DOCUMENT RESUME

ED 240 791	EC 161 864

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TITLE	Familial Social Support for Mildly Mentally Retarded Afro-Americans.
INSTITUTION	California Univ., Los Angeles. Mental Retardation Research Center.
SPONS AGENCY	National Inst. of Child Health and Human Development (NIH), Bethesda, Md.; National Inst. of Education (ED), Washington, DC.
PUB DATE	28 Apr 83
GRANT	HD-11944-93; NIE-G-80-0016
NOTE	16p.; Paper presented at the Annual Meeting of the Western Psychological Association (San Francisco, CA, April 27-30, 1983).
PUB TYPE	Speeches/Conference Papers (150) -- Reports - Research/Technical (143)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Adaptive Behavior (of Disabled); Adjustment (to Environment); Adults; Blacks; *Family Relationship; *Friendship; *Mild Mental Retardation; *Social Adjustment; Social Influences

ABSTRACT

The paper describes a study of the relationship between social support and well-being among 24 mildly mentally retarded Afro-American adults living with family, in group situations, or independently. Detailed observations, interviews, and questionnaires were used to collect data on the structural characteristics of the Ss' networks, use of ties as coping mechanisms, nature of transactions between study participants and ties, and the qualitative aspects of specific critical social ties. Results indicated reliance on kin ties to provide a variety of support and suggestded that degree of familial embeddedness was a primary determinant of the extent to which non-kin ties were developed. Successful adaptation to independent living and a more balanced network structure appeared to be related to the degree of responsibility given and contributions made in the home. The need for preparing retarded adults to form rewarding and useful non-kin ties were pointed out. (CL)

Familial Social Support for Mildly Mentally Retarded Afro-Americans

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Paper presented at the annual meeting of the
Western Psychological Association, San Francisco, California, April 28, 1983

Research supported in part by National Institute of Education grant no. NIE-G-80-0016 and National Institute of Child Health and Human Development grant no. HD-11944-93.

FAMILIAL SUPPORT FOR MILDLY MENTALLY RETARDED AFRO-AMERICANS

Our concern today is with special populations. For many of you, retardation is probably a rather remote concept. Oh yes, there's an increased concern about Down's Syndrome, now that so many of us professional women who delayed parenthood for career development are now opting for "middle aged maternity." But on the whole, we seldom think about retarded people; we never see them, we never talk with them. But this situation may be changing. Estimates provided by the National Institute of Child Health and Human Development indicate that in 1979, the number of retarded persons in the United States ranged from 2.2 to 6.6 million--with the difference depending on whether retardation is defined by clinical criteria or based on the normal distribution of intelligence tests. Approximately 75 to 90% of that number are classified as mildly retarded (i.e., have tested IQ scores ranging between 55 and 70) and are therefore fairly functional people. In the not too distant past, many such individuals were kept in public residential care institutions. However, due to the recent national deinstitutionalization movement, by 1980 only 139,000 retarded persons remained in such facilities--and those, of course, tended to be the more severely retarded cases. I cite these statistics to demonstrate that increasingly retarded persons live among us. They go to school with us, they work with us, they marry, they have children. Nevertheless, we don't know much about their experiences. How are they managing in this ever more intellectually demanding society? How are daily tasks taken care of? Where do they obtain support--of both an emotional and instrumental nature? If we know little about the community adaptation of mildly retarded persons generally, we know next to nothing about mildly retarded blacks. Are their experiences distinctive? How are particular features of Afro-American culture likely to affect the successful adaptation of retarded blacks?

The data that I will present today were collected as part of a large qualitative study of community adaptation by mildly mentally retarded adults directed by Dr. Robert Edgerton of the University of California, Los Angeles Mental Retardation Research Center and funded by the National Institute of Child Health and Human Development. For the past year, Dr. Claudia Mitchell- Kernan, an anthropologist, and I, a social psychologist, have been examining the relationship between social support and well-being among the Afro-American members of the sample. In the process, we have attempted to delineate the form and function of the primary social structures in which retarded Blacks are embedded. This afternoon, I will discuss our findings relative to familial support: what is the nature of the transactions that take place between retarded blacks and their kin; what factors influence their relationships with kin; how do retarded Blacks view such relationships? This paper is drawn substantially from a chapter prepared by Dr. Mitchell-Kernan and myself, currently in press, which will appear in the American Association on Mental Deficiency Monograph No. 6, edited by Dr. Edgerton and entitled Lives in process; Mildly mentally retarded adults in a large city (Mitchell-Kernan & Tucker, in press).

