
Evaluation of a Group Intervention to Assist Aging Parents with Permanency Planning for an Adult Offspring with Special Needs

Anne L. Botsford and David Rule

More than three-fourths of older adults with developmental disabilities and mental illness live in the community with aging parents, the majority of whom do not complete plans for the residential, financial, and legal future of their offspring. The authors used a true experimental design to evaluate the effectiveness of a six-week psychoeducational group intervention with 27 older mothers. Data collected in pre- and posttest telephone interviews were analyzed with repeated measures MANCOVA to test five hypotheses.

Significant multivariate effects were found for mothers' knowledge and awareness about permanency planning, confidence and competence to plan, planning activities, and stage of planning. Findings support use of group interventions with older parents and underscore the need for professional education about planning for adults with special needs.

Key words: caregiving; developmental disabilities; group interventions; older parents; permanency planning

As institutions for people with intellectual disabilities (ID) have been phased out and health care advances have increased survival rates, the percentage of older adults with special needs in the community has climbed dramatically (Hayden & Abery, 1994; Janicki & Ansello, 2000). As the result of increased longevity for both parents and offspring, parents provide care over longer periods, fulfilling the description of them as "perpetual parents" (Jennings, 1987). Although parents provide the dominant living arrangement for 85 percent of these older adults, studies of older parents consistently document their low rate of planning for the future of their adult offspring (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1989; Hayden & Goldman, 1996; Mengel, Marcus, & Dunkle, 1996; Roberto, 1993; Smith, Majeski, & McClenny, 1996).

Permanency planning involves major life domains, encompassing residential, financial, legal,

and health care domains. It is a complex, dynamic process that needs to allow for changing needs and circumstances of both the older parents and the individual with the ID (Kaufman, Adams, & Campbell, 1991). The consequences of inadequate planning are considerable, multiple, traumatic, and sometimes catastrophic. In addition to the older parents' living with pervasive fears about what will happen, their offspring is at risk of a lower quality of life. At stake is their offspring's identity, self-esteem, freedom of choice, and capacity to cope with the loss of the parent. Unplanned transitions are associated with depression, dementia, reduced coping capacity, and increased risk of Alzheimer's disease for adults with Down syndrome. Crisis admissions to service systems and agencies also result in more acute, costly levels and array of services. These crises affect staff, residents, and service recipients as well as the cost and quality of services.

Review of Literature

Studies of families at later stages in the life cycle have noted the pervasive concern of families about the future of individuals with ID and have recommended permanency planning programs to support older parents (Hayden & Goldman, 1996; Roberto, 1993; Smith, Tobin, & Fullmer, 1995). Older parents need key support services, require more assistance in planning, and are more reluctant to use formal services (Caserta, Connelly, Lund, & Poulton, 1987; Engelhardt, Brubaker, & Lutzer, 1988). Studies have found that older parents are more isolated and more in need of additional services as they age, often demonstrating heightened concern for their offspring to the exclusion of their own needs (Kelly & Kropf, 1995; Smith, 1997).

Factors identified as significant for residential planning include older mothers' perceptions of continued ability to provide care, use of formal services, perception of age-related changes, reliance on avoidance coping, and the quality and availability of family relationships (Seltzer, Begun, Seltzer, & Krauss, 1991). In summarizing their study of 61 aging parents, only 43 percent of whom had begun to make arrangements, Lehmann and Roberto (1993) concluded:

It is apparent that their families require a proactive systematic process to engage them in the planning process for the future of their child or sibling. Future research must identify those factors that predict an orderly and smooth transition for aging persons with developmental disabilities away from their families and into diverse residential arrangements. (pp. 123-124)

Other issues identified as significant for permanency planning include how the family deals with separation and individuation issues (Brunn, 1985; Wikler, 1986); typical variations in the family life cycles, such as delayed launching (Jennings, 1987; Smith & Tobin, 1993); and permanency planning as a recurring family and individual issue at predictable developmental stages and events, such as retirement.

