MODULE ONE:
Facilitating the Paradigm Shift for Consultants

Outline and Suggested Trainer's Time Schedule of Events

1:00–1:15 ..... **I. Introduction** Introduce trainer, brief welcome to trainees. Break trainees into smaller groups (5–8) if group is large and have them introduce themselves to each other. Ask trainees to stay in groups.

1:15–1:30 ..... **II. Identifying Components of the Paradigm Shift**

Group Exercise One: (Think of something you learned to do...) Have trainees answer this question with others in the group.

1:30–1:45 ..... Have reporters from groups report back to larger group on what trainee responses were to the question. Trainer should record responses in **feeling**, **knowledge**, and **skill** categories. Process responses to highlight importance of identifying what we feel, what we know, what we know how to do as part of the process of learning.

1:45–2:30 ..... **III. What is participant-directed care?** Present brief history of movement. Identify assumptions of participant-directed care. (15 minutes)

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

2:30–2:45 ..... **Break**

2:45–3:30 ..... **IV. Exploring Roles of Participants/Consultants (Needs and Wants)**

Group Exercise Three: Break into dyads, have trainees role-play the participant/consultant using case histories. Goal is for the consultant to identify at least three things that the participant needs relevant to care and to begin to establish a decision-making relationship with the consultant.

3:30–4:15 ..... Bring big group back together, identify answers to specific questions about what is difficult in allowing participants to assume these new roles and for professionals to take a back seat in the decision-making process.

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

MODULE ONE:
Facilitating the Paradigm Shift for Consultants

Learning Tasks and Outcomes

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.

OUTCOMES:

- Trainee will be able to identify their own *feelings* about participant-directed care and consider what feelings might arise for participants in participant-directed care.
- Trainees will be able to identify what new *knowledge* they and participants will need to be effective in facilitating participant-directed care and where to get that knowledge.
- Trainees will be able to identify what new *skills* they and participants will need to facilitate participant-directed care.

LEARNING TASK TWO:

Identify the underlying assumptions of participant-directed care including its contribution to participant empowerment.

OUTCOMES:

- Trainee will be given the opportunity to "struggle" with the underlying assumptions of participant-directed care in recognition of the complex interplay of feelings, knowledge, and skills present in this model of service.
- Trainee will be able to define "empowerment" as it is operationalized in participant or self-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 service models.

OUTCOMES:

- Trainee will be able to describe the role of the participant in participant-directed care.
- Trainee will be able to describe the role of the consultant/support broker in participant-directed care.
- Trainee will gain skills in helping participants identify both *wants* and *needs* as they both contribute to an improved quality of life.

MODULE ONE:
Facilitating the Paradigm Shift for Consultants

Consultant Training Program

Materials Needed:

- **LCD projector with computer for Power Point slides**
- **Flip chart and markers (for trainer)**
- **Case histories (See Trainee Handouts for Module One) for use later in the exercise**
- **Handouts for trainees (See Trainee Handouts for Module One)**

I. INTRODUCTION (Power Point Slides 1 and 2) (15 minutes)

- The trainer should be introduced by the sponsoring organization or agency. The sponsoring organization may use this opportunity to briefly describe the specific waiver program that employs the trainees. The trainer should clearly identify his or her position within state or agency sponsoring the training.
- The trainer should draw trainees' attention to the format for this three and one-half hour session (included in Trainee Handouts). **(Power Point Slide 3)**
- The image used throughout this training module (and in Module Two) is that of the circle. The circle represents the participant's greater environment and all the resources he or she might access to help him or her survive and thrive as independently as possible. Under traditional case management models, the participant is often heavily reliant on receiving services from an agency to meet his or her needs. The agency often has significant power in determining who, when, and where supports are provided. **(Power Point Slide 4)**
- Under a participant-directed model of care, the power to determine how needs will be met shifts from the agency to the participant. While the agency determines the level of need, the participant can determine how those needs will be met based on personal preference. **(Power Point Slide 5)** The participant may select from a broader range of options to meet their service needs, thus empowering him or her.
- The Learning Tasks for Module One of this training session are: **(Power Point Slides 6, 7, and 8)**

  1. **Learning Task One:** Identify the relationship between feelings, knowledge and skills as part of the learning process.
  2. **Learning Task Two:** Identify the underlying assumptions of participant-directed care.