Cross-ethnic comparisons were not a specific objective of this work. We instead focused on current interpretations of Afro-American social organization and sought to determine how these analyses help us to understand the social lives of Blacks who are developmentally disabled. Studies dealing specifically with the Black family as well as more general studies of Afro-American communities offer strong grounds on which to expect that the kin group is likely to be a source of especially significant ties for Black Americans (Billingsley, 1968; Hill, 1971; MacAdoo, 1978; Manns, 1981; Martin & Martin, 1978, Stack, 1974).

Both the anthropological and social support literature point to the importance of social ties in general (both familial and non-kin) in contributing to the psychological and physical well-being of the individual (cf. Bott, 1957; Cobb, 1974; House, 1980). Marital status, social disorganization, acculturation and intimacy, among other variables, have been shown to be associated with various indicators of distress, including cardio-vascular disease, mental health, and death (Cassell, 1976; Gurin, Veroff, & Feld, 1960; Lowenthal & Haven, 1968; Moriyama, Krueger, & Stamler, 1971; Srole, Langner, Michael, Opler & Rennie, 1962). Typically, individuals lacking in critical areas of support show greater impairment (e.g., have more heart disease, are more likely to be depressed, and are more likely to die) than those with the relevant ties. Other studies have stressed the buffering or mediation properties of social support. That is, under conditions of job stress, unemployment, economic crisis, loss, bereavement, illness, and a host of other undesirable circumstances, it appears that persons who have supportive relationships exhibit less psychological and physical distress (Caplan, 1979; House, 1980). Scientists have been a little less successful in delineating the particular features of human interaction that will lead to positive mental and physical outcomes; though there is evidence that emotional support (particular in the form of a confidant) is an especially important factor (Lowenthal & Haven, 1968). In addition, having someone to help you manage necessary life tasks is seen as a critical feature of support in distressed populations (Tucker, 1982).

Methodology

Sample

The study sample was a select subcomponent of the larger sample of approximately 50 mildly mentally retarded adults who comprised the Afro-American component of the overall research program on adaptive behavior (Edgerton, 1978; Kogel & Edgerton, 1982). Our intensive sample was chosen to represent a range of representative living circumstances and individual characteristics. The sample was limited in number in order to permit the conduct of a lengthy in-depth exploratory study. The participants consisted of 24 mildly mentally retarded Afro-American adults, 12 females and 12 males, who ranged between the ages of 21 and 37 at the time the study began. Mean age was 26.5 years for women and 26.8 years for men, with IQ scores ranging from 55 to 70. Both sexes were about evenly divided between three living arrangements: (1) with the family of origin, consisting usually of a mother or mother-figure, and often a father and siblings, (2) in a board-and-care facility, and (3) in an independent living situation—i.e., a conventional apartment, an apartment complex for the developmentally disabled (which included a full-time live-in counselor), or various boarding arrangements. Nearly all sample members, as well as their families of origin, were of low socio-economic status.

Procedure

The methods of procedure employed in this study represented a merging of quite disparate theoretical and empirical orientations--cultural anthropology and social psychology--and reflect an attempt to integrate qualitative and quantitative research styles. Nearly two years of qualitative data collection, consisting of detailed monthly observations and loosely structured interviews with the participants and selected significant others, was followed by a five-month period of additional observations and the administration of highly structured questionnaires, including some standardized instrumentation. Information gathered from a search of the fieldnotes and through questionnaire responses included: 1) the structural characteristics of the study participants' effective networks (e.g., symmetry, dispersion, dominant source, existence of intimate and critical ties), 2) whether and how ties were used as coping mechanisms (i.e., for everyday problem solving, critical incidents, child rearing), 3) the nature of transactions between study participants and ties, and 4) the qualitative (or affective) aspects of specific critical social ties.

A major concern of qualitative researchers is the proper context for interpretation of results. Some criticize such research for a lack of generalizeability, since sample sizes are necessarily limited. Our goal, however, is to gain in depth knowledge about the lives of certain mentally retarded individuals, living in varied circumstances (what Edgerton, 1967, has called the "texture and emotion of life")--with the hope that this information will help us to understand some aspects of the lives of similar others. For example, determining through extensive observations what environmental factors enable a given retarded person to function successfully in independent living, may lead to more successful adaptation by others.

