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Families and the Handicapped in Northern Jordan*

BY: WILLIAM C. YOUNG**

The image of the Arab family that is frequently presented in the ethnographic literature (cf. Fakhouri, 1984; Geertz, 1979:333) is that of a large household containing many nuclear families whose members interact frequently and intensively and share the burdens of daily life. Such an image may not be wrong so much as it is overgeneralized. When we perceive Arab families through this image we tend to recall the interests and opportunities – wedding celebrations, religious holidays (cf. Antoun, 1968), defense of family honor (cf. Antoun, 1972) – which bring family members together and forget the issues – politics and inheritance (cf. Shunnaq's article in this issue) – which can drive them apart. One such divisive factor can be misfortune; more specifically, the development of immobilizing handicaps in a family's children. One would expect that handicaps can generate stress and division in Arab families just as they do in families in other parts of the world.

Studies of families with handicapped children outside of the Arab world have confirmed the common-sense assumption that such families experience greater stress than families whose children are not handicapped (McKaig et al., 1986; Murphy 1982). Many such studies (ex. Covert, 1988; Singer and Irvin, 1989) are designed to identify the policy implications of home care for the handicapped and make recommendations about how the families of the handicapped should be supported by public agencies. Almost no research has been done on how - or, indeed, whether - Arab families cope with childhood handicaps.

Another problem with these studies is that they tend to assume that the burden of caring

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for a handicapped child - and the stress that this burden generates - is borne by the family as a whole, that is, as a unit undifferentiated by age and gender. As Traustadottir puts it, most of the literature on care for the handicapped treats the family "as the smallest unit of analysis..." and "routinely.. ignore gender as a socially important variable, thereby hiding the differences between mothers and fathers within the family..." (Traustadottir 1991:212). More recent studies in England (GlennDinning, 1993; Parker, 1990) and the United States (Marcenko and Meyers, 1991:187) demonstrate that mothers take on most of the day-to-day care of handicapped children and get very little practical support from their husbands. These studies show that, in these English-speaking societies at any rate, it is mothers, not "families," who actually do the work. Whether this is true of Arab societies has hardly been explored.

Some other important questions are: how much does social support reduce the burden on the mothers and families of the handicapped, and what kinds of support are needed? Again, studies in England and the United States (Bresford, 1994; Gallagher *et al.*, 1983; Havermans and Eiser, 1991) make it clear that mothers who have the support of their spouses, relatives, and neighbors cope with stress more successfully and can better care for the child. "Social support" in this context can mean many things. In the literature on the handicapped child, however, it is generally defined as either instrumental, informational or emotional. Instrumental support "refers to concrete assistance such as labor or money..." while informational support "consists of advice or information." Emotional support involves expressing concern and listening to the primary caretaker (Marcenko and Meyers, 1991:186).

Who are a mother's main sources of support? As mentioned above, English and American mothers of handicapped children get little instrumental support from anyone. Fathers of handicapped children generally provide little instrumental support for mothers of such children, and divorced or separated fathers offer almost none. Even under the best of circumstances (ex. when the father remains in the home and does not seek a divorce after the child becomes handicapped) the quantity of instrumental support provided by the father is limited (Marcenko and Meyers, 1991:189) Fathers do provide emotional support, however, and women whose husbands provided little instrumental support expressed satisfaction with spouses who supported them emotionally. English and American mothers who believed that their husbands were willing to help when necessary felt that they were highly supportive, and this perception enhanced their ability to cope (Barbarin *et al.*, 1985; Friedrich, 1979; GlennDinning 1993; Marcenko and Meyers, 1991:189).

The main other source of support for the families and mothers of handicapped children in the United States is the mother's own mother (Gallagher, Beckman and Cross, 1983), although the husband's parents also contribute. Outside of this narrow circle of kin there are almost no other people to turn to. Siblings, friends, and neighbors tend to distance themselves from a family with a handicapped child, since they are afraid that whatever assistance they provide

will never be reciprocated (Cant, 1992).

Is this picture of isolation accurate for all American and English parents of handicapped children? Probably not. It seems likely that a family's coping strategies and support networks vary according to its class and culture. Anthropological fieldwork among poor black families in the American Midwest demonstrates that black cultural traditions and the structural constraints of poverty generate a very different pattern of child care in which children are nurtured by a range of kin that is much broader than the nuclear family or the single-family household (Stack, 1974). Presumably parents of handicapped children who live in poor black communities receive more support from their communities than middle class white parents do, although no research has been published that would confirm this.

