

My Health-My Decision



Agency Guide for Conducting Training and Supporting Trainers

Developed through a coordinated effort of:

The Arc of Prince George's County
Ardmore Enterprises
Melwood

Montgomery County Dept. of Health and Human Services

Resource Connections of Prince George's County

Service Coordination: A division of The Arc of Frederick County

The Southern MD Regional Office of the Developmental Disabilities Administration

The Maryland Developmental Disabilities Council

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Introduction:

Thank you for taking the time to invest in training people who you support to be more meaningfully involved in their current and future health care decisions.

This guide should help you and your staff to best conduct training and support people you serve to be co-trainers. This training was developed by people with disabilities and experts in supporting them.

The training was developed in response to the desire to have people with disabilities be more meaningfully involved in their healthcare decisions. It was developed as one part of a multi-pronged approach to educate everyone in your organization. Staff will need access to information so they can support new learning. We suggest, at a minimum, that staff be trained on, or exposed to, the information sheet supplied to each participant. They will be asked to share it with their staff. For more in-depth information a full training DVD on Informed Consent and Medical Decision Making, written and presented by a multi-disciplinary panel (including a psychiatrist, lawyer, residential director of a program for people with developmental disabilities, and hospital social worker) will be available soon. Although it was designed primarily for staff from agencies providing support to people with developmental disabilities, it may be of interest to a wider audience. Information about this material can be obtained from Kendra Sampson, The Arc of Frederick County at 301-663-0909.

In order to best support people to be more involved in their own healthcare decision, they need more information. **We suggest that each agency develop a training team made up of staff and people with disabilities and conduct this training once a year for people you support.** If your agency is not able to develop in-house resources then contact the Regional Training Coordinator for alternative training teams in your area.

It is critical to recognize that people who are personally affected by this will be your best, most effective trainers. Our initial curriculum development team and pilot training team will be available to assist you to conduct the first trainings if you need their support. Contact Bea Rodgers at Resource Connections of Prince George's County for their contact information (301-429-9300).

It is recommended that identified trainers go through a two hour training together then meet to coordinate their efforts to practice and conduct ongoing training within their organization. Train-the-trainer courses may be arranged through the Southern Maryland Regional Office. Contact Vanessa Antrum for more information. In other areas of the State, you may contact the Regional Training Coordinator at the Regional Office of the Developmental Disabilities Administration.

Thank you again for taking on this commitment to provide on-going training. This guide should help you.

Suggestions for trainings:

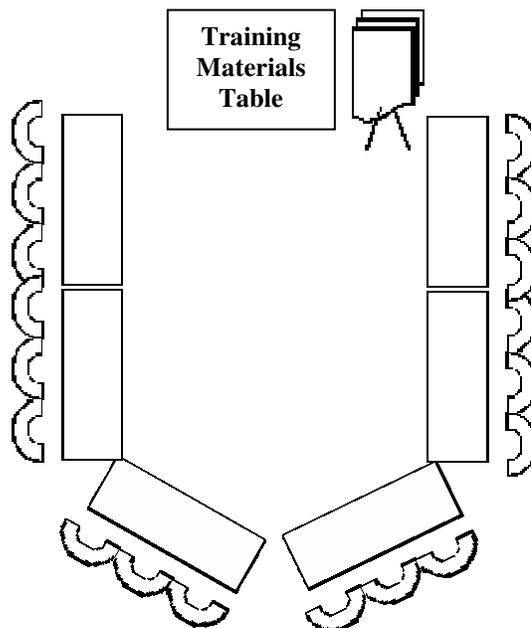
Each training should last about two hours. It is suggested that no more than 10 people attend each class. Each training team should consist of at least 4 people and can be as many as 6. Two or three of the trainers should be people with a disability. We suggest that each trainer be paid for their efforts and be supported to do their best.

The criteria for a good trainer:

- 1) Comfortable speaking in front of others.
- 2) Able to read and write.
- 3) Able to work well in a team.
- 4) Respectful of others.

Room Set-up

The training room should be large enough to accommodate 10 people and at least 4-6 trainers. There should be adequate wall space for hanging materials. Anticipate the need for extra space for wheelchairs. The best room-set up is long tables set up in the shape of a “U” with chairs around the outside. The open part of the “U” is where the speakers are and the visuals are on the wall behind the speaker. The extra speakers and trainers are scattered around the room, preferably off to the side and ready to help training participants locate the right page or to assist with writing. Certainly every room is different so make the best judgments about what will work best.



