Diversity, Shared Functioning, and the Role of Benefactors: A Study of Parenting by Retarded Persons

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In the past, being mentally retarded often meant restrictions in the life chances available to the individual. With the recent trend toward normalization, retarded persons can succeed in living their lives as normally as they are able to (Wolfensberger, 1972). This includes the right to take normal risks, to make consequential decisions, to come and go as they please, and to experience normal societal relationships (Kernan, Turner, Langness, & Edgerton, 1978). It is now recognized that healthy social and sexual relationships are basic to an individual’s successful adaptation in community life (Koegel & Whittemore, 1983). Historically, however, the sexuality of retarded adults has been both feared and denied, resulting in the implementation of strict controls (i.e., sterilization and segregation), justified in terms of the safety of the retarded individual and the good of society.

It is only in recent years that marriage and parenting have been viable considerations for retarded adults. Still, there is much apprehen-

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sion over the possibility of retarded persons becoming parents. Bass (1963) suggested that retarded persons be permitted to marry only if they have been sterilized. Johnson (1969) contended that while the deprivation of close human relations is inexcusable as a policy, parenthood is not the automatic right of all human beings and the rights of the child must be considered. Similarly, the 1976 President’s Committee on Mental Retardation qualified its statement that marriage and reproduction are rights, not privileges, for retarded individuals, by emphasizing the rights of children to an adequate home environment that prepares them both cognitively and emotionally for entry into school.

In general, discussions of retarded persons as parents have focused on three issues: (1) The effect of the parents’ retardation on the child’s cognitive and behavioral profile—for example, will retarded persons produce handicapped offspring? What problems in self-esteem maintenance will arise when the child becomes aware of his or her parents’ handicap? (2) The retarded persons’ competence as parents—Are they capable of setting adequate child-rearing goals, providing a suitable environment, and sustaining appropriate practices? (3) The effect on their self-maintenance skills of the additional burden of parenting—Will parenting be too much for the retarded person to cope with, resulting in their offspring becoming a burden to society?

Hall (1974) compared a number of studies that examined the likelihood that retarded persons would produce retarded children and found that estimates vary tremendously depending on the sample surveyed. The studies reviewed did indicate, however, that while the reproductive rates of retarded persons are lower than those of nonretarded people, the relative risks of retardation are much higher for the offspring of retarded parents. In response to such evidence, the fear that mentally retarded parents will beget mentally retarded children has resulted in the legal involuntary sterilization of mentally retarded adults in 26 states and the passage of laws prohibiting the marriage of retarded adults in all but 10 states and the District of Columbia (Winik, 1981).

The second issue, the adequacy of retarded persons as parents, is by no means a simple matter. The skills that constitute adequacy of any parents have yet to be agreed upon. However, studies have attempted to explore the competence of retarded persons as parents and in general have found them to be satisfactory parents; their children are reasonably clean, are within the normal range of intelligence, and exhibit no unusual behavior problems in school (Whitttemore & Koegel, 1978; Winik, 1981). When inadequacy was detected, it could be accounted for by factors other than retardation, such as family size, socioeco-


Johnson (1981) contends that these families appear incompetent and their home environments deprived because we tend to judge them using middle class standards of orderliness and efficiency.

If a retarded mother is careless in keeping her children clean, if she does not prepare nutritious meals, if her children are sent to school in secondhand clothing, or if her children have minor bruises from playing, the mother is much more likely to be suspected of incompetence or neglect than a mother who does not have a history of retardation. (p. 3)

Both Winik’s (1981) intensive study of two families and Johnson’s (1981) observations of six families concluded that none of the families could be considered abusive or neglectful of their children. And although certain problems [e.g., bureaucratic tangles or marital conflicts] were experienced, which tended to overwhelm the families and caused them to become temporarily less conscientious about their childcare responsibilities, the availability of an extensive amount of support aided them in coping with the pressures of self-maintenance and childcare.

The provision of assistance from outside sources directly relates to the third concern, the potential for having to remove the child from the home. While instances of custody being denied have been reported—one infant was unwittingly bathed in water too hot, resulting in burns on his bottom, and another was left at home alone when his parents went out for the evening (Koegel & Whittemore, 1983)—when family members, benefactors, or delivery system personnel are accessible to aid in the management of everyday problems and critical incidents, there is less likelihood of poor parenting becoming an issue (Johnson, 1981; Winik, 1981).

