

**A Group Intervention to Assist Older Parents
of Adults with Mental Retardation
in Permanency Planning**

Anne L. Botsford, Ph.D.
Ph.D., SUNY Albany, 1997
Director of Fieldwork Education,
Marist College

Statement of the Research Problem

The purpose of this study was to evaluate a group intervention designed to increase the permanency planning of older parents of adults who were mentally retarded. Previous studies found that older parents avoid planning and less than half make financial/legal and residential plans. The components of permanency planning encompass major life domains, as noted by Smith & Tobin (1989), and the process is a complex and dynamic one which needs to allow for the changing needs and circumstances of both the family and the adult with mental retardation (Kaufman, Adams & Campbell, 1991). "Perpetual parenthood" (Jennings, 1987) is one description of the role of the older parent of an adult with developmental disabilities and the "WIAG" or "When I am gone" syndrome (Lefly, 1987) aptly describes the older parent who verbalizes their pain and fear about their son or daughter's uncertain future.

Numerous studies have documented both the stress that parents experience in caring for and planning for adults with mental retardation and the low rate of planning by parents, but currently is no research on the effectiveness of interventions. Practice guidelines and training curricula to prepare social workers, case managers and others to effectively intervene and support parents in the planning process are also lacking. In short, the literature provides ample documentation of the need for effective interventions to help parents with the planning process, to increase their rate of planning and to reduce the traumatic consequences of not planning for themselves, their offspring and indeed, for the systems mandated to provide services to this population.

Although estimates on the number of adults with mental retardation are variable, depending upon definitions, degrees of retardation being considered, methodologies employed in data collection and evidence of a "hidden" group of developmentally disabled adults (Smith & Tobin, 1989; Horne, 1989), there is substantial evidence that the number of families involved in caring for an adult with mental retardation is increasing due to improvements in health care (Janicki & Wisniewski, 1985) and the phasing out of total institutions and developmental centers. The consequence is that more families are caring for adult family members with mental retardation and other developmental disabilities for longer periods of time. Using estimates of other researchers (Scheerenberger, 1987; Baroff, 1982) and in the

absence of reliable data, an estimate of approximately four million families of adults with developmental disabilities was used as the population for whom permanency planning is a significant issue.

Research Questions

The importance of family caregiving to adults with developmental disabilities has increasingly been recognized in the literature despite the fact that there is neither reliable epidemiological information about the number of adults living with their families nor specific demographic information about the characteristics of the families and adults. However, in comparison with the quantity and variety of research on caregiving to frail elderly family members, the literature in this area is both more sparse and more recent and has been hampered by definitional and methodological problems.

The literature has focused primarily on families with young children. Studies that have explored later stages in the family life cycle have noted the pervasive concern of families about the future of the individual with retardation and have recommended permanency planning programs (Turnbull et al., 1989; Roberto, 1993; Smith & Tobin, 1989). Studies have also identified some of the factors that may predict how likely families are to initiate plans; e.g., appraisal of caregiver capacity and health status, SES, informal support system, service utilization, age, and presence of mutual emotional and financial dependency (Kelly & Kropf, 1995; Smith, Tobin & Fullmer, 1995; Lehmann & Roberto, 1993).

O'Malley (1996) has described a group intervention for older parents and Smith et al. (1996) reported preliminary outcomes of a case study of a group program. These outcomes included increased information, increased awareness of services, and hearing of other parents' concerns as the most helpful aspects of the group experience.

Studies which examine significant clinical issues in permanency planning have identified family life cycle and developmental crises associated with the parents' aging and the need to consider future care of the adult offspring; individuation and separation issues; parents' grief, anxiety and guilt over relinquishing the care of the offspring; and questions about how to prepare the family and the offspring for separation (Goodman, 1978; Brunn, 1985; Wikler et al., 1981).