Training Participants

People best suited for this training are those over the age of 18 who do not have a guardian of the person. While we believe that children and people with guardians need to be involved in their healthcare choices, the information in this particular training is not specific to them and would be misleading.

This may be an opportunity for people to be exposed to this information for the first time. Deciding who should attend the training should not be a strict sorting of who can currently make a decision. Think of it as a way to help people decide how much support they need to make the best decisions regarding the very personal matter of their healthcare.

People do not need to be able to read or write to benefit from this two hour training. It is important, though, that individual support needs be provided for. Consider assistance with eating, going to the bathroom, communicating, turning workbook pages, or getting along with others.

People should never be forced to come to a training and it should be scheduled so people do not have to give up paid work time or opportunities.

Training Flow

Arrange the room and have a booklet, pen/pencils, and name tag at each seat. Scatter the markers and stickers around the tables.

As people enter the training room, welcome them. Let them know they are in the right place and that they are free to sit where they please. Have them sign in if needed. All trainers should help people individually print their first name on their name tag (using the markers, being careful to get the spelling of their name correct, and to write large enough for all to see and read). Then invite people to choose their favorite stickers to decorate their name tag. This will keep people busy until all are in the room.

Try to start on time. Some people always arrive late to training and it is disruptive when they come in so it is better to wait a few minutes to make sure that most of the people are there. Start no later than 15 minutes after the beginning of the training or you will not be able to finish on time. Thank people for being on time and ask permission to wait a few minutes longer if most are not there.

Once everyone has used the stickers, collect them (if not collected some people just keep adding stickers and do not pay attention to others introducing themselves) and begin the introduction section.

The training is best broken up in the following sections. In practice determine who will do each section and keep a list posted in the back of the room large enough for the speakers to see. The starred (*) sections are the most difficult and should be practiced and done by a more experienced trainer at first. Part 4 is the longest and should be done by your best reader. We recommend that the introduction and the next two sections always be done by a person with a disability to set the tone for the training and to help people be in a position of leadership.

Training Sections	Page #s	Name of Presenter
Introduction	Pages 2-4	
Part 1	Pages 5-6	
Example Prep	Pages 7-8	
*Example Chart	Page 9	
Example Close	Page 11	
Part 2	Page 12	
*Audience Participation	Page 13	
Part 3	Page 14-15	
Heart Invitation	Pages 16-17	
*Part 4	Pages 18-22	
Five Wishes	Page 23	
*Evaluation and Questions		
Final thoughts	Page 24	
Certificates		

Training Materials

You will need to supply the following materials for each training that you conduct:

- 1) One color printed training manual for each participant either stapled in the upper left corner or three-hole punched and bound in a clear covered report folder. While it is easier and cheaper to just black and white copies of the manual it is important for non-readers to see color and contrast.
- 2) Name tags
- 3) Variety of stickers suitable for men and women to personalize the name tags such as sports, flowers, stars. (ice breaker)
- 4) Water-based markers (dark colors only)
- 5) Masking tape
- 6) Chart paper (3 pieces)
- 7) Pens and/or pencils for participants
- 8) Scissors
- 9) Refreshments suitable for the time of day of the training
- 10) Heart shaped 3M stickers or regular square post it notes
- 11) Five Wishes booklets one for each participant. Call 1-888-594-7437 or go to www.agingwithdignity.org Check also with your Regional Training Coordinator.
- 12) Card stock for pre-printed visuals (“two to a page” and “plus/minus”) (See Audience Participation Section for more information).
- 13) Certificates of training for each person.
- 14) The fact sheet for each participant to share with their staff and families.

Training Script

Introduction

For the person leading the training, welcome people and let them know that you will begin the training. Thank everyone for coming. Introduce yourself as a trainer and then let the other trainers introduce themselves.

Remind people that they made a nametag and put stickers on them. Have everyone go around the room and introduce themselves and explain why they picked the stickers that they did. Some people may have chosen to not put on stickers let them know that this is their choice and this is OK. Thank each person after they have finished and move on to the next person. Keep this moving and do not allow someone to take up too much time. Gently figure out ways to keep it moving.

