DOCUMENT RESUME

ED 327 787 CG 023 091

AUTHOR	Smith, Gregory C.; Tobin, Sheldon S.
TITLE	How Case Managers Perceive Older Parents as Caregivers of Developmentally Disabled Adult Offsprings.
PUB DATE	Nov 89
NOTE	16p.; Paper presented at the Annual Scientific Meeting of the Gerontological Society (42nd, Minneapolis, MN, November 17-20, 1989).
PUB TYPE	Reports - Research/Technical (143) -- Speeches/Conference Papers (150)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Adult Children; Caseworkers; *Counselor Client Relationship; Dependents; *Developmental Disabilities; *Frail Elderly; Helping Relationship; Interviews; Long Term Care; *Mental Retardation; *Older Adults; Parent Child Relationship; Parent Counseling; Social Services

ABSTRACT

Developmentally disabled adults who are cared for at home by their older parents present a challenge because community-based social and health services are required to meet the needs of both the aging parents and the offspring. In this study, 11 local case managers were interviewed in depth, for 2 hours, about their work with parents of developmentally disabled adults. Findings from this pilot study affirmed parents' resistance to planning for permanency despite increased frailties. Augmenting resistance and impeding assistance is a scarcity of residential options. Like the parents, workers were ambivalent about disrupting interdependence. They wished to provide help with future plans before crises occur, and also to keep aging families together for as long as possible by arranging needed services. Workers remarked that parents were intimidated by their youth and professional status, and that they feared them as threatening separation. Also reported was frustration over the mandate not to treat parents as clients, as well as excessive caseloads prohibiting more interaction with older families. Workers desired, instead, to assist parents when they first encountered age-related losses, and to learn more about aging services. Results of this pilot investigation suggest that geriatric specialists are needed to serve both aging developmentally disabled clients and their elderly caregivers. Sixteen references are included. (TE)

HOW CASE MANAGERS PERCEIVE OLDER PARENTS AS CAREGIVERS OF DEVELOPMENTALLY DISABLED ADULT OFFSPRINGS

Gregory C. Smith and Sheldon S. Tobin
Ringel Institute of Gerontology
University at Albany
State University of New York

Paper presented at the 42nd Annual Scientific Meeting of the Gerontological Society of America, Minneapolis, MN (November, 1989)

Abstract

Following an interview study with older parents, 11 local case managers were interviewed in-depth (ave. = 2 hr) about their work with these parents. Findings from this seminal pilot study affirmed parents' resistance to permanency planning despite increased frailties. Augmenting resistance and impeding assistance is a scarcity of residential options. Like parents, workers were ambivalent about disrupting interdependence. They wish to provide help with future plans before crises occur, and also to keep aging families together for as long as possible by arranging needed services. Workers remarked that parents were intimidated by their youth and professional status, and feared them as threatening separation. Also reported was frustration over the mandate not to treat parents as clients, as well as excessive caseloads prohibiting more interaction with older families. They desired, instead, to assist parents when age-related losses are first encountered, and to learn more about aging services. Suggested by this pilot investigation is the value of developing geriatric specialists to serve both aging developmentally disabled clients and their elderly caregivers.

INTRODUCTION

Although there has been increasing recognition of the prolonged longevity of mentally retarded and other developmentally disabled (MR/DD) persons (Janicki & Wisniewski, 1985), little attention has been devoted to the needs of older parents who continue to care for their disabled offsprings (see, for review, Smith & Tobin, 1989). Mentally retarded persons, as well as other developmentally disabled persons, show signs of aging earlier than the general population and generally have similar needs to those of persons who are chronologically older (Cotten et al., 1981; Dickerson et al., 1979; DiGiovanni, 1978; Janicki & MacEachron, 1984; Janicki et al., 1985; Seltzer & Seltzer, 1985; Rose & Janicki, 1986; Waltz et al. 1986). Janicki et al. commented that especially the needs of aging mentally retarded persons reflect decreased functional abilities and increased physical frailty. Thus, developmentally disabled adults who are cared for at home by their older parents present a challenge because community-based social and health services are required not only to meet age-associated needs of parents whose increasing frailities adversely affect their caregiving capacities but, also, to meet the needs of their offsprings who are likely to be experiencing the effects of their own aging (Carswell & Hartig, 1979; Janicki et al., 1985; Rose & Janicki, 1986).

