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Evaluation of the Ohio double jeopardy  
demonstration project

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**EVALUATION OF THE OHIO DOUBLE  
JEOPARDY DEMONSTRATION PROJECT**

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## **EXECUTIVE SUMMARY**

The goal of Ohio's Double Jeopardy project was to support families in their efforts to plan for secure futures for family members with mental retardation/developmental disabilities (MR/DD) and for their aging parents. This report summarizes the results of the evaluation that was conducted to document the effectiveness of training offered as part of the Double Jeopardy project. Specifically, this report addresses the effectiveness of: a) legal and financial training for professionals; b) cross-training of professionals from the aging and MR/DD networks about the populations that are served and how the networks operate; c) training about life planning for professionals from both the aging and MR/DD networks; and d) training about life planning for family members.

Ohio's PSAs 5, 10-A, and 11 served as demonstration sites for the Double Jeopardy demonstration project training sessions. The "kick-off" was a state-wide, two day training designed to prepare professionals from the aging and MR/DD services networks to serve as trainers for future Double Jeopardy training. Subsequently, across the PSAs, three sessions targeted attorneys and financial planners, six sessions targeted professionals from the aging and MR/DD services networks, and nine sessions for family members were offered. To the extent possible, pre-test/post-test and four (or six) month follow-up data were collected for each session. Whereas the pre-test and post-test evaluation tools recorded participants' knowledge about, and self-evaluation of their abilities regarding, life planning, the follow-up tool inquired about families' related life planning behaviors since the training sessions. In addition, three "best practices" family interviews were conducted to identify the impact of training interventions on family planning behaviors and explore the dynamics of family responses to the Double Jeopardy experience.

The three groups of professionals entered their respective training sessions with self-identified need for information and skills and with concerns about service system issues and ethical issues. In general, at the completion of the training sessions, the three groups of professionals reported significantly more knowledge about the specific content covered in the training module(s), and significantly better abilities regarding life planning. Several exceptions did emerge for subgroups of trainees participating in specific sessions. Immediately following training, there were changes in participants' awareness of their knowledge (both what they have learned and what they have yet to learn), their incentive to engage in life planning activity, and need for communication and interpersonal skills to enhance the planning process.

At the four or six month follow-up, the three groups of professionals reported that the Double Jeopardy training had had a positive effect on the quality of their consultations related to MR/DD (legal and financial training participants), had positively affected their work in a number of specific ways (train-the-trainer and professional staff training participants) and resulted in successful trainings for other professionals (train-the-trainer participants). Immediately following the training, ongoing needs of participants who had attended the legal and financial training centered around information regarding laws, regulations, and planning mechanisms;

service system information; and contact/referral information. The ongoing concerns of train-the-trainer participants were heavily focused on service system issues, and the overarching theme for participants in the professional staff trainings was the need for conditions that foster planning work in everyday practice.

Attending family training sessions represents a major step in the process of life planning. Although family members did not identify specific concerns or questions prior to the training sessions, at the completion of the trainings, family members felt that they had a significantly better understanding of the basics of life planning for their relative with MR/DD. However, family members' comfort about the life planning process did not improve as a result of the training. Family participants left the training sessions with more specific questions, and indicated that they were motivated to specific action.

At the four month follow-up, nearly all (96%) family participants who responded indicated they would recommend life planning training to other families in their situation, and a number of participants had engaged in some life planning activity. Four months after training, family members' "biggest hurdles" in life planning are family decision issues.

"Best practices" interviews with three families revealed very different family circumstances and planning needs. For the three families, the role of life planning services ranged from outreach to education and referral to family mediation and support.

There is overwhelming evidence that training interventions have a positive effect on the learning of training content; life planning training immediately results in a significant increase in life planning knowledge. However, even when content is learned, interpersonal issues, and limited resources can present obstacles to life planning for both professionals and family members.

Even in the face of life planning obstacles, follow-up evaluations indicated enhanced professional and family activity related to planning. Furthermore, even modest changes in activity may actually represent significant changes in perspective, incentive, and interpersonal dynamics. The Double Jeopardy demonstration project represents an important first step in the development of interventions that make a difference in the life plans of families. This undertaking requires a sustained commitment of resources and energies from all parties involved: the aging network, the MR/DD system, families and the organizations who represent them, and legal and financial planning professionals. Finally, collaboration among these parties is required to assure adequacy and quality of life planning information and options, to assure peace of mind and quality of life for all family members.

## OVERVIEW OF THE EVALUATION

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## INTRODUCTION

Initiated in August, 1999, the goal of Ohio's Double Jeopardy project was to support families in their efforts to plan for secure futures for family members with mental retardation/developmental disabilities (MR/DD) and for their aging parents. The project was funded by the U.S. Department of Health and Human Services' Administration on Developmental Disabilities, and represented a partnership between the Ohio Department of Aging (the lead agency), the Ohio Department of Mental Retardation and Developmental Disabilities, and the Ohio Developmental Disabilities Council. As stated in the original grant application, there were four main objectives to the Double Jeopardy project: 1) "to obtain accurate data to identify the scope of the problem in Ohio"; 2) "to increase family incentive, knowledge, and activity related to planning"; 3) "to improve the coordination of services between the aging and developmental disabilities networks at the local level"; and 4) "to improve coordination of services between the aging and developmental disabilities networks at both the state and local levels, as well as with other networks and organizations" (pp. 16-17).

Scripps Gerontology Center, Miami University, Oxford, Ohio, was awarded a subcontract to evaluate the success of each of these four objectives. Three researchers from Scripps Gerontology Center were involved in the evaluation efforts. Dr. Suzanne Kunkel, Director of Scripps, offered strategies about how to best document the number of late life families who have an adult child with MR/DD. Dr. Kunkel's recommendations have been shared with the State of Ohio, and currently are serving as the basis for ongoing work in this area. Drs. Jennifer M. Kinney and Kathryn B. McGrew, Faculty Research Fellows of Scripps Gerontology Center, were responsible for evaluating activities related to the remaining objectives.

As is the case with any demonstration project, the Double Jeopardy Project was a "work in progress" that evolved throughout the development and implementation phases. As the project took shape, project activities focused on offering training to several different constituent groups. As such, Drs. Kinney and McGrew focused their efforts on evaluating the effectiveness the training offered under the auspices of the Double Jeopardy project. Specifically, Drs. Kinney and McGrew evaluated the effectiveness of: a) legal and financial training for professionals; b) cross-training of professionals from the aging and MR/DD networks about the populations that are served and how the networks operate; c) training about life planning for professionals from both the aging and MR/DD networks; and d) training about life planning for family members. The results of these efforts are presented in this report.



### **USING THIS REPORT**

Pages 31-34 present summaries of the evaluation of the Double Jeopardy training, and pages 36-43 present three case studies of families engaged in life planning. Taken together, these two sections serve as an expanded executive summary of the report. The reader might find it helpful to begin with these sections.

For the results of statistical analyses presented in the appendices, one-tailed tests of significance are reported, and  $p < .01$  was used as the cut-off for statistical significance.

**SUMMARY OF TRAINING OFFERED BY THE DOUBLE JEOPARDY  
DEMONSTRATION PROJECT**

Ohio’s PSAs 5, 10-A, and 11 served as demonstration sites for the Double Jeopardy demonstration project training sessions. The “kick-off” for the Double Jeopardy training sessions was a state-wide, two day training designed to train professionals from the aging and MR/DD services networks to serve as trainers for future Double Jeopardy training. Subsequently, in each PSA, separate training sessions that targeted attorneys and financial planners, professionals from the aging and MR/DD services networks, and family members were offered. The following tables summarize the Double Jeopardy training that were held in each PSA for the various target groups.

**Across the PSAs**

<u>Target Audience</u>	<u>Date</u>	<u>Curriculum</u>
Future Trainers Disabilities	07/20/00	Aging with Developmental
		Two Networks, Two Resources
Future Trainers	07/21/00	Life Planning 101 Life Planning 102

**PSA 5**

<u>Target Audience</u>	<u>Date</u>	<u>Curriculum</u>
Attorneys/Financial Planners	06/09/00	Financial Planning Legal Planning
Professional Staff	07/25/00	Two Networks, Two Resources
Professional Staff	10/19/00	Life Planning 101
Families	11/04/00	Life Planning 101

**PSA 10-A**

<u>Target Audience</u>	<u>Date</u>	<u>Curriculum</u>
Attorneys/Financial Planners	5/25/00	Financial Planning Legal Planning
Professional Staff Disabilities	10/20/00	Aging with Developmental  Two Networks, Two Resources Life Planning 101 Life Planning 102
Professional Staff Disabilities	12/05/00	Aging with Developmental  Two Networks, Two Resources Life Planning 101
Professional Staff Disabilities	12/06/00	Aging with Developmental  Two Networks, Two Resources Life Planning 101
Families	10/11/00	Life Planning 101 Life Planning 102
Families	10/18/00	Life Planning 101 Life Planning 102 Families
	10/25/00	Life Planning 101 Life Planning 102
Families	11/01/00	Two Networks, Two Resources
Families	02/21/01	Life Planning 101 Life Planning 102

**PSA 11**

<u>Target Audience</u>	<u>Date</u>	<u>Curriculum</u>
Attorneys/Financial Planners	06/23/00	Financial Planning Legal Planning
Professional Staff	12/04/00	Two Networks, Two Resources Life Planning 101 Life Planning 102
Families	11/06/00	Two Networks, Two Resources Life Planning 101
Families	11/06/00	Two Networks, Two Resources Life Planning 101
Families	11/13/00	Two Networks, Two Resources

## Life Planning 101

## **CONCERNS BROUGHT TO THE TRAINING**

*(concerns that professionals and family members brought to the Double Jeopardy Training)*

As part of the pre-test evaluation, participants were asked to identify questions and concerns they brought with them to the training sessions. Overall, there was wide variability in questions and concerns among participants, particularly within target groups of professionals: legal and financial planners, and professionals from the aging and MR/DD services networks. Very few family participants identified concerns or needs for specific information. Post-training, family members had more questions; these are discussed later in the report. Because less than half of professional participants entered questions or concerns, responses are aggregated here for all professionals, regardless of whether they attended legal and financial, train-the trainer, or professional staff training sessions.