Social work research, education, and literature on permanency planning, on practice with people with ID or other developmental disabilities have been minimal, reflecting that even among social workers, "people with severe or multiple disabilities are invisible" (Witkin, 1998,

p. 293; Mackleprang & Salsgiver, 1996; Mary, 1998). Limited research on the effectiveness of social work interventions with this population provides an example of the need for practice research to ensure that social workers are teaching, learning, and applying interventions with demonstrated effectiveness.

The purpose of this study was to evaluate a professionally led psychoeducation group designed to increase the permanency planning of older parents caring at home for an adult offspring with an ID. The effectiveness of the intervention was assessed using a true experimental design. Although the study used a small sample ($N = 27$), it contributes information significant for professional practice with the growing number of older parents and has implications for professional education, advocacy, policy, and research for this population.

Five hypotheses were formulated on the basis of a review of the literature and experience with pilot groups. We hypothesized that in comparison with mothers in the control group, mothers in the experimental group would demonstrate increases in awareness and knowledge of planning options; sense of competence and confidence about planning; positive appraisals of the planning process; planning behaviors, such as contacts with and use of planning services; and actual residential, financial, and legal planning. Hypotheses were ordered from most to least expected effects. Positive changes in mothers' level of awareness and knowledge of services were expected as the most likely outcome, followed by feelings of greater competence and confidence about the planning process. As a result of increased awareness, knowledge, and sense of confidence and competence, it was expected that mothers would view planning more positively and would take intermediate planning steps. Given the brief nature of the intervention and the complexity of the process, we hypothesized that actual planning was the least likely to occur.

Method

Design

Using a true experimental design, we matched mothers who fit the criteria for the study on the basis of age and marital status. The mothers were then randomized into either an experimental group to receive the intervention or a control

group placed on a waiting list for the intervention. Because mothers were most often the primary caregivers, data were collected from mothers only, although the group was open to fathers and other extended family members. Mothers in both groups were interviewed two weeks before the first group session (time 1), at which time measures of demographic and antecedent variables were administered, and two weeks after the sixth and last session (time 2). During these interviews, measures of dependent variables were obtained. The telephone interview at time 1 took 45 minutes to one hour. The interview at time 2 took 20 minutes.

Interview Coding Procedures

Five experienced MSWs were trained in administration of the interview using standardized interviewing techniques (Fowler & Mangione, 1990). A graduate student using a codebook with standards and rules for coding the interviews completed all coding; the researcher and a consultant monitored coding accuracy.

Participants

The sample population was recruited from mailings to 1,200 members of a parents' advocacy group and a targeted group of 500 older parents identified by the county's central registry as older parents of an adult with ID and as having made no definite plans for the future. Demographic data on this population were unavailable for comparison with the self-selected sample. Recruitment was a six-month effort with multiple strategies, including two mailings of brochures, radio and TV publicity, telephone contact with directors and case managers of agencies, and outreach and presentations to parent and professional groups. Professionals and parents were informed that a parents' educational discussion group would be open to a limited number of parents willing to participate in a study of the planning needs of parents of adults with ID.

To participate in the study, mothers had to meet four criteria: (1) the son or daughter was 23 years old or older, (2) the offspring was identified as having ID, (3) the offspring lived with the mother, and (4) the mother had not made appreciable permanency plans for the offspring. To obtain the final sample, a larger pool of 58 volunteers was screened by telephone. Of those screened out, 20 were mothers of offspring under

age 23, five were fathers, and five had made appreciable permanency plans. Twenty-eight mothers were eligible to participate in the groups and all accepted. One mother terminated participation because of her daughter's medical crises.

Analysis of demographic data confirmed that the two groups did not differ in age, religion, SES, marital status, ethnicity, education, or number of offspring. Participants in the groups were primarily married (70 percent, $n = 19$), white (96 percent, $n = 26$), Catholic (59 percent, $n = 16$) women of middle- and upper-middle class with some college education, and they ranged in age from 49 to 82, with an average age of 64.22 years ($SD = 1.62$). More than two-thirds of the offspring were male (70 percent, $n = 19$) ranging in age from 23 to 49, with an average age of 33.74 ($SD = 1.31$); the offspring of the two groups did not differ significantly in age or gender.