Reports from all sources—sample members, family members, and field researcher observations—suggest a relationship between family provision of support and the perception of adequate or competent childcare management by the retarded person as parent. When the more capable individual perceives an inability in the retarded person to carry out an activity independently, he or she either assumes responsibility for the task or provides the strategic assistance necessary for the less capable individual to organize his or her efforts in a task-appropriate manner (Vygotsky, 1978). While guided by the premise that a range of competence is possessed by our sample members, the intention of this chapter is to examine the relationship of the retarded person with family members as it relates to the issue of adequacy of parenting skills.
SAMPLE

For a number of years, the Socio—Behavioral Group of the Mental Retardation Research Center at UCLA has been investigating various aspects of the community adaptation of mildly retarded adults. More specifically, attempts have been made to identify factors responsible for facilitating or hindering these individuals' potential for normalization, particularly in independent living and competitive employment. In June 1980, a new phase was intiated with the same aim of employing naturalistic research methods to document the everyday life behaviors of mildly retarded adults. This time the sample was broadened to include black participants in addition to the original caucasian members.

During this phase of our research, 90 adults living in the greater Los Angeles area have been followed and intensely studied. All of the sample members were individuals who had been classified as mentally retarded at some point in their development, by a component of the service delivery system. From this larger sample, a subsample of those individuals with children were identified and their parenting practices examined. While IQ data were not available for all these individuals, all members of this smaller sample had been placed in special education classes during their school years and remained in them until they graduated or dropped out.

In total, 13 family units that included at least one retarded parent were identified. Three were white and 10 were black. Both parents were present in 8 of the families; in 3 of these, 1 spouse was of normal intelligence. Five families contained single or divorced mothers, 2 of whom had never had custody of their children but maintained regular contact with them. Eight of the families lived in their own apartment, 7 of them in close proximity to their own parents or other family members. Four families lived in the same house as their own parents; and one woman, who did live with her children, resided in a board and care facility. Additional details of age, IQ (when available), age and sex of the children, and source of income are presented in Table 5.1 (pp. 74-75).

No case is made for this being a representative sample; there simply are no figures available on the universe of mentally retarded individuals in the role of parent nor the retarded adult in the community. However, the heterogeneity of the sample permits at least preliminary examination of the effects of a number of factors such as marital status, family size, age of the children, and availability of support, on the child-rearing practices of retarded persons.

5. A Study of Parenting by Retarded Persons

METHOD

Sample members were located through a variety of sources. Regional Centers, residential facilities, sheltered workshops, social groups, and training programs were contacted; and a pool of potential sample members was identified. These individuals were then approached by the various agencies; an explanation of our research was given; and if interest was shown, permission was asked for them to be contacted by us. Other potential sample members were nominated by individuals already contacted or, in some cases, by their own parents.

Once a potential sample member agreed to become involved in the research, participant observation began. The technique of participant observation allows for the field researcher and sample member to engage in intensive interaction over a prolonged period of time during which discussions take place and observations are made as the sample member engages in various typical activities. Given the constant and long-term nature of the contact, close relationships developed between researcher and sample member, allowing for intimate conversations on a range of topics such as personal feelings, past events, and hopes or fears for the future.

A field researcher was assigned to each sample member, and visits were made approximately once a month. Over the course of the study, these meetings took place in the homes of the sample members as well as in less familiar settings [e.g., a relative's home, a neighborhood park, Disneyland, or a department store] to observe how they handled themselves and their children under different conditions.

Extensive fieldnotes were made after each contact, which serve as a record of the field researcher's observations of the sample member. They provide an account of everyday behaviors and skills as observed over time across different situations and have become extremely detailed, allowing us to examine a number of features, such as parenting practices and self-maintenance skills, of the sample members' lives.

