

# My Life Book: Future Planning for People with Developmental Disabilities - Phase II Report

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Program Name: **My Life Book: Future Planning for People with Developmental Disabilities**

## *Summary*

My Life Book was used by approximately 50 families who were interviewed four times at six week intervals during the time they used the video and workbook components of the program. Approximately 50 families in a control group who used alternative materials were interviewed on the same schedule.

Compared to the control group, participants who used My Life Book described themselves as less worried about future planning issues. They also felt they had increased the number of supports available to their child in the future, and had increased the amount of future planning they had actually completed.

## *Project Aims*

This Phase II Project had the following aims:

1. Develop draft of the content for the remaining four modules
2. Continue to develop and refine the content with inputs from the panel of experts.
3. Conduct three focus group meetings
4. Complete draft of scripts, workbook, and Resource Guide
5. Have panel of experts review all the material
6. Produce four thirty minute videos
7. Produce the written materials
8. Develop study instruments
9. Conduct a randomized controlled study

## *Research Results and Significance*

All of the above tasks were successfully completed in this project.

### *Develop initial draft of the content for the remaining four modules.*

The Principal Investigator and the Program Developer prepared initial drafts the materials (four video treatments, future planning worksheets and Resource Guide) that use a stages of change approach to simplify four key permanency-planning topics: 1) planning with your child, 2) legal and financial, 3) social and emotional, and 4) residential. This development effort aimed at simplifying permanency planning steps by presenting the process in a narrative, pictorial, and naturalistic form. The video treatments provided a thorough content description that includes information about narrative development, presentation format, protagonists, style, mood, and tone of the finished program.

### *Continue developing and refining the proposed content with a panel of experts.*

The expert panel was asked to provide consultation on the drafts of the video treatments and written materials. They were asked to assess the adequacy of the learning objective and whether the modules meet these aims. The panel will consist of four outside consultants. Dr. Heller is an expert in permanency planning and developmental disability. Dr. Baker is an expert in the development of training materials in the developmental disability field. Dr. Cohen is a nationally recognized expert in aging. Their feedback proved invaluable in the development of the product. The project team revised the materials based on expert input and prepared a more developed drafts for presentation to focus groups.

### *Conduct focus group meetings with 3 groups to evaluate content and provide feedback: a) an elderly parent focus group, and b) a panel of people serving as key persons and c) a group of individuals with developmental disabilities who live at home with their parents.*

We conducted 3 focus groups. The first focus group consisted of six parents who live with and care for their adult sons/daughters with developmental disabilities. The second focus group was composed of 5 persons who had assumed the key person role for an individual with developmental disabilities. The third focus group was made up of 8 individuals with developmental disabilities

who live at home with their parents. All three focus groups were held July 15th and 17th, 2003 at Iris Media in Eugene, Oregon.

Feedback from these focus groups was used to inform the scripts, the worksheets and the final form of the product.

***Complete program development: scripts for the four videos, finished drafts of worksheets, finished draft of the Resource Guide.***

The PI and Program Developer finalized the writing of program materials. As far as the videos are concerned, this involved converting treatments into script form. The script provided a detailed blueprint for the creation of the video product and included shooting directions, descriptions of the settings and action, dialog, graphics, animation, music directions and sound effects. The worksheets and the Resource Guide were further developed.

***Have the panel of experts review and critique the scripts and text materials and revise based on their input.***

Drs. Heller, Baker and Cohen reviewed the scripts and text materials in order to provide feedback. This last check by experts in permanency planning, developmental disability training, aging and legal issues helped ensure the quality of the information and help correct errors prior to production.

***Produce four 30-minute videos.***

We produced 4 30-minute videos with a connecting storyline that walked the viewer through the transition planning process. These materials are available on both DVD and VHS formats. (group experience) social support thru live models

***Format and print the written materials, e.g., worksheets, and Resource Guide.***

We produced a spiral-bound workbook that contained worksheets, scrapbook pages and information about the transitional process. These materials are also made available on a CD-ROM.