Results

A basic description of our sample members is obtained through examination of the key social structural variables (i.e., the quantitative objective dimensions). These variables suggest that on the surface, the retarded Black adults in our sample were not particularly distinctive. While they were less likely to be married than one generally would expect for this age group, exactly half were involved in romantic relationships during most of the study period (see Table 1). In addition, one-third of the women and one-fourth of the men had children. They had friends, with all participants naming at least one best friend. Somewhat more distinctive is their tendency to have focused rather than dispersed networks (that is, most drew upon networks that are primarily from a single source).

One very striking result of the treatment of the structural or demographic data is the strong similarity between males and females (see Table 1). The two sexes were equally likely to be either married or involved in an apparently romantic relationship. They were equally likely to have children, and to have friends and best friends. The distribution of kin vs. non-kin ties as the dominant source of networks was not substantially different, with women slightly more likely than men to be family focused (i.e., 9 of the 12 women primarily cited kin as network members, while 7 of the 12 men were family centered).

Differences were apparent, however, in the number of children had by parents (2.5 average for women and 1.3 for men) and in the greater tendency for men to be the sole occupant of a dwelling unit. No women had ever lived alone, while at least four of the men had at one time lived alone. These two results taken together represent an interesting parallel. Retarded women are undoubtedly considered to be too vulnerable (as opposed to incompetent) to live alone. Sexuality is a major factor in the reluctance of family members and institutional officials to allow retarded women that level of independence (i.e., a fear that men will take advantage of them sexually). This fear was explicitly expressed by family members of three female study participants and arose as a specific complaint of two additional women in the sample. Family efforts to discourage relations felt to be sexually exploitative did not in general seem to meet with success. The fact that women sample members with children tended to have multiple births (suggesting a lack of control over their reproductive capacity) may help fuel such beliefs.

These selected structural characteristics of the social networks of the study participants, however, represent only one perspective on their social lives. Simply knowing certain demographic characteristics and how many persons of what type interact with our participants proved insufficient to understand the social environments of retarded Blacks. More detailed examination of relationships between variables and the qualitative indicators suggest that the picture is far more complex.

The Role of Kinship in Afro-American Social Organization

The importance of kin ties as sources of support for both men and women in this study may be interpreted in relation to what is known about the role of kinship among Black Americans generally, as well as in light of the specific handicaps of sample members imposed by their disability.

Recent literature on the Black family (Billingsley, 1968; MacAdoo, 1978) places the study of family and family life within the context of larger kinship systems. In her work with poor Blacks, anthropologist Carol Stack (1980) has demonstrated that the extended family network performs many of the functions commonly associated with nuclear families, despite the fact that low-income Afro-American households are disproportionately female headed. In her words, "The material and cultural support needed to absorb, sustain, and socialize community members... is provided by networks of cooperating kinsmen" (p. 118). Stack also observed that these domestic networks do not have an obvious nucleus, nor are they characterized by defined boundaries. The focus, however, is often a cluster of adult females, which is thought to be related the importance of domestic networks in child care.

Spheres of kinship support

We have, in our data, found considerable confirmation of recent findings documenting the importance of networks of cooperating kin in domestic organization. With few exceptions, kinship relations constitute an important source of instrumental and emotional support for our sample members. While the level of familial involvement may vary, most provide a range of services perhaps most easily discussed under the broad headings of: life management; housekeeping; childcare; and guidance and empathy.

Life management. Many participants have difficulty negotiating environments and handling tasks which require literacy and/or arithmetic skills. This includes many of the ordinary requirements of everyday life, such as check cashing, completing a job application, ordering food in a restaurant, reading letters, obtaining a driving license, or negotiating with institutional officials and social service agents. Overall, sample members reported reliance on relatives more often than non-kin to take care of their instrumental needs. No basic gender distinctions were apparent.

The most sensitive area of familial involvement in life management is certainly financial. Of the 24 sample members, 21 indicated that they would go to a family member if they needed money. With respect to fiscal management, while most of our study participants receive some form of government assistance, either SSI (Social Security Insurance) or Aid For Dependent Children (AFDC) allotments, only a very few participants received and cashed the checks themselves. While exploitation may have existed in rare instances and occasional conflicts were apparent, overall, the assistance seemed to be genuine and responsibly motivated.