RESULTS AND DISCUSSION

Case study accounts of four family units are presented below. These four families were chosen for intensive description because their lives provide a sense of the range of competence—incapacity displayed by the sample members as they cope with the demands of parenthood. Issues related to adequacy in parenting, which are apparent in these
<table>
<thead>
<tr>
<th>Sample member</th>
<th>Marital status</th>
<th>Ethnicity</th>
<th>Age</th>
<th>IQ</th>
<th>Residence</th>
<th>Sex &amp; age of Child</th>
<th>Intelligence of children</th>
<th>Source of family income</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Faith</td>
<td>Married</td>
<td>Caucasian</td>
<td>28</td>
<td>78</td>
<td>Own apt.</td>
<td>M-5 (F-newborn)c</td>
<td>IQ = 90</td>
<td>SSI + AFDC + workshop salary</td>
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<tr>
<td>Roy</td>
<td></td>
<td>Mex.-Amer.</td>
<td>32</td>
<td>&lt;69b</td>
<td></td>
<td>F-4</td>
<td>Normal</td>
<td>SSI + AFDC + workshop salary</td>
</tr>
<tr>
<td>2. Marilyn</td>
<td>Married</td>
<td>Caucasian</td>
<td>34</td>
<td>85</td>
<td>With parent</td>
<td>F-3</td>
<td>Normal/lang. delayed</td>
<td>SSI + AFDC + workshop salary</td>
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<td></td>
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<td>F-2</td>
<td>Normal/lang. delayed</td>
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</tr>
<tr>
<td>Rich</td>
<td></td>
<td>Caucasian</td>
<td>40</td>
<td>67</td>
<td>Own apt.</td>
<td>M-1</td>
<td>Normal</td>
<td>SSI + AFDC + competitive employ</td>
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<td>3. Chrissy</td>
<td>Married</td>
<td>Caucasian</td>
<td>35</td>
<td>&lt;69b</td>
<td>Own apt.</td>
<td>M-1</td>
<td>Normal</td>
<td>SSI + AFDC + competitive employ</td>
</tr>
<tr>
<td>Lonnie</td>
<td></td>
<td>Caucasian</td>
<td>30</td>
<td>&lt;69b</td>
<td>With parent/own apt.</td>
<td>M-1</td>
<td>Normal</td>
<td></td>
</tr>
<tr>
<td>Michael</td>
<td></td>
<td>Black</td>
<td>20s</td>
<td>Normal</td>
<td></td>
<td>M-1¾</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>5. Ken</td>
<td>Married</td>
<td>Black</td>
<td>24</td>
<td>46</td>
<td>Own apt.</td>
<td>F-infant</td>
<td>NA</td>
<td>SSI + AFDC + workshop salary</td>
</tr>
<tr>
<td>Arlene</td>
<td>Black</td>
<td></td>
<td>26</td>
<td>50</td>
<td></td>
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<td></td>
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<tr>
<td>6. Dan</td>
<td>Married</td>
<td>Black</td>
<td>27</td>
<td>55-60</td>
<td>Own apt.</td>
<td>F-2</td>
<td>Normal</td>
<td>SSI + AFDC</td>
</tr>
<tr>
<td>Laura</td>
<td></td>
<td>Black</td>
<td>24</td>
<td>NA</td>
<td></td>
<td>F-6</td>
<td>NA</td>
<td></td>
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<tr>
<td>7. Manny</td>
<td>Married</td>
<td>Black</td>
<td>22</td>
<td>60</td>
<td>With parent</td>
<td>F-infant</td>
<td>Normal</td>
<td>SSI + AFDC + workshop salary</td>
</tr>
<tr>
<td>Stacey</td>
<td></td>
<td>Black</td>
<td>22</td>
<td>&lt;69b</td>
<td></td>
<td>F-infant</td>
<td>Normal</td>
<td>Unemployment ins. + inheritance</td>
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<tr>
<td>8. Marinda</td>
<td>Engaged</td>
<td>Black</td>
<td>27</td>
<td>&lt;69b</td>
<td>Own apt.</td>
<td>F-infant</td>
<td>Normal</td>
<td></td>
</tr>
<tr>
<td>Mike</td>
<td>Black</td>
<td></td>
<td>20s</td>
<td>Normal</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>10. Mary</td>
<td>Divorced</td>
<td>Black</td>
<td>31</td>
<td>58</td>
<td>With parent</td>
<td>F-6</td>
<td>Ment. ret.</td>
<td>SSI + AFDC</td>
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<td>F-4</td>
<td>Ment. ret.</td>
<td></td>
</tr>
<tr>
<td>11. Sandy</td>
<td>Single</td>
<td>Black</td>
<td>21</td>
<td>51</td>
<td>With parent</td>
<td>M-5</td>
<td>Ment. ret.</td>
<td>SSI + AFDC</td>
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<td></td>
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<td>F-4</td>
<td>Ment. ret.</td>
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<tr>
<td>12. Willa</td>
<td>Single</td>
<td>Black</td>
<td>26</td>
<td>69</td>
<td>Own apt.</td>
<td>M-10d</td>
<td>Normal</td>
<td></td>
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<tr>
<td>Penny</td>
<td>Divorceda</td>
<td>Black</td>
<td>31</td>
<td>63</td>
<td>Board &amp; care</td>
<td>M-NA</td>
<td>Ment. ret.</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td>F-NA</td>
<td>Ment. ret.</td>
<td></td>
</tr>
</tbody>
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a Not the natural father.
b Official records indicate IQ is below 69.
c Data was collected when only one child was present in the home.
d Children do not reside with mother.
more detailed accounts, such as judgments of competence by close family members, the relationship of familial support to those judgements, and the identification of factors related to the maintenance of a child care environment, will then be clarified further with data from the remaining families.

