Long Term Care Options Counseling Tool Kit

Module: Communication

Task:
Long Term Care Options Counseling provides people with disabilities and older adults and their caregivers an opportunity to explore their needs, discuss service options and make choices based on the information provided. Excellent communication skills are an essential component to providing this service.

Objectives:
1. Demonstrate understanding of common issues experienced by people with disabilities, older adults and their caregivers.
2. Identify core issues and needs experienced by consumers based on scenarios provided.
3. Utilize active listening techniques (i.e. paraphrasing, reflecting, open and closed-ended questions, etc.)
4. Ability to identify local supports through use of information and assistance resource database.
5. Ability to access and use assessment tools to support identification of needs.

Activity:
1. Read scenarios.
2. Fill in communication guide. Note: blank communication guides are provided in the tool kit.
3. Compare completed communication guide with the one you did.
4. Discuss communication guide with supervisor.

Sample Discussion Questions:
1. What are the central issues described in the scenario?
2. What key questions would you ask? Role play and discuss segments of the scenario.
3. Discuss resourses that may be helpful for the consumer and role play different approaches to sharing resource information.
4. Discuss what communication skills are most helpful in this scenario and why.
Family Profile: Perkins
(Spinal injury)

John Perkins is a 24 year-old young man who was injured in a car accident three months ago. He was hospitalized due to a spinal cord injury for one month and was moved to a rehabilitation unit where he is currently residing. The social worker of the rehabilitation unit has made a referral to the Aging & Disability Resource Center for options counseling. John will be discharged from the unit next week. The discharge planner provides you with the following information.

Social Background: John graduated from high school in 1999 and has been doing construction work on and off during the past 6 years. He enjoyed going to rock concerts, snowmobiling, drag racing and gathering with his friends at popular taverns on the weekends. He was living with his girlfriend, Melissa, at the time of the accident. Melissa came to visit frequently right after the accident, but has not called or come to see him at the rehabilitation center. Friends have told John that she is dating someone else and does not want him to move back to their apartment.

John’s parents, Margaret and Frank, are in their early sixties and both work at the local canning factory. They are active at their church, and have frequent Bible study groups at their home. They have offered to take John into their home. John would like to live independently again.

John’s brother, Jeff, has been very supportive. Jeff is a manager at Wal-Mart in town and lives with his wife, Beth, who is currently on bed rest related to her pregnancy. This is their first child. Jeff has told John he can move in with them, although Beth seems very quiet when Jeff talks about it.

John’s grandparents are retired and living on their farm about 30 miles out of town. They do not visit often, although they are interested in his progress and send cards frequently; they also call once a week.

Medical: John has a spinal cord injury resulting in tetraplegia. He is alert and oriented, but has bouts of hopelessness and anger. He is unable to transfer independently from his wheelchair or manage toileting independently. After he leaves the facility, he will need help with bathing, dressing, hygiene, transferring, homemaking, meals, shopping, and transportation. John has been fitted for a wheelchair, but the wheelchair has not yet arrived. Also ordered but not yet delivered are a patient lift, cushion for the wheelchair, and mattress. John has not received an assessment of his technology needs once he is in his own home. John had no prior health problems other than seasonal allergies. (Note: in order to maximize insurance benefits it is helpful to assess needs for assistive technology and secure equipment prior to discharge from a hospital.)

Financial: John has $800 he was saving for a new snowmobile. He currently has no income. He has MA through presumptive disability and has applied for SSI, which is expected to be granted. However, John has been working and paying into Social Security and there may be a problem maintaining Medicaid eligibility if he also receives SSDI.
Issues

- Housing
- Assistive technology and care needs
- Benefits
- Adjustment
- Future Planning
### Issue