Housekeeping. Not surprisingly, women were less often the recipients of housekeeping support from family than were men. Quite to the contrary, female sample members were more likely to perform a number of basic housekeeping chores, including cooking, cleaning, washing, and ironing. This was true whether participants lived with their families of origin, in a board-and-care facility, or independently. Nevertheless, family members were regularly involved in seeing that the basic housekeeping needs of sample members were met.

Childcare. The care and socialization of the children of sample members was in every case a primary responsibility of family members. At last contact, all but one of the 14 children of our participants were living in a household that contained a grandparent (although this had not always been the case for a number of them, and seemed to be the consequence of divorce, marital disputes, and housing problems). This situation was observed irrespective of gender, as men with children were just as embedded in the familial support structure as were women. Families consistently provided a range of childrearing services, including childcare instructions for the new parents, babysitting, feeding, education, and in some cases, the actual assumption of all childcare responsibilities. Examples of this latter extreme form of support ranged from the temporary practice of keeping the newborn baby in someone else's room (such as a sister or the new mother's parent) to physically removing the child from the custody of parents.

These findings are consistent with Robert Hill's (Hill, 1971; Hill & Shackleford, 1975) assessments of the practice of informal adoption, considered to be a distinctive feature of Afro-American extended family arrangements. Hill has observed that the taking in of dependent children is most often performed by grandmothers (as we observe in our own data) and due to a range of factors, including parental incapacitation, marital problems among parents, parental immaturity, and also a desire on the part of the adoptor for companionship. Patterns such as these have been traced to West African family structure by Melville Herskovits (1958) and Wade Nobles (1974), among others. In the case of mentally retarded parents, the grandparents have real doubts about the caretaking competence of their children, and may in essence be adopting the grandchildren, despite (as in our sample) the parents' physical presence.

Guidance and empathy. While family members appeared to be more significantly involved in the instrumental areas of support, some participants reported reliance on relatives for other more affective needs. This includes the discussion of personal problems, feelings, the need for companionship and general emotional support. One sample member listed her parents as her best friends. Siblings and in-laws were also occasionally mentioned as friends.

Structural Determinants of Network Linkages

Our results on the whole suggest that network linkages were in large part determined by a combination of two structural variables--gender and living situation. While not surprising in view of the recent findings of Stack and others, we found that women's ties to family were much stronger and more exclusive than those of males, leading to relatively little dependence on non-kin for either emotional or practical needs, when family members were proximate. Even after leaving home, family ties were still heavily utilized by many of the women, due in part to the fact that married women with children remained very dependent on kin for child care support.

On the other hand, male contact with and utilization of family ties decreased dramatically with attainment of independent living status--not always to the satisfaction of the study participant. Apparently families are considerably more comfortable about loosening their ties with retarded males, probably due largely to the perceived vulnerability of the women but perhaps also because males are expected to make it on their own. Two examples illustrate familial concern with male independence:

> Fred, who shares an independent living apartment with another sample member, lived in a board-and-care facility for two years prior to moving to his present residence. Although Fred is quite open about his preference to live at home, and has voiced the complaint that his mother "sent him away," she is quite firm in her insistence that "he is old enough to take care of himself." Fred has also expressed a desire to move in with his brother. This, too, is a wish which seems likely to remained unfulfilled.
>
> Mitchell was diagnosed as hydrocephalic shortly after birth and also has spina bifida with cerebral palsy. At the time data collection began, Mitchell had been living in a board and care facility for some time. His separation from his family seems to have been motivated initially by his mother's inability to find a suitable school for him in the town where she was then living. Mitchell sees his family fairly regularly at family occasions and tends to have regular telephone contact with his mother to whom he seems closest. His mother, however, clearly believes in his potential for independence and for the most part allows him to live his life quite free of parental interference, although she occasionally helps him out financially. Indeed, so much does Mitchell's mother expect considerable self reliance that when his subsequent marriage goes sour, she comments, "He just had to have this girl. He didn't want to listen to me or anyone. Then after he got into it, then he come crying on my shoulder and I told him I didn't want to hear it."