Debbie and Michael (Case No. 4)

Debbie, age 20, was first contacted when her son, Danny, was 10 months old. He was born out of wedlock, and the father, a steady boyfriend, refused to acknowledge Danny as his child. During the pregnancy, Debbie lived with her grandmother and after the birth, with her parents. While pregnant, she had been concerned that her handicaps—deafness in one ear and mental slowness—might be passed on to her child. This did not occur.

She recently married Michael, a normal man, who assumed support of and coresponsibility for Danny. They moved into their own apartment, but the marriage was shaky from the start as he started beating her and involving himself with another woman. She finally left him and went back to live with her parents but admitted to feeling bad about having separated Michael and Danny, who cared strongly for each other. At last contact, they had reconciled their differences and planned to move back together.

Debbie has always assumed complete responsibility in caring for Danny, whether she lived at home with her parents or in an apartment with Michael. She is, in fact, resentful when others try to interfere and to give advice without being asked. All those around her acknowledge that she takes good care of Danny and receives only minimal assistance from family members, mostly in the form of babysitting. She recognizes that others can be approached for advice and has sought their assistance when experiencing problems with Danny. For example, her frustration at not being able to toilet train Danny after repeated tries led her to ask her mother, Michael, and even Michael's boss for advice. Another problem, Danny's frequent masturbating, was discussed with an experienced aunt when he resisted attempts to discourage the behavior. Her aunt speculated that he might have a rash, but Debbie checked and, having found none, next sought help from the doctor.

Debbie has some definite ideas about how she wants to raise Danny. She pointed out that many people raise their children in the same manner in which they were raised. She, however, intends to improve on her experience. She described how her father used to beat her for not doing well in school and how she resented him for thinking she wasn't learning because she was lazy. She says, "I'm sure not gonna try to beat any knowledge into Danny when he has trouble in school. I'm gonna take time with him and if I can't, I'm gonna get someone else to tutor him."

She actually puts this philosophy into practice. When she and Michael were in the market buying food for dinner, Debbie wanted to buy eggs for Danny. Michael objected, saying they didn't have enough money and Danny could eat tacos along with them. Debbie argued that she didn't want to feed her baby "junk food," to which Michael responded that there were times when he, as a child, had to eat junk food for breakfast. Debbie insisted that she is "not gonna stand for him to raise Danny like he was raised and that families should always try to do the best they can for their children." When she threatened to go to her mother for eggs, Michael finally consented.

Debbie's ability to think in terms of future outcomes is evident in other areas as well. She currently receives tutoring in reading and math (i.e., learning to count money) and plans to find work when the tutoring ends. She is also one of the few sample members who regularly uses birth control. And although Michael keeps pressuring her to have another child, she is reluctant to do so at this time.