In general, the question of how support for handicapped children and their families varies according to culture and class has hardly been addressed by social science research. Traustadottir has, at least, raised the issue of how culture is related to the social allocation of child-care tasks. She points out the semantic link in English between "caring for" (i.e. feeding, bathing, dressing) and "caring about" (i.e. feeling concern or love for) a child, and suggests that this semantic link puts pressure on the mothers of handicapped children not to ask for assistance in child care. She argues that English-speaking mothers who admit that they need help can be accused of having diminished affection for their children. English semantic patterns thus serve as a cultural constraint and help explain why mothers do not petition their families for assistance more aggressively (Traustadottir, 1991: 217-18). In fact this argument is not simply about semantic equivalents of lexical terms. It implies a match between feeling, action, and gender-appropriate roles, according to which both parents are expected to "care about" their children but express this feeling in different ways. For mothers, "caring about" translates into active "caring for," while for fathers "caring about" means "providing for." Thus the traditional culture of white, middle-class, English-speaking Americans thus promotes a separation of roles as well as a semantic link between "caring for" and "caring about."

Although Traustadottir's argument is logically plausible it needs cross-cultural testing to be confirmed. To evaluate Traustadottir's semantic argument empirically, child care in societies which speak non-European languages could be studied. In Arabic-speaking societies, for instance, no close semantic link between "caring for" and "caring about" would be expected, since the Arabic equivalents for "child care" (*ri'āyat al - ṭifl* or *ināyat al - ṭifl*) are lexically and semantically distinct from "being concerned about a child" (*yahtamm bi al - ṭifl*). My field experience in Arabic speaking societies (in Egypt, Sudan, and Jordan) indicates that both parents are expected to "care about" their children. Whether "caring for" is defined as primarily the duty of the mother in Arabic-speaking societies, like in middle-class America, is an empirical question.

The present study, therefore, attempts to expand our knowledge of how families with

handicapped children cope by looking at families in a non-Western cultural and socio-economic setting: northern Jordan. It describes the impact of movement handicaps on families in Kufrinja, a small town near the Jordan Valley. The paper concentrates on the strategies families adopt for dealing with movement handicaps, the ways in which handicaps affect the patterns of reciprocity among family members, the impact of handicapped family members on the family's marriage strategies, and the transfer of family responsibilities from one generation to the next. In passing it points out some of the difficulties involved in carrying out research on people with movement handicaps and identifies some of the short-comings of public policies regarding the handicapped in Jordan. It is based on three month's exploratory fieldwork in Kufrinja in 1992, during which I lived in the town and interviewed handicapped children and their families, and on data collected during the following twelve months by means of frequent visits.

The Setting: Walking and Working in Kufrinja

Kufrinja, a large town with about 30,000 inhabitants, is situated on the southern side of Wadi Kufrinja, a narrow valley which descends from 'Ajlun (a city 6 km to the northeast) and continues down to the Jordan Valley (10 km to the west). A mountain which overlooks Kufrinja from the southeast rises to a height of 895 meters above sea level, and a mountainous ridge 2 km to the north varies in elevation from 840 meters to 980 meters above sea level. Kufrinja itself lies between these two elevated geographical features at about 500 meters above sea level.

The town's main streets run east to west, parallel to Wadi Kufrinja; its other streets, running north to south, are so steep that walking up them is difficult. Children and young men often bypass the paved streets when they go to the center of town; they scramble up and down the steep hillsides. Adolescent girls, whose comportment is expected to be more demure, do not take these shortcuts. They walk to school in small groups early each morning, keeping to the winding roads. They are seen less frequently later in the day and appear even less often at night, when the streets of the town become a male preserve, filled with strolling groups of boys and men.

Public transportation is available in Kufrinja. Buses operate from 6:00 AM to 6:00 PM and are mainly used as transport to neighboring towns, although some riders occasionally take the bus across town, since the fare is small (6 piasters). Taxis, more expensive, are used for travel to nearby villages that have no bus service; they also serve as emergency transportation at night. The wealthier residents, especially merchants, have trucks for hauling merchandise or agricultural produce, and not a few have cars. Poorer residents sometimes ride the horses or tractors that they use when cultivating their fields. The very poor ride buses or walk.

Many people in Kufrinja still work in agriculture, cultivating olives, grapes wheat, and

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1. Sometimes entire families *yu'azzibu*, "move into tents and live outside" to graze sheep or harvest olives. The families move down into the valley or up onto the hilltops, where they sleep and eat in tents and work in the fields. Women cook, process harvested olives, and care for children in the tents while the men and boys range farther afield.

barley near the valley and on the surrounding hillsides. Others herd sheep and goats, ranging as far as the Jordan Valley. Although men and boys do most of this work, during a few months each year women and children also participate.¹ Almost everyone has had some experience in herding or agriculture; even those who have salaried work take part in the olive harvest, for example. Because the traditional jobs require men to be mobile, paralysis is viewed as especially tragic for a young man. But agriculture and pastoralism no longer are the main sources of income for the majority of the townspeople. Most work in government jobs or operate shops, bakeries, and other small businesses. There are few steady jobs for the handicapped. One paraplegic man works for his father, selling vegetables, and another who is less severely handicapped helps his father cultivate the family fields. Small loans are supposedly available from the government which can enable a handicapped person to open up a shop or a business, but I know of no one who has taken advantage of them.