Professionals entered their respective training sessions with self-identified need for information and skills and with concerns about service system issues and ethical issues. Need for information was widely variable within target groups. Some entered training with very broad, "wide-open" questions, whereas others had very specific questions that appeared to motivate their attendance at the training. Examples of "wide-open" responses include: "I know nothing! Teach me!"; "Any information will be beneficial."; "Total ignorance of the subject." Examples of specific questions include: "Can a 1339.51 trust be established inter vivos?"; "Can funeral arrangements be paid for MR/DD before going on Medicaid?"; "Information for families interested in leaving their home to son or daughter to continue to live in (with other clients) and asking if agency (county board) can provide services there." Some professionals appeared to have a specific application of information in mind: "We are just beginning a PLAN program and appreciate any relevant information."; "How to tie my MR/DD background into my insurance-estate and financial planning career." Some aging and MR/DD professionals indicated a specific interest in learning about the other system of services: "To gain knowledge in the field of MR/DD"; "Learn more about elderly solutions." A prominent "need-to-know" area was the identified desire for names and contact information for qualified professionals. For example: "How do you know if the 'expert' really has the most up-to-date information?"; "Can there be a data base established ... through the DD Council to maintain a list of qualified people?"

Professionals identified skills that they need to communicate with families and motivate them to plan. Examples include: "How to establish a rapport with principal families"; "How to help families who do not trust anyone else with adult child's care"; "How to convince parents to take action early on"; "Direction to take in approach to parents who have MR/DD child to encourage financial planning."

Professionals also identified several service system issues, including concerns about less privileged families ("What can families do that have no assets?"); families already in need ("What do you do with a family already in crisis?"); families unknown to the system ("How do we find hidden cases?"); staffing resources ("How can we get a life planner in our county?"); and service resources ("Local roadblocks to more accessible, available congregate housing.").

Professionals identified ethical issues about guardianship: "Parents who want their child to have guardians to make themselves feel better, but this takes independence away from the individual" and manipulation of assets: "Ethical issues regarding using public funds (i.e., Medicaid) to support a person whose parents have money to pay for the support."

#### Summary of Concerns Brought to Training

Clearly, professionals who attended legal and financial training, train-the-trainer training, and professional staff training came to sessions with a variety of objectives for training. The next section of the report summarizes the extent to which the Double Jeopardy training resulted in changes in participants' knowledge of, and their self-evaluations of their abilities regarding, the content areas covered by the various training.

**PRE-TEST/POST-TEST EVALUATION OF TRAINING**

*(provides training overview, procedure, and number of participants; participant profile; and evaluation of changes in perceptions and knowledge)*

**PRE-TEST/POST-TEST EVALUATION OF THE LEGAL AND FINANCIAL TRAINING**

**Training Overview, Procedure, and Number of Participants**

A four-hour training session designed for attorneys, financial planners, and insurance agents was held in each of the three PSAs demonstration sites for the Double Jeopardy project. The table below summarizes the training conducted.

<u>PSA</u>	<u>Date</u>	<u>Module(s)</u>	<u>Duration</u>	<u>No. Part.<sup>a</sup></u>	<u>No. Pre/Post Evals</u>	<u>No. Follow-Ups</u>
5	06/09/00	Financial Planning	2 hours	38	28	21
		Legal Planning	2 hours	38	32	
10-A	05/25/00	Financial Planning	2 hours	33	25	14
		Legal Planning	2 hours	33	24	
11	06/23/00	Financial Planning	2 hours	104	47	21
		Legal Planning	2 hours	104	64	

<sup>a</sup> There is substantial (if not complete) overlap in participant attendance at multiple modules presented on the same day.

At the beginning and end of each of the two modules, participants were asked to complete pre-test and post-test evaluation tools. (Copies of the Financial Planning and Legal Planning Pre-Test Evaluation tools are included in the Appendices. Because of the high degree of overlap between pre-test and post-test evaluation tools, post-test tools are not included in the Appendices but are available upon request.) The pre-test and post-test tools assessed participants’ knowledge of, and their self-evaluation of their abilities regarding, financial and legal planning. In addition, the pre-test tools asked participants to identify the three major questions that they brought to the training, and the post-test tools asked participants to identify the three major questions that remained at the completion of the training. The results of changes in knowledge and self-evaluation of abilities are presented below. Questions that participants brought to, and left the sessions with, are presented in separate sections of the report. (Tables that present the statistical analyses on which findings are based are presented in the Appendices).

Results of the training are aggregated across the three PSAs. Such aggregation is possible due to consistency in the curriculum that was presented and the duration of the training; the fact that the same trainers presented each of the two modules; and because the implementation of the evaluation procedure was constant across the training.

Statewide Results of Legal and Financial Training

Across the three PSAs, almost three-fifths (i.e., 100:175) of participants who attended the financial planning training completed a pre-test and a post-test evaluation of the training, whereas 68.6% (i.e., 120:175) of participants who attended the legal planning training completed a pre-test and a post-test evaluation of the training.

### Participant Profile

Results from the pre-test evaluation indicated that 69.2% of participants were employed in professions where providing legal/financial advice was a primary aspect of their job (e.g., attorneys, financial planners, accountants, insurance agents), and the remainder (30.8%) were employed in social service professions (e.g., social work). Evaluation results are presented for all participants in the aggregate, and for legal/financial professionals and social service professionals separately.

Participants averaged 19.3 years of employment in their occupation (SD = 14.2; range = 1-61). Prior to the training sessions, approximately one-third of participants (32.5%) had received MR/DD-specific training. Approximately one-fourth (24.3%) of participants had a family member or person who was close to them who had mental retardation or other developmental disability. In the six months prior to the legal and financial training sessions, 37.6% of participants had provided life planning services for an older person with MR/DD and/or their family members. Of the 47 participants who provided services during this time, the number of clients served ranged from 1 to 35, with an average of 6.6 clients (SD = 8.7). Participants had been consulted regarding trusts, guardianships, housing issues, interpreting government benefits, and wills.

### Evaluation Components

Participants' self-evaluation of their abilities regarding financial and legal planning. Participants indicated: 1) how competent they felt in the area of financial planning for older persons with MR/DD, 2) how comfortable they were in the area of financial planning for older persons with MR/DD, 3) how competent they felt in the area of legal planning for older persons with MR/DD, and 4) how comfortable they were in the area of legal planning for older persons with MR/DD. Results indicated that, at the end of the training, participants felt significantly more competent and comfortable in the areas of both legal and financial planning for older persons with MR/DD.

To determine whether there was a differential impact of the training as a function of whether participants were employed in legal/financial versus social service occupations, separate pre-test/post-test comparisons were made for the two groups. The results for the two groups were the same as the overall analyses with one exception. The feelings of competence and comfort that participants from social service occupations felt in the area of financial planning for older persons with MR/DD did not improve as a function of the training. All other findings for participants from both legal/financial and social service occupations demonstrated significant improvement at the completion of the training.

Participants' knowledge about financial and legal planning. Participants completed a



series of items designed to assess their knowledge about: 1) financial planning and 2) legal planning. Pre-test/post-test comparisons revealed that, at the end of the training, participants demonstrated significantly more knowledge about both legal and financial planning for older persons with MR/DD.

To determine whether there was a differential impact of the training as a function of whether participants were employed in legal/financial versus social service occupations, separate pre-test/post-test comparisons were made for the two groups. The results for the two groups were the same as the overall analyses. That is, participants from both legal/financial and social service occupations were significantly more knowledgeable about legal and financial planning at the completion of the training.

## PRE-TEST/POST-TEST EVALUATION OF THE TRAIN-THE-TRAINER TRAINING

### Training Overview, Procedure, and Number of Participants

A two-day Train-the-Trainer training was held July 20 and 21, 2000 in Mansfield, Ohio. The purpose of the training was to prepare participants to serve as trainers for subsequent Double Jeopardy training. The Day 1 training emphasized basic knowledge about aging and MR/DD, the aging services network, and the MR/DD network. The Day 2 training emphasized the basics of life planning, legal aspects of life planning, and financial aspects of life planning. Twenty-eight of the approximately 30 participants who attended the Day 1 training completed a pre-test and a post-test evaluation of the training, whereas 26 of the approximately 30 participants who attended the Day 2 training completed a pre-test and a post-test evaluation of the training.

At the beginning and end of each of the two days of training, participants were asked to complete pre-test and post-test evaluation tools. (Copies of the Day 1 and Day 2 Pre-Test Evaluation tools are included in the Appendices. Because of the high degree of overlap between pre-test and post-test evaluation tools, post-test tools are not included in the Appendices but are available upon request.) The pre-test and post-test tools assessed participants' knowledge of, and their self-evaluation of their abilities regarding, the material covered in the training. In addition, the pre-test tools asked participants to identify the three major questions that they brought to the training, and the post-test tools asked participants to identify the three major questions that remained at the completion of the training. The results of changes in knowledge and self-evaluation of abilities are presented below. Questions that participants brought to, and left the sessions with, are presented in separate sections of the report. (Tables that present the statistical analyses on which findings are based are presented in the Appendices).

### Participant Profile

Almost three-fifths (60.9%) of participants were employed in the aging services network, and the remainder (39.1%) were employed in the MR/DD services network. Participants averaged 12.5 years of employment in the network in which they were currently employed ( $SD = 8.3$ ; range = 1-30). Prior to the Train-the-Trainer sessions, almost 70% of participants (68.8%) had received aging-specific training, and 73.9% had received MR/DD-specific training. Almost one-fifth (17.4%) of participants had a family member or person who was close to them who had mental retardation or were developmentally disabled. In the six months prior to the Train-the-Trainer sessions, 65.2% of participants had provided life planning services for an older person with MR/DD and/or their family members. Of the 15 participants who provided services during this time, the number of clients served ranged from 1 to 120, with an average of 12.5 clients ( $SD = 30.4$ ).

### Evaluation Components

#### Evaluation of Day 1 Training

Participants' self-evaluation of their abilities regarding the aging and MR/DD populations and the services networks. Participants indicated how well they thought they understood three issues: 1) the needs of aging families with older adults with developmental disabilities, 2) the aging services network, and 3) the MR/DD services network. In addition, participants indicated

how prepared they felt to train others to understand: 1) the needs of aging families with older adults with developmental disabilities, 2) the aging services network, and 3) the MR/DD services network.

Results indicated that, at the end of the Day 1 training, participants did not have a significantly better understanding of the needs of aging families with older adults with developmental disabilities although participants did believe that they had a better understanding of the aging services network and the MR/DD services network. Similar analyses were conducted separately for participants from the aging and the MR/DD networks. Results of these analyses indicated that, at the end of Day 1, participants from the aging network were more knowledgeable about the MR/DD services network, and professionals from the MR/DD services network were significantly more knowledgeable about the aging services network. Participants' understanding of their own network did not change as a result of the Day 1 training.