***Design and evaluate measures using face validity, item difficulty, and test-retest instrument development procedures.***

In lieu of developing our own interview measure on future planning, we received permission from our project manager to adapt an interview instrument developed by our consultant, Dr. Tamar Heller. The original instrument had questions covering financial, legal and residential planning and questions eliciting the parents' attitudes towards future planning and their experience with barriers to carrying it out. We added sections covering future plans for a key person, support network, employment, social interactions and leisure time activities. Our new sections generally followed the pattern of questions in the original instrument, first asking parents what plans they had in place and then asking them whether they'd discussed those plans with their adult child, how much the child agreed with the plans and how satisfied the parent was with those current plans. This instrument was designed as a computer-assisted telephone interview (CATI).

In addition to developing the future planning phone interview, we also developed a consumer satisfaction CATI and additional consumer satisfaction items used in the future planning interview at each assessment point beyond Baseline. See Appendix for copies of these instruments.

***Conduct a randomized controlled study with a sample of 120 parents that evaluates knowledge, skills and behavioral outcomes.***

***Participants.***

Participants for the study were recruited using several methods. Recruiting flyers were sent to individuals and organizations in the IRIS Media database, state DD councils and ARC offices. Additionally, a recruitment notice was posted on 3 internet bulletin boards

([lookinglass.org](http://lookinglass.org), [Familyvillage.wisc.edu](http://Familyvillage.wisc.edu), [www.e-bility.com](http://www.e-bility.com) and on the IRIS Media website. A recruiting announcement was also posted on a listserv maintained by the ***national ARC***.

Interested individuals were given a toll-free telephone number and an email address for contacting project staff. At the intake phone call, participants were screened for eligibility and given a verbal explanation of the study. To be eligible for the study, participants had to be either parents of a child with mental retardation aged 18 or older or be a relative designated as a caregiver of such a child. Audio recordings were made of a participant's verbal consent. Demographic information was also obtained during this intake interview. Following the intake interview, participants were randomly assigned to condition (Intervention/Alternate Treatment Control) and mailed a printed study explanation and a copy of the informed consent. A total of 120 participants from 28 different states were recruited.

***Procedures.***

Four telephone interviews were conducted with each participant. After the Baseline Interview, participants were mailed the materials. Those in the Intervention Group received ***My LifeBook***; those in the Alternate Treatment Group received a spiral-bound copy of "A Family Handbook on Future Planning." Approximately 6 weeks after Baseline, participants were called to administer a Consumer Satisfaction interview. Twelve weeks post-Baseline, an Exit interview was conducted. A Follow Up interview was conducted at 16 weeks post-Baseline.

Participants were paid separately for each completed interview using the following payment schedule:

- ∴ \$25 for Baseline
- ∴ \$15 for Consumer Satisfaction Interview
- ∴ \$40 for Exit Interview
- ∴ \$20 for Follow Up Interview

109 participants completed the Baseline Interview, 98 completed the Consumer Satisfaction and Exit Interviews, and 81 completed the Follow-Up Interview. The overall attrition rate from Baseline to Follow-Up was 26%. The attrition rate from Baseline to Exit was 10%, and from Exit to Follow-Up 18%.

**Results.**

**Sample Demographics.** Demographic information was obtained for 119 of the original 120 participants. We were unable to obtain demographic information from one participant at the intake interview; subsequent attempts to contact him/her were unsuccessful.

109 (92%) of the participants were women. 106 (89%) were mothers, 9 were fathers, 1 was an aunt and 3 were sisters. Almost all (97%) were non-Hispanic; 95% were white, 3% Black, and 2% Native American. They ranged in age from 29 to 88; the mean age was 54 (s.d. 10). 68% were married, 26% divorced/separated, 4% widowed and 2% had never been married.

19% had at least a high school degree, 23% some college, and 51% a bachelor's degree or beyond (24% BA/BS, 9% some post-graduate work and 18% graduate degree). 44% were working full-time, 28% part-time, 14% were retired and 14% unemployed. Chi Square and ANOVA were used to determine whether the groups differed on any of these demographic variables. Only one statistically significant difference was found; all Hispanic participants were in the Control group (Chi square(1)=4.20, p<.05).

