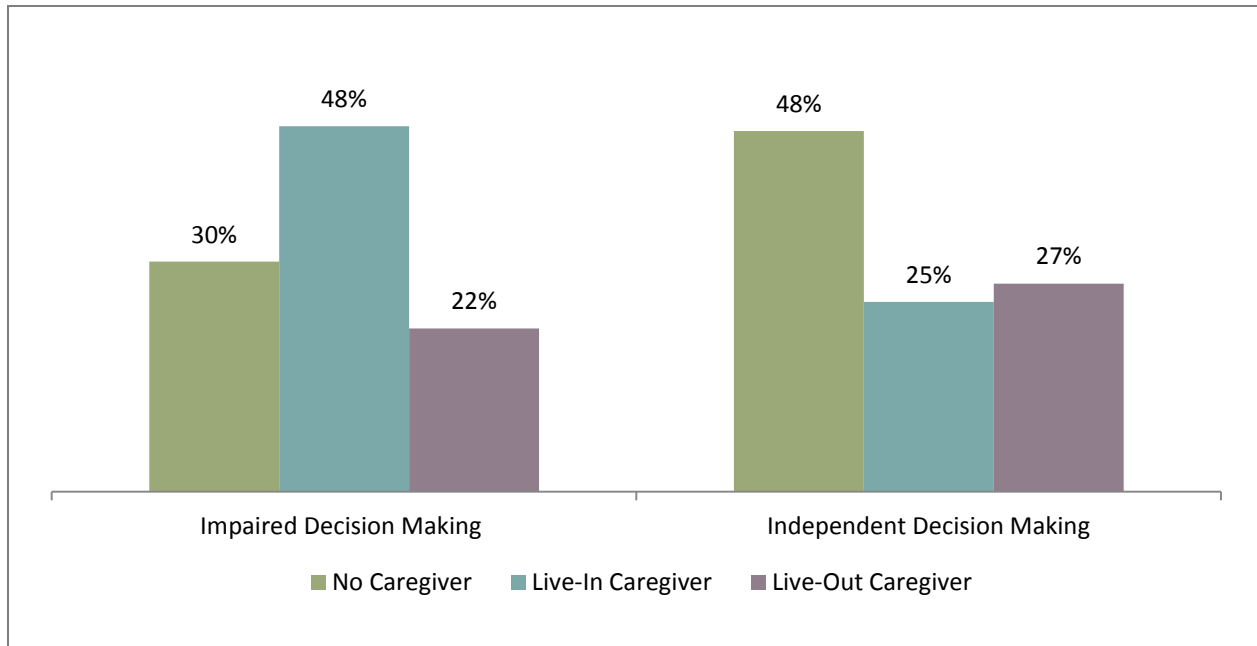


Notes: N = 4198.

Access to Informal Caregivers among Home Care Participants

Over half (55%) of the people receiving home care services also have an informal caregiver to provide support. Of those, 28% live with the person receiving home care. Almost half of home care participants (44%) have no informal caregiver.

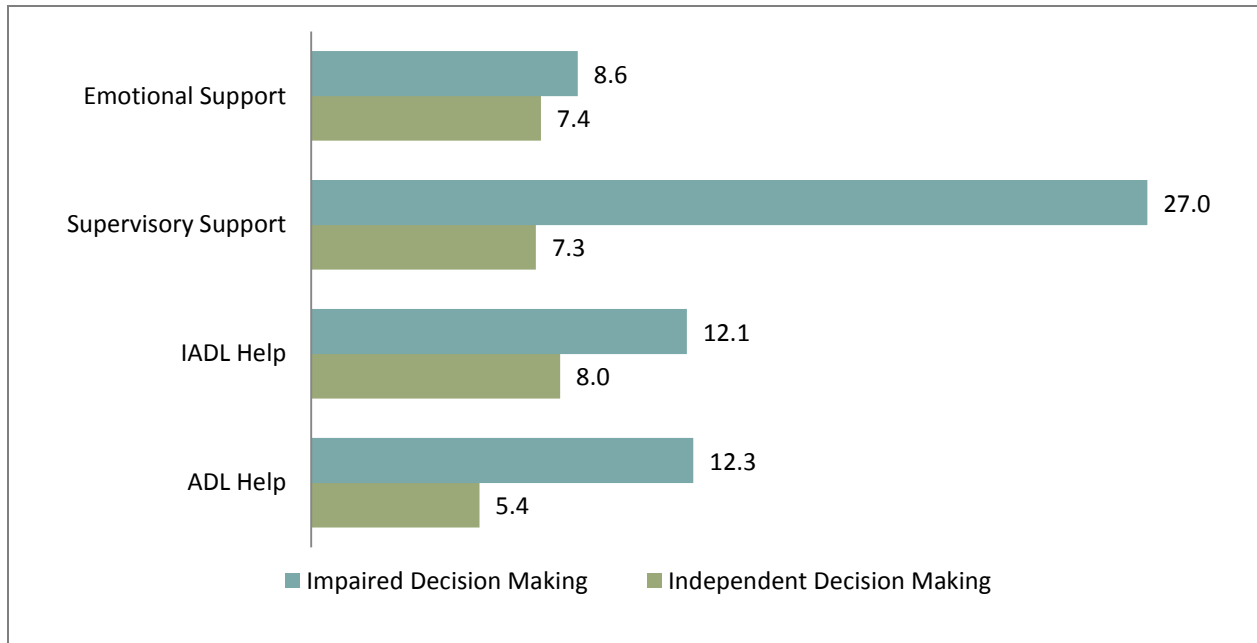
Figure 11. Caregiver Support by Decision-Making Capacity