Intervention Condition

The intervention was developed from a review of the literature and from experience with three pilot groups. The intervention was designed to focus, like caregiver support groups, on providing opportunities for parents to express concerns about the future of their offspring, increasing participants' awareness and knowledge about options and resources, identifying obstacles to planning, strengthening relationships with professionals, and problem solving on specific planning issues and concerns.

The intervention provided positive group dynamics, supportive interaction with other parents, and a knowledgeable, experienced social worker. The first, second, and last sessions were devoted exclusively to parents' discussions and interactions. The third, fourth, and fifth sessions were equally divided between speakers on residential, financial, and legal resources followed by group discussion led by the MSW group leaders. Each session was two hours long. A consideration from the outset was that the effectiveness of the intervention would be enhanced when followed by, or combined with, more long-term support for planning.

Group leaders were recruited from the New York State Developmental Disabilities Services offices and from a voluntary provider. All group leaders were MSWs with many years of experience with older parents, with adult clients with ID, and with extensive knowledge of resources. Group

leaders were trained using a group leaders' guide (Botsford, 1996). MSWs were provided six hours of training in permanency planning and in the protocol for the intervention and met with the researcher before and after each session. Because earlier studies (Smith et al., 1995) suggested that older parents are more receptive to services not specifically identified with the developmental disabilities services system, the intervention was offered through the county Office for the Aging under the auspices of the parent advocacy group. This arrangement underscored the practice implications of the Americans with Disabilities Act of 1990 (P. L. 101-336).

Measures

The independent variable was membership in the experimental or control group. Based on earlier literature, four antecedent variables were identified as potentially influencing the outcome of the study: (1) "mothers' perceptions of age-related changes," (2) "mothers' independence in self-care," (3) "reliance on avoidance as a coping style," and (4) "medical and behavioral characteristics of the individual offspring." Both standardized and original measures were used to compare the experimental and control group for significant differences on these variables.

Shanas' (1962) scale of six five-point Likert-scaled items was used to measure parents' perception of age-related changes (coefficient of reproducibility = .76). Examples of items are: "My health has deteriorated" and "It is harder for me just to get through the day." Lawton and colleagues' (1969) eight-item Instrumental Activities of Daily Living Scale was used to measure mothers' independence in self-care instrumental tasks such as shopping, doing laundry, and managing finances. High coefficients of reproducibility were reported to indicate strong internal reliability of this measure (Spilker, 1990). Smith and colleagues' (1995) eight-item Avoidance Coping Scale was used to measure mothers' propensity to rely on avoidance coping. The scale has a reported Cronbach alpha reliability of .85; in the present study it had an alpha of .64.

To measure functional, health, and behavioral characteristics of the adult offspring that might influence the mothers' likeliness to plan, items from the New York State Developmental Disabilities Profile were used (New York State Office of Mental Retardation and Developmental Disabili-

ties, n.d.). Mothers described their son or daughter by responding to binary items about behaviors, need for ongoing medications, and self-care.

Mothers in both groups were highly independent in their instrumental activities and rated their reliance on avoidance coping as low. The only significant difference found between the two groups on measures of antecedent variables was the control group's reporting of more age-related changes [$t(25) = 2.22$, $p < .05$]. No significant differences were found between the two groups of offspring. Thirteen (48 percent) of the offspring had mild deficits, and at least one-half in each group were independent in self-care (50 percent, $n = 7$, of the control group and 70 percent, $n = 9$, of the experimental group); more than one-half required at least some support in daily living activities (79 percent, $n = 11$, of the control group and 70 percent, $n = 9$, of the experimental group).

In view of the small sample, dependent variables delineated in the study's hypotheses were clustered, based on theoretical considerations, to limit the number of tests performed to the five hypotheses. The hypotheses are ordered from most to least likely to be supported.