**Housing**

<table>
<thead>
<tr>
<th>Common Questions to ask</th>
<th>Items to consider</th>
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</thead>
<tbody>
<tr>
<td>Where would you like to live?</td>
<td>Safety issues related to goal to live alone</td>
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<tr>
<td>What features are important to you?</td>
<td>Accessibility</td>
</tr>
<tr>
<td>If the ideal housing situation is not an immediate option, what alternatives would be</td>
<td>Consider short term vs. long term goals, also financial resources to pay for housing,</td>
</tr>
<tr>
<td>ok with you?</td>
<td>related expenses and potential compromises</td>
</tr>
<tr>
<td>If you can’t live alone, who would you want to live with?</td>
<td>Location to supportive services and access to transportation</td>
</tr>
<tr>
<td>What do you think the advantages and disadvantages would be to living with your</td>
<td>Impact on family if John moves in with them</td>
</tr>
<tr>
<td>parents? Your brother and sister-in-law? In an apartment or another setting?</td>
<td>Consideration of John paying his “fair share” toward the housing expenses if he moves in with the family.</td>
</tr>
</tbody>
</table>

### Potential Resources/Referrals

- Accessible housing options
- Independent living center
- Subsidized housing – may explore subsidized apartments and voucher program
- Living with parents
- Living with brother (need to explore sister-in-law’s thoughts on the subject)
- Assisted living options
- Transportation providers
- Information from the Internet
### Issue
Assistive technology and Care needs

### Common Questions to ask
What areas do you feel you may need help with? Did the hospital/rehab unit identify any other areas?

Who would you feel comfortable with to provide your personal care?

New technologies help people to drive vehicles and help in other ways. Do you feel you have all of the equipment or devices to help you? Would you like to learn more?

### Items to consider
John’s understanding of his needs, is he realistic?

Different ways to pay for care

Determine John’s comfort level with care and caregivers

Consider the training needed and capacity of the caregiver to learn

Assistive technology assessment, to evaluate needs, select right equipment and support access to a qualified dealer to modify vehicle or assist with other equipment needs

### Potential Resources/Referrals
- Physical therapy/Occupational Therapy
- Home care agencies
- Supportive home care agencies
- Transportation providers
- Durable medical equipment providers
- Loan Closets
- Referral for Medical Assistance Personal Care
- Assistive technology services and devices (WisTech)

Note: Caregiver may benefit from caregiver support groups, education and financial support.
### Issue
Benefits

### Common Questions to ask

John, let’s talk about your financial support and benefits.

Do you take care of your bills and financial matters or does someone help with that? Tell me about your current bills? Are there any in particular that you are concerned about?

Did anyone help you with the medical assistance and SSI application?

Do you have a Power of Attorney for Health Care?

### Items to consider

Determine John’s level of involvement with his finances and benefits

If support is needed, who helps? Consider local programs that support individuals with budget counseling or patient assistance programs.

Determine where in the Disability Determination process the case is
Consider referral to Disability Benefit Specialist

### Potential Resources/Referrals

- Referral for SSI-E
- Food Share
- Disability Benefit Specialist
- Emergency Response Service (Lifeline)
- Homestead Tax Credit
- Energy Assistance

Note: Health insurance options/benefits are more likely to arrange and pay for equipment and services (e.g. home health) while the person is still residing in the hospital.
## Issue
Adjustment

### Common Questions to ask
- How do you feel about your life at this moment?
- How have you gotten through difficult times in the past – what helps you?
- Would you consider talking with someone about the many changes that have occurred in your life?
- Would you be interested in meeting other people who have survived similar accidents?

### Items to consider
- Need to meet him where he is – don’t jump ahead
- Identify strengths and survival strategies used in the past. Would these strategies be helpful now?
- Potential for depression/denial
- Potential for anger/grieving
- Hopelessness was identified – ensure not a suicide risk

### Potential Resources/Referrals
- Spinal Cord Support Group
- Peer Support Programs
- Counseling services
- Evaluation – psychiatric
- Independent Living Center
- Friends & Family
- Church support (is he involved in a church or other religious or spiritual group?)
### Issue
Future Planning  (note: this subject may be discussed at future meetings)

### Common Questions to ask
- John, let’s talk about your goals: What would you like to see happen? Accomplish?
- What do you feel you need for that to happen?
- There is a variety of devices that help people with their day to day lives. Can we talk about these options and agencies that can help figure out what equipment is best?

### Items to consider
- Is setting goals of interest to him at this time?
- If goals are identified, break them down into parts that will allow John to experience success in attaining them.
- What assistive technology and/or resources are needed? What agencies may be helpful to assess his needs?