Medical Eligibility Determination Assessment Data MeCare FY2011. Independent Decision-Making n = 3469; Impaired Decision-Making n = 729.

People with impaired decision-making capacity are more likely to have an informal caregiver: 48% have a live-in caregiver, 22% have an informal caregiver who lives outside the home.

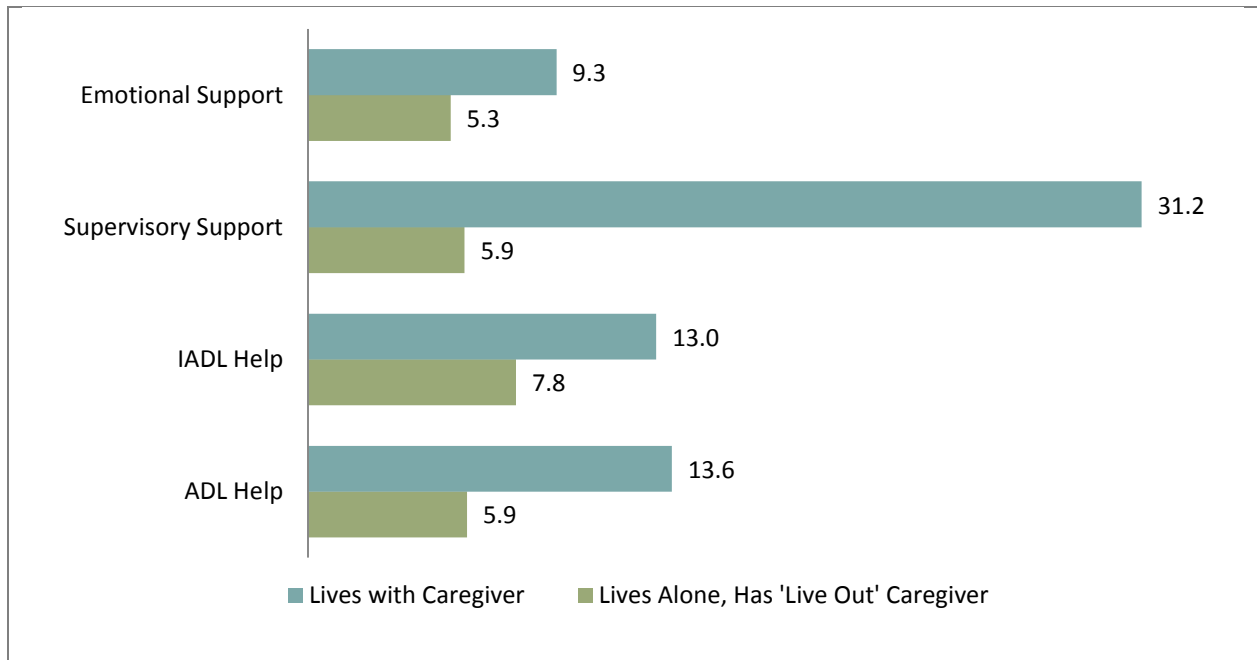
Figure 12. Average Hours of Caregiver Support Per Week by Decision-Making Capacity



Notes: Among persons with identified caregiver, n = 2328.

Informal caregivers provide on average 27 hours per week of supervisory support to persons with impaired-decision making capacity. This group also tends to need higher levels of emotional support, and IADL and ADL assistance.

Figure 13. For Persons with Impaired Decision-Making Capacity, Average Hours of Caregiver Support Per Week by Whether Caregiver Lives in Home



Notes: Persons with impaired decision-making capacity who receive home care and live with their caregiver, n = 424. Persons with impaired decision-making capacity who receive home care, live alone and have a “live out” caregiver, n = 84.

Of those with impaired decision-making capacity, the level of support received from informal caregivers is significantly greater when the caregiver lives with the person who has impaired decision-making capacity (n = 424).

Helping People with Impaired Decision-Making Capacity to Live at Home

We talked to providers and advocates to learn about what Maine could do to better serve persons with impaired decision-making who live at home. Four key themes emerged from these interviews:

1. Maine needs to have better systems in place for monitoring people with impaired decision-making who live on their own.
2. Maine can prevent or delay nursing facility admission for many people by increasing the availability of homemaker and other low cost alternative home and community-based services.
3. Maine needs more options for intervening early to prevent problems from escalating.
4. Maine needs better worker training for serving people with impaired decision-making.