With respect to participants' perceptions of how prepared they were to train others, analyses indicated that, at the end of Day 1, participants believed that they were significantly more prepared to train others to understand the aging services network. When these analyses were conducted for participants from the two networks, results indicated no significant changes among participants from the aging services network. In contrast, participants from the MR/DD services network felt significantly more prepared to train others to understand the needs of aging families and to train others to understand the aging services network.

Participants' knowledge about the aging and MR/DD populations and the services networks. Participants completed a series of items designed to assess their knowledge about: 1) MR/DD; 2) MR/DD services; 3) aging; and 4) aging services. Pre-test/post-test comparisons revealed that, at the end of Day 1, participants demonstrated significantly more knowledge about both content areas. When these analyses were conducted for participants from the two networks, results indicated that, at the end of Day 1, participants from the aging services network demonstrated significantly more knowledge about MR/DD and the MR/DD services network, whereas participants from the MR/DD services network demonstrated significantly more knowledge about aging and the aging services network. Participants were not significantly more knowledgeable about the population with which, and network in which, they worked.

#### Evaluation of Day 2 Training

Participants' self-evaluation of their abilities regarding life planning. Participants indicated how well they thought they understood the basics of life planning for older individuals with developmental disabilities. In addition, participants indicated how prepared they felt to: 1) assist MR/DD families with life planning, 2) train others to understand the basics of life planning, and 3) to train others to assist MR/DD families with life planning.

Results indicated that, at the end of the Day 2 training, participants believed that they had a significantly greater understanding of the basics of life planning, and believed they were significantly more prepared to assist MR/DD families with life planning, to train others to

understand the basics of life planning, and to train others to assist MR/DD families with life planning. Similar analyses conducted separately for participants from the aging and the MR/DD networks indicated that the degree of improvement was greater among participants from the aging services network than among those from the MR/DD services network.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) life planning in general and 2) legal/financial aspects of life planning. Pre-test/post-test comparisons revealed that, at the end of Day 2, there was no difference in participants' knowledge of life planning in general. However, at the end of the Day 2 training, participants reported significantly more knowledge about legal/financial aspects of life planning. These findings emerged for participants from both the aging services network and the MR/DD services network.

## PRE-TEST/POST-TEST EVALUATION OF THE PROFESSIONAL STAFF TRAINING

### Training Overview, Procedure, and Description of Participants

Across the three PSA demonstration sites for the Double Jeopardy Project, a number of trainings were held for professional staff from the aging and MR/DD services networks. These training differed from the previously discussed training efforts directed at legal and financial training and the Train-the-Trainer sessions in two major ways. First, the content of the professional staff training could include any combination of four distinct modules: Aging with Developmental Disabilities; Two Networks, Two Resources; Life Planning 101; and Life Planning 102. Second, across the many training sessions for professional staff from the aging and MR/DD services systems, there were inconsistencies with respect to curriculum, duration, trainers, and implementation of the evaluation tools.

It is important to point out that when PSA-5 offered the 07/25/00 training, the final Double Jeopardy curriculum was not yet available. For the 10/20/00 training offered in PSA 10-A, pre-test/post-test data were only collected for the Life Planning 101 module, and for the 12/05/00 and 12/06/00 training, a shortened version of the pre-test/post-test evaluation tools was used. Finally, for the 12/04/00 training in PSA-11, the Double Jeopardy curriculum was not used for the Two Networks, Two Resources module, although the curriculum was used for the remaining two modules. As such, pre-test/post-test data are available for PSA-5's 10/19/00 Life Planning 101 training and PSA 10-A's 10/20/00 Life Planning 101 training. In addition, abbreviated data are available for PSA 10-A's 12/05/00 and 12/06/00 training, and for PSA 11's training on 12/04/00. Four-month follow-up data are available for PSA 5's 10/19/00 and PSA 11's 12/04/00 training.

The table on the next page summarizes the training conducted.

<u>PSA</u>	<u>Date</u>	<u>Module(s)</u>	<u>Duration</u>	<u>No. Part.<sup>a</sup></u>	<u>No. Pre/ Post Evals</u>	<u>No. Follow-ups</u>
5	07/25/00	Two Networks, Two Resources	4.5 hours	51	na	na
5	10/19/00	Life Planning 101	3.0 hours	49	46	23
10-A	10/20/00	Aging with Developmental Disabilities	1.5 hours	85	na	
		Two Networks, Two Resources	1.0 hour	85	na	
		Life Planning 101	1.5 hours	85	73	00
		Life Planning 102	1.5 hours	85	na	
10-A	12/05/00	Aging with Developmental Disabilities	1.25 hours	63	55	
		Two Networks, Two Resources	1.25 hours	63	55	00
		Life Planning 101	2.50 hours	63	55	
10-A	12/06/00	Aging with Developmental Disabilities	1.25 hours	61	59	
		Two Networks, Two Resources	1.25 hours	61	59	00
		Life Planning 101	2.50 hours	61	59	
11	12/04/00	Two Networks, Two Resources	1 hour	na	19	
		Life Planning 101	1 hour	40	19	19
		Life Planning 102	2 hours	42	40	

<sup>a</sup> There is substantial (if not complete) overlap in participant attendance at multiple modules presented on the same day.

As indicated above, participants were asked to complete pre-test and post-test evaluation tools. (A copy of the Comprehensive Professional Staff Pre-Test Evaluation tool is included in the Appendices. Because of the high degree of overlap between pre-test and post-test evaluation tools, post-test tools are not included in the Appendices but are available upon request.) The pre-test and post-test tools assessed participants' knowledge of, and their self-evaluation of their abilities regarding, the material covered in the modules. In addition, the pre-test tools asked participants to identify the three major questions that they brought to the training, and the post-test tools asked participants to identify the three major questions that remained at the completion of the training. The results of changes in knowledge and self-evaluation of abilities are presented below. Questions that participants brought to, and left the sessions with, are presented in separate sections of the report. (Tables that present the statistical analyses on which findings are based are presented in the Appendices).

Results of the training are presented separately for each PSA. Aggregation of pre-test/post-test data across the PSAs is not possible due to the aforementioned inconsistencies in curriculum, duration, trainers, and the implementation of the evaluation tools.

## PSA 5

### Participant Profile for the 10/19/00 Training

Forty-six of the forty-nine participants who attended the professional training completed a pre-test and a post-test evaluation. Results from the pre-test evaluation tool indicated that slightly more than one half (52.2%) of participants were employed in the aging services network, and the remainder (47.8%) were employed in the MR/DD services network. Participants employed in the aging services network averaged 8.6 years of employment in that network (SD = 5.6, range = 1-21 years), and participants employed in the MR/DD services network averaged 14.2 years of employment in that network (SD = 6.6, range = 1-23 years). Prior to the training, almost all participants (95.6%) had received aging-specific training, and 91.1% had received MR/DD-specific training. Almost one-sixth (15.6%) of participants had a family member or person who was close to them who had mental retardation or other developmental disability. In the six months prior to the training, 30.2% of participants had provided life planning services for an older person with MR/DD and/or their family members. Of the 13 participants who had assisted with life planning during this time, the number of clients ranged from 1 to 25, with an average of 7.5 clients (SD = 7.8).

### Evaluation Components

Participants' self-evaluation of their abilities regarding life planning. Participants indicated: 1) how well they understood the basics of life planning for older individuals with developmental disabilities and 2) how prepared they felt to assist MR/DD families with life planning. Pre-test/post-test comparisons indicated that, at the end of the training, participants felt that they had a significantly better understanding of the basics of life planning for older individuals with developmental disabilities, and were significantly more prepared to assist families with life planning.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) the general life planning process and 2) legal/financial issues associated with life planning. Pre-test/post-test comparisons revealed that, at the end of the training, participants demonstrated significantly more knowledge about the general process of life planning and about the legal/financial issues associated with life planning.

## PSA 10-A

### Participant Profile for the 10/20/00 Training

Seventy-three of the eighty-five participants who attended the professional training completed a pre-test and a post-test evaluation. Results from the pre-test evaluation tool indicated that almost all (97.2%) of participants were employed in the MR/DD services network, and the remainder (2.8%) were employed in the aging services network. Participants employed in the MR/DD services network averaged 15.3 years of employment in that network (SD = 7.5, range = less than one year - 35 years), and participants employed in the aging services network averaged 13.5 years of employment in that network (SD = 2.12, range = 12-15 years). Prior to the training, almost one-fourth of participants (23.9%) had received aging-specific training, and 90.3% had received MR/DD-specific training. Almost one-fourth (23.3%) of participants had a family member or

person who was close to them who had mental retardation or other developmental disability. In the six months prior to the training, 9.7% of participants had provided life planning services for an older person with MR/DD and/or their family members. Of the 6 participants who had assisted with life planning during this time, the number of clients ranged from 1 to 50, with an average of 10.33 clients (SD = 19.5).

#### Evaluation Components

Participants' self-evaluation of their abilities regarding life planning. Participants indicated: 1) how well they understood the basics of life planning for older individuals with developmental disabilities and 2) how prepared they felt to assist MR/DD families with life planning. Pre-test/post-test comparisons indicated that, at the end of the training, participants felt that they had a significantly better understanding of the basics of life planning for older individuals with developmental disabilities, and were significantly more prepared to assist families with life planning.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) the general life planning process and 2) legal/financial issues associated with life planning. Pre-test/post-test comparisons revealed that, at the end of the training, participants demonstrated significantly more knowledge about the general process of life planning and about the legal/financial issues associated with life planning.

#### Participant Profile for the 12/05/00 Training

Fifty-five of the sixty-three participants who attended the professional training completed a pre-test and a post-test evaluation. Results from the pre-test evaluation tool indicated that almost all (94.5%) of participants were employed in the aging services network, and the remainder (5.5%) were employed in the MR/DD services network. Participants employed in the aging services network averaged 10.6 years of employment in that network (SD = 7.1, range = 1-29 years), and participants employed in the MR/DD services network averaged 12.67 years of employment in that network (SD = 12.5, range = less than one year -25 years). Prior to the training, almost all participants (96.4%) had received aging-specific training, and 38.2% had received MR/DD-specific training. Approximately one-fourth (25.9%) of participants had a family member or person who was close to them who had mental retardation or other developmental disability. In the six months prior to the training, 21.3% of participants had provided life planning services for an older person with MR/DD and/or his/her family members. Of the 10 participants who had assisted with life planning during this time, the number of clients ranged from 1 to 35, with an average of 8.0 clients (SD = 14.2).