The sparse writings on these parents has focused primarily on their use of formal and informal social supports to continue in the caregiving role as long as possible, with minimal attention to their concerns for the future well-being of their disabled offsprings after they are no longer able to provide care (see, for discussion, Smith & Tobin, 1989. In turn, the few investigators (Carswell & Hartig, 1979; Gold, Dobrof, & Torian, 1987; Goodman, 1978; Heller & Factor, 1987) who have studied issues regarding peremanency planning have done so from the perspective of older parents themselves, rarely considering the views of practitioners who directly serve these parents.

Knowledge of how practioners perceive older parents of MR/DD adults is important for several reasons. First, the issues that confront these parents are both logistically complex and emotionally draining. Permanency planning, for example, not only entails detailed planning regarding financial, legal, and residential arrangements (Seltzer & Seltzer, 1985), but also requires the resolution of the guilt and anxiety over relinquishing the care of ones' dependent offspring. Obviously, aging parents can be helped through this maze of feelings and details with professional assistance.

Another reason why the views of service providers must be explored is because conflicts frequently exist between older parents and practitioners who serve them, as revealed by interviews we have conducted with both parents and practitioners. Both groups reported that conflicts often relate to parents' fears that the role of practitioners is to remove adult developmentally disabled offspring from parents. Yet, practitioners do not perceive their role as separating adult offsprings from parents. The erroneous perception of parents distorts communication between them which, according to practioners, is compounded because frail older parents are likely to be intimidated by their youthfulness and expertise.

Finally, it is necessary to explore practitioners' perceptions of their work with older parents because few, if any, of these workers have had any formal training in gerontology. Consequently, their attitudes and knowledge of aging parents are likely to be distorted by inaccurate societal stereotypes toward the elderly. This, in turn, may have a negative impact on their work with older parents.

Service providers that are most likely to have a direct impact on the lives of older parents of MR/DD adults are case managers who work in the developmental disabilities service system. Although their job description typically states that their primary function is to monitor and arrange supportive services for families with MR/DD offsprings, these workers also spend considerable time assisting older parents with permanency planning and serving as confidants to them. Moreover, older parents of MR/DD offspring more frequently rely on this group of practitioners for services than those from the aging services network. Older parents have typically utilized the MR/DD service system during the lifespan of their dependent offsprings and, thus, have generally developed a reliance on its workers.

The objective of this pilot study was to portray the perceptions of case managers who work with families comprised of older parents who care for their MR/DD adult offsprings at home. Specifically, respondents were administered in-depth open-ended interviews regarding their perceptions of how aging affects parents' ability to provide direct care and to be involved in case-related activities; the impact of case managers'attitudes, feelings and beliefs on practice with older parents; how service utilization differs among older and younger parents; the most salient issues confronting older parents; major obstacles to permanency planning faced by older parents; case managers' effectiveness in assisting older parents with permanency planning; and innovative programs and services that should be developed for older parents. Although the present study was conducted as a pilot to facilitate the planning of a more extensive investigation, our relatively small sample enabled us to obtain the sort of rich qualitative data that is best generated by in-depth exploratory interviews.

Method

The Sample

Eleven case managers from the Developmental Disability Services Office (DDSO) located in the Capital District of New York State were interviewed. The DDSOs of New York State include not only a complete continuum of services for MR/DD clients but also case managers whose task is to work with families to facilitate adaptation of their MR/DD offsprings. This sample of case managers was particularly advantageous, because the MR/DD service system in New York State is among the most sophisticated of systems.