3. **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.

These three learning tasks are aimed at accomplishing a "paradigm shift." That is, shifting from the mindset of professional as expert in designing services to individuals to empowering the participant to take a more active role in designing his or her own service plan.

(Power Point Slide 9) The process of participant-directed care has also been described as "self-direction" or "consumer-direction." For the purposes of this training, the recipient of services is called the "participant." Other terms used to describe a participant include "consumer" or "individual." The individual who works with the participant to help him or her identify and connect to the needed services will be referred to as the "consultant" This role is also described as the "supports broker" or "facilitator."

Trainees' training materials should be located at the tables where trainees will be sitting. Logistics about how long the program will be, when the break is and where the restrooms are should be addressed during this time.

II. IDENTIFYING FEELINGS, KNOWLEDGE, AND SKILLS IN THE LEARNING PROCESS

Group Exercise One: (15 minutes for trainee response, 15 minutes to report to group and summarize observations)

- If number of trainees is smaller than 10, individuals should be asked to introduce themselves, indicate where they work, their previous experience with participant-directed care. If there are more than 10 trainees, divide trainees into groups of 5–8 and have them introduce themselves to each other.
- Once trainees have introduced themselves, ask the trainees to answer the following question in the same groups:
- **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? (Power Point Slide 10)**
- Have them share their answers with others in the group. If the group needs to be divided into smaller groups, the groups should identify a reporter to summarize what group members discussed.

Processing the exercise:

When the groups report back to the larger group, the trainer should summarize responses (before and after feelings) on a flip chart. *For example:*

Feelings Before	**Feelings After**
Fear, uncertainty	Proud, confident

Ask trainees what happened to change their feelings. Their responses will likely include the acquisition of knowledge and/or skills. That is the point of the exercise. Feelings precede the accomplishment of any new learning. Focus on what knowledge and skills moved them from their feelings before learning something new to their feelings after. **(Power Point Slide 11)**

Implementing participant-directed models of service provision involves these three components (feelings, knowledge, and skills) for both the consultant/support broker *and* for the participant. Consultants/support brokers who are most comfortable and familiar with traditional case management models will have strong feelings about participant-directed care (both positive and skeptical), as will participants. Obtaining knowledge about how this model works, what resources can be developed to encompass a larger circle perspective for the participants, and learning the skills necessary to "consult" with participants rather than "manage" them will enhance the empowerment of the participant. This is the purpose of this model for those participants who select this option. Successful completion of acquiring new knowledge and skills (for both the consultant and the participant) constitutes the "paradigm shift."

II. WHAT IS PARTICIPANT-DIRECTED CARE?

This exercise is consistent with the ways in which adults learn. That is, they have an emotional response to new material, need time to reflect and struggle with new knowledge and skills and then accept new material as part of a "paradigm shift." This is a natural introduction to the concept of participant-directed care and how promoting self-direction and independence in participant populations encompasses improving feelings of the participants about themselves, learning more about themselves and their care needs, and learning new skills in supervising/directing their own support workers, supports, and services.

- If needed, information about the particular waiver program may be added here.

History of Self-Determination:

- Participant-directed or self-directed care grew out of the independent living and disability rights movement of the 1960's. While traditional service models in which an agency arranges, coordinates and delivers services to a participant may meet physical needs, it fosters a powerlessness that deprives the participant of true choice and responsibility.
- However, the participant-directed approach, emphasizes the importance of the principle of autonomy in which individuals with physical disabilities take charge of their paid service providers to preclude dependence on others for basic daily activities. With the ability to hire, train, supervise, pay, and if necessary, fire paid support workers, individuals gain the authority and power to direct the provider.
- The movement has expanded to include adults with physical disabilities, children and adults with developmental disabilities, persons with a diagnosis related to mental health or substance abuse, and older adults under the nomenclature of "participant or consumer-directed care."