#### Evaluation Components

Participants' self-evaluation of their abilities regarding life planning. Participants indicated: 1) how well they understood the basics of life planning for older individuals with developmental disabilities and 2) how prepared they felt to assist MR/DD families with life planning. Pre-test/post-test comparisons indicated that, at the end of the training, participants felt that they had a significantly better understanding of the basics of life planning for older



individuals with developmental disabilities, and were significantly more prepared to assist families with life planning.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) the general life planning process and 2) legal/financial issues associated with life planning. Pre-test/post-test comparisons revealed that, at the end of the training, participants demonstrated significantly more knowledge about the general process of life planning and about the legal/financial issues associated with life planning.

#### Participant Profile for the 12/06/00 Training

Fifty-nine of the sixty-one participants who attended the professional training completed a pre-test and a post-test evaluation. Results from the pre-test evaluation tool indicated that almost all (94.9%) of participants were employed in the aging services network, and the remainder (5.1%) were employed in the MR/DD services network. Participants employed in the aging services network averaged 10.9 years of employment in that network (SD = 7.4, range = 1-40 years), and participants employed in the MR/DD services network averaged 13.7 years of employment in that network (SD = 13.7, range = 6-20 years). Prior to the training, almost all participants (91.1%) had received aging-specific training, and 35.1% had received MR/DD-specific training. Approximately one-fifth (20.7%) of participants had a family member or person who was close to them who had mental retardation or other developmental disability. In the six months prior to the training, 32.1% of participants had provided life planning services for an older person with MR/DD and/or their family members. Of the 17 participants who had assisted with life planning during this time, the number of clients ranged from 1 to 12, with an average of 2.6 clients (SD = 3.0).

#### Evaluation Components

Participants' self-evaluation of their abilities regarding life planning. Participants indicated: 1) how well they understood the basics of life planning for older individuals with developmental disabilities and 2) how prepared they felt to assist MR/DD families with life planning. Pre-test/post-test comparisons indicated that, at the end of the training, participants felt that they had a significantly better understanding of the basics of life planning for older individuals with developmental disabilities, and were significantly more prepared to assist families with life planning.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) the general life planning process and 2) legal/financial issues associated with life planning. Pre-test/post-test comparisons revealed that, at the end of the training, participants demonstrated significantly more knowledge about the general process of life planning and about the legal/financial issues associated with life planning.

#### PSA 11

#### Participant Profile for the 12/04/00 Training

Forty of the forty-two participants who attended the professional training completed a pre-test

and a post-test evaluation. Results from the pre-test evaluation tool indicated that slightly more than one-half (55.0%) of participants were employed in the aging services network, and the remainder (45.0%) were employed in the MR/DD services network. Participants employed in the aging services network averaged 12.6 years of employment in that network (SD = 9.7, range = 1-40 years), and participants employed in the MR/DD services network averaged 9.2 years of employment in that network (SD = 7.2, range = less than one year -22 years). Prior to the training, almost three-fourths of participants (70.0%) had received aging-specific training, and 70.0% had received MR/DD-specific training. Approximately one-fifth (22.5%) of participants had a family member or person who was close to them who had mental retardation or other developmental disability. In the six months prior to the training, 32.4% of participants had provided life planning services for an older person with MR/DD and/or their family members. Of the 11 participants who had assisted with life planning during this time, the number of clients ranged from 2 to 30, with an average of 6.00 clients (SD = 8.3).

### Evaluation Components

Participants' self-evaluation of their abilities regarding life planning. Participants indicated: 1) how well they understood the basics of life planning for older individuals with developmental disabilities and 2) how prepared they felt to assist MR/DD families with life planning. Pre-test/post-test comparisons indicated that, at the end of the training, participants felt that they had a significantly better understanding of the basics of life planning for older individuals with developmental disabilities, and were significantly more prepared to assist families with life planning.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) the general life planning process and 2) legal/financial issues associated with life planning. Pre-test/post-test comparisons revealed that, at the end of the training, participants demonstrated significantly more knowledge about the aging and MR/DD networks, the general process of life planning, and about the legal/financial issues associated with life planning.

PRE-TEST/POST-TEST EVALUATION OF THE FAMILY TRAINING

Training Overview, Procedure, and Number of Participants

Across the three PSA demonstration sites for the Double Jeopardy Project, a number of trainings were held for families. Training varied in the content that was covered, in duration (i.e., from 2.5 to 4.5 hours), and in terms of who conducted the training. The table below summarizes the training conducted.

<u>PSA</u>	<u>Date</u>	<u>Module(s)</u>	<u>Duration</u>	<u>No. Part</u>	<u>No. Pre/Post Evals</u>	<u>No. Follow-up</u>
5	11/04/00	Life Planning 101	2.5 hours	27	23	4
10-A	10/11/00	alternate curriculum used	4 hours	11	na	
10-A	10/18/00	alternate curriculum used	4 hours	12	na	
10-A	10/25/00	alternate curriculum used	4 hours	13	na	13
10-A	11/01/00	alternate curriculum used	4 hours	12	na	
10-A	02/21/01	Life Planning 101	2 hours	23	18	
11	11/06/00	alternate curriculum used	3 hours <sup>a</sup>	11	na	
11	11/06/00	alternate curriculum used	3 hours <sup>a</sup>	11	na	7
11	11/13/00	alternate curriculum used	3 hours	10	na	

<sup>a</sup> These were two separate trainings, with no overlap in participants.

It is important to point out that only the training presented in PSA-5 (11/04/00) and PSA 10-A (02/21/01) used the Double Jeopardy curriculum. Although the other training presented content comparable to that contained in the Double Jeopardy curriculum, the curriculum was not directly followed. As such, pre-test/post-test evaluation data were only collected for the two training that used the Double Jeopardy curriculum. Nonetheless, four-month follow-up data were collected for all of the training listed in the table. Despite the fact that the Double Jeopardy curriculum was not followed, the importance of education for families was deemed sufficiently important that four-month follow-up data were collected wherever possible. In addition, an interview with one “best practices” family from each of the three participating PSAs provided particular insight into the impact that the Double Jeopardy project had on life planning for families. The results of the best practices interviews are presented in a separate section of the report.

As indicated above, participants were asked to complete pre-test and post-test evaluation tools. (A copy of the Family Pre-Test Evaluation tool is included in the Appendices. Because of the high degree of overlap between the pre-test and post-test evaluation tools, the post-test tool is not included in the Appendices but is available upon request.) The pre-test and post-test tools assessed family members’ knowledge about, and their self-evaluation of their abilities regarding, life planning. In addition, the pre-test tools asked family members to identify the three major questions that they brought to the training, and the post-test tools asked participants to identify

the three major questions that remained at the completion of the training. The results of changes in knowledge and self-evaluation of abilities are presented below. Questions that participants brought to, and left the sessions with, are presented in separate sections of the report. (Tables that present the statistical analyses on which findings are based are presented in the Appendices).

## PSA 5

### Participant Profile for the 11/04/00 Training

More than four-fifths (i.e., 23:27) of participants who attended the family training completed a pre-test and a post-test evaluation. Results from the pre-test evaluation tool indicated that the average age of participants was 58.6 (SD = 10.41; range = 40-84 years). One-half of participants had graduated from high school; an additional 22.7% had completed some college; and an additional 22.7% had graduate from college. Less than 5% of participants (4.5%) had not completed high school. Over three-fourths (88.3%) of participants were married.

Almost three-fourths (72.7%) of participants had a child with MR/DD, and slightly more than one-fifth (22.7%) had a sibling with MR/DD. Because in six instances there were two members of the same family in attendance, participants represented the interests of 16 individuals with MR/DD. The average age of the family member with MR/DD was 38.1 years (SD = 11.0; range = 17 - 57). Of the individuals with MR/DD whose family member(s) attended the training, slightly more than three-fifths (62.5%) resided with the participant(s) who attended the training, 6.3% resided in group housing (with supervision), and 18.8% lived independently in the community. Participants indicated that their family member with MR/DD demonstrated a variety of limitations including limitations in communication (68.8%), supporting him/herself financially (75.0%), self-direction (62.5%), self-care (62.5%), learning (56.3%), and walking (31.3%). Over three-fifths (68.7%) of the family members with MR/DD received formal services.

Over four-fifths (85.7%) of participants had not participated in life planning prior to this training, and slightly more than one-half (52.4%) had not engaged in any life planning for their family member with MR/DD.

### Evaluation Components

Participants' self-evaluation of their abilities regarding life planning. Participants indicated: 1) how well they understood the basics of life planning for older individuals with developmental disabilities and 2) how comfortable they felt about planning for their family member with a developmental disability. Pre-test/post-test comparisons indicated that, at the end of the training, family members felt that they had a significantly better understanding of the basics of life planning for their relative with MR/DD. However, family members' comfort about the life planning process did not improve as a result of the training.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) the general life planning process and 2) legal/financial issues associated with life planning. Pre-test/post-test comparisons revealed that,

at the end of the training, family members demonstrated significantly more knowledge about the general process of life planning and about the legal/financial issues associated with life planning.

#### PSA 10-A

##### Participant Profile for the 02/21/01 Training

Nearly four-fifths (18:23) of participants who attended the family training completed a pre-test and a post-test evaluation. Results from the pre-test evaluation tool indicated that the average age of participants was 67.9 (SD = 10.5; range = 44-84 years). Slightly more than two-fifths (44.4%) of participants had graduated from high school; an additional 27.8% had completed some college; and an additional 22.2% had graduate from college. Slightly more than 5% of participants (5.6%) had not completed high school. Over three-fifths (66.7%) of participants were married.

Almost 90% (88.9%) of participants had a child with MR/DD, 5.6% had a grandchild with MR/DD. Because in six instances there were two members of the same family in attendance, participants represented the interests of 13 individuals with MR/DD. The average age of the family member with MR/DD was 34.7 years (SD = 6.8; range = 24 - 50). Of the individuals with MR/DD whose family member(s) attended the training, three-fourths (75.0%) resided with the participant(s) who attended the training, 16.7% resided in group housing (with supervision), and 8.3% lived independently in the community. Participants indicated that their family member with MR/DD demonstrated a variety of limitations including limitations in supporting him/herself financially (83.3%), self-direction (50.0%), self-care (58.3%), communication (58.3%), and learning (50.0%). Almost three-fifths (58.3%) of family members with MR/DD received formal services.

Over nine-tenths (94.1%) of participants had not participated in life planning prior to this training, and slightly more than one-half (52.9%) had not engaged in any life planning for their family member with MR/DD.

##### Evaluation Components

Participants' self-evaluation of their abilities regarding life planning. Participants indicated: 1) how well they understood the basics of life planning for older individuals with developmental disabilities and 2) how comfortable they felt about planning for their family member with a developmental disability. Pre-test/post-test comparisons indicated that, at the end of the training, family members felt that they had a significantly better understanding of the basics of life planning for their relative with MR/DD. However, family members' comfort about the life planning process did not improve as a result of the training.