The three variables included in the cluster changes in mothers' awareness and knowledge of planning issues were (1) "overall knowledge of resources" as measured by a single five-point Likert-scaled item created for this study, (2) "awareness of planning resources," and (3) "identification of service needs in relation to planning." The single item to measure overall knowledge of resources was "Overall, how would you rate your knowledge about community resources?" with response categories ranging from 1 = excellent to 5 = poor. Five items, using the format of Heller and Factor's (1991) and Toseland and Rossiter's (1989) community resources scales, asked mothers to indicate to what extent they were aware of and needed assistance with planning (for example, legal and financial plans). Awareness items were binary; need items were three-point Likert-scaled items ranging from 1 = a good deal to 3 = not at all. Cronbach's alpha reliabilities for the Awareness subscale were .75 and .88 (pre- and posttest, respectively) and .82 and .70 (pre- and posttest) for the Service Needs subscale.

Variables for the cluster changes in sense of competence and confidence to engage in planning were measured using 10 five-point Likert-scaled items developed for this study. Sample items were

"How competent do you feel to find services that you or your offspring need?" and "...to get your child on a waiting list for residential service?" Responses to these items ranged from 1 = very competent to 5 = not at all competent or 1 = strongly agree to 5 = strongly disagree, with scores summed for a cumulative score. Cronbach's alpha reliabilities for the Competence subscale were .89 and .88 (pre- and posttest, respectively) .81 and .93 (pre- and posttest) for the Planning Confidence subscale.

Cluster changes in caregivers' appraisals of the planning process were measured by three variables: "overall satisfaction with community resources" for people with ID, "satisfaction with planning services," and "appraisals of the helpfulness of professionals." One five-point Likert-scaled item developed for this study measured "overall satisfaction with community services" for people with ID. Satisfaction with five planning services was measured by the Community Resources Scale (using the format of the previously cited scales), which obtained Cronbach's reliabilities of .86 on the pre- and posttests. On two Likert-scaled items, mothers rated the helpfulness of professionals and their degree of comfort working with them on issues of permanency planning. Alpha reliabilities for the present sample were .76 and .75 on pre- and posttests.

The cluster changes in proximal steps taken toward planning was measured by three variables: "number of planning services used," "frequency of contacts," and a 10-item scale of "intermediate planning activities." The number of planning services used and frequency of contacts were collected by the Community Resources Scale (for example, assistance with guardianship or with a special needs trust). Alpha reliabilities for the present sample were .73 and .81 on pre- and posttests for services used and .53 and .70 for contacts. The scale of intermediate planning activities was adapted from Heller and Factor's (1991) Parents Permanency Planning Survey and consisted of 10 items with binary responses as to whether the mother had taken that step (for example, contacting a residential program or visiting a residence); alpha reliabilities were .75 and .71 for this scale.

The cluster changes in mothers' financial, legal, and residential planning was viewed as the "acid test" of planning behaviors and was measured by two five-point Likert-scaled items that asked the

mother to select the rating that best described her current stage of residential, financial, and legal planning (Smith et al., 1995). Stages were: "No discussion yet," "Early discussion," "Considering alternatives," "Provisional plans made," or "Definite plans made." Alpha reliabilities were .84 for on pre- and posttests.

Analysis

Before the analysis, data were prepared to meet the assumptions of this model (that is, homogeneity of covariance, normality, and, whenever possible, outliers). Data collected in the pre- and posttest interviews were analyzed using a multiple analysis of covariance (MANCOVA) approach. This approach was chosen because the unit of analysis selected for the hypotheses was the difference in dependent variables' posttest scores, taking into account any differences in the pretest scores. And because we hypothesized the dependent variables for this study to be highly intercorrelated, a MANCOVA approach allowed testing of the multiple dependent variables in each of the five hypotheses simultaneously while controlling for Type I errors. Because each of the five hypotheses contained several dependent variables, an overall MANCOVA was first performed for each hypothesized cluster. With the initial Type I probability rate for the five MANCOVAs set at the alpha .05 level, the resulting overall experiment-wise error rate was calculated using the Bonferroni method (Tabachnick & Fidell, 1989), and was found to be $p = .23$. Given the small sample size of this study and its focus on discovering initial findings for follow-up studies, this Type I error was deemed acceptable.