The findings from these interviews are summarized below.

Monitoring Safety

For some people, impaired decision-making can present a clear threat to safety. A person with memory problems or confusion might leave stove burners on unattended, become confused about which medications to take when, or forget to pay bills or take care of their home. People with impaired decision-making are at greater risk of self-neglect and of being neglected, exploited or abused by others. The providers we interviewed look for signs of a problem including indications that the individual is not looking after a pet or taking care of themselves or their home, or signs of fearful behavior around others in the home.

Our interviewees see a high number of people with cognitive problems living on their own, without any informal supports. Paid providers might be in a home for as few as two hours each week, providing only a limited time to observe how well that individual is functioning. Neighbors and landlords can sometimes be counted on to identify people who need help, but not always. We heard several suggestions for how Maine could do more to make sure a person living on their own remains safe:

- Develop better connections with police and the postal service to create a more systematic way of identifying people experiencing difficulty.
- Use in-home monitoring technology.
- Conduct daily check-ins by phone.

Less Expensive Alternatives to Nursing Facility Care

There was general consensus among those interviewed that many people with impaired decision-making end up in a nursing facility when they could live at home with less expensive services. When others are not available to help, the following services were identified as low cost and effective strategies for preventing or delaying nursing facility admission:

- Independent support services (also known as homemaker services), such as assistance with grocery shopping and meals, and other household chores and errands.
- Money management, such as paying bills and managing accounts. Some of Maine's area agencies on aging sponsor volunteer money management programs although these services are not available statewide.
- Medication management, including daily phone calls to make sure medications are taken on schedule.

- Independent living adaptations (e.g., calendars and other triggers) to compensate for memory loss or other deficits.

Some of the providers we talked to were concerned that some people can only access homemaker services if they also accept personal care services, such as assistance with bathing. This requirement can create a barrier to access: a homecare worker may need to work with an individual for a long time before they agree to assistance with a bath or other personal care.

Several of those interviewed noted that independent support services, which are funded with state dollars only, are particularly vulnerable to budget cuts, although these services can actually save Maine money overall.

Adult day services were identified as another important low cost community-based service. Family caregivers can play an important role in helping a person stay in their own home. However, taking care of someone who needs 24-hour supervision can take a toll, and caregiver burn-out often leads to nursing facility admission. Adult day services provide caregivers respite, helping to delay or prevent nursing facility admission.

One provider noted that adult day services are not for everyone or available in all parts of the state. Ideally, in-home supervision would be a covered service. Alternatively, small (i.e., no more than four beds) residential settings were identified as an efficient way to provide supervision and still provide a familiar, homelike setting not typically available in a nursing facility.

Intervening Before a Problem Escalates

Providers are mandatory reporters whenever they suspect an incapacitated adult has been or is likely to be abused, neglected (including self-neglect) or exploited.² However, APS does not have statutory authority to intervene in all of these cases. If an individual is not an incapacitated adult, that is, if APS determines an individual understands the consequences of his or her choices even if those choices might be risky, APS cannot act. That means a person might not be taking care of themselves or their home, or someone might be exploiting them but, because they are competent, APS cannot intervene. We heard from one provider who believes that many of the people involved in these kinds of cases eventually come to harm that might have been prevented. This provider suggested that Maine implement an early intervention strategy similar to that employed by Child Protective Services – even when CPS does not have statutory authority to intervene, they can still make a referral for other early intervention services to prevent escalation further down the road.

Training for the In-Home Workforce

There was also general consensus that better training for direct service workers could help people with impaired decision-making live at home longer. Some providers believe direct service workers need a different set of skills to work with people with cognitive and behavioral health needs, to provide a more flexible and problem solving approach, adapted to each individual. Often impaired decision-making is associated with disruptive or inappropriate behavior. A worker understanding the behavior as a form of communication can sometimes avoid triggering that response or know what to do when it is triggered. A direct service worker unprepared to manage these kinds of situations can be putting the worker or the individual at risk.

² Maine statute defines an “incapacitated adult” as “any adult who is impaired by reason of mental illness, mental deficiency, physical illness or disability to the extent that that individual lacks sufficient understanding or capacity to make or communicate responsible decisions concerning that individual’s person, or to the extent the adult cannot effectively manage or apply that individual’s estate to necessary ends.” 22 M.R.S.A. §3472(10).

