Trainee Handouts For Module One

1. Any State or waiver-specific promotion material

2. Schedule of Events and Learning Tasks

3. Copies of Power Point Sheets (Six to a Page)

4. Group One, Two, Three or Four Assumptions Sheet

5. Randomly Assigned Case History Roles as Participant, Consultant or Observer

6. Format Evaluation Form

7. Content Evaluation Form

MODULE ONE:
Facilitating the Paradigm Shift for Consultants

Schedule of Events

1:00–1:15 ..... **I. Introduction to Learning Tasks:**

Learning Task One: Identify the relationship between feelings, knowledge, and skills in the learning process particularly as it applies to consultants and participants in adopting a participant-directed approach to services.

Learning Task Two: Identify the underlying assumptions of participant-directed care including its contribution to participant empowerment.

Learning Task Three: Identify the knowledge and skill development necessary for both consultants and participants to move to proficiency in participant-directed care service models.

1:15–1:45..... **II. Identifying Components of the Paradigm Shift:**

Group Exercise One: (Think of something you learned to do…)

1:45–2:30 ..... **III. What is participant-directed care?**
Present brief history of movement, Identify assumptions of participant-directed care.

Group Exercise Two: Exploring Differences between Traditional Case Management and Participant-Directed Care. Larger group is divided into four smaller groups by assumptions to identify knowledge and skills needed to accomplish the paradigm shift.

2:30–2:45 ..... **Break**

2:45–4:15 ..... **IV. Exploring Roles of Participants/Consultants (Needs and Wants)**

Group Exercise Three: Participant/Consultant Dyad Interviewing

4:15–4:30 ..... **V. Evaluations:** Parts One and Two

Consultant Training Program

Module One: Facilitating the Paradigm Shift for Consultants/Support Brokers

Developed by:

Boston College Center for the Study of Home and Community Life

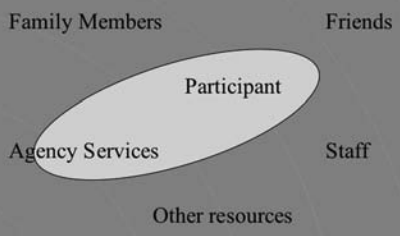
MEDSTAT Consultants

Department of Health and Human Services Centers for Medicare & Medicaid

Module One: Facilitating the Paradigm Shift for Consultants/Support Brokers

I. Introduction/Overview
II. Identifying the Components of the Paradigm Shift
III. What is Participant-Directed Care?
IV. Exploring the Roles of Participants and Consultants or Support Brokers
V. Summary and Evaluation

Traditional Case Management



Participant-Directed Care

Learning Task One:

Identify the relationship between feelings, knowledge and skills as part of the learning process.

Learning Task Two:

Identify the underlying assumptions of participant-directed care.

Learning Task Three:

Identify the knowledge and skill development necessary for both consultants and participants to move to proficiency in participant-directed care.

Terms in Participant-Directed Care

- Participant-directed care: Also known as self-direction or consumer-direction
- Participant: The person who receives services. Also known as consumer or individual.
- Consultant: Professional who consults with participant in designing care plan. Also known as supports broker or facilitator.

Think of something you learned how to do that was difficult or challenging. How did you feel before you learned how to do it? After?

Accomplishing something new consists of three components:

1. Feeling/emotional components.
2. Knowledge/information components.
3. Acquisition of skills components.

Empowerment:

- Creation of opportunities for self-directed support services.
- Enhances learning, self-motivation and accountability.
- Increases participants' sense of competence and independence.

Assumptions of Participant/Self-Directed Care Models

- Participants are experts on their own care
- Self-directed options should be available regardless of source of payment.
- Some participants prefer to make their own decisions about their care.

Assumptions continued

- Some participants wish to take a more active role in their care.
- Personal assistance services are not medical services.

Assumptions continued

- Participant-directed care may save money with lower administrative costs.
- Participants will exercise their choices and spend money wisely.

Group One:

- Assumption One: Because of professional training, care managers are in a position to best determine what services will support a participant.

Consultant Knowledge/skills? Participant knowledge/skills?

- Assumption Two: The participant is the "expert" in identification of service needs and preferences.

Group Two:

- Assumption One: Traditional agencies select and employ workers who provide services.

Consultant Knowledge/skills? Participant knowledge/skills?

- Assumption Two: The participant should be responsible for hiring/firing/supervising.

Group Three:

- Assumption One: Goals/Outcomes determined by consultant with some participant input.

Consultant knowledge/skills? Participant knowledge/skills?

- Assumption Two: Goals/Outcomes determined by participant with some consultant input

Group Four:

- Assumption One: Participants receiving public monies should limited decision-making.

- Assumption Two: Participants should have maximum choice regardless of source of payment.

Exploring Participant Needs and Desires

- What services would make your life better?
- What activities would make your life better?

- Think about the things you need help with…
- How could supports best fit into how you want your life to be?

- What is the one thing you miss most about your life before you needed support services?
- If supports have always been in place, what do you wish you didn't need help with?