- The common themes of participant-direction, regardless of participant population, include the importance of the participant maintaining a high degree of involvement in their services and supports and having choices about the "who, what, when, and where" of service delivery. Service providers become accountable to the participant or representative directly, not to an agency that employs them on behalf of the participant. Sometimes under participant-directed care, there is an increased connectedness to the "circle" of family and friends.
- **Empowerment, as used in participant-directed care, is defined as the creation of opportunities for self-direction of support services enhancing the participant's (or his or her representative's) learning, self-monitoring, and accountability. The participant (or representative) gains an increased sense of competence and independence. Empowerment is a feeling and an action. (Power Point Slide 12)**
- Assumptions of the movement toward participant-directed care model include: **(Power Point Slides 13, 14, and 15)**

    1. Participants with disabilities are experts on their own care
    2. Individuals with disabilities and access to private funds are able to determine all aspects of their own care with minimal intervention from professionals. This right should exist for individuals who rely on Medicaid to fund personal and health care needs.
    3. Some participants prefer to make decisions about their own service needs.
    4. Some participants wish to take a more active role in managing their own care.
    5. Personal assistance services are not medical services therefore the provision of those services should not be directed by health care providers. Participants are better equipped than health care providers to assess housekeeping and personal assistance services and direct and monitor their delivery.
    6. Participant-directed care may save money with lower administrative costs.
    7. With support, participants will exercise their choices and spend government resources wisely.

After presenting these assumptions, it is often necessary to give the group an opportunity to process their current feelings about participant-directed care. Ask the group to simply share their feelings and concerns—this is the feelings part of the "paradigm shift" necessary when moving from traditional care management to the participant-directed model. It is important for the trainer not to become defensive at this point but rather simply allow trainees to offer their own responses. Trainees may have very strong opinions and may offer lots of "yes, but" responses.

The trainer should clearly state at this point that participant-directed care is an option that individuals (or their representatives) may select but that it may not be appropriate for everyone. Making the successful transition from a traditional case management model to participant-directed care involves the acquisition of knowledge and skills for consultants and participants.

The following group exercise is based on what knowledge and skills participants and consultants must develop if they (or their representatives) choose a participant-directed option.

Group Exercise Two:
Divide the larger group into four smaller groups. The four different "assumption groups" should be included, by random distribution, in the trainees handouts. Each group is assigned one of the following categories (See groups as designated below). The groups are instructed to indicate what knowledge and skills are needed to move from Assumption One (more traditional case management) to Assumption Two (more reflective of participant-directed care). Expect that some groups will argue about the validity of either assumption for some time before moving to the identification of knowledge and skills.

Trainees should find others who are in the same groups to work together.
(Power Point Slides 16, 17, 18, and 19)

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.

Processing the exercise:
Have groups report back to the larger group with emphasis on what knowledge and skills are necessary to move from each Assumption One to Assumption Two. This exercise is an example of the connection between feelings, knowledge and skills.

- It gets trainees thinking about specifically what both participants and consultants will need to learn to make participant-directed care successful and meaningful to both parties.
- It also allows for the feelings component to surface, often before group members can even start to recognize the need for new knowledge and skills on the part of both the consultant and the participant.
- Moving from Assumption One to Assumption Two should widen the circle of choices for services to participants.
- The trainer should reinforce the point that the paradigm shift addressed in this training module is contingent on the trainee's awareness of all components of learning.

BREAK: 15 minutes

IV. EXPLORING THE ROLES OF PARTICIPANTS AND CONSULTANTS

(Presentation by trainer and Group Exercise Three, 30 minutes)

One of the first responsibilities of a consultant or support broker is to work with the participant to identify what services they **need** to function as independently as possible. However, needs are best understood and identified when placed within the total context of an individual's life. This exercise is intended to help trainees see the "life context" in which needs are identified. It supports the idea that supports are also part of a greater life context that participants (or their representatives) envision. It helps the consultant see the participant as a total person rather than a package of needs and services.