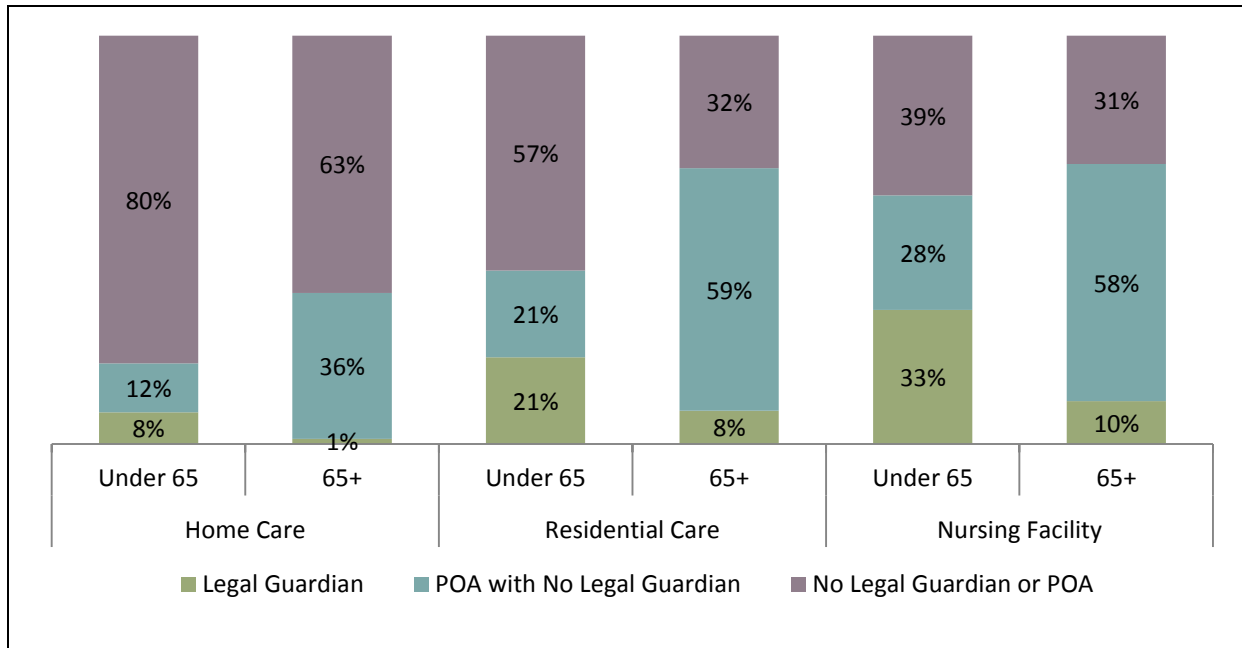
There is a growing sense that the needs of the home care population are significantly more complicated than they used to be. Partly, this can be attributed to people living longer and choosing to live at home longer. Some providers also believe that cuts to mental health services have increased the number of people with behavioral health needs in the older adult and adult service populations. One provider believes a mid-level professional, possibly someone with a bachelor's level social work degree, would be better prepared to serve people with the most complex cognitive and behavioral needs. This person pointed to the types of workers who provide services in the children's behavioral health system as comparable examples.

Finally, we heard from multiple sources that providers and workers need better training and reminders on the responsibilities under mandatory reporting laws. Many workers do not know that they are mandatory reporters and often mandatory reporters report to someone other than Adult Protective Services.

Legal Status and Informed Consent

This section provides an overview of the legal status of persons receiving long term services and supports in Maine and providers' recommendations for improving the process of obtaining informed consent for persons with impaired decision-making.

Figure 14. Presence of Legal Guardian or POA by Age and Setting Where Services are Received