Significant multivariate effects discovered for a hypothesized cluster were followed up by post-hoc examination using univariate analysis of variance (ANOVA). Because of the Type I error inflation associated with a large number of univariate analyses, significant univariate p levels were used to determine the relative influence of the univariate variables to the overall multivariate effect, rather than "absolute" statistics implying causal relationships.

Results

Awareness and Knowledge of Planning Options

A significant multivariate effect [$F(1, 23) = 6.61, p < .004$] was found for the hypothesis concerning

mothers' awareness and knowledge of planning options and resources (see Table 1). Univariate effects were found for the variables "aware of services" [$F(1, 19) = 14.26, p = .001$] and "overall knowledge" about planning resources [$F(1, 19) = 6.02, p = .024$].

Sense of Competence and Sense of Confidence to Plan

A strong multivariate effect [$F(1, 26) = 12.53, p = .000$] was found for this variable cluster. Correspondingly, significant univariate effects were found for the variables "sense of confidence" [$F(1, 19) = 20.65, p = .000$] and "sense of competence for planning" [$F(1, 19) = 12.73, p = .002$].

Appraisal of Planning Process and Intermediate Planning Behaviors

No significant multivariate effects were found for the variable clusters addressing mothers' "appraisals of the planning process" [$F(1, 24) = 2.53, p = .081$] or for their "intermediate planning behaviors" [$F(1, 23) = 1.60, p = .226$]. On the measures of appraisals, the experimental group's posttest means were considerably (but not statistically significant) higher than the control group's, with the exception of "plan implementation." Potentially strong univariate effects were found only for "overall satisfaction with community services" and with the extent to which "professionals were helpful." Although the experimental group's mean posttest scores were higher than the control group's on all of the "intermediate planning" behaviors, no strong univariate effects were found.

Stage of Residential and Financial Planning

A primary assumption of the study was that planning was a complex, long-term process, and that

significant change in actual planning was unlikely. However, for the fifth and final hypothesis, a significant multivariate effect was found for "financial planning" [$F(1, 27) = 6.94, p = .005$] with strong univariate effects for both residential [$F(1, 23) = 8.16, p = .009$] and financial variables [$F(1, 23) = 13.31, p = .001$].

On the pretest means for both residential and financial planning, the experimental group scored lower than the control group; on the pretest the experimental group was at the stage of "no discussion yet" in financial planning, whereas the control group reported being at the stage of "early discussion." Comparing the posttest means, the experimental group advanced to the stage of "considering alternatives" and the control group was unchanged in "early discussion." In residential planning, the experimental group at pretest was at the stage of "no discussion yet"; the posttest mean indicated the group had advanced to "early discussion." By comparison, the control group regressed in their stage of planning in the six weeks between the pretest and posttest.

Issues and Implications for Practice

This evaluation of the group intervention found strong positive effects for the experimental group of older mothers as measured by increases in their knowledge and awareness of resources for planning, their sense of competence and confidence to plan, and their advance in the planning process. Why the intervention produced such positive effects in such a short time invited speculation. One factor was likely the readiness of this sample of mothers to proceed with planning. Provided that parents were ready to act, the intervention helped mothers translate readiness into action by removing internal and external barriers, providing

Table 1

Multivariate Analysis of Covariance of Hypothesis Outcome Clusters

| Variable Clusters | Experimental Group N | Control Group N | F | p |
|---|-------------------------|--------------------|-------|------|
| 1. Knowledge and awareness about planning | 11 | 13 | 6.61 | .004 |
| 2. Competence and confidence to plan | 13 | 13 | 12.53 | .000 |
| 3. Appraisals of the planning process | 11 | 14 | 2.53 | .081 |
| 4. Intermediate planning behaviors | 12 | 12 | 1.60 | .226 |
| 5. Residential and legal planning | 13 | 14 | 6.95 | .005 |

positive models, and establishing connections with people and agencies crucial to the planning process. Indicators of the readiness of the mothers to act were their self-selection for the intervention and their low avoidance coping scores.