Two criteria were established for selecting the case managers who were interviewed: (1) At the time of the interview they must have been employed at least one year as a DDSO case manager, and (2) they had clinical experience with several families in which parents age 65 and older care for their MR/DD offspring at home. These criteria insured that only case managers with a sufficient amount of relevant experience were interviewed.

To recruit this sample, the clinical supervisors from each satellite office of the DDSO were asked to supply the names and phone numbers of interested case managers who met the selection criteria. The first author then phoned each worker to explain the purpose of the study, obtain informed consent, and arrange an interview date.

Of the 11 participants, there were nine females and two males. The average length of professional experience as an MR/DD case manager was 10.5 years (range = 2.5 to 19 years). Nine of the case managers were from satellite offices that served clients from urban and suburban environments, whereas the other two served clients in rural areas.

The Interview

All interviews were individually conducted by the first author at the case managers' offices. The open-ended interview, which took about two hours to complete, was used to elicit case managers' perceptions regarding the following content areas: how aging affects parents' ability to provide direct care and to be involved in case-related activities; the impact of their attitudes, feelings and beliefs on practice with older parents; how service utilization differs among older and younger parents;

the most salient issues confronting older parents; major obstacles to permanency planning faced by older parents; their effectiveness in assisting older parents with permanency planning; and innovative programs and services that should be developed for older parents.

Findings

The in-depth exploratory interviews with case managers generated rich data that are best presented qualitatively.

When asked, for example, in what ways they perceive their work with older parents to be different from that of younger parents the case managers gave the following kinds of responses:

> I must be more nurturing. Older parents become more isolated and need more interaction. They need to know that someone is there.
>
> A lot of older parents talk about things they have given up as a result of the choice they made many years ago to keep their disabled child at home.
>
> Parents become more pessimistic and more emotionally charged as they grow older.
>
> Older parents feel that they might be asking questions that professionals will view as foolish.
>
> They are more accepting of the offspring's disability than younger parents.
>
> Older parents have greater difficulty with forms and the system is more overwhelming to them.
>
> They are not as strong physically. Frequently thev land in the hospital, and I must arrange respite care for their disabled offspring.
>
> The focus becomes a lot more on the needs of the parents so that they can continue to care for their offspring.
>
> Older parents are not bitter or resentful, but they are extremely concerned about what will happen to their disabled offspring when they are gone.

> It's difficult to arrange the services they need, especially in rural areas. And, often, older parents don't want services even if they need them. They just don't want to face the realization that after so many years of care, they can't do it any more. Seeing someone stronger than they are taking over leads to a sense of failure.

The following kinds of responses were given when we asked case managers about the involvement of older parents in case-related activities:

> Younger parents are more confident and optimistic and they are actively involved, but older parents are not actively involved and they don't want the case manager to become involved because of a fear that their disabled child will be removed. Older parents are less trusting.
>
> In general, older parents are more doubtful when progress or independence is spoken of due to their overprotectiveness.
>
> There is often conflict with young staff. Older parents will say: "I've cared for my child my entire life, who are you to tell me what to do"
>
> Involvement drops off. They fought issues for 20 years and now see it as someone else's job. Their advocacy lessens.
>
> Physical disability also makes older parents less able to be involved.
>
> The focus of older parents in case reviews is on their offspring's basic needs, whereas younger parents are as equally concerned or even more so about helping them to maximize potential. Parents are diverse. Some will come no matter how disabled, while others handle these things at a distance.

The following kinds of responses were provided by case managers when we asked them how parents' abilities as caregivers were affected by their aging:

> Strongly. Some can't even get out of bed, but they have their offspring on the bus by 6:00 am for the day program. They can't meet the child's needs any more, like giving a bath or lifting.
>
> It depends on the client's functional level. With clients who are lower functioning, it can be very taxing for older parents.