Methodology

I began research in Kufrinja by asking informants to identify “handicapped people” (*al-mu’awwaqin*). It became clear that they defined this category very broadly; they included cases of mental retardation, epilepsy, blindness, and deafness as well as movement handicaps. I also contacted a local general practitioner who had recorded many more names of “the handicapped.”

I assumed that the local perceptions of and definitions of “the handicapped” would affect family strategies. But I did not want to be guided entirely by local ideas about what a “handicap” (*i’āqa*) is. Since I wanted to see how variables such as family size and family income affect the ways in which families deal with handicaps, I thought it best to make the character and severity of the handicap a constant in my study and concentrate on a single kind of handicap. Hence I asked my informants to single out “paralyzed people” (*al-mashlūlīn*), stressing that I was mainly interested in cases of “movement handicap” (*i’āqa ḥarakiyya*). They responded with 24 names.

This was by no means a complete list. Most informants knew only of cases from within their own descent groups (*‘ashāyir*) and were very poorly informed about “paralyzed people” who were not close relatives. Since I did not have time to interview informants from each of the town’s 20 descent groups, I could not compile a comprehensive list. I decided to collect basic information about these 24 cases and carry out more lengthy interviews with a smaller number of families. To select this smaller sample, however, I could not rely on native categories and statements. Although the class *al-mashlūlīn* might be homogeneous from the local point of view, I had to characterize each case with more precision, in terms of three dimensions: severe vs. mild, simple vs. multiple, chronic vs. progressive.

After making these discriminations, I first excluded 2 cases of movement handicaps which were not severe enough to effect the family. I wanted to study only those people who could

not leave their homes without crutches or assistance. Second, some cases (9) involved other kinds of neurological disfunction (seizures, loss of balance, mental retardation) as well as paralysis. Since I assumed that caring for people with multiple handicaps might involve different problems than caring for those with simple movement handicaps, I excluded multiple handicap cases.

Another complication was that some crippling illnesses (ex. multiple sclerosis) are progressive while others may simply persist without change (ex. polio). The effects of a progressive illness on the family are quite different from the effects of a chronic or stable handicap. To illustrate: 4 cases of disability in children apparently are hereditary and usually result in the death of the child by the age of eight. In such progressive cases the parents simply wait for their children to die. In chronic cases, however, they must care for their child for decades. I decided to focus on chronic cases, since these create greater burdens for the family.

I had to make all of these distinctions (severe vs. mild, simple vs. multiple, chronic vs. progressive) without reference to a medical diagnosis, since very few people have been given detailed explanations of their handicaps by doctors. Without a doctor's help I cannot say exactly how many cases of severe, simple, chronic paralysis there are in Kufrinja. Rather than present an arbitrary figure I have preferred to concentrate on 13 people who meet these criteria fairly well. They have relatively severe to very severe movement handicaps which are not complicated by other disabilities. Their handicaps do not appear to be rapidly progressive, since they have been disabled for many years without change. They can be expected to outlive their parents. These 13 people are not a random sample nor do they represent any precise percentage of the town's handicapped. Their cases are simply good illustrations of the problems faced by the family.

Basic Data about the Wider Sample

The 24 case of handicapped people contacted vary according to age, sex, and marital status, as indicated in Table 1:

Table 1
Handicapped People Contacted in Kufrinja,
Sorted by Age, Sex, and Marital Status

	Single Age < 25	Married, Age < 25	Single, Age > 25	Married, Age > 25	Total
Males	9	0	5	1	15
Females	7	0	2	0	9

Note that only one of the handicapped people, a man, is married. This man was married many years before becoming handicapped. Now 45 years old, he was paralyzed in January, 1989, and completely lost the use of his legs. He has 11 children and shares a small, two-room

house with his wife and 10 unmarried children. His married son and daughter-in-law live in an adjoining house, right next to his. His case is exceptional, in that he has a wife and many children who care for him.

The sample also varies with regard to the size and structure of the handicapped person's household. The 24 cases are distributed among 18 households. Two households have two handicapped members, and two households have three members who are handicapped; most, however, have only one. There are 187 people living in these 18 households, which means that the average household size is about 10.4. Despite the large size of the households, most (12) are nuclear in form; that is, they consist of one or both parents and their children. (One household that consists of only a brother and sister, both handicapped, has been counted as a nuclear household.)

Some of the "non-nuclear" households are rather difficult to classify. They are culturally anomalous, as well, because they include adults who would be married if they were not handicapped. In one case, for example, a handicapped man who is 35 years old lives with his married elder brother, but his elderly parents live in the same house, as well. All are supported financially by the elder brother, so from an economic perspective this is a "multiple-family household"² that includes two families: the elder son and his wife and the handicapped son and his parents. But the handicapped man, the elderly parents, the younger married couple, and the couple's children, all have separate rooms where they sleep. One could argue that their dwelling is spatially divided into two or three separate "families." If we count the handicapped man as a member of his parents' family and the other married couple and their dependent children as another, then their house contains two families. It seems odd, however, to place the handicapped man in the "family" of his parents since he neither depends on them economically nor shares their living space. If he were married, of course, he and his wife would constitute a third family in a "multiple-family household."