Support for the intervention's effectiveness, rather than the influence of self-selection factors in producing the positive benefits, was provided by the stability or decline in the mean posttest scores of the control group, an equally "ready" group.

A particular and curious incidence of control group regression was found in the area of residential planning: The control group regressed from a mean of 2.07 at pretest to a mean of 1.93 at posttest. This regression contributed to the highly significant finding of $p = .009$ when the posttest mean was compared with that of the experimental group, whose mean increased from 1.77 at pretest to 2.62 at posttest. Because no follow-up interviews had been conducted at the time of this writing, it is not possible to provide an informed, nonspeculative explanation. Perhaps the pretest questions on planning heightened the control group's awareness of the need to plan and increased both stress and avoidance, with unanticipated negative statistical effect (Cook & Campbell, 1979). In any event, the regression points out the need for further studies with increased sample size and diversity.

A major question about the findings was the extent to which the positive effects would be maintained. After this study the control group received the intervention; analysis of pre- and posttest data on both groups is in progress, as is a one-year follow-up study of both groups. Analysis of this longitudinal data may improve understanding of the intervention's durability. As is the case with any experiment of small sample size and limited effects, replication of the study's original design and treatment is essential. For all of these reasons, caution is necessary for the generalizability of the findings.

To put the findings of the present study into the context of similar studies, group psychoeducational interventions have been reported with couples (Worthington & Drinkard, 2000); adolescents exposed to violence (Goldich, 1999); men who batter (Browne, Saunders, & Staeker, 1997); caregivers of older adults (McCallion & Toseland, 1995); caregivers of people with Alzheimer's disease (Walker, Pomeroy, McNeil, & Franklin, 1994); foster par-

ents of sexually abused children (Barth, Yeaton, & Winterfelt, 1994); families of people with schizophrenia (Beels & McFarlane, 1982); parents of adolescents (Cohen & Irwin, 1983), and others. As Walker and colleagues (1994) noted, research on the efficacy of psychosocial group interventions typically uses clinical impressions and participant satisfaction, generally yielding positive findings. With use of objective measures, research more often yields inconclusive findings. The development of objective, standardized measures of the effectiveness of interventions with a range of populations is consequently a high priority for social work research.

Despite the limitations of the present study, and despite the resistance of the current cohort of older parents to plan for the future, as reflected in the efforts recruiting for this study, the group intervention was highly effective in assisting parents. Such group interventions are cost-effective, can be developed with some thought, and do work in terms of increasing parents' propensity to plan. In view of the importance of planning for a growing number of older adults with special needs, for their families, and for the systems that serve them, offering such groups is urgent. The cost-effectiveness and quality of care are increased to the extent that such groups reduce the traumatic effects of loss and reduce the cost to service systems attempting to manage the ensuing crises. In addition, to prepare professionals knowledgeable and skilled at these critical junctures, the process of permanency planning for populations at risk of chronicity (Ferguson, 1994) warrants inclusion in the social work education curriculum.

Helping aging parents plan for the future also involves policy. One of the parents in the group asked, "But what good is planning if the resources are not there when we need them?" The inadequacy of services and supports frustrates and frightens older parents (Hayden & DePaepe, 1994). Better planning for adults with special needs requires our joining with parents for sustained, effective advocacy in political and judicial arenas. We cannot expect parents to engage in the planning process unless we as professionals and as a society engage in planning for the care of this population. ■

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Anne L. Botsford, PhD, ACSW, is associate professor and director of Fieldwork Education, Social & Behavioral Sciences Department, Marist College, 3399 North Road, Dyson Center 380, Poughkeepsie, NY 12601; e-mail: anne.botsford@marist.edu.

David Rule, PhD, is academic vice president, Columbia Greene Community College, Hudson, NY.

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