### Potential Resources/Referrals
- Department of Vocational Rehabilitation
- Adaptive Equipment and Technology
- Recreation (hunting)
- Support groups
- Peer support
- Disability Navigator
- Colleges, Vocational schools
- Electronics
- Internet groups
- Independent Living Centers
Smith Family Profile:
(Transition for young adult with Developmental Disabilities)

Jane Smith is a 17-year-old with Down’s Syndrome who will be graduating from high school in 4 months. She will turn 18 years old the following month. She resides with her parents and a younger brother, aged 14 years. Both of her parents work fulltime. The family is covered by private health insurance through Mr. Smith’s employer. The Smith’s live 10 miles outside of town in a rural community.

At school, in addition to her regular classes, she has had the opportunity to participate in an afterschool supported work program. Jane has stated to her teachers and classmates that she is going to get a job after she graduates. She has also talked about getting her own apartment. Her friends have told her they want to come over for a party when she gets a place of her own. Her younger brother has noticed that 3 or 4 of the kids who talk with his sister regularly at school occasionally ask her for money.

At home, Jane is never left alone. If her parents or brother are not going to be around, an elderly neighbor comes over to stay with her until they return. Jane’s parents cue her daily regarding appropriate dress, grooming and hygiene. She is able to dress herself, wash her face and brush her teeth. She needs some assistance with bathing and fixing her hair. Her parents prepare her meals and watch her food intake so she doesn’t overeat, or overload on pop and snacks. They help her manage her money. Jane’s parents or brother usually work together with her on a variety of household chores such as making beds, folding laundry, setting the table and picking up the house.

ISSUES:
- Housing Options
- Medical Coverage
- Employment
- Independent Living Skills Development
- Long Term Planning (Health & Safety)
### Issue

**Housing**

### Common Questions to ask

In the future, where would you like to live?

Jane, besides living at home with your parents, have you thought of or visited other kinds of places you would like to try some day?

(directed to Jane’s parents) Where do you see your daughter living now and in the future?

There are a variety of places people live, some with services others without. Jane, can we talk about the things you do for yourself and the things you get help with from your family and friends.

### Items to consider

Learn more about Jane’s wishes regarding where she wants to live

Are Jane’s expectations within the realm of possibility? Has she had the opportunity to think about or investigate other types of places to live?

Are the parents’ goals different from Jane’s?

Determine level of functioning and help needed – Consider offering the Long-Term Care Functional Screen

### Potential Resources/Referrals

- Long-Term Care Functional Screen
- Department of Vocational Rehabilitation Assessment
- School Evaluations and IEPs
- Housing options – living with family, Adult Family Home, Community-based residential facility, supported apartment, subsidized apartment with formal and informal supports, case management, transportation, Assistive devices/technology, Personal Care, Supportive Home Care, Respite Care for parents
- Independent Living Center

*Long-Term Care Options Counseling: A Service of the Aging and Disability Resource Center*
<table>
<thead>
<tr>
<th><strong>Issue</strong></th>
<th>Medical Coverage</th>
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| **Common Questions to ask** | You have mentioned that medical coverage is a concern. Jane will lose her medical coverage when she leaves school and she is going to need money for living expenses, especially if she lives away from home. Let's talk about some potential options. |

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<tr>
<th><strong>Items to consider</strong></th>
<th>Explore the public benefit programs that might be options</th>
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<td></td>
<td>Does she have a work history? What are her financial assets, if any?</td>
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<td></td>
<td>Will her disability meet Social Security Administration guidelines - involve Disability Benefit Specialist</td>
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<table>
<thead>
<tr>
<th><strong>Potential Resources/Referrals</strong></th>
<th>Medical Assistance programs: MADA, MAPP and BadgerCare</th>
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<td>SSI/SSI-E</td>
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<td>SSDI</td>
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<td>Disability Benefit Specialist</td>
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**Issue**  
Employment

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<tr>
<th><strong>Common Questions to ask</strong></th>
<th><strong>Items to consider</strong></th>
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<tbody>
<tr>
<td>Jane, have you thought about what kind of job you would like to have?</td>
<td>Information from school regarding her current level of functioning and the level of functioning she is capable of; the kind of support she will need to be successfully employed.</td>
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<tr>
<td>Tell me about what job possibilities you have looked into.</td>
<td>Is there funding to support her employment goals?</td>
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**Potential Resources/Referrals**  
Department of Vocational Rehabilitation  
Job Service  
Employment Benefits Counselor  
Medicaid services  
Supported Employment
### Issue
Independent Living Skill Development

### Common Questions to ask
To Jane’s family/parents – what kinds of skills have you been working on with Jane?

Can you tell me about the skills the school has been working on with her?