Although these findings are not statistically significant, due to the small, non-random sample, they bring out an important point: most handicapped people in Kufrinja probably do not live in "extended families" or "multiple-family households." This means that the burden of care falls mainly on the parents and, especially, the mother. When I asked the handicapped living in nuclear family households (17 of the 24 cases) who they spent most time with, all but one of them said, "My mother." (The one exception proves the rule: the informant, whose mother had died when he was an infant, said that his mother's mother took care of him when he was young; he has lived in her house for 16 years, ever since his mother died. Thus his case is an extension of the principle that mothers care for the handicapped.) Even when the handicapped person lives in a multiple-family household, the care he or she receives is most often provided mainly by his or her mother (illustrated later in Case Two).

2. See P. Laslett and R. Wall (1972) for a detailed typology of households.

The burden on the mother seems to lighten somewhat with time if she has daughters who can help her. Some handicapped children seem to depend equally on their mothers and their co-resident sisters. But this re-distribution of work does not always last. When a handicapped person's sisters marry and move out, the burden of care reverts to his mother, at a stage in her life when she is less able to bear it physically than before.

It would be good to have a precise estimate of the magnitude of this burden. Unfortunately there are conceptual and practical difficulties involved in measuring it. The main conceptual problem revolves around defining the maximum and minimum amount of work needed to provide good care for people with movement handicaps. The minimum effort is fairly easy to determine; if the patient suffers from pressure sores, frequent bladder infections, and so forth, these are signs of serious neglect. But it is harder to define a reasonable maximum. Just how much should be done to maintain the patient in good health and promote rehabilitation? Can the patient's family be expected to make heroic efforts at rehabilitating him when the potential improvements may be slight? Even if we can characterize a disability exactly (for example, paraplegia caused by damage to the second and third lumbar vertebrae), we cannot prescribe a particular amount of care for all such cases, because they are always influenced by other factors (such as age, other illnesses or chronic problems and so on). Yet without some measure of the amount of work that can reasonably be expected from the family, we cannot judge how well the family is accomplishing this task. Casual observations tell us little. If we notice during a visit that the handicapped person is simply lying on a mattress, unattended, it is easy to conclude the family is neglecting him. A legitimate evaluation must take into account the total amount of time spent in caring for the handicapped and the total amount of effort that they both need and can reasonably expect.

Another conceptual difficulty is that most cases of movement handicaps are not completely comparable. Cases vary along at least three continua (severe vs. mild, simple vs. multiple, chronic vs. progressive). Certainly these kinds of variation increase or reduce the burden of work assumed by the family and affect the strategies adopted for carrying it out. This difficulty is compounded when other types of handicap (blindness, mental retardation, and so on) are also considered.

The practical problem is that measuring the amount of care actually given and its distribution among family members requires extraordinary trust in the investigator and intimacy with the family. The researcher could take "time per day spent with the patient" as a measure of each family member's work. But to collect these data, the researcher would have to sit for days with the handicapped person, recording the pattern of activities. Furthermore, he or she would have to repeat these observations on different days at different times of the year to be sure not to miss significant variations in the household division of labor. Intensive research such as this is a major intrusion into the family's life and is not likely to be permitted.

I assumed that the family's ability to care for the handicapped is affected by its income and eligibility for medical insurance. I asked the sample families about their monthly incomes but could not verify their answers; on the whole, however, they seem too low (an average of JD 60 per month). This could be explained by their perception of me as a representative of social service agencies. Many families clearly wanted me to regard them as poor, and some even asked me to intercede for them and procure monthly stipends from welfare agencies. A more objective (if less exact) indicator is the source of the family's income. I obtained information about this from 16 of the 18 households (see Table Two).

Many households have income from more than one source. The main sources of income are employment in (or pensions from) the armed forces, agriculture, and unskilled work. Only one household receives a small monthly stipend (JD 30) from a social service agency. This is despite the fact that most of them are not wealthy and some are quite poor. Only one household has a car, and at least three households have no refrigerator. None of the families subscribes to a private health insurance plan. Those who have medical insurance obtained it from the armed forces as a result of a family member's employment in the army. In a large number (9) of households it was this army medical insurance that made initial treatment (and in some cases surgery) for the handicapped possible; without this insurance the handicapped may very well have died after being paralyzed or could not have had any treatment. Medical insurance has clearly been of great benefit to them.