The adult children of these participants split evenly on gender. They ranged in age from 18 to 48; mean age was 25 (s.d. 8). 94% were non-Hispanic; 92% were Caucasian, 4% Black/African American, .8%(1) Asian, .8% (1) Native American, and 2.4% (3) mixed (Caucasian/Black, Caucasian/Asian and Caucasian/Pacific Islander). 81% were living at home with their parents, 8% living independently, 7% in some type of staff supported residence, 2% in foster care, and 2% in some other type of living situation. 86% were in some type of day program or employed. Of those, 34% were in school, 19% in day activity or work activity centers, 11% in a supported job, 12% had a "regular" job; the remainder were in combinations of day programs, jobs and work activity centers. Work hours for those employed ranged from 2 to 35 hours a week; the average was 19.5 (s.d. 9).

Information on functional ability and diagnoses of the adult children was obtained from parents in 83 families. Based on these parental reports, 25% of the adult children had mild mental retardation, 55% had moderate retardation and 20% had severe/profound disabilities. 75% had a single diagnosis, 19% a dual diagnosis, and 2.4% had 3 diagnoses (3% declined or were unable to report a diagnosis). 25% had Down's Syndrome, 22% autism, 28% had a non-specific diagnosis, 22% had cerebral palsy or other birth injury, 8% had a seizure condition, 4% some type of brain injury, 8% some type of genetic disorder and 4% some type of neurological disorder. When asked how difficult it was to manage their child's behavior, 40% said "not at all", 34% "A little", 19% "Moderately" and 7% "Extremely". Chi Square and ANOVA were used to determine whether the groups differed on the characteristics of their adult children; no significant differences were found.

**Outcomes.**

**Barriers to Future Planning.** At the Baseline and Exit interviews, participants were asked which, of a list of 12 issues, they had experienced as barriers to doing future planning. Table 1 displays the percentages choosing each barrier in the whole sample, ranked from most often chosen to least often chosen.

**Table 1: Perceived Barriers to Future Planning**

| <b>Barrier</b>   | <b>Percent choosing</b> |
|--|-------------------------|
| Emotional barriers of fighting the system for services | 69                      |
| Procrastination  | 67                      |
| Lack of access to residential services                 | 60                      |
| Difficulty affording an attorney                       | 60                      |
| Difficulty trusting the service system & professionals | 57                      |
| Lack of access to employment or day programs           | 57                      |

|   |    |
|---|----|
| Difficulty finding helpful people in service system | 56 |
| Lack of information on legal/financial planning     | 54 |
| Emotional barriers in thinking about own mortality  | 51 |
| Difficulty finding knowledgeable attorney           | 42 |
| Lack of access to case management                   | 28 |

Table 2 displays the changes in percentage endorsements by group from the Baseline to Exit Interview. In the Intervention Group, five issues showed a drop of 5% or more between Baseline and Exit (Emotional barriers of fighting the system for services, Difficulty affording an attorney, Difficulty trusting the service system and professionals, Difficulty finding helpful people in the service system and Lack of access to case management). Two issues showed at least a 5% increase in endorsement: lack of information on legal/financial planning and disagreements with their son/daughter about the future).

In the Alternate Treatment Group, this pattern was much the same, though the issues that changed were somewhat different than for the Intervention Group. Five issues showed at least a 5% drop in endorsement (Lack of access to residential services, Lack of access to day program or employment services, Lack of information on legal/financial planning, Difficulty affording an attorney, and Emotional Barriers in thinking about own mortality). Only one issue showed an increase of 5% or more: Disagreement with son/daughter about the future.