Debbie's biggest concern right now is getting Danny to mind her. She is disturbed that her yelling and spanking have little effect. Nonetheless, she adores her son and shows him a great deal of warmth and affection even when disciplining him. For example, when the field researcher accompanied Debbie and Danny shopping, Debbie was observed to be quite responsive to Danny's needs. When they entered the store he was given a toy from the shelf to play with. As they prepared to leave, the toy was replaced and Danny began crying. Debbie tried comforting him and finally resorted to picking him up and carrying him to the car as she firmly explained, "How come you so bad? You think every time you go into the store you suppose to get something." After a short while he calmed down and she began playing with him, tickling him, and enjoying his laughter.

Faith and Roy (Case No. 1)

Faith, age 28, and Roy, age 32, have been married for 6 years. They met while working at Goodwill Industries, a sheltered workshop, and married 9 months later against the advice of both sets of parents.
They have always lived in their own apartment and are supported by Social Security Insurance (SSI), Roy's workshop salary, and Aid to Families with Dependent Children (AFDC).

Both Faith and Roy admit to being handicapped, and Faith recognizes that she is the more competent of the two. She has assumed responsibility for managing financial matters and running the household as well as for the maintenance and safety of her four-year-old son, John, and her husband. She is an immaculate housekeeper and prepares all the family meals, being careful to include meat as well as vegetables and starch. Occasionally they eat out, mostly pizza or hot dogs, which is recognized as junk food.

Faith is the primary caretaker of John and she receives only a minimal amount of support from others. Her parents and siblings live out of state as do Roy's parents. Faith remains very close to her family. Her mother was there initially after John's birth to lend a helping hand, and Faith telephones her sister once a week to chat and seek advice.

Faith's formula for raising a child includes two essential ingredients: love and supervision. Children, she feels, must know there are limits and be disciplined if they exceed them, but above all, they must know they are well loved all of the time.

Her handling of John reflects this philosophy. She deals with him in a patient and loving, but firm, manner and is an attentive parent. She takes him to the park regularly, sees that he gets his daily afternoon nap, takes him to children's movies, and carefully watches over him when they are close to traffic. She is careful about planning for his future, when he reached preschool age she spent time searching for a good school to be paid for by money carefully saved. Having attended private school herself, she was unaware of the possibility of public education from six years and up and so was quite prepared to pay for 13 years of private schooling as well. And in terms of John's development, fearful that Roy's or her handicap might have been passed on, requested that John be evaluated to make sure he was developing normally.

She believes that Roy, on the other hand, does not show enough of an interest in John and that when he does, does not exhibit what she feels to be good qualities in a parent. During an outing with the field researcher to an amusement park, the contrast in parental styles was quite obvious. John had earlier indicated that he wanted cotton candy and had been easily distracted by Faith with a drink and a ride. Later that day, Roy quietly decided he wanted cotton candy and disappeared for a short time only to reappear eating the candy. John immediately became upset, reminded of what he had been diverted from, and Faith glared, overtly disgusted with Roy's action. When an unhappy John approached his father with an open mouth for his share of the candy, Roy reluctantly gave him a taste, which by no means satisfied John.

Faith, by contrast, had indicated throughout the day that she was very attuned to the needs of her son. Without being overprotective, she always knew where he was and made sure that he did not wander off. She reminded him to use the bathroom from time to time and urged him to drink milk rather than coke during lunch. When John played in a playground specially designed for young children, she went in to show him some of the playground equipment he had missed.

John seems to recognize the differential care he receives from each of his parents and gives signs that he is aware of his mother's position of control. For example, he knows he has to mind her and is less likely to mind his father; he has also learned to approach his mother when he needs or wants something.

Roy's desire to have more children had been resisted by Faith for she knew the burden of caring for them would fall on her shoulders. She felt Roy liked the idea of having a lot of kids but had no idea of what was involved in raising them. She wanted to wait until John was old enough to assume some responsibility for caring for himself. When John was five and a half years old, she informed us she had given birth to a baby girl.