Participants' knowledge about life planning. Participants completed a series of items designed to assess their knowledge about: 1) the general life planning process and 2) legal/financial issues associated with life planning. Pre-test/post-test comparisons revealed that, at the end of the training, family members demonstrated significantly more knowledge about the general process of life planning and about the legal/financial issues associated with life planning.

## **CONCERNS THAT REMAINED IMMEDIATELY FOLLOWING THE TRAINING**

*(summarizes the concerns that remained at the completion of the Double Jeopardy training)*

As discussed earlier, the pre-test evaluation asked participants to identify questions and concerns they brought with them to the training sessions. As part of the post-test evaluation, participants were asked to identify questions and concerns that remained with them immediately following the training sessions. As in the pre-test responses to this open-ended request, there was wide variability in post-test responses. Similar to the pre-test, these responses are aggregated for professionals who attended legal and financial, train-the-trainer training, and professional staff training sessions.

### **IMMEDIATE POST-TRAINING QUESTIONS/CONCERNS OF PROFESSIONALS**

Post-training, professionals identified information and skills questions, ethical concerns, and service system concerns. In addition, professionals identified training effects on their knowledge and thinking about life planning. Professionals also responded with ideas about further training and with evaluative comments about the sessions themselves.

Regarding information needs, professionals appeared to move from pre-training broad "wide-open" questions, to more focused questions for specific information ("Who should be the trustee of an ILIT?"; "When is it best to have a corporate trustee?"); clarification of information ("I don't think I'll ever truly understand IRD!"); or depth of information ("Are there legal statutes that govern which non-profits can set up pooled Medicaid payback trusts? If so, please site rule and case law."); ("More info on PLAN: too quick!"). As in pre-training responses, professionals indicated a need for names and contact information of qualified experts for referrals ("Do we do the research for elder care attorneys ourselves?").

Post-training, professionals identified needs for skills to communicate with and motivate families. These concerns were similar to those with which other professionals entered training. ("Ways of encouraging hard-to-convince cases that future planning is necessary"; "What is my responsibility as a case manager working with resistant families/parents of MR/DD?").

Professionals identified concerns about the service system ("What is the state of Ohio doing about this problem?") and ethical issues ("Why can't people with disabilities enjoy their inheritance as anyone else would. Why not Hawaiian vacations? The rest of us would, including you.").

Professionals commented liberally about the effect of training on their personal sense of confidence ("More confident about my advice in this area"; "I now have knowledge to share with families that will benefit their loved ones. This is a good feeling!"), motivation ("I will approach parents who I think have made no plans to help them think about planning for their son and daughter's future life."), and direction ("I need to read up on qualified plans"; "I need to become more knowledgeable about guardian role in DNR, to give a fresh look at competency when signing documents, to adjust advocacy techniques for my disabled (vs. elderly) clients e.g. focus

on extras, not sheltering assets."). Some participants suggested a need for ongoing training ("Retaining all the information given.").

Finally, professionals used the request to identify remaining questions and concerns to indicate ideas for further training ("Provide handouts.") and to provide evaluative comments about the sessions themselves ("Presentation was good. Above my head in some areas as I'm not well-versed in math"; "I wish we could have discussed the case studies in more detail.").

#### IMMEDIATE POST-TRAINING QUESTIONS/CONCERNS OF FAMILIES

Although few family participants responded to the request to identify questions and concerns pre-training, post-test responses of family participants suggest that they left the sessions with more specific questions (e.g., "What are legal obligations after child's age 21?"). More frequently, they indicated that they were also motivated to specific action (e.g., "Have a life planning check list"; "Have a Family Survival Kit"; "Writing down daily routine"; "Getting important documents into one place"; "Getting the financial plan done immediately"; "Completing the Family Survival Kit soon"; "Finding a competent attorney for the trust"; "Write it all down and review yearly.").

#### Summary of Concerns That Remained Immediately Following the Training

A variety of concerns existed among all participants immediately following training. In summary, training appears to have had an immediate impact on participant awareness of change in knowledge (both what they have learned and what they have yet to learn); participant incentive to engage in life planning activity; and need for communication and interpersonal skills to enhance the planning process.

## **FOLLOW-UP EVALUATIONS OF TRAINING**

*(provides 4-, 5-, or 6-month follow-up of changes in professionals' practices, and family members' behaviors, regarding life planning)*

### **SIX MONTH FOLLOW-UP EVALUATION OF LEGAL AND FINANCIAL TRAINING**

Six months following the training, follow-up surveys were mailed to a representative at each PSA who distributed the surveys to training participants. Whereas the pre-test and post-test evaluation tools recorded participants' knowledge about, and their self-evaluation of their abilities regarding, the content covered in the modules, the follow-up tool inquired about participants' related professional activities since the training. (A copy of the Legal and Financial Planning Follow-Up Evaluation tool is included in the Appendices.)

Approximately one-third (i.e., 56:175) of participants returned the completed follow-up survey in the postage-paid envelope that was provided in the initial mailing. Of the participants who returned their follow-up survey, slightly more than four-fifths (81.6%) reported that the Double Jeopardy training had had a positive effect on the quality of their consultations related to MR/DD. However, there was no significant change in the *number* of cases for whom participants had provided life planning services for an older person with MR/DD as compared to the number served in the six months prior to the Double Jeopardy training.

At the time of the follow-up evaluation, almost half (46.2%) of participants who returned the survey indicated that they accepted, but did not actively seek, referrals for life planning with this population; 25.6% were actively seeking this type of client; and 17.9% specialized in life planning for families who have an older member with MR/DD.



## SIX MONTH FOLLOW-UP EVALUATION OF TRAIN-THE-TRAINER TRAINING

Six months following the Train-the-Trainer training, follow-up surveys were mailed to all participants. A total of 18 participants returned the completed follow-up survey in the postage-paid envelope that was provided in the initial mailing. Whereas the pre-test and post-test evaluation tools recorded participants' knowledge of, and their self-evaluation of their abilities regarding, the content areas, the follow-up tool inquired about participants' related professional activities since the Train-the-Trainer sessions. Specifically, participants indicated the extent to which their participation in the Double Jeopardy Train-the-Trainer sessions had affected their life planning work with their clients. In addition, participants indicated whether they had conducted any training using the Double Jeopardy modules(s) since their participation in the Train-the-Trainer sessions and, if so, provided basic information about these training. (A copy of the Train-the-Trainer Follow-Up Evaluation tool is included in the Appendices.)

The percentage of participants who indicated that the Double Jeopardy training affected their work in each of the following areas appears in the right column:

providing life planning referrals within/to the MR/DD service system	72.2%
identifying life planning needs in families in their case load	61.1%
providing life planning advocacy for families in their case load	58.8%
providing life planning referrals within/to the aging network	55.6%
providing life planning consultation to families in their case load	50.0%
resulted in participation in continuing education on life planning issues	44.4%
resulted in independent study on life planning issues	38.9%
identifying additional life planning needs in families with whom they have already worked on life planning issues	38.9%
resulted in service on committees regarding life planning issues	29.4%

Results indicated that almost two-fifths (11:18) of participants who returned their follow-up survey had conducted at least one training for professionals or families since they participated in the Train-the-Trainer sessions. The average number of modules offered ranged from 1.7 (Two Systems, Two Resources) to 3.0 (Life Planning 102). The following table summarizes the participants' self-evaluations of their efforts as trainers of other professionals and families.

<u>Module</u>	<u>Percentage of Trainers who Felt....</u>		
	<u>Mean Number Trainings (min, max)</u>	<u>Prepared to Conduct the Training</u>	<u>The Training was Successful</u>
Aging with Dev. Dis.	2.0 (1-4)	85.7	85.7
Two Networks, Two Resources	1.7 (1-4)	70.0	70.0
Life Planning 101	2.8 (2.8)	71.5	87.5
Life Planning 102	3.0 (1-5)	83.3	100.0

#### FOUR MONTH FOLLOW-UP EVALUATION OF PROFESSIONAL STAFF TRAINING

Four (PSA 5, 10/19/00; PSA 10-A, 10/20/00; PSA 11 [12/04/00]) or five (PSA 10-A, 12/05/00, 12/06/00) months following the training, follow-up surveys were mailed to a representative of each PSA who distributed the surveys to participants. Whereas the pre-test and post-test evaluation tools recorded participants' knowledge of, and their perceptions of their abilities regarding, the material covered in the modules, the follow-up tool inquired about participants' related professional activities since the training sessions. Five-month follow-up intervals were employed for the PSA 10-A 12/05/00 and 12/06/00 training to capitalize on additional training being held May 5 and 6, 2001 that would permit onsite collection of follow-up surveys. Unfortunately, follow-up surveys were not administered at the beginning of each training as planned; as such, follow-up data are not available. In addition, insufficient numbers of follow-up surveys for PSA 10's 10/20/00 training were returned. As such, the only follow-up data that are available are the four month follow-ups for PSA 5 (10/19/00) and PSA 11 (12/04/00). (A copy of the Professional Staff Follow-Up Evaluation tool is included in the Appendices.)

#### **PSA 5**

Almost half (23:49) of the participants from the PSA 5 (10/19/00) training returned the completed follow-up survey in the postage-paid envelope that was provided in the initial mailing. When asked about the extent to which the Double Jeopardy training had affected nine aspects of their work with families with MR/DD (e.g., providing referrals within/to the aging and MR/DD networks), almost half (47.8%) indicated that the training had increased their ability to identify families with life planning needs in their case load. In addition, close to one-third of participants indicated that the training had increased life planning consultations to families in their case load (30.4%) and close to one-third (30.4%) indicated that the training had resulted in an increase in providing life planning advocacy for families in their case load. There was no significant difference in the number of services that were provided concerning life planning for an older person with MR/DD.

#### **PSA 11**

Almost half (19:42) of the participants from the PSA 1 (12/04/00) training returned the completed follow-up survey in the postage-paid envelope that was provided in the initial mailing. When asked about the extent to which the Double Jeopardy training had affected nine aspects of their work with families with MR/DD (e.g., providing referrals within/to the aging and MR/DD networks), almost three-fifths (58.8%) indicated that the training had increased their ability to identify families with life planning needs in their case load, and slightly more than two-fifths (41.2%) indicated that the training increased their ability to identify additional life planning needs in families with whom they had already worked. One-half of participants indicated that the training increased their ability to provide life planning referrals within/to the MR/DD network, and almost two-fifths (38.9%) indicated that the training increased their ability to provide life planning referrals within/to the aging network. In addition, approximately one-third of participants indicated that the training had resulted in an increase in providing life planning advocacy for families in their case load. Finally, compared to the six months prior to the Double Jeopardy training, following the training participants provided services for significantly more clients about life planning for an older person with MR/DD ( $t = -2.156$ ;  $df = 17$ ;  $p < .046$ ).