**Table 2: Changes in Perceived Barriers by Group**

| <b>Intervention Group</b>                              |           | <b>Percent</b> |  |
|--|-----------|----------------|--|
|  | <b>BL</b> | <b>Exit</b>    |  |
| Emotional barriers of fighting the system for services | 77        | 69             |  |
| Procrastination  | 71        | 75             |  |
| Difficulty affording an attorney                       | 65        | 54             |  |
| Difficulty trusting the service system & professionals | 63        | 47             |  |
| Difficulty finding helpful people in service system    | 59        | 50             |  |
| Lack of access to residential services                 | 56        | 60             |  |
| Lack of access to employment or day programs           | 56        | 60             |  |
| Lack of information on legal/financial planning        | 52        | 60             |  |
| Difficulty finding knowledgeable attorney              | 52        | 53             |  |
| Emotional barriers in thinking about own mortality     | 50        | 48             |  |
| Lack of access to case management                      | 26        | 19             |  |
| Disagreement with son/daughter about the future        | 12        | 21             |  |
|  |           |                |  |
| <b>Control Group</b>                                   |           | <b>Percent</b> |  |
|  | <b>BL</b> | <b>Exit</b>    |  |
| Lack of access to residential services                 | 66        | 60             |  |
| Lack of access to employment or day programs           | 62        | 51             |  |
| Emotional barriers of fighting the system for services | 60        | 56             |  |
| Procrastination  | 60        | 57             |  |
| Lack of information on legal/financial planning        | 58        | 44             |  |
| Difficulty trusting the service system & professionals | 56        | 53             |  |
| Difficulty affording an attorney                       | 54        | 48             |  |
| Difficulty finding helpful people in service system    | 51        | 49             |  |
| Emotional barriers in thinking about own mortality     | 49        | 40             |  |
| Difficulty finding knowledgeable attorney              | 34        | 36             |  |
| Lack of access to case management                      | 23        | 21             |  |
|  |           |                |  |

A repeated measures ANOVA was conducted to examine whether the number of perceived barriers changed from Baseline to Exit. Neither the main effects nor the interaction effect were significant. An exploratory ANOVA were conducted to examine whether the adult child's functional ability (mild, moderate, severe) was related to the number of barriers perceived by the parent. This ANOVA was significant ( $F(2,76)=3.99, p<.05$ ). A Tukey-HSD test between the 3 groups revealed that parents whose children had severe disabilities perceived more barriers to future planning than those whose children had moderate disabilities. No significant relationship was found between number of perceived barriers and the difficulty of the child's behavior. Table 3 displays the means and standard deviations for these analyses.

**Table 3 Perceived barriers**

| <b>A. Number of perceived barriers by Group</b>                      |                     |      |             |      |          |
|--|---------------------|------|-------------|------|----------|
|  | <b>Baseline</b>     |      | <b>Exit</b> |      | <b>N</b> |
|  | Mean                | s.d. | Mean        | s.d. |          |
| Intervention   | 6.18                | 2.42 | 6.04        | 2.7  | 48       |
| Alternate Treatment  | 5.77                | 2.83 | 5.21        | 3.0  | 43       |
| <b>B. Number of perceived barriers by child's functional ability</b> |                     |      |             |      |          |
|  |                     |      | Mean        | s.d. | N        |
| Child's functional ability   |                     |      |             |      |          |
|  | Mild impairment     |      | 6.55        | 2.35 | 20       |
|  | Moderate impairment |      | 5.16        | 2.73 | 43*      |
|  | Severe impairment   |      | 7.06        | 2.43 | 16*      |
| Whole group  |                     |      | 5.89        | 2.68 | 79       |
| * indicates groups significantly different at the .05 level          |                     |      |             |      |          |

**Attitudes towards Future Planning.**

At the Baseline and Exit interviews, parents were asked how much they agreed (using a 5 point Likert-type scale) with five statements expressing both negative and positive attitudes towards future planning.

A scale reliability analysis was conducted on these items, after reversing the coding on 3 items so that high scores indicated positive attitudes. Chronbach's alpha for the scale was only .48. Rather than calculate a score from the five items, given that the scale statistics were poor, repeated measures MANOVA was conducted to examine differences in attitudes between the two groups over time. Neither the Group effect nor the Interaction effect was significant; the Time effect was significant ( $F(5,80)=2.71, p<.05$ ). Inspection of the univariate ANOVAs for the time effect revealed 3 items that changed over time: regardless of group, parents tended to see future planning as less of a waste of time, as worthwhile, even though the future is uncertain, and to increase the importance they place on having a vision for the future of their child. Table 4 displays the means and standard deviations for these variables.