It is clear from the observations that the functions of kin ties are determined in significant ways by structural variables, primarily those of situational context and gender. The living arrangement of the participant appears to strongly influence the type of relationships that the retarded person enters into (see Table 2). (While we are unable to make to determinations of causality from the data, the alternative proposition is highly implausible.) Sample members who lived at home were thoroughly embedded in familial dominated networks. Many had no contact with non-relatives. Once away from the family of origin, the nature of the distinctions between socialized roles for women vs. those of men became paramount. Women in both board-and-care facilities and those living independently remained in greater contact with and more dependent on their families than did men in the same living arrangements. Evidence from our analyses of the structure of non-kin relations among the sample members sheds further light on this observation. While this presentation will not cover those findings, it is clear that familial ties are reinforced by the constraints on the development of non-kin ties by retarded persons: e.g., due to limitations of resources, skills, and mobility, retarded persons often have little to offer potential associates in exchange for benefits received; retarded persons have few activity fields (such as the work setting) from which to draw new relationships.

Attitudinal Dimensions of Familial Support

We felt that a more "objective" assessment of support from family and non-kin would be obtained through questioning and observations of specific instances or acts of support. That is, asking for the specific ways that a given individual is helpful was thought to be a more accurate assessment of actual support received that merely asking whether or not a given associate is helpful. Nevertheless, such global perceptions are indicative of the perceived quality of relationships. For example, while persons X and Y may both occasionally provide me with transportation, it does not necessarily follow that my overall satisfaction with those relationships are equivalent. I may not like one very much at all, but I may have no viable alternative to accepting the ride. These kinds of conflicts are particularly likely to pervade associations between retarded persons and others, since intellectual disabilities tend to foster dependence.

In an attempt to explore this subjective dimension of familial relationships, we asked each of our participants if he or she was "satisfied with your family life and the things you do with your family;" followed by "why" or "why not." Most participants professed to be satisfied with family life: 15 (62.5%) said yes, 7 (29,2%) said no, and two others (8.3%) provided responses that fell somewhere between yes and no. While these responses evidence a high degree of familial satisfaction, contrasts with a similar assessment of satisfaction with friendships are revealing: 22 of the 24 participants (91.7%) responded affirmatively. Clearly then, despite the fact that most of our respondents are dependent on their families for primary support, those relationships are not, in their view, entirely satisfying. Examination of the reasons behind their responses (see Table 3) revealed that the most prominant source of satisfaction was the amount and type of contact enjoyed between family members and participants. One respondent who lives in an independent living apartment building expressed content because his family "lets me come and visit them.." Another offered, "because they're there" and "we go places like Bakersfield and Disneyland." Other categories cited as sources of satisfaction included the provision of assistance to the family by the participant (e.g., "I like to help my mother"); the provision of assistance by the family (e.g., "because they help me a lot"); and lack of conflict among family members (e.g., "my family gets along fine"). Dissatisfaction seemed to stem primarily from family conflict (e.g., "they don't trust each other;" "my family is not as close as they need to be, every morning someone wakes up and wants to argue"). Other sources included the way family members treated the participants (e.g., "they still treat me like a baby") and the lack of contact with family (e.g., " I'd like them to call, come see me, and be concerned about how I'm doing").

Taken as a whole, these attitudinal results demonstrate the developmental conflicts experienced by retarded adults. When families push them toward independence, by placing them out of the home and decreasing the level of contact between them, the behavior is often viewed by the participant as disinterest and rejection. On the other hand, most express the desire to be treated like adults; appreciate the ability to help others; but are cognizant of their tremendous needs for assistance. It is an adolescent-like conflict that is never ending for the retarded. An it is a conflict of which they are very much aware.

Discussion and Conclusions

The activation of kin ties to provide a variety of types of support seems very much a way of life for the majority of our study participants. The cultural roots of such kinship support is evident in the fact that the parents of sample members also receive and expect help from their relatives. While our fieldnotes do not provide complete residential histories for all sample members, a number of them have been in the primary care of relatives, other than their parents, during their childhoods for extended periods. Aunts, uncles, inlaws, and cousins, in addition to lineal relatives, provide some support as well. And while kin relations are not uniformly smooth, as would be expected in any group of people, relatives not only seem willing to be involved in the lives of members of the sample, some seem to derive significant satisfaction from the nurturance they offer.