- Trainer presents how to explore needs with the participant. The following questions are suggested as ways to begin the exploration. Trainees should be encouraged to volunteer other suggestions for questions. **(Power Point Slides 20, 21, and 22)**

  What services or products 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 the most about your life before you needed support services? (or if supports have always been in place, what do you wish you didn't need assistance with?)

Ask the group to identify additional questions to get at a participant's needs without directly asking "What do you need?"

• • • • • Learning Point • • • • •

The purpose of this presentation is to get trainees in the frame of mind of asking the participant what s/he ***wants*** first rather than to jump into "expert" mode and tell the participant what they ***need.*** It also helps trainees to see the participant first as a **person** rather than just as person with a need or disability.

- **Group Exercise Three:** Trainees are divided into triads. Each is given a brief case history. These can be geared to the trainees in terms of what kind of participant population they will be working with. The case histories have two parts, one that gives the perspective from the participant side (with information only the person playing the participant has access to) and one that gives barebones information the consultant has about the participant with information only the person playing the consultant has access to. **(Power Point Slide 23)**
- The case histories should be in the trainee's packet, thus they will be randomly assigned to be either a consultant or a participant or as an observer. They should find others in the groups who have been assigned the same cases. Every group should have one participant, one consultant, and one observer for the same case.
- Have the individual role-playing the consultant begin to explore what the participant wants/needs using the questions presented by the trainer or other trainees.The goal is to identify at least three things the participant needs but the consultant cannot identify those needs for the participant. The consultant's job is to help the participant explore wants and needs. The third person in the group is asked to observe the role-playing and may recommend questions the consultant might ask to identify needs. **(30 minutes)**

Bring group back together and ask the following questions: **(Power Point Slides 24, 25, and 26) (30 minutes for these questions)**

1. What was difficult about letting the participant identify needs?
2. From the participant's perspective, what is difficult about being asked what you need or want in your life?
3. Did you (consultant) feel a need to take over the direction of the conversation?
4. Did you at any time feel your participant should not be allowed to make these decisions for him or herself?
5. Does this process go against the grain of what you already know about identifying needs with "clients?"

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.

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.

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.

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.

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 cognitively disabled 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.

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.

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.

Trainer should summarize the following learning points.

• • • • • Learning Points • • • • •

1. Participants often have difficult identifying what they want to improve the quality of their lives, rather than continuing to echo what professional case managers feel they "should have" to meet basic activities of daily living. This difficulty may come because no one has ever asked them what they want.
2. As participants struggle with identifying what they want, in terms of services, the consultant/support broker may find it easier to make suggestions and "rescue" the participant than to let them struggle with the question.
3. Making decisions and choices involves some risk. What the participant wants may contradict what the consultant thinks the participant "should want." Learning to make decisions involves both practice and experience.
4. Traditional approaches to identifying and securing services emphasize the authoritarian role of the professional as "expert." Transitioning to a participant-directed model involves letting go of the need to "do the right thing" for the participant and allowing the participant to take greater control of his or her own life. **(Power Point Slides 27 and 28)**
5. Both participants and consultants will approach participant-directed care models with a complex set of feelings. Making participant-directed care work successfully requires the acquisition of complex knowledge and skills.

V. EVALUATIONS (15 minutes)

- There are two forms of evaluation. The first evaluation form is to evaluate the format of the training using a simple check list of numbers.
- The second evaluation form is actually a post-test to evaluate whether trainees have accomplished the learning objectives of the program. Trainees should feel free to use any notes or handouts from the training to complete this form.
- Both forms are located in the trainee handouts section of this manual.

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

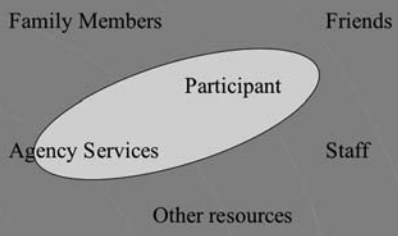
MEDSTAT Consultants

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.

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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.

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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?