> Clients can take advantage of parents' increasing frailties and behavioral regression starts to occur.
>
> Higher functioning clients will often take on some of the parental role, and they will become frightened by their parents' increasing frailities.
>
> In some cases, I've seen the child helping the parent as the parent instructs the child on what to do. Also, disabled children often bring financial benefits. These kinds of assistance make it even more difficult for older parents to place their child.
>
> Their increasing physical disabilities and health problems cause a breakdown in the system they previously maintained.
>
> Some parents realize their increasing frailty and want relief, yet they feel that they must continue to do everything and thus feel angry and resentful. Then, they may deny their offsprings' some of their needs, and this can lead to conflict between them.

We obtained the following kinds of responses when we asked case managers about their own feelings and attitudes regarding their work with older parents:

> Frustration over matching older parents with service providers. Often, the client and parent have similar needs, but legally we're supposed to serve the client only.
>
> For all parents, but especially with older ones, it's difficult and painful to expect that you'll severe the relationship that has lasted all those years.
>
> I feel a lot of compassion. I want to nurture these people, I love and respect them. I admire their ability to care for someone for 60 years. I feel sympathetic, yet I marvel at their strength.
>
> I'm getting older too, so I understand. You have to be empathic and give credit for keeping the home together and for accepting the responsibility. But, I also encourage them to share their burden with the rest of the community.
>
> Dying is a sensitive issue, so I'm more sensitive to the way I discuss placement with older parents.
>
> Working with older parents surely makes my job more difficult! It takes more patience and listening.

> I'm frustrated when I can't get them to place their disabled offspring before death or even to talk about a visit to a community residence.

> I enjoy it. I like working with older people.

Case managers provided responses like these when we asked them what their discussions with older parents about permanency planning have been like:

> I help parents process their thoughts about permanency planning from the abstract to the concrete. We identify feelings, explore options and solidify plans. However, developing willingness is usually the most important step.

> Some discussions have been rocky. You discuss it one month, and the next month they've forgotten all about it. For some, you have to work in small spurts such as taking them to visit a community residence and, later, discuss options.

> I acknowledge their love for their offspring and praise them for being good parents. I help them to remenisce their whole lifetime with the child. I acknowledge their desire to see the child always well taken care of. We start off with very general issues such as love and the family, and then move to discussing their old age, the future and planning.

> I reassure them that we are not there to take their child away, and remind them that they will always be the parent in complete control. I also remind them that they can reverse a decision if they want to.

> It depends on parents personality and their comfortableness with thinking about death. Some are very open while others won't even bring it up.

> Sometimes parents go as far as making all the applications, but then won't visit the placement site or carry through the plan.

> It happens in stages. First they discuss money issues like making a will. Next they want to know in detail what a community residence is like. Then, they want to know what community day programs are like. Then, for months, they will ask all three of these questions over and over again. Next, I'll try to get them used to separation as much as possible by using day programs or respite. Often parents will resist these attempts even though their disabled offsprings look forward to them.

> They are threatened that an "institution" rather than a service agency will take responsibility for care of their child. I explain to them that this is not true.
>
> I can tell that I've helped them by the way they cry and thank me. I give them a lot of information because their fear of the unknown is scary. They begin to like and trust me, and they know that I'll be the one who places their child and that I'll use my good judgment.
>
> I make the idea of the "State" seem more personal. Also, I provide services to them to make their life better in the mean time. So, they look forward to my visits and have a better dying process.

When we asked about the major obstacles to permanency planning faced by older parents we obtained responses like these:

> Too few openings in the community residences. If one of my parents died today, I don't know where my client would spend the night.
>
> Parents' ambivalence to the idea of permanency planning. They don't want to see it in their lifetime because it would be too painful.
>
> Interviews for placements are very stressful, it's like going for a job interview. It's competitive and parents know it.
>
> Parents overcoming their guilt associated with placing their child.
>
> Financial difficulties regarding paying for legal services to establish guardianship.
>
> Distrust that no one else can do what they have done. Parents still have the term "wards of the state" in their minds.
>
> Difficulty for parents to deal with agencies because of the energy required to deal with all the red tape.
>
> Their own feelings. It would be emotionally tormenting for them. And, they think of their own feelings ahead of their child's Some feel as long as they live they don't have to worry about the future, and someone else can deal with it after they die.
>
> Timing! When parent eventually reaches a decision, placement must be available and it often isn't. This feeds parents' ambivalence.