What specific skills would you like to see her learn?

Jane, tell me about what skills you have and what things you would want to work on.

Jane, tell me about the social activities you would be interested in?

### Items to consider
Level of ability; she has to learn independent-living skills

Explore if the school has discussed with Jane and family about her staying in school until she is age 21 (to continue to develop independent living skills)

Understand what skills she would need to learn before she could live outside her home, without her parents/family

Learn what social activities are important to Jane

### Potential Resources/Referrals
Day Services/Treatment
Training
Medicaid services
Independent Living Center
Daily Living Skills training
Social organizations and activities in the community
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<tr>
<th>Issue</th>
<th>Future Planning (Health &amp; Safety)</th>
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<tr>
<td><strong>Common Questions to ask</strong></td>
<td><strong>Items to consider</strong></td>
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<tr>
<td>Tell me about your planning for Jane; have you talked about who will look after Jane if something happens to you? Sometimes when people grow older they find that they can no longer provide the level of oversight that they used to. Have you planned for who will look out for Jane?</td>
<td>What other kinds of short range and long range planning needs to be done to help Jane live the way she wants to, to be independent, safe and happy?</td>
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<tr>
<td><strong>Potential Resources/Referrals</strong></td>
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<td>Guardianship</td>
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<td>Power of Attorney for Finances</td>
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<td>Representative Payee</td>
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<td>Advocacy Organizations</td>
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<td>Financial and Estate Planning</td>
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Long-Term Care Options Counseling: A Service of the Aging and Disability Resource Center
Family Profile: The Stevenson Family
(Elderly person looking at moving to a nursing home)

Mabel Stevenson is an 87 year old woman who has lived in her farm home in Wisconsin for 55 years and was recently widowed. She has two children, each living in different states, and 6 grandchildren. Due to her husband’s death, Mabel finds it difficult to go places as her husband was her primary source of transportation. She likes to attend church, the local senior center, her neighbors, the beauty shop and local shops (including grocery stores). Without transportation to these places, she notes that she feels isolated, lonely, and does not have nutritious eating habits due to the inability to reach the grocery store easily. Her neighbor drives her to frequent doctor appointments, but her neighbor will be moving at the end of the month. Mabel owns her home and receives social security. Her savings account, income and assets are limited.

Mabel struggles with her performance of ADLs. She is prone to falls and broke her hip about 1 year ago after slipping on ice on her outdoor steps. This makes it difficult for her to get in and out of the bathtub. She uses a walker to ambulate, is incontinent of bowel and bladder and uses Depends which she changes independently, but with difficulty. She has impaired vision with cataracts in both eyes. Mabel takes 6 medications daily for various things (i.e. high blood pressure, hypertension and edema, anxiety, pain and supplements (calcium, vitamin D, and potassium). The medications are taken at different times during the day, and Mabel reports difficulty with managing her medications.

Her children do not feel that she is safe in her home and are encouraging her to move into a nursing home. Her children are not aware of long-term care community options, but are adamant on getting Mabel out of her home. She would prefer not to have to move into a nursing home. Her children will be coming to Wisconsin to assist her, and they wish to receive information from your agency on local nursing homes. Conversations take place with Mabel and her family.