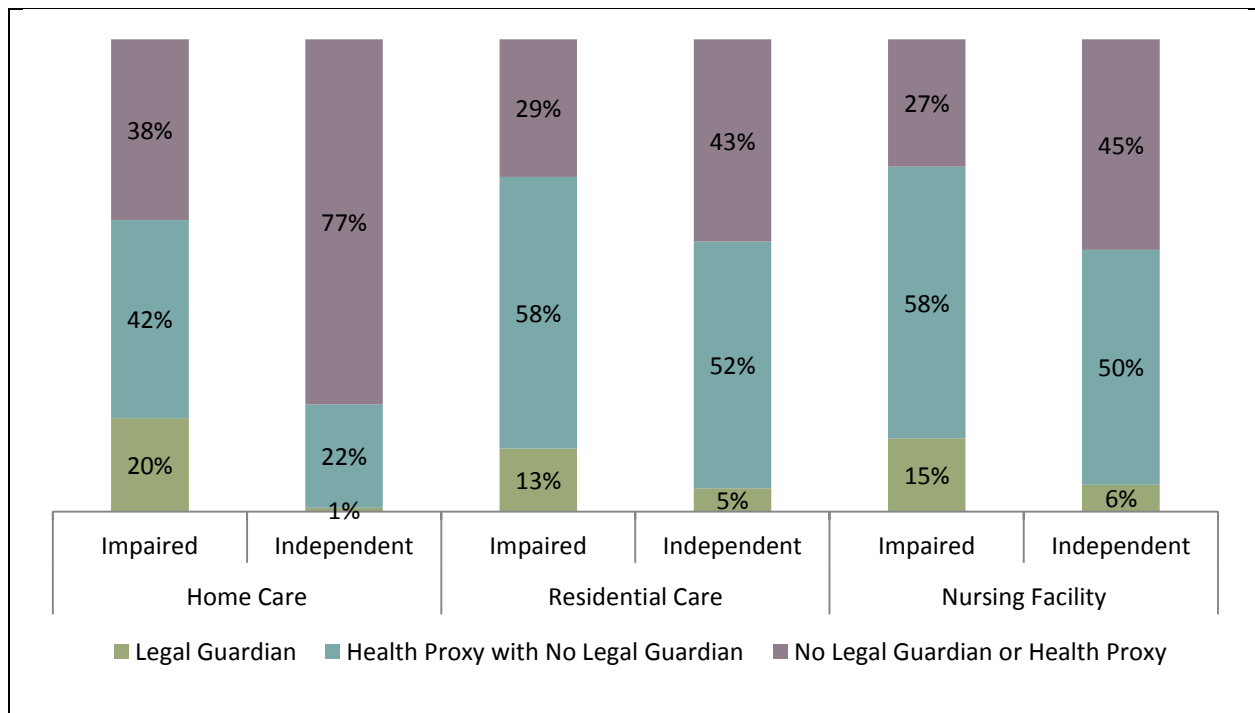


Notes: Persons receiving home care, under age 65, n = 1837; age 65 and older, n = 2361. Persons receiving residential care, under age 65, n = 433; age 65 and older, n = 3475; Persons receiving nursing facility services, under age 65, n = 496; age 65 and older, n = 4608.

Power of Attorney and Guardianship across Service Settings

The legal status of persons receiving long terms services and supports in Maine varies significantly across settings and age groups. Younger adults receiving services are more likely to have a guardian than older adults, in all settings. Persons in residential care and nursing facilities are more like to have a guardian or power of attorney (POA) than persons receiving home care.

Figure 16. Presence of Guardian or POA by Decision-Making Capacity and Setting Where Services are Received

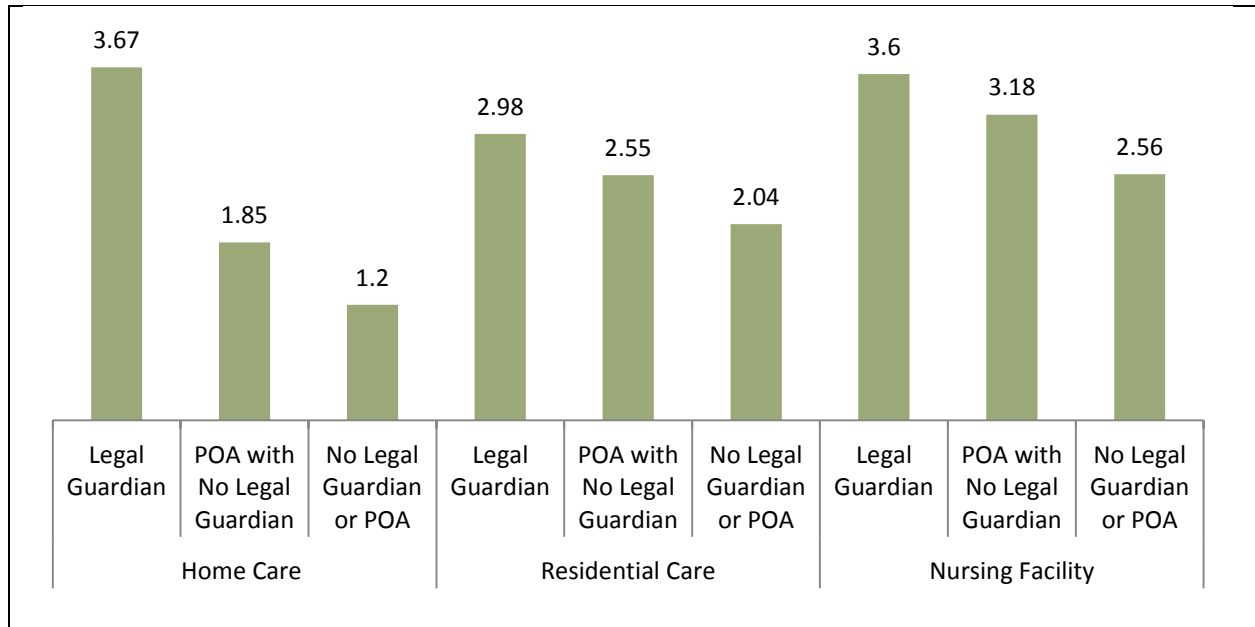


Notes: Persons receiving home care, with independent decision-making, n = 3469; with impaired decision-making, n = 729. Persons receiving residential care, independent decision-making, n = 1734, impaired decision-making, n = 2174. Persons receiving nursing facility services, independent decision-making, n = 1507; impaired decision-making, n = 3590.

Legal Status by Decision-Making Capacity Across

A significant portion of those with impaired decision-making capacity do not have a legal guardian or a POA in place. Thirty-eight percent of those with impaired decision-making capacity participating in home care are without either a legal guardian or POA.