**Table 4 Attitudes Towards Future Planning**

| Note: Scores for items 1, 2 and 5 have been reversed so that high scores signify positive attitudes.     |                 |      |             |      |          |
|--|-----------------|------|-------------|------|----------|
| <b>** 1. Future planning is a waste of time given the current status of the service delivery system.</b> |                 |      |             |      |          |
|  | <b>Baseline</b> |      | <b>Exit</b> |      | <b>N</b> |
|  | Mean            | s.d. | Mean        | s.d. |          |
| Intervention   | 4.08            | 1.26 | 4.47        | .98  | 46       |

|   |      |      |      |      |    |
|---|------|------|------|------|----|
| Alternate Treatment   | 4.25 | 1.00 | 4.52 | .75  | 40 |
| For entire sample   | 4.16 | 1.14 | 4.5  | .88  | 86 |
| <b>*2. The future is uncertain, so it is better to live day-to-day rather than plan for the future of my child.</b> |      |      |      |      |    |
| Intervention  | 4.50 | .86  | 4.58 | .71  |    |
| Alternate Treatment   | 4.50 | .90  | 4.75 | .58  |    |
| For entire sample   | 4.50 | .87  | 4.66 | .66  |    |
| <b>3. Planning for the future of my child is the best thing I can do to ensure his/her safety and security.</b>     |      |      |      |      |    |
| Intervention  | 4.63 | .82  | 4.87 | .34  |    |
| Alternate Treatment   | 4.95 | .22  | 4.85 | .42  |    |
| For entire sample   | 4.77 | .64  | 4.86 | .38  |    |
| <b>4. Planning for the future is too emotionally costly.</b>  |      |      |      |      |    |
| Intervention  | 4.02 | 1.12 | 3.87 | 1.14 |    |
| Alternate Treatment   | 3.82 | 1.15 | 3.90 | 1.17 |    |
| For entire sample   | 3.93 | 1.13 | 3.88 | 1.15 |    |
| <b>*5. It is important to clarify a vision for the future of my child.</b>  |      |      |      |      |    |
| Intervention  | 4.47 | .75  | 4.69 | .46  |    |
| Alternate Treatment   | 4.55 | .74  | 4.72 | .45  |    |
| For entire sample   | 4.51 | .74  | 4.71 | .45  |    |
| ** indicates Time effect, $p < .005$ ; * indicates Time effect, $p < .05$ .   |      |      |      |      |    |

**Concerns about the Future.**

At Baseline and Exit, parents were asked to rate, on a 5 point (0-4) Likert-type scale, how worried they were about the future of their child in 6 different areas: Residential support, Employment or day activities, Recreation or Leisure opportunities, Support networks and friendships, Financial Support and Benefits, and Primary Caregiver. A scale reliability analysis was performed on these 6 variables. Chronbach's alpha for the scale was .84. A composite score indicating overall level of concern was computed by taking the mean of the 6 variables. A repeated measures ANOVA was conducted to examine changes in overall level of concern between the two groups over time. The Group effect was not significant. The Time effect was significant ( $F(1,90)=18.17, p < .001$ ) as was the Group by Time effect ( $F(1,90)=5.20, p < .05$ ). Parents in both groups decreased their level of concern over time, but those in the Intervention Group showed a greater decrease. Table 5 displays the means and standard deviations for these variables.

**Table 5 Concern about the Future**

|                     | <b>Baseline</b> |      | <b>Exit</b> |      | <b>N</b> |
|---------------------|-----------------|------|-------------|------|----------|
|                     | Mean            | s.d. | Mean        | s.d. |          |
| Intervention        | 2.91            | .88  | 2.41        | .92  | 48       |
| Alternate Treatment | 2.64            | 1.04 | 2.48        | .94  | 44       |
|                     |                 |      |             |      |          |

|             |      |     |      |     |    |
|-------------|------|-----|------|-----|----|
| Whole group | 2.77 | .96 | 2.44 | .92 | 92 |
|-------------|------|-----|------|-----|----|

**Overall Level of Planning.**

At Baseline and Exit, parents were asked to rate, on a 5 point (1-5) Likert-type scale, how much they'd planned for the future of their child in six specific areas (Residential support, Employment or day activities, Recreation or Leisure opportunities, Support networks and friendships, Financial Support and Benefits, and Primary Caregiver). A scale reliability analysis was conducted on these items; Chronbach's alpha was .85. A composite score, reflecting overall level of planning, was computed by taking the mean of the 6 items. Repeated measures ANOVA was conducted to examine changes in level of planning over time between the two groups. Neither the main effects nor the interaction effect were significant, though the data show a trend for parents in the Intervention Group to increase their level of planning while those in the Alternate Treatment group reported virtually no change. Table 6 displays the means and standard deviations for these variables.