Strategies Adopted for Dealing with Movement Handicaps

Although I could not measure the amount of extra work needed to care for the handicapped, I was able to detect some strategies employed by the mothers of handicapped children for enlisting the aid of others. Mothers generally did not welcome the suggestion that they might ever leave their children in the care of others; they usually said they bore this burden exclusively. Men backed up these statements saying that they themselves spend little time caring for their handicapped children. Mothers make whatever arrangements they can for obtaining help from other women and girls, appealing first to other women in the household, then to relatives, and in the last resort to neighbors.

Case One : Fā'ida³ ***(Mild Handicap, Multiple-Family Household)***

Fā'ida is 38 years old and lives in a multiple-family household with her widowed mother, two married brothers and their two wives, an unmarried brother, an unmarried sister, and her brothers' eight children. Her mother is 68 and her brothers, sisters, and sisters-in-law are all, like her, in their thirties. Fā'ida seemed normal at birth but by the time she was 10 developed

3. The name of this handicapped person, and those of all others mentioned later in this paper, have been changed to preserve their privacy.

Table 2
Sources of Income for 16 Households in Kufrinja

Household No.	Armed Forces	Agriculture	Social Service Stipend	Shop Owner	Skilled Work	Unskilled Work
1						x
3		x				
5	x					
6		x				
7	x			x		x
8			x			x
9	x				x	
10	x					
11	x					
12	x					
13					x	
14		x				
15	x					
16	x					
17						x
18	x			x		

difficulty in walking. The family took her to a doctor for an examination once, but he could not diagnose the problem. She began stumbling more and more frequently, and gradually her movements away from her house became shorter. She continued to help her family work the small gardens near the house but could not go down to the valley to work on the family land there. Now she cannot stand unassisted and does not leave the house at all. She can move around the house by leaning against the walls for support, and needs no assistance when dressing herself or eating. Her mother and brothers all go down to the valley during the summer to harvest crops and work their land; they stay in tents for days at a time, *mu'azzibin* ("living outdoors"). Fā'ida stays behind with her sisters-in-law and their children. Although she seldom needs help, her mother can rely on Fā'ida's sisters-in-law to look after her.

Case Two: Ahmad and Rīm
(Severe Handicap, Multiple-Family Household)

Rīm, 3 years old, and Ahmad, 2 years old, are completely paralyzed and suffer from constant tremors. They can see and hear perfectly, have an unimpaired sense of touch, and seem alert; they recognize their names when their parents talk to them. They both appeared normal at birth but showed signs of increasing paralysis at the age of 2 months. When Rīm, the elder of the two, first developed this problem her father took her to government hospitals in Amman for examinations and treatment. Her medical expenses were covered by her father's

insurance, to which he is entitled as a member of the armed forces. After a year of tests and constant (expensive) trips to Amman, the doctors diagnosed the problem as “hereditary” and said it was incurable. Rīm’s mother was pregnant with Aḥmad at the time, and after his birth she watched him with trepidation to see how he would develop. To her dismay Aḥmad developed the same problem. In the meantime Rīm’s condition declined rapidly. Their parents decided not to seek medical treatment for Aḥmad because they were convinced that his condition was incurable, like Rīm’s. They are waiting for the children to die.

At present Rīm can no longer hold her head up and has trouble swallowing solid food. Aḥmad can still move his head and chew normally. Both children must be fed, kept clean, and moved to prevent the formation of pressure sores. Their mother does all of this for them, in addition to caring for her other two children (aged 5 years and 7 months, respectively). The other children, fortunately, are not handicapped. When the mother wants to sit outside the house she takes her paralyzed children with her, but if she has an errand to attend to she can sometimes leave them with her sister, who lives in the same multiple-family household.

Rīm and Aḥmad live with their family in one of seven apartments in a building owned by their paternal grandfather. The building constitutes a large multiple-family household headed by the grandfather and his wife, who live with the three unmarried siblings of Rīm and Aḥmad’s father in their own apartment. The remaining five apartments are occupied by Rīm and Aḥmad’s paternal uncles and their wives; these five couples have 15 small children among them. In short, there are 12 married adults in this household and 19 children.

Despite the large number of adults present in the household, Rīm’s mother reports that she only asks one of them (her sister, who is married to a brother of Rīm’s father) to help her care for the children. Although this sister works outside the home, she is sometimes available after working hours. She married recently and has only one child of her own; presumably she will have less time to help her sister after she bears other children.

The male head of this large household, Rīm’s paternal grandfather, is consulted when decisions about treatment for the children are made. A year ago the insurance office of the armed forces contacted Rīm’s father and said that the army was willing to send the children abroad for treatment. Rīm’s paternal grandfather said he doubted that any treatment would succeed, and counseled the parents against it; they agreed.

In view of the hereditary nature of the problem, Rīm’s parents have considered family planning. They plan to have only one more child and stop after that. They asked me if I knew of any tests that could determine the likelihood of their next child being handicapped, and unfortunately I was not able to advise them.