Once everyone has introduced themselves get started. Let everyone know that they have a booklet in front of them and that it is theirs. They can write their name on the front now if they do not want to get their mixed up with others. Let them know that they will be able to take the workbook home with them after the training is finished.

Have everyone turn to page two. Read this page out loud. **Always let people know what page you are on and give them time to make sure that they are turned to the right page.** Read slow and loudly. Look up every now and then to make sure that you are being understood and people are following you.

When you get to the four things you want to teach, you may want to have each of these printed on half page piece of colorful card stock so when you go over each of the 4 things that you would be sticking each one on the wall as a visual cue and for interest. Keep the four cards on the wall and refer back to these when you begin each new section.

Part 1

Another trainer will begin on page 5. Point to the “How to make decisions” card and explain that you will be going over the next section. Have people turn to page 5 and follow along as you read this page. Go ahead and read page 6. Remember to tell people that you are turning to page 6 and make sure that they follow along.

Example Prep

The next trainer will begin reading on page 7. Make sure that you read the questions to sound like questions. This may take some practice. Remember that you are just asking the question out loud but you are not wanting people to answer at this time. Continue reading to page 8.

Example Chart

The next section could be done by one or two people. One person will have to be able to write fast and another will be getting answers from the audience.

One person will begin and refer to a re-created chart on page 9 which should be on the wall. You can either copy it to two pieces of large piece of paper or you can create the chart using pieces of colorful paper taped to the wall to look like the chart in the book. Make sure the paper is thick so when you write on it, the marker will not bleed through to the wall. All the anticipated answers are on page 10 but people will not know this unless they look. Try and walk through the chart starting with the question in the bottom block and work your way up the chart. Some people will wildly answer questions but try and direct the answers back to the anticipated answers. Certainly add other things that the group comes up with that we may not have anticipated. Here is where you may want to have one person write the answers and one person pull the answers from the group.

Explain that the middle part of the chart is where you can slow down, ask more questions, figure out who can help you make a good decision. Explain once again that waiting can be good but waiting too long can be the same as saying no.

Once the chart is complete thank everyone for their help and ask them if this was helpful in helping them organize their options. Briefly discuss their comments.

Example Close

The next trainer should tell everyone to now turn to page 11 and read this page.

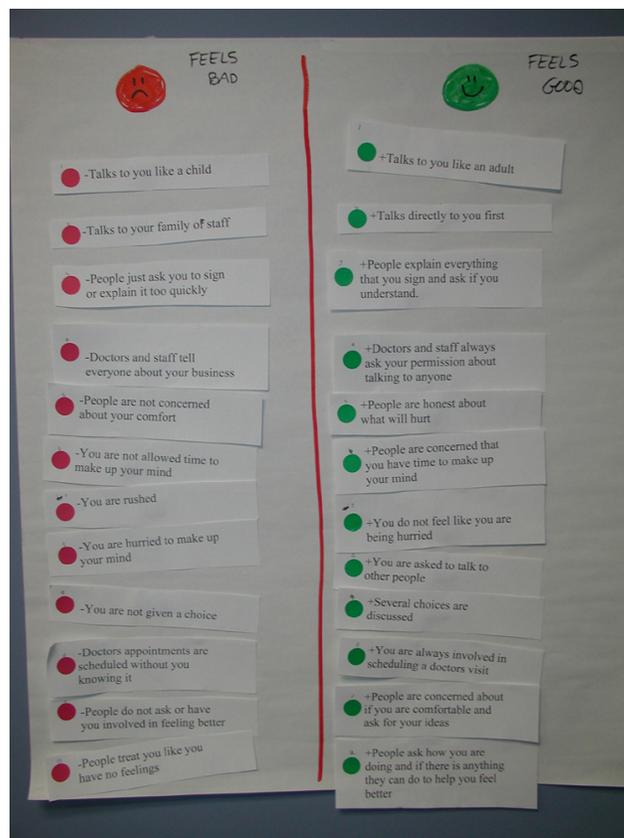
Part 2

The next trainer will ask people to turn to page 12 and begin reading this page.

Audience participation

This next section takes a little more practice so a more experienced trainer should do this part. Ask people to turn to page 13 and tell people that you will now be talking about the things that need to be there in order for people to feel more in charge of their healthcare decisions.