Ken and Arlene (Case No. 5)

Ken, age 24, and Arlene, age 26, met in a sheltered workshop and married shortly after Arlene became pregnant. Arlene had given birth to twins before having met Ken but was not allowed custody of them and had had no contact with them since birth. Ken and Arlene now have three children: two boys, Ken, Jr., 2, and Clifford, 1, and an infant daughter, Shannon. They lived with Ken's parents after the marriage and continued to live with them until the third baby was due. Arlene's poor skills in caring for herself, the house, and her family were the main reason for their moving out, as her mother-in-law could no longer tolerate the situation.

Ken's parents still assume the bulk of responsibility for caring for Ken, Arlene, and the children; they handle all their money, depositing their SSI and AFDC payments, paying their bills, doing the major shopping for the family, and until recently, doing the laundry. Arlene as-
researcher got up and freed his finger. During another visit, the field researcher, Arlene, and her sister-in-law were out on the porch when Ken's brother came out to strongly suggest that Ken, Jr., who was covered from head to toe with filth and smelling of urine, be bathed. He also pointed out that the boy had a bowel movement in his pants and that if it was not tended to immediately, it might wind up on the carpet. Arlene remained seated and simply replied that he had on rubber pants, which would prevent such an occurrence. At that point, her sister-in-law got up and escorted Ken, Jr., into the house, announcing that she would give him a bath.

Family members other than Ken's parents assume a large role in caring for the children. Ken's two sisters planned to take the two boys to live with them and raise them for a while, presumably to give Arlene a rest. Ken's brother and sister-in-law moved in with Ken and Arlene for a short period to help out and to take a firm hand with the boys. And when Arlene returned to her job at the sheltered workshop, arrangements were made with a cousin to come by every morning to get the two boys ready for nursery school.

At last contact, Ken, Arlene, and the boys had moved out of their home and had returned to live with Ken's parents.

Marilyn and Rich (Case No. 2)

Marilyn, age 34, and Rich, age 40, met while working at a sheltered workshop and married shortly afterward. They moved into Rich's mother's house and have continued to live with her except for a brief period after the birth of their first child. Although Rich's family had advised them not to have children, after five years of marriage they have three daughters, Janice, 4, Marion, 3, and Melody, 2. Rich's mother admits that "they had been able to manage one baby, taking good care of her and keeping up the house, but after the second and then the third, things became more and more difficult for them to handle." After the birth of their third child, Rich was persuaded by Marilyn and his mother to have a vasectomy, an idea he initially resisted because he wanted a son.

Both Marilyn and Rich admit to being slow but reject the label "retarded." Marilyn had been concerned that Marion was slow in talking and so had all three girls evaluated. The assessments revealed normal intelligence, but indicated Marion and Melody were each a few months behind in their language development.

Marilyn is the more capable of the two and assumes most of the
responsibility for the girls and the housekeeping. Rich generally eats, sleeps, and works, and when he is home spends most of the time yelling at the girls or being involved with his hobby. Rich's mother shares a lot of the childcare and household responsibilities with Marilyn, including cooking, cleaning, shopping, paying the bills, chauffeuring the family, and tending to the girls' needs. Her efforts, however, are largely unacknowledged by Marilyn, who complains her mother-in-law does not help enough.

The Mormon church is another source of support for Marilyn and Rich. They purchase their food from the bishop's storehouse and members of the church act as handymen, provide transportation, and babysit for the girls. When Rich's mother was out of state for a prolonged period, Marilyn experienced trouble handling the family's bills, and the bishop assumed responsibility.

The major problem that preoccupies the family is getting the children to mind their parents. Things are generally out of control in their home. The children are always running from room to room, fighting over their toys, and creating quite a commotion. All three girls have minds of their own, which is all the more evident as they grow older. Attempts to bring things under control by Rich or Marilyn are usually ineffective. Rich typically begins by requesting that the girls stop what they're doing, then pleads with them, and finally escalating to threatening them. He almost never follows through on any of his threats but occasionally resorts to hitting them. Marilyn usually raises her voice but sometimes, when unable to cope with the situation, locks the girls in their bedroom.

A real fear among family members is that Rich, in desperation, may abuse the children. Marilyn's sister observed during a visit that Rich was much too hard on the girls, yelling and hitting them in a manner too harsh for their age. Rich's mother and Marilyn agree that the children are really too much for Rich and that he does not know how to handle them. Rich, himself, admits that the situation is driving him crazy.