#### FOUR-MONTH FOLLOW-UP EVALUATION OF FAMILY TRAINING

Four months following the training, follow-up surveys were mailed to a representative of each PSA who distributed the surveys to participants. Whereas the pre-test and post-test evaluation tools recorded participants' knowledge about, and self-evaluation of their abilities regarding, life planning, the follow-up tool inquired about families' related life planning behaviors since the training sessions. Four month follow-up surveys were sent to participants of all training conducted under the auspices of the Double Jeopardy project, regardless of whether they used the Double Jeopardy curriculum. (A copy of the Family Follow-Up Evaluation tool is included in Appendices.)

Across the three PSAs, 24 participants returned the completed follow-up survey in the postage-paid envelope that was provided in the initial mailing. More than nine-tenths (95.7%) of participants indicated they would recommend life planning training to other families in their situation.

When asked whether they had engaged in each of 27 life planning activities (e.g., reviewed an existing life plan, expanded or changes a circle of support, established a durable power of attorney for health care) since attending the training, a number of participants had engaged in some life planning activity. Specifically, across the training offered in the three PSAs, since attending the training, almost three-fourths (70.8%) of participants had talked with other family members about life planning; slightly more than one-half (54.2%) had started the life planning process; and one-half had talked with an MR/DD professional about life planning. In addition, slightly more than two-fifths (41.7%) of participants had talked with their family member with MR/DD about life planning; the same percentage of participants had decided that they needed to appoint a guardian for their relative with MR/DD; and approximately one-third of participants had spoken with an attorney (37.5%) or financial planner (33.3%) about the life planning process. Of the 24 participants, all but one participant had engaged in at least one new life planning activity since attending the training.

## **LONG-RANGE CONCERNS REGARDING LIFE PLANNING**

*(summarizes the concerns that remained 4-, 5-, or 6-months following the Double Jeopardy training)*

Follow-up surveys also identified issues arising or remaining since training. The follow-up survey responses were evaluated by specific target group, as opposed to aggregating participants of legal and financial training, train-the-trainer training, and professional training, as was done with pre- and post-tests. Participants of legal and financial training and professional staff trainings were asked to respond to the following: "Please list three major areas of information or skills that would improve your ability to serve older families of individuals with MR/DD."

### **IDENTIFIED NEED FOR INFORMATION OR SKILLS AFTER SIX MONTHS: LEGAL AND FINANCIAL PARTICIPANTS**

Six months after their training, legal and financial training participants expressed need for information in the following broad areas: training-specific content, i.e. laws, regulations, planning mechanisms; service system information; and contact/referral information.

Content needs ranged from broad to specific. Examples include: "Better in-depth knowledge of the various trusts"; "Medicaid"; "Health benefits for aging caregivers' HMOs vs. Medicare"; "Case law on mechanisms to protect assets of MR/DD individuals." Legal and financial training participants also indicated a need to be kept up-to-date: "Notice of any change in regs regarding income/assets."

Service system questions and concerns include: "Better understanding of residential options"; "There are some issues for funding and portability of funding that need to be addressed by the legislature"; "Vocational alternatives"; "More direct access (e.g. internet or 24-hr. toll-free number for the public to call"; "Information about housing options"; "In-home care."

Finally, participants of legal and financial training expressed a need for contact information as follows: "Referral to attorneys"; "Referral to financial planners"; "A referral list of qualified professionals for each area of Double Jeopardy planning broken down by geographical area and specialty."

### **IDENTIFIED NEED FOR INFORMATION OR SKILLS AFTER SIX MONTHS: TRAIN-THE-TRAINER PARTICIPANTS**

Participants of train-the-trainer training were asked to respond to the following: "Please list three main areas of information or skills that would improve your ability to serve older families of individuals with MR/DD."

Although these participants expressed some information needs, their concerns were heavily focused on service system issues. These participants appeared particularly tuned in to logistical issues of facilitating life planning: "Establishment of formal statewide hotline # or local 800# where folks to call and identify themselves as needed specific help with life planning issues to MR/DD network; establishment of case managers with aging expertise at local MR/DD boards

(specialists!! Life planners)”; “Access to families: we don't get referrals from MR/DD. Need to make sure phone numbers for all county boards of MR/DD are available; need to ensure everyone has new statewide number for aging service referral”; “As an AAA rep, our people should work families into the Co. Bd. Of MR/DD system if they are not already and have them lead the life planning initiative with these families. Our staff would assure aging services become available to these folks as appropriate”; “Major concern/problem in Ohio with waiting lists is MR/DD parents are tired of being told to plan. Plan for what?”; “Fund a life planner position in each county.”

Train-the-trainer participants also expressed ideas about the future of this initiative: “Continue to think innovatively. Don't stop here with this project”; “Simple publicity (e.g. pamphlets) to pass out at presentations/health fairs, etc.”; “While the Double Jeopardy project is designed to give life planning information to older individuals and families, there is a growing demand for life planning from families with young children.”

As in all other target groups, at pre- and post-test as well as follow-up, the train-the-trainer participants reiterated a need for a contact list of qualified planning professionals for referral to clients.

Finally, train-the-trainer participants had suggestions for trainer training. Particularly, they indicated a need for study time, videos and longer training.

#### IDENTIFIED NEED FOR INFORMATION OR SKILLS AFTER FOUR or SIX MONTHS: PROFESSIONAL STAFF PARTICIPANTS

Approximately half of professional staff from the aging and MR/DD services networks who responded to the follow-up survey wrote responses to two open-ended questions: 1) Identify three major areas of information or skills that would improve your ability to serve families. 2) Identify other information that we should be aware of. In general, the responses identify a variety of needs such as “grant money”, “community resources books”, “forms”, and “pamphlets/handouts on services for the elderly.” The need for a list of contact persons and planning experts was mentioned by several respondents. However, the overarching theme of most other comments was the need for conditions that foster planning work in everyday practice, e.g. “the need for trust”, “how to have older generation accept your help/information without bruising egos”, more communication with MR/DD staff”, “lack of residential options”, and “more options available for our clients.” Finally, several respondents declared a need for a designated Life Planner in their service area.

#### IDENTIFIED NEED FOR INFORMATION OR SKILLS AFTER FOUR MONTHS: FAMILY PARTICIPANTS

Family members who responded to the follow-up survey overwhelmingly report that their “biggest hurdles” in life planning are family decision issues. It appears that family members left training with some sense of direction but encountered resistance or apathy from others. Specifically, family respondents mentioned: “Choosing person(s) as trustee, advocate”; “Dynamics of family”; “Getting husband to understand how important to do this. Getting him to

face up to what's needed as he won't look into anything"; "A father who does not fully recognize the needs of the one with special needs and do what is best for that individual"; "For me, not knowing today which of my children will be caring for [my son]"; "Co-operation from other family members"; "Deciding how we want things set up"; "Getting other siblings involved in my brother's care." These issues appear to supersede other concerns, such as need for particular information, four months after training. Issues identified in the training post-tests, such as need for particular information or a list of qualified professionals, will not be relevant until consensus about planning objectives is reached among family members.

## **SUMMARY OF EVALUATION**

*(summarizes the results of the evaluation findings for each of the four types of training)*

### **SUMMARY OF THE EVALUATION OF THE LEGAL AND FINANCIAL TRAINING**

- Across the state, 175 professionals completed the Double Jeopardy Legal and Financial training.
- Response rates for the pre-test/post-test evaluation ranged from 57.1% (financial training) to 68.6% (legal training); 32% of participants completed the six month follow-up survey.
- Immediately following the training, participants felt significantly more competent and comfortable in the areas of both legal and financial planning for older persons with MR/DD.
- Immediately following the training, participants demonstrated significantly more knowledge about both legal and financial planning for older persons with MR/DD.
- Six months following the training, slightly more than four-fifths (81.6%) of participants reported that the training had had a positive effect on the quality of their consultations related to MR/DD.
- Six months following the training, participants were not seeing significantly more clients with MR/DD-related issues than they were prior to the training.
- Six months following the training, 25.6% of participants were actively seeking clients with MR/DD-related issues, and 17.9% were specializing in this type of client.

## SUMMARY OF THE EVALUATION OF THE TRAIN-THE-TRAINER TRAINING

- Across the state, approximately 30 professionals completed the Double Jeopardy Train-the-Trainer training.
- The response rate for the pre-test/post-test evaluation ranged from 86.7% (day 2 training) to 93.3% (day 1 training); 60% of participants completed the six month follow-up survey.
- Immediately following the training, participants from the aging network felt that they had a significantly better understanding of, and were significantly more knowledgeable about, the MR/DD network, and participants from the MR/DD network felt that they had a significantly better understanding of, and were significantly more knowledgeable about, the aging network. There was no significant change in participants' understanding of the needs of aging families with MR/DD.
- Immediately following the training, participants from the MR/DD network felt significantly more prepared to train others to understand the needs of aging families and to train others to understand the aging services network.
- Immediately following the training, participants from the aging network demonstrated significantly more knowledge about MR/DD and the MR/DD service network, and participants from the MR/DD network demonstrated significantly more knowledge about aging and the aging service network. There was no increase in participants' knowledge of their own network or the primary clients it serves.
- Immediately following the training, participants believed that they had a significantly greater understanding of the basics of life planning, and believed they were significantly more prepared to assist MR/DD families with life planning, to train others to understand the basics of life planning, and to train others to assist MR/DD families with life planning.
- Immediately following the training, participants reported significantly more knowledge about legal/financial aspects of life planning, although there was no increase in general knowledge about life planning.
- Six months following the training, participants indicated that the Double Jeopardy training had affected their work in a number of positive ways.
- Six months following the training, almost two-fifths of respondents had conducted at least one training for professionals or families, and they reported feeling both prepared to conduct the training and that the training was successful.