This case brings out the tendency for mothers to assume most of the burden of care even when they live in households where other women live. Neighbors do even less than the other

members of a multiple-family household. All informants said that they never asked for help from their neighbors and in fact I found that neighbors who are not close relatives know little about handicapped people living a few houses away.

Case Three: Yūsuf
(Moderate Handicap, Single-Family Household)

Yūsuf was stricken with polio when he was six months old and since then has been unable to walk. His father took him to a number of hospitals in Amman for treatment; the costs were covered by his army medical insurance. When he was six years old Yūsuf was enrolled in a special government school for the handicapped in al-Mafraq (a town some 70 km east of Kufrinja). He studied there for eight years, living in their dormitory at government expense. The school also paid for a pair of metal leg braces for Yūsuf so that he could walk with crutches. The braces were expensive (JD 750) and had to be changed every year as Yūsuf grew out of each set. Since the family income was small, they depended on the school for the braces. When he was fourteen, however, he had to leave the school because it did not offer a complete secondary school education. He returned to Kufrinja to complete his schooling.

Yūsuf's departure from the special school had negative consequences for his health, however. His family could not afford to buy him new braces when he grew out of the latest set, so after one year he could no longer walk. He left school and became confined to his family's small house. His father applied for braces through the army medical program, but they refused to supply them and offered Yūsuf a much cheaper (JD 160) wheelchair (made in China) instead. Since Yūsuf's house is built on a steeply-inclined street, Yūsuf could not use the wheelchair outdoors. It broke after three months of light use indoors, and after making two attempts to repair it the family abandoned it. Yūsuf can push himself across the floor with his hands at any rate and never really needed the chair when inside the house. The loss of the braces has been much more important. Now immobilized, Yūsuf no longer gets any exercise and consequently has gained about fifty pounds in the past two years. The lack of exercise may also be weakening his heart and kidneys; as is well-known, this is a common problem for paraplegics.

Now seventeen, Yūsuf lives with his father (60 years old), his mother, and his young unmarried sister. He has no difficulty dressing or eating and needs little special care. His married brother lives downstairs in the same building but cannot contribute to the household's support. His father, who is retired, receives a small pension from the army and also gets JD 27 per month from a social service agency. He tries to work two or three days per week whenever he can find employment. Their poverty is evident. Their house is small, they have no tables or chairs (they sit on the traditional *firāsh 'arabi*, a row of cushions lined up against one wall) and they have no refrigerator or oven in their kitchen. They cook on a small, two-burner gas stove.

This family is one of only two in Kufrinja which was able to enroll a handicapped child

in the special school in al-Mafraq (northeastern Jordan). They clearly benefitted from the school and, especially, the free provision of leg braces. The interruption of this service is especially regrettable because Yusuf has reached the age when he will soon stop growing. After that he could probably use a single set of braces for ten or fifteen years before needing a replacement.

Case Four: Hâtim
(Moderate Handicap, Single-Family Household)

Hâtim was born normal but was stricken with a high fever when he was five months old. He recovered but seemed less coordinated than before, so his mother took him to a doctor in a nearby town. The doctor told her that Hâtim had a blood clot in his brain and that there was no treatment for the problem. Hâtim learned to walk and was able to attend one year of school, but after that his condition grew worse. He fell more and more frequently and eventually stopped walking completely because he had no sense of balance.

His condition has gradually worsened. He is now 20 years old and is subject to seizures. He takes a medication to control them three times per day. His intelligence is not affected, but his neurological condition interferes with his speech; since he cannot speak clearly he prefers not to talk with non family members. He points mutely to contusions on his head and feet to show the evidence of his falls.

Hâtim lives with his mother, four 'unmarried sisters, and unmarried brother in his father's house in Wâdi Kufrinja. His mother was divorced eight years after Hâtim was born. Hâtim's father now lives in the town of Kufrinja with four wives and refuses to contribute to the support of the family; instead, he has given them his house. Hâtim's eldest brother is married and also lives in town, but he contributes part of his salary to support Hâtim's household. The brother who lives with him is in the army and gives all of his salary to his mother. One of his sisters works as a teacher and also supports the family.

Hâtim's mother's brother lives right next door but he does not contribute to their support and does not help the family take care of Hâtim. Three years ago the family tried to enter Hâtim in a government center for the handicapped so that he could live there, but the center refused to admit him because he was too old - "Not because they thought he was retarded," his mother stressed; "he is not retarded."

Patterns of Reciprocity among Family Members

When I began my research I said that I wanted to hear about anyone who needed help in order to walk. My informants mentioned a number of old men who were not truly handicapped but simply had trouble walking because of their advanced age. They pointed out that Jordanians almost never put their elderly parents in convalescent homes like in America. Jordanians, they said, spend a lot of money on their children, paying for their education and their marriage, and

often build extra rooms for them in their houses so that they can live cheaply after they marry. In return, children are grateful and take care of their parents when they are old. American children are not grateful, they said, because their parents did not do very much for them when they were young; everyone in America simply works for himself.