Small Group Exercise:

- One person takes the role of the consultant/support broker.
- One takes the role of the participant.
- Consultant/support broker should begin the process of exploring what the participants wants/needs.

Discussion Questions:

- What was difficult about letting the participant identify needs and wants?
- From the participant's perspective, what was difficult about being asked what you need/want in your life?

Discussion Questions

- Did the consultant feel a need to take over the conversation?
- Did you feel at any time that the participant should not be allowed to make decisions for him or herself?

A Final Question…

- Does this process go against the grain of what you already know (or have done in the past) in identifying needs with persons requesting services?

Points to Remember…

- People may not know what they want or need because they have never been asked.
- It is easy to "rescue" a participant when they are hesitating or having trouble expressing themselves.

Points to Remember…

- Making decisions involves risk.
- Transitioning to a participant-directed state of mind involves "letting go" of the need to do the right thing as you see it.

Group One:

Assumption One:
Because of professional training, care managers are in a position to best determine what services will support a person with special needs.

What knowledge/skills does the *consultant* need to develop?

What knowledge/skills does the *participant or representative* need to develop?

Assumption Two:
The participant or representative is the "expert" in identification of service needs and preferences.

Group Two:

Assumption One:
Traditional agencies with experience in hiring and supervising workers should take primary responsibility for selecting and employing the workers who provide supports to participants.

What knowledge/skills does the *consultant* need to develop?

What knowledge/skills does the *participant or representative* need to develop?

Assumption Two:
Participants should be responsible for hiring, firing, and supervising their own workers.

Group Three:

Assumption One:
The goals and outcomes of providing service supports are determined by the professional with some input from the participant and/or representative.

What knowledge/skills does the *consultant* need to develop?

What knowledge/skills does the *participant or representative* need to develop?

Assumption Two:
The participant and/or representative identifies the goals and outcomes of providing service supports with some input from the professional.

Group Four:

Assumption One:
Individuals whose services are funded through Medical Assistance or other public monies should have limited decision-making in their care plans because someone else is paying for their care.

What knowledge/skills does the *consultant* need to develop?

What knowledge/skills does the *participant or representative* need to develop?

Assumption Two:
Participants or representatives should have as much input and choice as possible regardless of the source of funding for their services.

CASE HISTORY 1:
Mrs. Mertes

Mrs. Mertes is a 65-year-old woman who has multiple health problems including chronic lung disease, severe osteoporosis, arthritis, and chronic depression. She has no cognitive limitations and is very capable of making decisions about what she wants. Although technically she is not bedridden, she spends most of her days in her bed watching television and talking on the telephone. She lives with her husband (83 years of age) who has his own health problems but does not appear to need services other than perhaps housekeeping and meal preparation. He is able to prepare meals but usually does not and the couple eats prepared frozen and canned foods most of the time. Mrs. Mertes doesn't mind eating so simply but her physician has indicated that the high salt content in these prepared meals is dangerous for her blood pressure problem.

Mrs. Mertes has recently enrolled in the consumer-directed care option through Elder Services in her community hoping to get more services than the housekeeper and health care aide that come three times a week. She doesn't feel the aides have been doing enough for her in such infrequent visits. She is a difficult woman to work for because she is very demanding and inconsistent in what she expects of her workers. The couple has no extended family in the area.

Your role is that of the observer.

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Your role is that of the consultant.

Note to consultant:

Mrs. Mertes is famous in agency circles for being very difficult to work with and always complaining about who and when the agency sends housekeeping and health care aides. Mr. Mertes is not a good choice for providing services as he has early dementia and is openly hostile to his wife. The couple is extremely isolated except for ongoing relationships with a local mental health agency and the agency that provides the aides. She is actually capable of cooking and doing light housekeeping but uses her health as an excuse not to. You see the need for home mental health care, a health care aide to help with bathing and personal hygiene, and someone to clean up the mess in the home which the Mertes' don't seem to notice.

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Your role is that of the participant (Mrs. Mertes).

Note to trainee playing Mrs. Mertes:

Imagine how lonely and difficult it must be to be Mrs. Mertes, lying in bed all day with only the television to watch and to be living with a husband who rarely talks to her. What you really want as Mrs. Mertes is to have some company—the days are long and make you even more depressed than you already are. You want a decent meal cooked once in awhile and you want something for your husband to do that will take him out of the house and out of your hair. You want the right to hire and fire your own workers who will come when you want them to come and do what you want them to do.

CASE HISTORY 2:
The Helsing Family

The Helsing family has three children including Marcia, a 10-year-old daughter with a cognitive disability for whom they have been caring since birth. Marcia has no self-help skills, needs to be fed, bathed, and constantly supervised. She is able to crawl but is not otherwise ambulatory. Kathy, the mother, is the primary caregiver for Marcia although Bob, the father helps when he comes home from work. Their other two children Kara (16) and Kevin (12) occasionally care for Marcia but are busy with their own school and sports activity. The Helsings have never used any agency services for their daughter although they have been eligible for such services since Marcia's birth. The couple is experiencing family tension as Marcia becomes more challenging to care for and Kathy has developed back problems from lifting her for so many years. Bob feels like he has "lost" his wife to caring for their daughter and really misses the time they used to spend together. The other children basically stay away from home as much as possible because they feel no one pays attention to them anyway because of all the attention Marcia needs.