The ordering of the hypotheses from most to least expected was based upon personal experience with the population and review of the literature. In order of expectation of change, the five specific hypotheses were, that in comparison with older mothers in a control group, mothers in an experimental group participating in the group intervention would demonstrate:

- 1) increased awareness and knowledge about planning options and increased identification of service needs.
- 2) increased sense of competence and confidence about planning.
- 3) increased positive appraisals about the planning process, including their priority for planning tasks, their time frame for implementing plans, their appraisals of the helpfulness of professionals and other parents in the planning process.
- 4) increased planning behaviors, such as increased thinking about and talking about planning, use of services, contacts with services.
- 5) increases in actual residential and financial/legal planning.

Given the brief nature of the intervention and the complexity of the planning process, both psychosocially and in terms of the realities of financial, legal and residential issues of planning, it was not expected that group participation would measurably influence actual planning.

The six-week group intervention developed from three previous pilot groups and consisted of weekly two-hour psychoeducational sessions which included discussions with parents who had already made permanency plans, discussion of a film in which older parents were interviewed; and discussions with representatives from a range of community programs. Group leaders were MSWs selected on the basis of their considerable experience working with older families and adults with mental retardation and their knowledge of the service system. In addition, they were trained in the intervention using A Group Leader's Guide to Working with Parents of Adults with Mental Retardation (Botsford 1996).

Methodology

A sample of twenty-eight older mothers who had not made definite plans and who were caring for an adult offspring aged twenty-three or older at home was recruited using multiple and extensive outreach strategies. The study design was a true experimental one with mothers' matched on the basis of age and marital status and randomized into experimental and control groups.

Antecedent and dependent measures were administered in telephone interviews two weeks before the intervention and two weeks after. No significant differences, with one exception, were found between the two groups of mothers and none were found for the two groups of offspring on these variables.

Mothers' age, gender, marital status, ethnicity, religion, adult offspring's age and gender, were assessed by single items. Some of the other measures included the Activities of Daily Living Scale (Lawton & Brody, 1969), the Lawton Instrumental Activities of Daily living Scale (Spilker, 1990), Tobin's Perceived Ability to Provide Care Scale (1995), Shanas' (1962) perception of age-related changes scale, Hollingshead's two factor index of social position (Miller, 1983), Heller and Factor's (1991) informal support indices, Tobin & Smith's (1995) Avoidance Coping Scale, and measures from the New York State Developmental Disabilities Profile (DDP2). Parents' rating of the effectiveness of the group intervention was measured using a twelve-item scale adapted from Toseland, Rossiter & Labrecque's (1988) study of the effectiveness of caregiver support groups.

The primary analysis was multiple analysis of covariance (MANCOVA) with pretest scores as covariates for post-test scores. Measures of skewness and kurtosis were used to determine if variables required transformation in order to meet assumptions of normality; seven variables were transformed. Outliers were eliminated to the extent possible with a small sample. With these preparations, results of evaluation of MANCOVA analysis assumptions of normality, homogeneity of variance and linearity were satisfactory.

Given the small sample and the model of analysis, variables were clustered based on theoretical considerations in order to limit the number of tests performed to five. Overall MANCOVA was performed for each cluster of variables. With these five MANCOVAs at the alpha .05 level, experiment-wise error rate was $p=23\%$ using the Bonferroni method (Tabachnick and Fidell, 1989).

Any significant multivariate effects were followed up by univariate analysis of variance (ANOVA) for post hoc examinations of univariate effects; significant univariate p levels were used to determine the relative influence of the univariate variables to the overall, multivariate effect. Univariate F s were ranked in importance by strength of association with the multivariate F (Tabachnick & Fidell, 1989).

Sample size and the exploratory nature of the study warranted treating the findings as tentative. The interpretations of findings of multivariate significance as well as of the relative influence of any significant univariate tests were accordingly conservative. The criterion for multivariate statistical inference chosen for use with the cluster tests was Wilks' Lambda.