This notion – that there is a bond of reciprocity between the generations – cannot be put into practice by handicapped children. Instead, family members consciously try to create alternative patterns of reciprocity, so that those who provide care and support for the handicapped can be compensated, at least to some extent. This is illustrated by Case Five.

Case Five: Hānī
(Severe Handicap, Small Multiple-Family Household)

Hānī was paralyzed by an automobile accident two years ago, when he was 25. Immediately after the accident he was completely paralyzed, but after treatment he regained the use of one leg. Because he was in the armed forces his medical care was covered by insurance. He had a number of operations to repair his crushed vertebrae. His mother stayed with him in the hospital for fourteen days during the surgery and visited him frequently during the six months of therapy that followed. He has full control over his bladder and bowels and partial use of his hands, but he cannot sit up unaided.

Hānī received JD 2,000 in compensation from the insurance company of the driver who hit him. He used half of this sum to buy a small adobe-brick house in the Jordan Valley for his mother. He chose to buy a house there because it was cheap and because the neighbors were members of his mother's descent group a ('ashira). He moved in with his mother and youngest (unmarried) brother when he completed his therapy last year. His mother feeds him, helps him to bathe, and helps him stand or sit when he needs to do so.

Hānī's mother is divorced; his father lives in Kufrinja with his four wives and refuses to support her. Hānī receives a monthly pension of JD 40 from the army, but this is not enough to support the family. In August, 1992, Hānī's youngest brother (age 14), who had been living with him and his mother, joined the army. This brother now gives his entire salary to the family, which helps them cope.

Hānī gave the other half of his insurance compensation to his other brother, Ṣāliḥ, so that he could get married. For the first few months after his marriage Ṣāliḥ rented a room in Kufrinja near the house of some of his wife's patrilineal relatives. In October, however, Ṣāliḥ moved into a new room in Hānī's house that had been built for Ṣāliḥ and his wife. Ṣāliḥ's help is important for Hānī. Hānī has a wheelchair that a friend of his bought for him in the United States but depends on Ṣāliḥ (or, sometimes, a neighbor) for help in using it. He must be lifted bodily from his bed and placed in the chair whenever he wants to use it, and Hānī's mother is not strong enough to do this.

Hānī tries to bring in some income by working when he can in a small used clothing shop. He tries to go out every day in the chair and open the shop for a few hours. Since he has control of his hands and forearms, he can take money from customers and make change. His profits are small, however.

The Transfer of Family Responsibilities from One Generation to the Next

In light of the close bond between mother and child that has been illustrated in the previous cases, it is important to learn what happens to the handicapped after their mothers die. As the following case shows, there is no means of transferring this responsibility from the mother's generation to the sibling's generation, which means that the situation of the handicapped might be particularly perilous if they outlive their mothers.

Case Six: 'Abd al - Raḥīm (Moderate to Severe Handicap, Nuclear Household)

'Abd al-Raḥīm, age 45, has been confined to a wheelchair for about twenty years. He cannot walk and has a neurological disorder that makes it difficult for him to speak; most of my data about him were obtained from a neighbor. He was born normal but gradually lost strength and feeling in his legs, so that by the time he was 10 years old he had to use canes to walk. He did not see a doctor at that time. There was no doctor in the area, and to visit one he would have had to go by donkey long distance, which would have exhausted him. His sister, who was born a year or so before him, is also paralyzed; she lives with him in the same room.

When 'Abd al- Raḥīm's family came to live in Kufrinja his father built a large house of mud and stone on the site of the present house. His father had two wives. After he married his first wife and she gave birth to two children whose handicaps gradually became apparent, he was afraid to continue to father children with her. This woman's *khāl* (mother's brother) was also paralyzed, and people suspected a hereditary illness. So 'Abd al-Raḥīm's father married a second wife and fathered the remainder of his children with her.

Both wives lived with him in the same large, mud and stone house; each had their own room. After he remarried, however, he stopped paying attention to his first wife and also did not give her much money. He died thirty years ago. After that his two wives continued to live in the same house, the first wife living in one room with her two paralyzed children. She had no regular income at all but lived on the charity of neighbors and relatives. At some point the mud-and-stone house was knocked down by 'Abd al-Raḥīm's eldest half-brother and was replaced by the current concrete house.

'Abd al-Raḥīm has three half-brothers through his father's second wife. Their mother continues to live in her portion of the house, but two of her married sons have moved out. 'Abd al-Raḥīm's mother died three months ago. He and his sister continue to live in her room,

subsisting on charity. (The neighbor who was assisting me apparently contributes to their support occasionally but modestly did not admit this; he said he did not know who supported them.) The house originally had been registered in their father's name, and when he died it was inherited by his other sons. Apparently 'Abd al-Raḥīm has no share in the house and does not own the room where he and his sister live. His sister cooks for them and they take care of each other as best as they can. Their eldest half-brother was living upstairs but died a few months ago; his widow and eight children still live there. Although she visits her handicapped neighbors, she seems unable to accept full responsibility for them. Apparently they live constantly on the edge of destitution and survive by making emergency appeals to whomever will take pity on them.