Your role is that of the observer.

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Your role is that of the consultant.

Note to consultant:

This family is coming apart at the seams as the amount of work caring for Marcia continues to increase. They have always felt they should be able to care for Marcia without outside help but this is becoming more difficult as Kathy's back problems worsen. Everyone in the family seems depressed and desperate. They have mentioned putting Marcia in a care facility although you know that is not financially feasible for this family regardless of who pays for the care. They have to find a way to provide this very labor intensive care for Marcia without having their family fall apart.

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Your role is that of the participant (Kathy Helsing).

Note to trainee playing Kathy Helsing:

You are very tired and in almost constant pain with your back problems but you strongly feel you are the best person to provide care for Marcia. You think getting paid yourself for caring for Marcia might be the best for Marcia but could spell trouble for you. You vacillate between being overprotective of Marcia and wishing she would die and put everyone out of their misery. You want your life back. You want to save your marriage before it falls apart. You want your children to be home more so it feels like a real family rather than a day care center for a retarded daughter. You feel isolated and angry. And you are very sick of "professionals" telling you that you just need a few days away from Marcia. Most days you just want to run away from it all.

CASE HISTORY 3:
Ellen Ellis

Ellen Ellis is a 25-year-old woman with moderate developmental disabilities. She has lived in a structured independent living apartment with two other women for about a year. She works at a day care center and is able to make enough money to pay her portion of the rent and buy food and basic necessities. She can cook simple meals and is capable of keeping her room tidy. However, she and her roommates all struggle with housekeeping tasks resulting in a very messy living situation. It is not clear whether Ellen knows how to do serious cleaning and won't or doesn't really understand the process of housekeeping. She also has difficulty in understanding and handling money. When she was given an ATM card, she kept taking money out of her account until she was overdrawn every month, not quite understanding how the ATM card works with her money. She is very generous by nature and is always giving other people money when they ask, even if she cannot afford to. She has been victimized several times by people who "befriended" her only to take her money. She loves to go out to bars to meet people and dance but occasionally has trouble finding her way home. When she is confused, she takes a taxi, another expense she cannot afford. She forgets appointments with her doctor and counselor on a regular basis because she has difficulty in keeping a personal calendar.

Your role is that of the observer.

CASE HISTORY 3:
Ellen Ellis

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Your role is that of the consultant.

Note to consultant:

Ellen is very outgoing and friendly. It is easy to see why she is taken advantage on a regular basis. She wants friends and to have a social life but it rarely seems to work in her favor. You suspect she probably could learn housekeeping skills, if taught and structured, but like most people she doesn't like doing housework. Her roommates are also mildly developmentally disabled and not much help in keeping Ellen on track. She is a loyal employee and well-liked at her job so she is capable of good relationships. She is a disaster with money but doesn't want to have someone give her an "allowance" to solve the money problem. She is strong-willed and somewhat temperamental but is serious about wanting some assistance in improving her life.

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Your role is that of the participant (Ellen).

Note to trainee playing Ellen:

You know very well you have screwed up with your money but it is all so complicated that you wonder if you will ever straighten it out. You don't want someone to give you an allowance or control your money—that is what happened when you lived at home with your parents. Who cares if the apartment is a mess—it doesn't seem to bother your roommates and no one ever sees the place. Like others, you want to go out and meet people at night clubs. You just want a life like other young adults and hope to meet someone special to share your life with.

MODULE ONE:
Facilitating the Paradigm Shift for Consultants
Evaluation of Training Format

Date _____ Trainer _____
Please read the following statements carefully. Indicate by circling the number in the box whether you agree or disagree with the statements.

	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I found there was adequate time to cover the training content.	5	4	3	2	1
I found there was too much material covered.	5	4	3	2	1
I found the presentations effective.	5	4	3	2	1
I found the small group activities beneficial.	5	4	3	2	1
I found the handouts helpful.	5	4	3	2	1
I found the PowerPoint slides helpful.	5	4	3	2	1
I felt the trainer was knowledgeable about the subject matter.	5	4	3	2	1
I felt the trainer interacted effectively with the trainees.	5	4	3	2	1
I felt the trainer respected my experiences.	5	4	3	2	1
I found the setup (i.e., physical space, room temperature) was satisfactory.	5	4	3	2	1

What aspects of the training, if any, were most helpful?

What aspects of the training, if any, were least helpful?

Please pick something you learned today and state how it applies to your work:

What improvements, if any, would have made the training more effective?
Please add any additional comments.

MODULE ONE:
Facilitating the Paradigm Shift for Consultants
Content Evaluation

Please answer the following questions: You may use any notes or handouts from the training session.

1. Did any "feelings" you had about participant-directed care before the training session change as a result of today's presentation?

2. What new knowledge do you feel you still need to work effectively in participant-directed care?

3. Define participant "empowerment" as you understand it.

4. Are there any of the assumptions underlying participant-directed care that you do not agree with?