Issues:
- Defining help that is needed
- Housing options
- Help to live at home
- Funding for living expenses and services
**Issue**
Defining help that is needed

<table>
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<tr>
<th>Common Questions to ask</th>
<th>Items to consider</th>
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<tbody>
<tr>
<td><strong>Would you prefer me to call you Mrs. Stevenson or Mabel?</strong></td>
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<tr>
<td>Your children have asked me to visit you and talk about services to help you. It is my understanding that you are interested in exploring all of your options.</td>
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<td>In order to get a clear picture of what help you need, I need to ask you several questions. Is this ok?</td>
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<td>Tell me about your typical day?</td>
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<tr>
<td>Tell me about your general health?</td>
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<tr>
<td>Do you take any medications?</td>
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<td>What help do you currently receive?</td>
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<td>What would be most helpful to you right now?</td>
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<tr>
<td>What do you as her children think is the most concern/most helpful right now?</td>
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<td><strong>Consider offering Long-term care functional screen</strong></td>
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<tr>
<td><strong>Explore areas of concern</strong></td>
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<tr>
<td>Clarify blood pressure problems, depression issues, continence problems</td>
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<tr>
<td><strong>Learn about who is helping her.</strong></td>
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<tr>
<td><strong>What are her current priorities? Are they different from her children’s?</strong></td>
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**Potential Resources/Referrals**
Long term care functional screen, consider scheduling a family meeting to discuss information learned
**Issue**
Housing Options

<table>
<thead>
<tr>
<th><strong>Common Questions to ask</strong></th>
<th><strong>Items to consider</strong></th>
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<tbody>
<tr>
<td>Are you familiar with all the places older people live and receive help?</td>
<td>Discuss the different types of options including adult family homes; community based residential facilities, residential care apartment complex and nursing homes.</td>
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<tr>
<td>There are advantages and disadvantages to each of these different choices, let’s talk about them.</td>
<td>Review advantages and disadvantages based on her needs and desires</td>
</tr>
<tr>
<td>Would you be interested in visiting any of these places?</td>
<td>Share checklists that help consumers know what to look for when touring a facility.</td>
</tr>
<tr>
<td>Do you have any friends who have moved to one of these places?</td>
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**Potential Resources/Referrals**
Adult family homes, Community based residential facilities, nursing homes, residential care apartment complexes, facility checklists
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<tr>
<td>Help to live at home</td>
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<table>
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<tr>
<th><strong>Common Questions to ask</strong></th>
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<tr>
<td>What kinds of help would you need to keep you happy and safe at home?</td>
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Earlier you mentioned that it is difficult to get around, your husband did the driving. Let’s talk about transportation services.

One of the things you shared with me is that you fell last year. We are learning more about what causes falls, can we talk about this?

You mentioned since you broke your hip it is hard to get out of the bathtub. We could explore getting a bath chair for you to use in the tub and adding grab bars? How does this sound to you?

Also it might be helpful to have someone help you get in and out of the tub, help with general housekeeping. There are lots of agencies that do this kind of work.

Tell me about the medications that you take? When was the last time you went to the doctor(s)?

<table>
<thead>
<tr>
<th><strong>Items to consider</strong></th>
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<tr>
<td>Establish her priorities</td>
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</table>

Consider places she wants to go and choices available including informal supports.

Fall prevention initiatives may be able to provide a fall risk assessment.

Consider what home repair, modification needs she may have and what assistive devices may be helpful.

Explore willingness to have in-home help.

Are there any medical needs that have not been addressed? Would it be helpful to have a nurse meet with Mabel?

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<tr>
<th><strong>Potential Resources/Referrals</strong></th>
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<tbody>
<tr>
<td>Fall prevention risk assessment</td>
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<tr>
<td>Home care agency</td>
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<tr>
<td>Personal Care agency</td>
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<tr>
<td>Home repair</td>
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<tr>
<td>Independent Living Center (Assistive Technology)</td>
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</table>
### Issue
Funding options for services

### Common Questions to ask
Sometimes one of the challenges older people face is having the money to pay for different services. Can we talk about the cost of services and some benefit programs?

### Items to consider
Development of a plan to determine how long resources may last.

Discuss what funding sources are available.

May offer joint home visit with Elder Benefit Specialist.