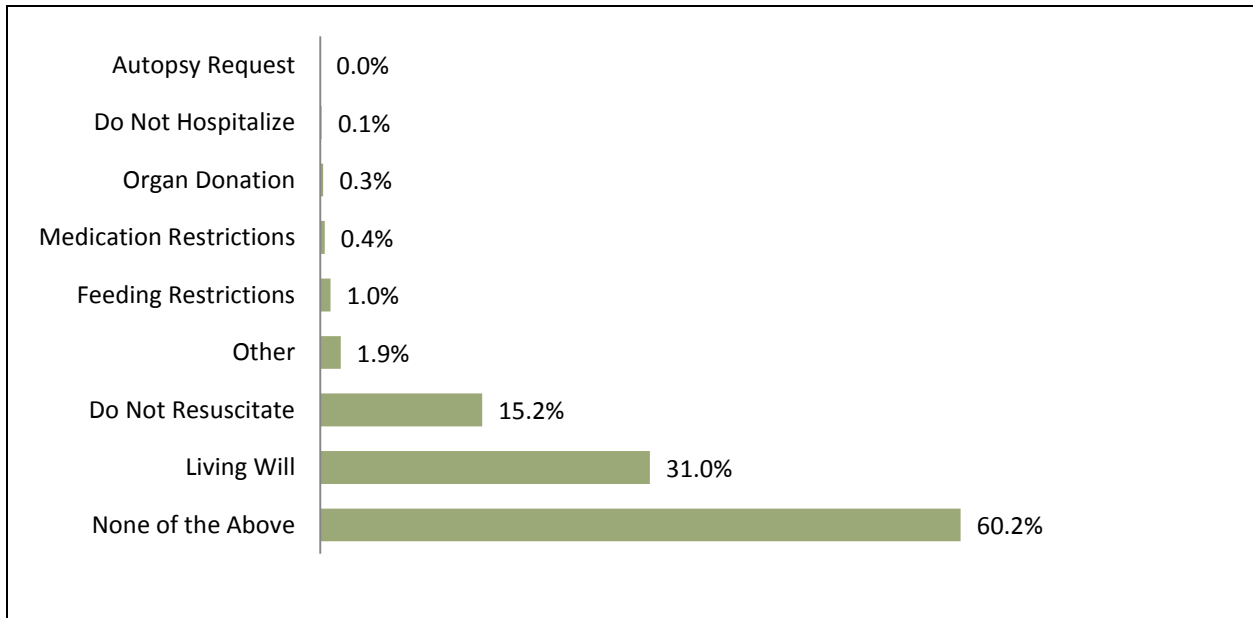
Figure 17. Average CPS Score by Presence of Guardian or POA and Setting Where Services Are Received



Notes: Nursing facility service recipients, n = 5097. Residential care service recipients, n = 3908. Home care service recipients, n = 4198.

The average CPS score is used to evaluate a person’s level of cognitive ability. The score is based on a combination of information about a person’s ability to make daily decisions, the person’s ability to make him or herself understood, memory impairment, and dependence in eating. CPS scores range from 0 (intact) to 6 (very severe impairment). The CPS score varies by setting and by legal status. Persons in nursing facilities have higher CPS scores on average than people receiving services in other settings. Persons with a legal guardian also are more likely to have a higher CPS score, on average, across settings. For people in the home care setting without a legal guardian or POA, the average CPS score is 1.2.

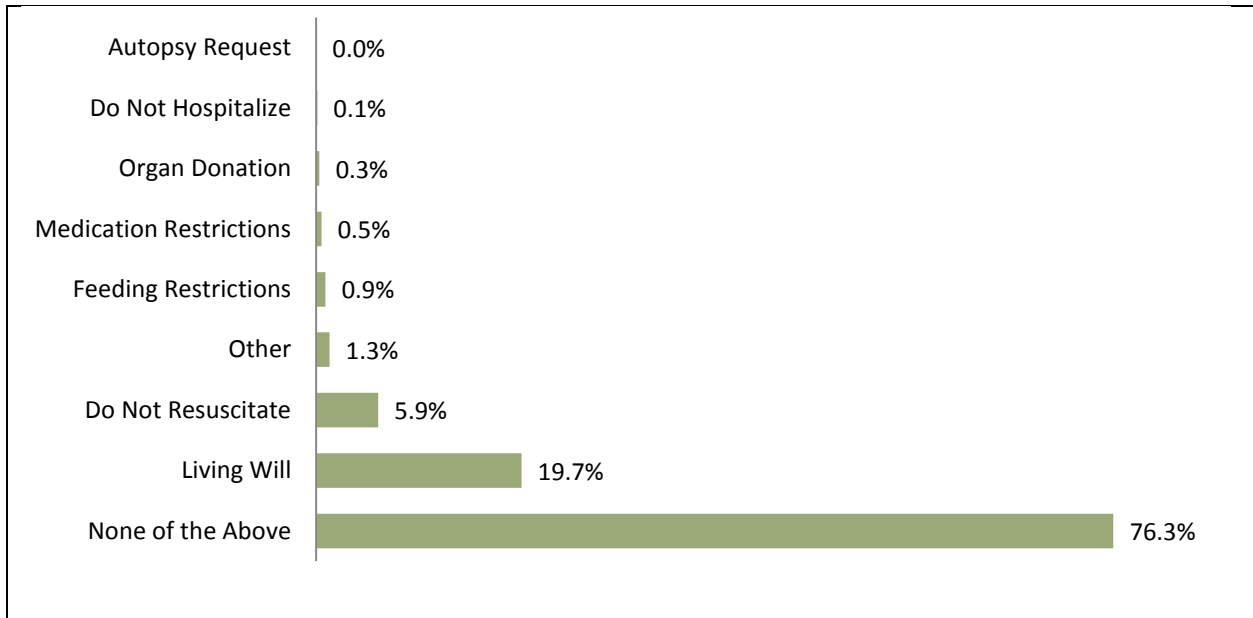
Figure 18. Type of Advanced Directive for Those With Impaired Decision-Making Capacity, Receiving Home Care Services