The protective web of kinship is not problem free, however. Several sample members came from situations with weak levels of familial integration and some characterized by patterns of stressful interaction. It may also be the case, that heavy kin embeddedness may serve to accentuate the sense of dependency of some individuals, particularly those who have never successfully taken the step toward independence typically associated with adulthood--moving away from the family home.

Our data suggest that degree of familial embeddedness is a primary determinant of the extent to which our sample members were able to develop non-kin ties, of any nature. Such embeddedness, in turn, seems to be largely a function of residence. Most appeared to be entrenched in a greatly extended period of adolescence-- continually testing and challenging parental authority in order to achieve some measure of independence but cognizant of their tremendous needs for familial support (would anyone else take care of them?). Those who were more fully enmeshed in non-kin (or mixed) networks were usually those who experienced familial loss through parental death, incapacitation, or abandonment. Others who left the family home under less traumatic circumstances, generally under the protection of independent living programs, attempted to maintain strong family ties.

Successful adaptation to independent living and a more balanced network structure also seemed related to the degree of responsibility the sample member was given in the home. It is easy to think of retarded people only as recipients of aid. Our observations demonstrate, however, that many of our participants made substantial contributions to their households as well as to others. Among other tasks, they regularly engaged in child-care, performed major housekeeping functions (including regular cooking of meals), one did automobile maintenance, and many made very significant financial contributions to those around them. In fact, the current extremely depressed economic climate in low-income minority communities may even make the SSI benefits a critical component of the family's economy. A number of other sample members were competitively employed and from both a psychological and practical perspective became significant sources of family support. Recall too that when queried about the source of satisfaction with family life, several participants expressed particular content with their roles as contributors of assistance to the family.

The social network then provides contact with a range of people who not only provide assistance, but who also need help. We would suggest that it is in providing this sort of help that significant training toward responsible adult roles takes place. One's self-esteem is clearly bolstered by the ability to provide assistance to others.

The variety of adaptations evident among sample members suggests that caution should be observed in specifying what factors ultimately determine whether an individual achieves some semblance of a "normal" adult lifestyle--living independently, working, and taking care of her or his basic needs. While it is unclear whether the individuals who achieved such stature in our sample were inherently more capable or were exposed to more adaptive socialization experiences, our research as a whole suggest that friendship linkages seem central to successful adaptation (Mitchell-Kernan & Tucker, in press). Given the fact that more adult mentally retarded persons are being forced to "make it on their own" (due to deinstitutionalization) and (as we have observed in this sample) their aging parents are either dying or becoming less functional, this latter question is critical. In an age of dwindling social resources as well as ideological change, strategies to better prepare retarded adults to form affectively rewarding and socially useful non-kin ties, which utilize existing family ties in the process, must be developed.

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Table 1

Demographic Characteristics of Sample

	Females (n=12)	Males (n=12)
Age		
Mean age	26.5	26.8
Age range	21 - 37	22 - 32
Marital Status/Romantic Involvement		
Married, together	1 (N)[1]	1 (R)
Married, separated	1 (R)	1 (R)
Divorced, uninvolved	1	0
Has romantic tie	4 (3R,1N)	4 (2R,2?)
No involvement	5	6
Parental Status		
Has children -average number	4 (2.5)	3 (1.3)
Does not have children	8	9
Primary Living Arrangements During Last Six Months of Study		
With family of origin	6	4
Board & Care facility or in boarding arrangement	3	2
Independent living apartment building	0	3
In own apartment with spouse, roommate or alone	3	3

[1] N=nonretarded, R=retarded

Table 2

Relationship Between Living Arrangement, Gender and Dominant Network Source

Females (n=12)

Living Arrangement	Dominant Network Source Family	Non-kin	Mixed
Family	6	0	0
Boarding	2	0	1
Independent	1	1	1

Males (n=12)

Living Arrangement	Dominant Network Source Family	Non-kin	Mixed
Family	4	0	0
Boarding	2	0	0
Independent	1	4	1

Table 3

Reasons for Satisfaction and Dissatisfaction with Family Life

	Satisfied with Family	
Reasons	Yes	No
Family conflict/lack of conflict	2	3
Contact/lack of contact	4	2
Provision/lack of provision of assistance by family	2	1
Provision/lack of provision of assistance to family by participant	3	0
Treatment of participant by family	0	2
General--e.g.,"everything is fine"	3	0
No response	1	0

Note: n = 24; more than one response given by several respondents.