## SUMMARY OF THE EVALUATION OF THE PROFESSIONAL STAFF TRAINING

- Across the state, 302 professional staff completed the Double Jeopardy training.
- Response rates for the pre-test/post-test evaluation ranged from 85.9% to 96.7%, with an average response rate of 90.4% across all training. With respect to the follow-up evaluation, for the two training for which follow-up tools were returned, response rates were 45.2% (PSA 11, 12/04/00) and 46.9% (PSA 5 10/19/00); the follow-up response rate across all training was 13.9%.
- Immediately following the training, across all training, participants felt that they had a significantly better understanding of the basics of life planning.
- Immediately following the training, across all training, participants felt that they were significantly more prepared to assist families with life planning.
- Immediately following the training, across all training, participants demonstrated significantly more general knowledge about life planning.
- Immediately following the training, across all training, participants demonstrated significantly more knowledge about legal/financial aspects of life planning.
- Four months following the training, participants indicated that the Double Jeopardy training had enhanced several aspects of their work with families with MR/DD.
- Four months following the training, participants were not seeing significantly more clients with MR/DD-related issues than they were prior to the training.

## SUMMARY OF THE EVALUATION OF THE FAMILY TRAINING

- Across the state, 107+ (2/21) family members completed the Double Jeopardy training.
- Response rates for the pre-test/post-test evaluation were 78.3% and 85.2% with an average response rate of 82.0% across the two training. With respect to the follow-up evaluation, for the training for which follow-up tools were returned, response rates were 14.8% (PSA 5), 21.9% (PSA 11) and 27.1% (PSA 11); the follow-up response rate across all training was 22.4%.
- Immediately following the training, across both training, participants felt that they had a significantly better understanding of the basics of life planning for their relative with MR/DD.
- Immediately following the training, across both training, participants did not feel any more comfortable about the process of life planning for their family member with MR/DD.
- Four months following the training, participants indicated that they would recommend life planning training to other families who had a relative with MR/DD.
- Four months following the training, all but one participant had engaged in at least one new life planning activity.

## **BEST PRACTICE FAMILY INTERVIEWS**

*(presents three examples of Double Jeopardy participants who are engaged in the process of life planning)*

Three family interviews were conducted to 1) identify the impact of training interventions on family planning behaviors and 2) explore the dynamics of family responses to the Double Jeopardy experience. Each of the three pilot sites identified one family who 1) had attended a family training session and 2) subsequently engaged in some planning activity. The families were interviewed face to face. Interviews were tape-recorded.

Interviews with these families revealed three very different family circumstances and planning needs. Double Jeopardy played a different role in each of the families' planning process. Finally, the experiences of these families suggest important implications for the future of life planning programs in Ohio.

## THE MILLERS<sup>1</sup>: RESPONDING TO PLANNING INITIATIVES

Issue: A family may have done minimal planning.

The Role of Life Planning Services: Outreach.

Participating in the Interview: Robert and Harriet Miller, ages 65 and 62 respectively. Both are disabled: Mrs. Miller has had several back surgeries and Mr. Miller has orthopedic problems that limit his mobility.

Mr. Miller was a construction manager and his wife is a nurse by training who quit working when their only child, Jeff, was born with congenital rubella syndrome 37 years ago. According to Mrs. Miller, “ I worked a year and a half until God gave me Jeff.”

Jeff has severe mental retardation and Hirschsprung’s Disease which has caused significant bowel management problems all of his life. Jeff is ambulatory and, according to his mother he has “few physical hindrances.” Still, he requires 24-hour care. Jeff has extremely limited language and several characteristics that affect his care and social interaction. Jeff has under-developed nerve endings and this affects most of his activities of daily living. He doesn’t like to touch anything or have anything touch him. He walks and eats with his hands up in the air. He has hypersensitive hearing; loud sounds and noises cause him great distress. Jeff drools and his parents identify this as a social barrier. “People don’t want to be around someone who drools.” The Millers describe their son as a loner.

At this time, Jeff lives in a group home, and there are no other family members to look after him when his parents are no longer able to do so. The Millers describe the invitation to come to Double Jeopardy life planning family training as a “propellant.” “There are more families out there that are unaware of this. The MR/DD people, this is just coming into their view right now. See, all of a sudden somebody woke up and said we've got all these old folks out there, and the thinking years ago was that you kept your disabled person at home. And all of a sudden they cannot handle or do this, and they come to the MR/DD Board and we want services, and the MR/DD people say You're Number 394 on our services list. So, people have got to become more aware of this. I mean it's hard to walk up to a parent and say you know, after 45 years of taking care of your child at home, now you are going to put him or her into the system. And of course the thinking among folks our age is that there is absolutely no one out there that can take care of their person as well as we can. Unfortunately, they are right, and that's the long and short of it. And then a lot of the people that I have come in contact with, and they say, what happens when we are gone? Our case is, there is no other son, daughter. Jeff is an only child.”

Since Double Jeopardy training, the Millers are riding the momentum of the “propellant,” working to assure the appropriateness and adequacy of their financial plans. Mr. Miller describes the complexity of planning as “mind boggling.... Every asset has to be accounted for or we could

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<sup>1</sup>All names have been changed in the Best Practices case studies.

jeopardize everything.” The Millers are getting ready to complete a Family Survival Kit and to make a video of Jeff’s care and daily life for future caregivers.

## THE BRADLEYS: IDENTIFYING INFORMATION AND RESOURCES FOR PLANNING OBJECTIVES

Issue: A family may come to life planning services with a clear objective, seeking information, tools, and individuals with expertise to help facilitate a plan.

The Role of Life Planning Services: Education and referral.

Provide information and tools for planning.

Provide access to informed, qualified planning professionals.

Participating in the interview: Susan Bradley, age 52.

Susan Bradley is the mother of one child, Ellie, who is 32 years old. Susan was divorced from Ellie's father when Ellie was one year old. There was very little contact with him after the divorce and he paid no child support; he is now deceased. Ellie has cerebral palsy and severe mental retardation. She is ambulatory but uses a wheelchair for extended mobility. She has poor fine motor skills and needs cuing and/or assistance with bathing, grooming, dressing, toileting, and eating. Ellie wets her bed every night and will not wear an adult diaper. Ellie's expressive language skills are very limited. She can say "Mama" and "Bye-bye" and, according to Susan, "she is trying to learn how to say, 'Hi'." Ellie has what her mother calls "behaviors" which are difficult to manage. "She is very strong. She will throw herself around, throw herself into things and on the floor. Right now I can still handle her. I don't know how much longer.....I get back the time when she is an angel and she gives you kisses and that sort of thing, but I actually don't get a lot back to be real honest. She's kind of a distant child. She is not a cuddler and doesn't like to be close to anybody, whether it's me or somebody else."

Ellie requires 24-hour care and supervision. Except for one year, when Ellie lived in a group home at age 12, Susan has cared for Ellie at home. Susan has no other living family members and her only friends (two women she describes as her "best friends") live out of state. Susan has a college degree and works full time in a small company, where her boss is very flexible about Susan's schedule. Susan works while Ellie is at the MR/DD workshop, and is home by the time Ellie returns from the workshop by bus. Susan gets 4-6 hours of weekly respite from Supported Living. It has been difficult for Susan to find other "sitters" for Ellie. Susan finds that most teenagers and young adults are "intimidated" by the idea of caring for Ellie; it is rare to find one who works out. "When you ask a 16-year-old to babysit and they ask how old is she and you say 32, they are just stunned usually." An extremely important source of support has been a 62-year-old former teacher of Ellie's who has taken Ellie for short respite periods so that Susan could get away for a visit to friends or a brief vacation. On most vacations, however, Susan and Ellie travel together. Ellie loves the beach, and Susan wants to be sure that Ellie has continued vacations to the beach over her lifetime.

Ellie did not adjust well to her experience at the group home twenty years ago. Ellie's name has been on a waiting list for group homes, but when an opening came up, it was in a home with five men. Susan believed the placement would be difficult and inappropriate and she had to fight to keep Ellie's position on the waiting list after turning down the opening.

Based on family history, Susan believes her own life expectancy to be relatively low, and she has developed a vision for Ellie's future that will provide Ellie with a secure future and will also give herself a few years of retirement from Ellie's care before she dies. “ I would like to have five or ten years to myself, where I don't have somebody, where I don't have to be her.... maybe that seems selfish, but...” Susan would like to remodel her home and establish it as a supported living home within the next five years. She would like to staff it with others and administer it herself while living nearby. She wants Ellie to continue to live in the home she has always known, and she wants Ellie to gradually get used to life without her. “For the first six months to a year I would be here for Ellie's waking hours with other staff people and then kind of phase myself out a bit...Right now I am the only one who can really manage her behaviors, calm her down.”

Susan has a clear objective and is passionately committed to it. Before Double Jeopardy training, Susan had sought information about related policies and regulations from her own small county Board as well as the Boards of two large Ohio counties. She did not get very far. “I have a sense that I may be the first who has asked to do this.... I don't understand the logic of policies, and the rules change.” She went to Double Jeopardy family training hoping to obtain needed information, but found the training over-broad for her needs. Even so, she believes the training is an excellent idea, and plans to attend all subsequent offerings. “It's frustrating to know where you want to go and not know how to get there, and not know the people to help you get there. For someone who has no plan? I can't imagine what they must be doing.” Susan says that she will seek help privately from the attorney involved in the Double Jeopardy training if she does not get what she needs in an upcoming session. Meanwhile, Susan has completed the Family Survival Kit and has necessary trusts and legal arrangements in place for Ellie's future. Susan would like to see a Life Planning Coordinator position funded in her county; actually, Susan says she would like to assume that position herself!

Susan is a good example of a family member who is motivated to plan and eager for and open to information and consultation.

## THE CUNNINGHAMS: NEGOTIATING FAMILY DIFFERENCES IN PLANNING OBJECTIVES

Issue: A family may have all necessary information and tools for planning but need help negotiating a plan among family members, including the individual with a developmental disability.

The role of Life Planning Services: Family mediation and support.

Provide counseling/mediation to families engaged in planning decision making.

Participating in the Interview: Mary Cunningham, 81, and son Jack, 40; Ellen Morris, County Futures Planning Coordinator. Mary's husband and Jack's father, David Cunningham, 81, is very ill with a chronic disease and did not participate in the interview.

David owned and operated a small business for fifty years. Mary is a homemaker. They have two children: Mark, who is married with two children, and Jack, who is 40 years old. Jack has lived with his parents since birth. They live in a large two-story home in a suburban-style residential neighborhood. Jack's older brother Mark, in his forties, lives close by, in the Cunningham's neighborhood. Mark is married and has two teenaged children.

Jack has mental retardation that Mary attributes to pneumonia tests and treatments, including X-rays, that she underwent during her pregnancy. Jack has no named disorder or syndrome; Mary said she knew at birth that Jack would develop differently. "I could tell by looking at his eyes." Jack received special education through the public schools from kindergarten through high school except for a three-year period (age 11-14) when Mary took Jack every three months to Doman-Delacato training in Philadelphia. During those years he had a tutor.