### Potential Resources/Referrals
- Elder Benefit Specialists, Medicaid home and community based waiver programs, elderly nutrition program, lifeline medical alert service, energy assistance and weatherization services, homestead credit, powers of attorney for health care, SeniorCare/Medicare Part D
Family Profile:
The Hartman - Hood Family
(elderly parents, caregiver concerns, adult son with developmental disabilities)

Sara Hartman called; she didn’t know where to turn. She is concerned about her mother and brother. Her mom, Nona Hood is 78 and is recovering from a broken arm. Nona lives on the family farm; the farm land is rented to the neighbor who lives down the road. Nona and Sara’s dad are divorced; her dad is remarried and has no contact with the family. Her younger brother Samuel is 38 years old and is developmentally disabled. Samuel has lived with their mom all of his life. He participates in a sheltered workshop in town 5 days a week. Nona is active; they have some goats and chickens on the farm. Nona serves on the board of the local senior center and delivers meals to individuals who are homebound one day a week. Nona’s level of activity changed dramatically (about 3 weeks ago) when she fell and broke her arm. Nona is recovering slowly and can’t drive for the time being. Nona is a retired school teacher; her monthly income (pension and rent from the farm land) is about $2500 a month. Sara lives 30 miles from her mother, is married with 3 children (ages 6, 10 and 12) and teaches school full-time. Nona has needed extra help because of the broken arm. It is because of this that Sara is calling. She can see future needs arising and wants information on services and options. Sara knows her mom has made no arrangements for Samuel in the case of her death. Sara has also been taking her mom to the doctor, doing the grocery shopping, but school is starting soon and she will be going back to work.

Issues:
Help around the house.
Transportation
Planning for the future
Caregiver support
**Issue**
Help around the house

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<thead>
<tr>
<th>Common Questions to ask</th>
<th>Items to consider</th>
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<tbody>
<tr>
<td>How would your mom feel about getting some extra help around the house?</td>
<td>Understanding of help available</td>
</tr>
<tr>
<td>Tell me about what happened when she fell?</td>
<td>Explore events that precipitated the fall and any environmental changes that could be made. Consider offering the “get up and go” test to evaluate her strength and balance.</td>
</tr>
<tr>
<td>Could you describe her current health status?</td>
<td>Comfort level with people she doesn’t know coming into the house</td>
</tr>
<tr>
<td>How would she feel about someone coming to the home to talk with her about options?</td>
<td>Starting on a trial basis – making it comfortable</td>
</tr>
<tr>
<td>What kinds of help do you think she needs? Getting dressed? Preparing meals? Cleaning the house?</td>
<td>Does Nona know anyone who helps clean her friends’ homes?</td>
</tr>
<tr>
<td>Do you think Nona would accept help? What about this would be uncomfortable for her, Samuel and/or you?</td>
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**Potential Resources/Referrals**
Homemaker services (private pay) workers who are bonded

Home assessment for fall prevention

Home-delivered meals
**Issue**  
Transportation

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<th>Common Questions to ask</th>
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<tbody>
<tr>
<td>Is Nona going to need help to get to the doctor when you go back to work?</td>
<td>Cost sharing – mileage fees</td>
</tr>
<tr>
<td>Tell me how has Samuel been getting to his day program? Does he need other help to continue to participate?</td>
<td>Ability, willingness to pay</td>
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<tr>
<td></td>
<td>Clarify the process: scheduling the ride, paying for the service, etc…</td>
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<td></td>
<td>Explore informal supports, transportation services</td>
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**Potential Resources/Referrals**  
Volunteer driver program

Bus services via Commission on Aging
## Issue
Future Planning

### Common Questions to ask
Tell me about the planning Nona has in place. Does she have advance directives? A will?

What financial support does Samuel receive? Is there a guardianship in place?

What would Nona do in an emergency if she couldn’t reach the phone? How would Samuel respond?

Do you see your mom living on the farm for years to come?

There is a variety of low cost equipment that helps people maneuver in the bathroom or open a door or cabinet. Would you be interested in talking about some of their choices?

### Items to consider
Previous discussions on the subject

Development of a plan – Involve Samuel

Explore housing options

Describe floor plan of the home – any stairs? First floor laundry? Bathroom? Grab bars?

### Potential Resources/Referrals
Packet on advance directives available through Coalition of Wisconsin Aging Groups
Disability Benefit Specialist for Samuel
Social Security Disability
Human services department
Legal services
Purchase/rent emergency response service
Housing options
Financial Planner
Independent Living Centers
Handyman services
### Issue
Caregiver information

### Common Questions to ask
Sara, I know you have a lot going on right now, balancing kids, your Mom and getting ready for school. It is hard.