Medical Eligibility Determination Assessment Data MeCare FY2011; n = 729.

Among persons with impaired decision-making capacity who receive home care services, 31% have a living will, and 15.2% have a do-not-resuscitate order in place.

Figure 19. Type of Advanced Directive for Those Without a POA or Guardian, Receiving Home Care Services



Notes: Persons receiving home care with no POA or Guardian, n = 2961.

Among persons receiving home care who have neither a guardian nor a POA, few have advanced directives in order; 19.7% have a living will and 5.9% have a do-not-resuscitate order in place.

The Practical Challenges of Obtaining Informed Consent

Making decisions about the use of long term services and supports can be difficult for anyone, with or without impaired decision-making. Some people might resist care when others think care is needed. Some people might want to live at home when others think a higher level of care and support is needed. While some people might want to consult with others when weighing these kinds of choices, ethical principles and Maine law place the ultimate decision about care and services with the person who will be receiving them – assuming that person is mentally and physically competent to give consent.³

Informed consent might not be possible if an impaired decision-making limits the individual's ability to understand the consequences of a decision. Conversely, when an individual is able to understand the consequences of a decision, they are entitled to make a decision even if it is risky.

Decision-making capacity is often discussed as five different sub-capacities:⁴

Understanding: The ability to understand the facts associated with a decision.

Appreciation: The ability to appreciate the significance of the decision they are asked to make and how alternative choices are likely to impact that person's life.

Reasoning: The ability to weigh the risks and benefits associated with a decision.

Choice: The ability to express a choice, whether verbally or through gesture.

Values: The ability to apply a set of values to a range of choices, to order preference for one potential outcome over another.

Decision-making capacity is also contextual – capacity is determined relative to a particular decision, at a particular time, in a particular context.⁵ Where the risk associated with a choice is greater the degree of necessary decision-making capacity might be higher. For example, a person might have the capacity to decide what to eat and when but might not have the capacity to make other decisions with higher levels of risk associated with them.

For Maine's LTSS providers, honoring the right to informed consent can sometimes be challenging. We interviewed a number of providers and advocates to learn more about the situations they confront and whether they have the resources and authority they need to handle challenging situations. This summary addresses several types of situations:

- When an individual is able to make decisions for him or herself but family members disagree with their choices.
- When an individual is not able to make decisions but he or she does not have anyone to act as a surrogate, agent or guardian.
- When an individual has a Power of Attorney.
- When an individual has a Guardian.

Emerging from these conversations are several recommendations:

- Maine LTSS providers and advocates need a better understanding of how Maine law governing surrogate decision-making operates. It is possible that surrogacy law may need to be modified

³ 24 M.R.S.A. §2905.

⁴ See, e.g., Charland, Louis, "Decision-Making Capacity", *The Stanford Encyclopedia of Philosophy (Summer 2011 Edition)*, Edward N. Zalta (ed.), URL = <<http://plato.stanford.edu/archives/sum2011/entries/decision-capacity/>>.

⁵ Ibid.

to provide Maine LTSS providers with different options for protecting individual rights while avoiding unnecessary legal intervention.

- Providers and advocates both reported that many providers do not understand the limits of granting of Power of Attorney and that more training is necessary.
- Maine citizens need to be more aware of the need to plan ahead for their LTSS needs, with more of an emphasis on having a Power of Attorney in place when needed.

Risky Choices by Persons who are Competent

Some persons in need of LTSS may be faced with the critical choice of deciding to remain at home or move into a residential setting or nursing facility. For persons with fragile conditions, remaining at home might be a risky choice. The providers we talked to discussed how difficult these decisions can be. One provider discussed the reality that some people who choose to remain at home in spite of the risk will end up dying as a consequence of that decision. However, as long as the individual understands the risks they are entitled to make that choice.