The Marriage Strategies of the Family

In Kufrinja the presence of handicapped people in a family can strongly affect its marriage strategies. This is due to the prevailing notion that if a movement handicap is not the direct result of an accident it must be hereditary. This belief affects the marriageability of the handicapped person's siblings. Other families do not want to marry their children to the siblings of a handicapped person, fearing that his or her "hereditary" disability will appear in their grandchildren. A handicapped person may protest that his paralysis or lameness was caused by a childhood fever, but this protest generally falls on deaf ears.

The prejudice against marrying into a family with a handicapped person seems to affect girls more than boys. I learned of two cases of handicapped brothers (one deaf and mute, the other mildly retarded) who were recently engaged to be married, despite their handicaps. In neither case did the boy's in-laws appear worried about their daughter's children. I asked an informant about one case. Why were the girl's parents so complacent? Did they not believe that the boy's handicap was inheritable, or did they somehow believe that the boy could not transmit his handicap to his offspring? According to my informant, the attitude of each boy's parents-in-law was shaped, not so much by medical beliefs, as by their appraisal of the structure of the marital relationship. Once they had married off their daughter, the responsibility for "caring for" any children she might have would rest with her and her husband's kin, not with her own kin. "The children belong to the husband, not the wife," they said. So if any children were in fact born with hereditary handicaps, all of the expenses for maintaining them would be shouldered by the husband and his kin, not by his wife or his in-laws. I wondered what the newly-married wife's feelings about this subject might be – since if she did give birth to retarded children she would be made responsible for taking care of them — but I was not able to interview her.

In another case, however, an engagement was broken off because a congenitally handicapped child had been born to a close relative of the bride. The bride and groom were legally married (having completed the marriage contract) but the marriage had not been celebrated and consummated. They were planning for the wedding, but when the handicapped child was born the groom's side asked for a divorce. Obviously they thought that the handicap

might be transmitted through the girl to their son's children, and if this happened they and their son would have to pay for any medical treatment that might be required.

The prejudice against marrying the siblings (especially sisters) of handicapped people makes families reluctant to admit that they have handicapped children. It is only when the handicap is obviously the result of an accident that the family does not hesitate to make the child's presence known. They tend to hide children with congenital disorders (whether hereditary or resulting from difficult births), and sometimes only close relatives of the parents are aware of their existence.

Conclusions

My first conclusion is that the idealized picture of extended family cooperation in caring for the handicapped is not a faithful image of reality. Most of the burden of care seems to fall on the mother and, at best, some of her co-resident daughters. Neighbors, whether close kin or not, do relatively little to help her. Most of the handicapped live in nuclear family households and rely almost exclusively on the other household members. Even in those cases where many nuclear families share a single house, most of the care is provided by the handicapped person's mother. The mother-child link is so central to the family that it is difficult for families to find a substitute for it. Handicapped people try to establish relations of reciprocity with other family members in cases where the mother alone cannot bear the burden. The handicap also affects the marital strategies of the family. The sisters of handicapped people, especially, face discrimination when they wish to get married.

The results of this study also tend to disconfirm Traustadottir's hypothesis that English-speaking families assign almost all child-care tasks to the mothers of handicapped children because of a culture-specific link between the notions of "caring for" (a mother's task) and "caring about" (a parent's normative attitude). There is no cultural link in Arab societies between "caring for" children and a specifically maternal role. Both sexes stress the importance of "taking care of/bringing up young people properly" (*ri'ayat al-shabab al-salima*), and one hears both men and women being urged to pay serious attention to their children's upbringing so that children will reciprocate with loving care when their parents are old. This notion, in fact, justifies the practice of arranged marriage and gives parents key roles in choosing (or at least approving of) the spouses of their children. Despite these significant cultural differences between English-speaking and Arabic-speaking societies, we find almost the same allocation of child-care tasks to the mothers — and not the fathers — of handicapped children. If cultural similarities cannot explain this unexpected parallel, then perhaps structural similarities (for example, a common encapsulation in a market economy) can explain why women in both the Arabic- and English-speaking worlds carry out a disproportionate amount of the work necessary for raising a handicapped child.

The final point is that the reluctance of Arab men and their families to accept the sister of a handicapped person as a spouse is derived from Arab notions about paternity and responsibility. Although it seemed at first that medical beliefs (ex. the idea that handicaps are more readily transmitted genetically through females than through males) might be at the root of these attitudes, informants made it clear that it was much more a matter of specifically Arab definitions of paternal obligations. I would predict that the effect of handicaps on marriage strategies would vary cross-culturally but would not be related to social class, occupation, educational level, or other structural factors.

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