You should have printed out a copy of the good and bad examples for the 12 indicators listed. (See file plus and minus) You will have 24 examples. Half will have a red mark on them and half will have a green mark on them. You will ask which one is the good example and what should be there and which are the feel bad examples and what should not be there. Discuss each example and either post examples on a red and green side of a piece of paper or have participants do this. The example sort should end up looking something like this:



It helps to keep you organized if you mark each response with the number of the example that it relates to so there will be a red and a green 1, a red and a green 2, etc. Once sorted thank everyone for thinking and working so hard. Close by reading the last section on page 13.

Now is the time to take a break. You should be about halfway through the training and should have 45-60 minutes left. You will be the best judge of whether or not to take a break here. If you have only 45 minutes left then it will be hard to get it all done and you may want to work on through. If you have 60 minutes left then you can take a 5 or 10 minute break.

Part 3

The next trainer will make sure that people are focused and ask them to turn to page 14. Begin reading this page. Continue to read on page 15 to the part about asking them to write a name on a piece of paper. As you ask them to do this pass out the heart shaped 3M sticker or a regular square post it note. Have them write their person on this piece of paper. Give them a few minutes to think and make sure that everyone gets help to write by the other trainers. Try and encourage them to only write one name on the paper. Some people feel the need to put several names but help them decide on just one name.

Once everyone has written a person's name, explain that you will now help them to think about this person more. Simply recreate the chart on page 15 to reflect a small circle in the middle that will represent the person and a line down the middle with one side writing "paid" and the other side writing "not paid". Like this:



One at a time help people to come up and sort whether the person is paid or not paid and decide how close to them that they are. The closer they are the closer the sticker gets placed in the middle. Remember to not suggest that paid or not paid is good or bad. It just represents a difference and it is important to know this difference. Once everyone has done this thank them for sharing this information.

Heart Invitation

The next trainer will ask people to write the name of the person that they selected in the heart on page 16. People can either retrieve the heart they already filled out and place the sticker there or they can re-write it if they changed their minds. Have other trainers help people to put the name of someone in this heart. Really emphasize the importance of the words underneath the heart. Strongly emphasize the point that people need to let the person know that they picked them and help them to understand the importance of sharing the booklet with this person. Talk about this a little more.

Read page 17.

Part 4

The next trainer will point to the last section to be covered and remind people that you are almost finished. Have the group turn to page 18 and begin reading. Read slowly and with meaning. This section is very long and very important so your best reader should do this part.

Read to the middle of page 19. When you begin asking the questions in the box make sure that people know that they are not expected to answer out loud, although many people will. (You are not as much asking people a question for them to answer but just to think about the question). Give everyone enough time to think, or for some to answer out loud, and move to the next question. Keep this part moving and do not get bogged down in too many stories. Be respectful that some people want to be able to share what they are thinking. Continue asking the questions to page 22. Once you get through all the questions in the box, read the last two sections on page 22 to finish this section.

Five wishes

The next trainer will read the material on page 23. Have a copy of the Five Wishes booklet to pass out to each person. There will not be time to read or go over the booklet. Just let people have it and encourage them to share it with the person that they have identified on page 16.

Evaluation and Questions and Answers

The next trainer will ask people if they have any questions as you are almost finished. Answer people questions as best as you can.

Then let people know that since you all are conducting ongoing training that you want to get their ideas on how well they enjoyed the training and if they have any suggestions for making the training better. Write people's opinions down either on a large piece of paper for all to see or just jot down on a smaller piece of paper. You may ask "what was the best part of the training?" and "what was the worst part or the part that could be better?" Thank people for their ideas.

Final Thoughts

The final trainer will ask people to turn to the last page, (page 24) and then review this information. Thank everyone for coming, remind them to take their booklets with them, and to share it with the person they identified. There is a flyer to give each participant to take home and share with family and/or staff. It will explain the course and help people to be able to support the learning. You may also remind people to take off their name tags. People especially enjoy receiving certificates of training. A template is available on disk for you to print and give to each participant.

If your agency plans to conduct, or offer, this training on a regular basis, you may want to let people know that they can take the training again in a year if they feel the need to refresh the information.

Our Final Thoughts

Good luck to your agency as you conduct, or offer, this training on a routine basis. The people you support need this information and the encouragement to get more meaningfully involved in their healthcare decisions. Agency staff, trainers, and peers can be the best encouragement to help people see this for themselves.