Sara, what kind of support would be most helpful to you?

Sara, can you tell me about your family? Do you have other siblings?

Would a family meeting be helpful?

### Items to consider
Explore Sara’s feelings about her role as a “caregiver” and Nona’s feelings about the changes in their roles.

Explore Sara’s willingness to receive information on caregiver services? Support groups?

Explore social support network, friends, other family etc.

### Potential Resources/Referrals
Aging unit’s National Family Caregiver Support Program

Caregiver fact sheets

Guidelines for having a family meeting
Family Profile: The Millicent Family
(Dementia)

Harold Millicent is 78 years old, and his wife Marjorie is 76. They have three children, Dennis, Bob, and Linda, all married. Bob and Linda live in the area, and Dennis lives about 35 miles from their home.

Harold had worked in the paper industry for years. They are financially comfortable at this time in retirement. Marjorie was a stay-at-home mom, and counted on Harold to take care of the handyman/yard chores in their home.

Two years ago, Harold started showing signs of repetition and short-term memory issues. He also stopped doing things around the house. Marjorie was very upset with this change. Their three children arranged an appointment with the Memory Assessment Clinic after consulting with his primary care physician. He was diagnosed with frontal lobe dementia and placed on some medications. Marjorie and Harold recently moved from their home to a condominium in another town about 10 miles from their previous home.

Marjorie became more upset with Harold’s annoying behaviors—the repetition, the lack of personal care, and “not doing anything all day but rocking in a chair and sleeping…” As time passed, the children became aware that Harold was losing a great deal of weight—he was 6’1” and now weighed only 130 lbs. Marjorie was not preparing meals—she said he would say he wasn’t hungry. Dennis, however, said that when he took his Dad out to eat, he would eat voraciously—there was nothing wrong with his appetite. In a follow-up appointment at the Memory Clinic, the doctor was concerned about the weight loss and behaviors that were worsening, and that his medications didn’t seem to be helping him. Harold had become aggressive with Marjorie on a few occasions when she challenged him, and now she feared for her safety.

Dennis, Linda, and Bob felt that their mother did not understand the disease nor how to cope with the new behaviors, and that she wasn’t providing things he now needs—food made for him, cueing him to attend to personal care, etc. Marjorie now thinks she cannot have him at home anymore and is worried about the financial implication of outside placement. She also has some health issues—besides arthritis and needing a knee replacement, she has some heart rhythm problems. The family was concerned that she was becoming overwhelmed and the stress was wearing her down. Dennis contacted the ADRC and you meet with the family.

**Issues:**
- Concern with Harold’s weight loss and aggressive behaviors
- Education/support group for Marjorie on dementia
- Options for caregiver stress
- Financial/legal concerns and future housing options for Harold

*Long-Term Care Options Counseling: A Service of the Aging and Disability Resource Center*
**Issue**  
Concern with Harold's weight loss

<table>
<thead>
<tr>
<th>Common Questions to ask</th>
<th>Items to consider</th>
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<tbody>
<tr>
<td>I am wondering if he understands the question “are you hungry?” …What do you think?</td>
<td>Marjorie’s understanding of Alzheimer’s disease and how it can effect processing and responding to questions and information.</td>
</tr>
<tr>
<td>Do you feel Harold would eat if meals are prepared for him?</td>
<td>Marjorie’s desire to cook given her own health limitations and the couple’s receptivity to outside meals</td>
</tr>
<tr>
<td>Has Harold had a recent visit to the doctor or dentist? I am wondering if he has some pain or difficulty with his throat that could be a concern.</td>
<td>Last medical/dental exam, potential need to schedule a visit to the doctor(s).</td>
</tr>
<tr>
<td>Tell me about the medication he is taking… could it affect his appetite?</td>
<td>Side effects and medications and importance of regulation and distribution</td>
</tr>
<tr>
<td>Are there foods Harold enjoys that could help his appetite?</td>
<td>Help with meal preparation and what is needed to make certain Harold is getting proper nutrients and eating properly</td>
</tr>
<tr>
<td>Selecting foods with high nutritional value can be a challenge, what foods have you tried?</td>
<td>Availability of supplemental nutrition</td>
</tr>
</tbody>
</table>

**Potential Resources/Referrals**  
Home-delivered meals, or meals from a private food supplier

Nutritional consults to address: high nutrition in easy foods, Ensure, Carnation Instant Breakfast and easy no-cook lunches

Physician to evaluate medications, referral to a dentist.