**Table 6 Overall Level of Planning**

|                     | <b>Baseline</b> |      | <b>Exit</b> |      | <b>N</b> |
|---------------------|-----------------|------|-------------|------|----------|
|                     | Mean            | s.d. | Mean        | s.d. |          |
| Intervention        | 3.46            | .77  | 3.61        | .72  | 48       |
| Alternate Treatment | 3.65            | .87  | 3.63        | .70  | 44       |
| Whole group         | 3.55            | .82  | 3.62        | .71  | 92       |

The assessment instrument was divided into sections related to specific areas of future planning: Key Person, Support Networks, Housing, Work, Leisure and Recreation, and Legal and Financial Planning. Repeated measures ANOVAs were conducted to examine differential change between groups in each of these 5 areas. Significant findings are summarized below.

**Key Person:** No significant findings.

**Support Networks:** From Baseline to Exit, families in the Intervention Group increased in the number of supports they thought would be available to their child in the future (Baseline mean 6.9, s.d.3.2; Exit mean 8.1, s.d. 2.3) vis a vis families in the AT Group (Baseline mean 7.1, s.d.3.3; Exit mean 7.1; s.d. 3.3) ( $F(1,91)=3.98, p<.05$  for Group by Time interaction effect).

**Housing:** From Baseline to Exit, families in the Intervention Group reported an increase in their level of planning (Baseline mean 3.1, s.d. 1.0; Exit mean 3.4, s.d. .97) while families in the AT group reported a slight decrease (Baseline mean 3.6, s.d. .98; Exit mean 3.4, s.d. 1.1) ( $F(1,90)=4.24, p<.04$  for Group by Time interaction effect).

**Work, Leisure and Recreation:** No significant findings.

**Legal and Financial Planning:** From Baseline to Exit, families in the Intervention Group reported increased levels of satisfaction with the legal planning they'd accomplished (Baseline mean 2.4, s.d.1.5; Exit mean 2.9, s.d.1.2) while families in the AT group showed no change (Baseline mean 2.62, s.d. 1.4; Exit mean 2.62, s.d. 1.4) ( $F(1,91)=6.33, p<.01$  for Group by Time interaction effect).

**Consumer Acceptance and Satisfaction.**

Questions measuring Consumer Acceptance and Satisfaction were administered at 3 times; 6 weeks after the materials were delivered, at the Exit interview (12 weeks after materials were delivered) and at the Follow Up Interview (1 month after the Exit interview). Not every question was asked at all 3 time points. The results are summarized below.

**Initial Consumer Satisfaction Interview.**

All participants in the AT group and 85% of participants in the Intervention Group had read/used the materials at this interview. Participants in both groups were equally happy with the materials when asked how well the materials were designed for families like theirs, whether they'd recommend the materials to other families, whether the materials had increased their knowledge about future planning and whether the materials had increased the importance they place on future planning. However, parents in the Intervention Group reported their materials had motivated them more to do future planning (mean 4.13, s.d. .80) than parents in the AT Group (mean 3.7, s.d. 1.2) ( $F(1,85)=4.48, p<.05$ ). 65% of parents in the Intervention Group had talked to someone about future planning while only 48% of parents in the AT Group had done so ( $\chi^2(1)=2.7, p=.10$ ).

**Consumer Satisfaction at Exit Interview and compared to Initial Consumer Satisfaction Interview**

There were no significant differences between the two groups in consumer satisfaction variables at the Exit interview and no significant changes in these variables over time. Both groups reported relatively high levels of satisfaction with and acceptance of the materials they were using.

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