Results

The effectiveness of the group intervention was supported by tests of three of the hypotheses for which significant multivariate effects were found where they were most expected as well as where least expected; mainly, knowledge and awareness of planning options, sense of competence and confidence to plan and stage of planning for residential and

financial/legal future. No significant multivariate effects of the intervention were found for tests of hypotheses of positive effects for mothers' appraisals of the planning process nor for intermediate planning behaviors.

Univariate effects that were strongly associated with the significant multivariate effects included mothers' awareness and overall knowledge of services, sense of confidence and competence about planning and actual residential and financial/legal planning. Participants evaluated the effectiveness of the intervention highly and felt that it was particularly useful in increasing their knowledge and sense of competence about planning.

Qualitative data collected in observation of the parent groups included the relevance of retirement for older parents' reassessing the adequacy of their plans for themselves as well as for their offspring, the impact of the socio-economic context on planning and specifically their concern about the availability and adequacy of future resources, identifying steps to take in the process of "letting go" of an offspring, the value of the group in modeling the exploring of planning options, strategies for redefining the relationship and dealing with the uncertainty of the future.

Factors that were identified as important in explaining why the intervention had such a positive effect for the parents in such a short time included the readiness of the parents to proceed with planning, the selectivity of the sample, the care with which the intervention was designed meet the needs of older parents, the training of experienced and knowledgeable MSWs in the intervention model and the support system established for parents.

Major questions about the results were concerned the durability and generalizability of the findings; i.e., whether the changes that the participants made would be maintained and whether they were generalizable to other subgroups of older parents. It was hypothesized that the intervention effects plateaued at termination of the group and that follow-up "booster" sessions would help to maintain the planning process, as might ongoing support groups, such as one that a pilot group established. Research is in progress to re-test the experimental and control groups at six months, to provide the control group with the intervention, to analyze pre and post-test data on the second experimental group and to continue follow-up with the first experimental group of this study.

Utility for Social Work Practice

The group intervention was highly effective for those older parents who participated. Most older parents, however, want to avoid the future, as reflected in the difficulties experienced in recruiting a sample for this study. Given the high demand for so many other services, is it worthwhile for agencies and service systems to expend resource on outreach?

There are compelling ethical, economic, psychosocial and systemic reasons for social workers to improve the planning process. The consequences of not planning extend to the parents and families, the sons and daughters with disabilities, and to the service system and individual agencies. For parents, the consequences of not planning are long term psychological and physical stress, the financial cost of long term care and inevitable crisis for the spouse, other adult children and extended family who survive the caregiving parent.

For the adult child with a disability, the consequences of inadequate plans include intense psychological and emotional trauma, which may require more acute, costly levels of care and services; decreased quality of life as a result of trauma; the loss of either parent resources or benefits; and reduced options for residential, financial and legal arrangements.

Unplanned crisis admissions to service systems and individual agencies impact staff, other residents and service recipients and the quality of services, which can be measured in increases in incident reports, increases in expenditures for staffing overtime and additional treatment planning, and increased service utilization on behalf of both the newly admitted individuals and those affected by them.

If planning is not improved, we can expect parents to continue to struggle with care, individuals with disabilities to suffer the long-term consequences, and the systems intended to serve them to expend scarce resources on the systemic fallout.

Because of the importance of parents making plans, efforts should be made to develop these kinds of groups and to adapt and modify them to the needs of subgroups of parents. Despite the resistance of the current cohort of older parents, future cohorts of older parents, who are likely to be more involved in planning throughout their offspring's lifespan, may be more amenable to this type of intervention.

For parents' planning to be effective, there must also be an appropriate range of quality long-term care resources. Current policy "reforms" are acutely constraining resources for residential, educational, vocational, home care and other long term care essential to the families of adults with developmental disabilities. Political and possibly judicial action by professionals and parents are critical to meeting the needs of families and their adult sons and daughters with developmental disabilities.

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