Alzheimer’s Association to help with disease education and work with the family to learn different strategies for communication with Harold and to teach cueing.
### Issue
Concern with Harold’s aggressive behavior

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<th><strong>Common Questions to ask</strong></th>
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<tr>
<td>Can we talk about your fears about Harold’s aggressive behavior?</td>
<td>Marjorie’s safety and risk issues</td>
</tr>
<tr>
<td>Marjorie, tell me what do you do when Harold acts this way?</td>
<td>Communication style that has been in use throughout the marriage may no longer be effective.</td>
</tr>
<tr>
<td>You mentioned earlier about Harold’s medication. How often does he take his medication?</td>
<td>Side effects of medication. Are other medications needed? Is a medical exam needed?</td>
</tr>
<tr>
<td>What do you think Harold is trying to communicate through his behavior?</td>
<td>Implications for behavior with this disease</td>
</tr>
</tbody>
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### Potential Resources/Referrals
Area Geriatric psychiatrist to look at medications and behavior

Caseworker from the Alzheimer’s Association to work with Marjorie and family regarding symptom management and progression of the disease

Alzheimer’s Association 24 hour helpline for support and suggestions on how to approach situation/behaviors
### Issue
Education and support for Marjorie regarding dementia/disease.

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| Marjorie, tell me what you know about dementia?  
Have you had a chance to talk with other people who care for someone with dementia?  
Have you attended a support group?  
It must be difficult to know what to do when Harold is aggressive…. | Marjorie and her family’s understanding of the disease  
Her willingness to receive support outside of the family  
Need to assess safety risk for Marjorie and options if she feels threatened. |

### Potential Resources/Referrals
Alzheimer’s Association for education and support  
Alzheimer’s Association library for recourses to address specific behaviors  
Also are there support groups
## Issue
Options for caregiver stress

### Common Questions to ask
Marjorie, tell me about the stress that you have in your life?

How do you feel about Harold’s diagnosis?

Sometimes people feel resentful that their spouse isn’t able to do the things they used to do around the house….do you ever feel that way?

Are you worried about how the stress is affecting your own health?

Marjorie, how would you feel about getting some extra help around the house?

What fun leisure activity would you like to be able to do for yourself?

### Items to consider
Knowledge of support services available for caregivers

Knowledge of caregiver burn out

Awareness of support services and ways to reduce stress before a crisis

Understanding of home health options, respite, and adult day care, etc…

Need for self care and fun.

### Potential Resources/Referrals
Alzheimer’s Association for caregiver support groups
Socialization programs, senior activity centers
Adult Day Services, respite options
Powerful tools for caregiver classes or other caregiver education
Home health options
National Family Caregiver Support Program
Alzheimer’s Family Caregiver Support Program
### Issue
Financial/legal concerns & future housing options for Harold

### Common Questions to ask
Marjorie, let’s talk about what would happen if Harold no longer lived at home.

I’m wondering if there is power of attorney for health care in place for Harold and Marjorie.

I don’t want to intrude on your private information, but cost of care is often a concern. Can we talk about assisted living options and their costs?

### Items to consider
Discuss options, advantages and disadvantages among assisted living options (Community Based Residential Facilities, etc).

Power of Attorney packet

Discuss long term financial considerations for Harold’s care. You may include financial eligibility for publicly funded long-term care and also share information on spousal impoverishment.

### Potential Resources/Referrals
- Long-term support agency
- Information on assisted living options
- Attorney referral agency
- Benefits counseling
This document was developed under grant CFDA 93.779 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal government.

Wisconsin Department of Health & Family Services
Division of Disability & Elder Services
Bureau of Aging & Disability Resources
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