to provide help with future plans before crises occur, and also to keep aging families together for as long as possible by arranging needed services. They also remarked that parents were intimidated by their youth and professional status, and feared them as threats to separation from their offsprings. There was also frustration expressed over the mandate not to treat parents as clients, as well as over excessive caseloads prohibiting more interaction with older families. Indeed, the case managers desired to assist parents when age-related losses are first encountered, and to learn more about aging services. Several believed that there ought to exist case managers with geriatric expertise who would serve exclusively both aging developmentally disabled clients and their elderly caregivers. We also found that those case managers who were located in rural areas possessed a greater familiarity with the aging services network due to the high amount of informal contact they experienced with other helping professionals in less bureaucratic rural settings. Yet, they voiced more concerns about the paucity of MR/DD and aging services.

The findings have obvious implications for case management practice, as well as significant policy implications. However, it is also obvious that additional research is needed to confirm and extend the findings of this pioneering pilot study before any firm conclusions may be drawn.

References

Carswell, A.T., and Hartig, S.A. (1979). *Older Developmentally Disabled Persons: An investigation of Needs and Social Services*. Athens, GA: Georgia Retardation Center, Athens Unit, University of Georgia.

Cotton, P.D., Sison, G.F.P., and Starr, S. (1981). Comparing elderly mentally retarded and non-mentally retarded individuals: Who are they? What are their needs? *The Gerontologist, 21*, 359-365.

Dickerson, M., Hamilton, J.Huber, R.and Segal, R. (1979). The aged mentally retarded: The invisible client, a challenge to the community. In D.P. Sweeney and T.Y. Wilson (Eds.). *Double Jeopardy: The Plight of Aging and Aged Developmentally Disabled Persons in Mid-America.* Ann Arbor, MI: University of Michigan, Institute for the Study of Mental Retardation and Related Disabilities.

DiGiovanni, L. (1978). The elderly retarded: A little-known group. *The Gerontologist, 18*, 262-266.

Cold, M., Dobrof, R., and Torian, L. (1987a). *Parents of the Adult Developmentally Disabled*. Final report presented to the United Hospital Trust Fund.

Goodman, D.M. (1978). Parenting an adult mentally retarded offspring. *Smith College Studies in Social Work, 48*,209-234.

Heller, T., and Factor, A. (1987). Elderly parents caring for disabled adult offspring: Issues in permanency planning. Paper presented atthe 40th Annual Scientific Meeting of the Gerontological Society of America,

Janicki, M.P., and MacEachron, A.E. (1984). Residential, health and social service needs of elderly developmentally disabled persons. *The Gerontologist, 24*, 128-137.

Janicki, M.P., Otis, J.P., Puccio, P.S., Rettig, J.H., and Jacobson, J. (1985). Service needs among older developmentally disabled persons. In M.P. Janicki and H.M. Wisniewski (Eds.). *Aging and Developmental Disabilities: Issues and Approaches*. Baltimore, MD: Paul H. Brookes Publishing Co.

Janicki,M.P., and Wisniewski, H.M. (1985). *Aging and Developmentally Disabilities: Issues and Approaches*. Baltimore, MD: Paul H. Brookes Publishing Co.

Rose, T., and Janicki. M.P. (1986). Older developmentally disabled adults: A forgotten population. *Aging Network News, 3*, 102,19.

Selter, M.M., and Selter, G.B. (1985). The elderly mentally retarded: A group in need of service. *Journal of Gerontological Social Work, 8*, 99-119.

Smith, G.C. and Tobin, S.S. (1989). Permanency planning among older parents of adults with life-long disabilities. *Journal of Gerontological Social Work, 14*, 35-59.

Walz, T., Harper, D., and Wilson, J. (1986). The aging developmentally disabled person: A review. *The Gerontologist, 26*, 622-629.