Some providers and advocates also talked about the challenge of navigating differences of opinions within a family. In some cases, when a family member is also a caregiver, a consumer can be influenced by a fear of burdening that family member. In other cases, the family caregiver will resist a consumer's decision to remain at home if that caregiver is unable or unwilling to continue in that role. Some of the providers and advocates discussed the special procedures they have in place for working with a consumer and family members when there is disagreement about a consumer's cognitive function or a consumer's decision to accept risk. These procedures usually involve bringing in a high level professional, whether a supervisor, social worker, or program director.

One provider stressed how important it is for providers to remember who their client is. Very often a consumer will informally or formally delegate decision-making authority to someone else: "Talk to my daughter. She can decide." This provider emphasized how important it is to continue to make contact with the individual, to make sure that everything is working as it should. This provider did not want its staff to rely only on information filtered through a family member – the consumer is their client and their needs, not the family member's, are what need to be addressed.

When Decision-Making Capacity is Impaired for People Living on Their Own

Under 18-A MRSA §5-805, Maine law allows a physician to rely on a surrogate's decision to withhold or withdraw life-sustaining treatment, when the physician has determined that the patient lacks capacity and there is no agent or guardian appointed or reasonably available and the patient is in a terminal condition or a persistent vegetative state. "A surrogate also is authorized to make any other health care decision for a patient who is an adult or emancipated minor if the patient has been determined by the primary physician to lack capacity and no agent or guardian exists, except that a surrogate may not deny surgery, procedures or other interventions that are lifesaving and medically necessary." Section 5-805 identifies who may act as a surrogate, with those having the most direct relationship being first in priority (e.g., a spouse, or someone with a relationship similar to a spouse, then an adult child, then a parent, and so on).

There was confusion or disagreement among providers about how the surrogate statute applies in the context of long term services and supports. We heard that the surrogate statute applies only in the case of emergency. We also heard that only physicians, not non-physicians, may rely on the surrogate. At the same time, we understood some LTSS providers invoked the surrogacy statute in order to obtain informed consent, when the consumer was not able to provide it. Based on our conversations we believe providers and advocates need more clarification on how the surrogacy statute applies, and under what circumstances, if any, an LTSS provider may rely on a surrogate to make care decisions. Depending on how the statute is interpreted, it may be necessary to consider whether modifications to

the statute are needed. At the end of the day, LTSS providers are likely to encounter persons with impaired decision-making capacity. Surrogacy law needs to reinforce a provider's obligation to obtain informed consent without unnecessarily forcing LTSS providers to pursue restrictive options, such as guardianship, in order to comply with the law.

When a Power of Attorney for Health Care is Involved

Using a legal device called, "Power of Attorney," a person, termed the "principal," may designate someone as their agent for the purpose of making health care decisions. A durable Power of Attorney allows the agent to make decisions beyond the time the principal is no longer capable of directing the agent. Under state law, the agent must act in accordance with the principal's reasonable expectations and within the scope granted under the Power of Attorney.⁶ A Power of Attorney provides an individual the opportunity to decide in advance who should make decisions when he or she is no longer able to.

One person we interviewed told us that, before reforms, the law governing Power of Attorney used to be a "license to steal" but now provides much more protection for the consumer. We also heard that those protections are needed for only a limited few: most POAs do their best on behalf of the person they are acting for. However, several people we talked to said not all providers understand the role of the POA and sometimes a POA is given more authority than they have been granted by the individual. Unlike guardianship, discussed below, a POA is the principal's "agent" acting according to the principal's wishes, while a guardian is the ward's surrogate, making decisions more as a parent would.

An advocate illustrated the limits of the POA. In this case, an individual in a residential setting wanted to move home again. A family member, who had Power of Attorney, did not agree with this choice. However, because the individual was competent to make her own choices, the POA authority could not be invoked and the individual made arrangements to move home, against the family member's wishes.

One provider told us they always ask for a written copy of the Power of Attorney document so that they know what authority the POA has. The people we interviewed suggested topics for needed training for providers including better training on the difference between a POA and guardianship and training on when a POA may be invoked.

When a Guardian is Involved

A guardian is appointed by a Probate Court judge to care for an incapacitated individual, with the same powers, rights and many of the same duties⁷ that a parent has for an unemancipated child. For example, a guardian has authority to establish where the ward lives and may place the ward in a hospital or other institution; the guardian may make decisions about medical care. The guardian is to make decisions in accordance with the ward's instructions made while the ward had capacity. Otherwise, the guardian is to make decisions in accordance with the guardian's determination of the ward's best interests. A guardian can withhold or withdraw life-sustaining treatment without court approval unless the decision is made against the advice of the ward's primary care physician or in the absence of the ward's instructions made while the ward had capacity.

Even though a guardian can substitute his or her judgment for the ward's, one provider told us that guardians need to but do not always consider the ward's preferences when making decisions. Maine currently does not have a system for monitoring the quality of private guardians.

⁶ 18-A MRSA §5-914.

⁷ Unlike a parent, a guardian is not legally obligated to provide from his or her own funds for the ward and is not liable to third parties for the acts of the ward. 18-A MRSA §5-312.