Jack has many skills and talents as his lifestyle will attest: he drives a car, is a secretary's assistant at the County Board of MR/DD, and has a new deejay business on the side. Jack is fond of sports. He goes to the Y and is an avid golfer and baseball fan. Jack follows his favorite sports teams on the internet, using a home computer. Jack is very popular in his community. Many of his loyal friends are college graduates whom Jack met through sports. Jack also has friends with developmental disabilities. He is very close to his brother and parents, and they are very loyal to him.

Before attending Double Jeopardy training, Mary and David had established a special needs trust through an attorney identified for them by an insurance agent. After Double Jeopardy training, the Cunninghams called Ellen, who conducted the training, and went to see her to review their plans and receive further consultation. According to Mary, "The thing that I remember is that Ellen said she would set everything up, and so we called her, and we went over there." Ellen provided the Cunninghams with a life planning workbook which they have completed. According to Ellen: "This family is very well prepared on paper. They have everything from a living trust, and how it's going to evolve, to Jack's trust, and who is going to help Jack to spend that money." Jack's brother Mark has agreed to manage Jack's finances when it becomes necessary.



Left unresolved is the housing/living arrangement issue, and this is a source of anxiety for Mary and some frustration for Jack. Jack would like to live independently and his program coordinator supports his desire to move out of the home. According to Jack, he lives at home because “they (his parents) need me.” His mother agrees. “He's a big help. He'll help his dad when he's sick. He helps me with his dad. He takes care of the basement. Takes care of the garage. Takes care of his own room. He carries out the trash..... Oh, and he shovels the driveway.” Jack adds, “I run lots of errands. I always run to the store.” Mary responds, “We do need his help right now.” Turning to Jack, Ellen asks, “And you're OK with that aren't you?” Jack replies, Oh, yeah.” Jack is very good-natured about this. When it comes to the future, it is clear that all parties disagree at some level. Discussions are characterized by ambivalence, competing objectives, and competing values.

The following interview excerpt illustrates:

Mary: He's going to live in a condo when we sell this house.

Jack: We're not selling this house. I'm living here and you're moving into the condo.

Mary: [His program coordinator] says she's gonna help him find somebody to live here.

Jack: [My program coordinator] is all for me moving out.

Mary: My other son says if Jack likes it here I think you should let him live here and let me take care of him later on. But I think he should be in a smaller place. I'd like him to be in a condo where there's a lot of people. He loves people.

Jack: I don't want to live in a condo.

Mary: So, maybe, if we stay here and something should happen to us soon, we'll just let my [other] son handle it. That's part of the plan right now. Then he tells me to do what I want to do.

Jack: I don't want to live in a condo because I practice my deejay music, and I won't be able to do that in a condo, because there would be somebody right next to you. And I like to have my friends over to entertain and that wouldn't go over good either.

Mary: No, Jack, this is too big of a house for you.

Jack: [If I lived alone] I wouldn't need help, but I would like to have it. It would be nice to have it. It's really cool, like I have a friend who has a caretaker who picks her up and goes places with her and helps her out. That would be really nice, for the company if nothing else.

Jack: I would need help with writing checks.

Mother: He's not as neat as I'd like him to be.

Jack: I've asked my parents to go on vacation but they won't!

Jack and the Cunninghams have many things going for them. Jack has a strong circle of support, a close relationship with the County MR/DD board, and open family communication. This is a family with all the necessary tools and information for planning; their financial and housing resources allow them some flexibility. Even with these strengths and assets, life planning remains a very real challenge. The Cunninghams need help negotiating family differences about planning; they will also need support as they carry out their plans. The role of life planning services must necessarily include mediation and support.

## THE MILLERS REVISITED: SEEKING ASSURANCES OF LONG-TERM CONTINUITY

Issue: Once a plan is in place, aside from ongoing review, the family may need help dealing with issues of trust that their plan will be implemented in good faith and in the best of interests of their family member.

The role of Life Planning Services: Counseling. Advocacy.

Provide support to anxious families with related concerns.

Promote policies, laws, services, and regulations that assure continuity of care and support consistent with life plans.

We revisit the Millers to consider the needs of families concerned about the trustworthiness of others to carry out a plan. Jeff's parents cared for him at home for approximately 12 years before Mrs. Miller was hospitalized with what she describes as a "nervous breakdown." Upon her discharge, Jeff moved to the county long-term care facility for mental retardation. The Millers report that Jeff's care in this setting was good for the first few years and that Jeff "loved it." The staff-to-resident ratio was low. "The staff was energetic, and wonderful, and Jeff's progress was enormous." The situation changed, however, and "as the residence grew, so did the behavior problems." Although the Millers did not want to go into detail, they share that "Jeff had some serious things that happened there. He is vulnerable. He had a bad experience there, a very serious incident." At age 31, Jeff transferred to a group home; he comes home every weekend. The group home has been through five providers in the six years Jeff has been there, and the Millers are keenly aware that the quality of Jeff's care and life is directly related to the quality of staff in the home. At the time of the interview, "things are good," but as Mr. Miller says, "There are times when I've laid in bed and thought I can't believe I'm leaving my son out there with that person. I would rather Jeff come home and stay in the shed all night. His chances for survival are better out there [in the shed]."

"We can't rely on Jeff to tell us there is a problem with his situation. You can't always rely on the staff, or the system to come up and say, you know Jeff doesn't really like it here. I mean give me a break, that would be a first in [this] county. He has a person from supported living and a case manager that comes out, and there is a social worker at the workshop. So there are people who are there." The Millers say that "right now we have a good staff and a wonderful provider" but they are well aware from experience that personnel come and go and "it's only as good as the staff you get in there." The Millers also describe the mixed impact of policies and regulations on Jeff's quality of life; they point particularly to housing limitations and restrictive policies that leave them feeling vulnerable and frustrated.

The Millers have virtually no informal support system. What few family and friends they have have made it clear that they do not want responsibility for Jeff. "Some [family] live right around here but haven't seen Jeff for 25 years." It is telling that when Mr. and Mrs. Miller sought to take a vacation, they had nine offers to care for their dog, but none to look out for Jeff even while the group home cared for him.

Inspired and educated by the Double Jeopardy family training, the Millers have made financial and legal arrangements for Jeff's care. The Millers must now rely on "the system" to see that their plan is carried out and that care for Jeff is what they call "life sustaining." Because their faith in the formal system has been shaken on many occasions, and because Jeff will have no family to advocate for him, the Millers sometimes despair at what will become of Jeff even with the best plans in place. "We don't know if [the plan] will work. We've been told that you can have your trusts and plans in place, but the unfortunate thing about it is that we'll never know if they work because they'll be put in place after we pass away." Mr. Miller believes that, upon their deaths, "Jeff would probably go into some sort of depressed mode that would eventually probably claim his life, that's what we think." The Millers seem to find more comfort in that idea than they find in the plans that they have made for a future without them.

## **DISCUSSION AND IMPLICATIONS**

*(presents observations and implications that derive from the evaluation)*

This evaluation sought to identify the impact of training on both life planning knowledge and life planning activity. There is overwhelming evidence that training interventions have a positive effect on the learning of training content; life planning training results in a significant increase in life planning knowledge. It is especially important to understand what happens with that learning. Follow-up evaluations indicate an increase in professional and family activity related to planning. Changes in the level of professional and family activity may be underestimated (the 4-6-month follow-up period of evaluation may be too short to capture the impact of training sessions over the long range) or under-appreciated, especially regarding families. That is, modest changes in activity may actually represent significant changes in perspective, incentive, and interpersonal dynamics.

Even when content is learned, and when new steps toward a life plan are taken, several obstacles to life planning are evident. The major obstacles are summarized here, including implications for life planning program planning and development.

### **KNOWLEDGE ISSUES**

Participants in all training areas expressed an awareness and concern that their knowledge after one training session was tenuous and limited. This suggests that participants came away from sessions with a healthy respect for the complexity and dynamic nature of the life planning process. It was never anticipated that life planning content could be learned in one session, no matter how successful that session. These single training sessions should be regarded as *initial* sessions that introduce the basic elements of life planning and act as what Mr. Miller calls a “propellant” to life planning learning and activity for both professionals and families. Life planning training must be ongoing, not only because multiple sessions are required to cover content, but also because that content changes over time.

### **INTERPERSONAL ISSUES**

#### Family Dynamics

Family members may have an excellent grasp of life planning knowledge but be stymied by obstacles at home. Families reported no significant change in their level of comfort with life planning after training. Life planning is a family matter and requires communication and negotiation about very sensitive issues, sometimes in the context of conflicting personalities and competing objectives. In the face of these dynamics, just attending life planning training may represent an act of courage or an outcome of family compromise. Many family participants expressed a need for help negotiating family decisions. Counseling and consultation with families must be regarded an essential component of life planning facilitation. Without this component, life planning knowledge will have minimal utility.

#### Agency and Work Dynamics

Professionals may also have an excellent grasp of life planning knowledge but may face obstacles at work. In particular, agency professionals identified concerns about whether and

where life planning activity belongs in their job description. Agencies need to clarify the life planning role for staff members, then provide support for that role, including adjustment to work load and support for ongoing training. Several agency professionals called for the funding of a full-time life planning facilitator in their communities.

The need for interagency and interprofessional communication, coordination, and collaboration was also reported. Several participants identified concerns about gaps, overlaps, and duplication in aging and MR/DD intervention into life planning. The two systems must work to clarify roles and relationships within and between their organizations. Without necessary role clarification and support, life planning knowledge will be under-utilized.

#### Legal and Financial Professional Issues

Legal and financial professionals identified a need for communication skills and guidance in working with families. This must be regarded a companion component to content training; it also suggests a need for a system of ongoing support for these professionals.

#### RESOURCE ISSUES

Knowledge about life planning cannot be utilized when planning resources are limited. Families may be motivated and prepared to consult with a financial planner and/or attorney, but get “stuck” when they seek to identify those particular professionals with expertise in this area. There needs to be some mechanism for life planning programs to identify, then help families to identify, qualified professionals. Without them, the important legal and financial components of life planning cannot be effectively accomplished. The objective of a life planning program must be not only to train these professionals, but also to facilitate family access to them.

Both families and agency professionals point to a lack of actual options with which to plan as another, obvious, obstacle to planning. Of particular concern is the lack of satisfactory housing options in many communities. Life planning training must account for these obstacles, but beyond that, the situation suggests a program planning and advocacy role for agencies and professionals. Agencies, professionals, and families can work to increase the number and acceptability of options for quality life plans for all families.