On two different occasions Rich has actually been suspected of child abuse, and the last time the girls were temporarily removed from the house. Rich was so full of remorse he even offered to leave the home, if required, so as to permit the court to return the girls to Marilyn and his mother. The children were eventually returned, and at the court's recommendation, Rich and Marilyn enrolled in counseling at the Children's Institute and in a parent education class at UCLA.

Rich's sister has urged the family to move to Utah, close to her, so she can help manage things. She is concerned that if the girls continue to be raised by Marilyn and Rich "they won't have a chance for a normal life." Rich and Marilyn, after much consideration, rejected her offer, deciding to remain in Los Angeles, independent of her supervision.

Chaos continues in their home and last contact Rich's mother planned to retire from work in a few weeks and hoped to be around during the day to provide additional support for Marilyn and the girls.

RELATIONSHIP OF FAMILY MEMBERS TO RETARDED PARENTS

The four families described illustrate the differing levels of awareness and competence in parenting ability possessed by our sample members and the corresponding responsiveness of extended family members to their realized needs.

Debbie, whether single and living with her parents or married and living with Michael, assumed the position of control, making all the decisions pertaining to Danny's care and taking responsibility for seeing things through. Moreover, she displayed a sense of the future, which was evident in her parenting philosophy and her own life goals.

Family members were available when needed and provided assistance when called upon to do so. For example, Debbie was permitted to return to her parent's home when she separated from Michael. While appreciative of the assistance of others, as in the case of toilet training Danny or supporting Danny's need to eat well, Debbie resented any uninvited attempts by others to intervene in her life. She was confident of her ability to take care of her own and Danny's needs and was offended by others' interference, seeing it as lack of confidence in her competence.

Faith also assumed the burden of care for her child as well as for her home and did a remarkable job. Her son was well cared for, their home well managed, and their money carefully budgeted. Her husband was recognized as being less competent than she and, therefore, was not expected to share most responsibilities with her. Faith accepted his need to depend on her and realized that she in turn had to do certain things that a husband might normally do.

For the most part, Faith functioned as an independent person who usually handled problems on her own. However, she was not unwilling to seek help when the situation was beyond her ability. She was close with family members, who came to her assistance when called upon. Her mother, while living out of state, came to help when John was
born, and her sister provided advice on marital and parental concerns when consulted during weekly phone conversations.

In the cases of Ken and Arlene and Rich and Marilyn, as in that of Faith and Roy, the wives assumed more of the responsibility for the children and the home. In both of these cases, however, the situation was so out of hand that extended family members stepped in to actively help out.

Ken and Arlene’s lives were very closely supervised by family members whether they lived on their own or with Ken’s parents. They were allowed little autonomy to the extent that even the amount of time spent with friends was regulated by Ken’s mother. Relatives were taking care of all their money, their bills, their shopping. Ken’s sisters, brother, and cousin aided in the day-to-day care of the boys. And Ken’s mother, cognizant of the difficult enough time they were having managing two children, assumed total care of their infant daughter. While aware of their extensive dependence on Ken’s family for support in almost every area of their lives, Ken and Arlene showed little initiative to assume more responsibility for their own lives. Rather, they seemed to accept the way things were carried on accordingly.

For Rich and Marilyn, while the management of one child was within their capability, coping with three children, all under the age of five, in addition to the strain of running a household, proved too difficult a load for them to handle. With the presence of Rich’s mother, the family seemed to be coping somewhat better. She shared responsibility for some tasks, such as cleaning, cooking, and providing discipline and routine care for the girls, and assumed sole responsibility for other tasks, such as paying the bills. However, even this was not sufficient, and other family members, such as Rich’s sister, church members, and service delivery system personnel, recognized the need for additional support and acted to make such assistance available.

The cooperative relationship that evolved between family members and the retarded parents seems to have been determined by the surrounding support systems’ assessment of the retarded individual’s adequacy in parenting. In all these instances, the extended family has adapted to the perceived needs of the retarded persons. They have their own standards for judging adequacy, which are based on personal, cultural, and social class experience rather than some general normative criteria; and these standards are applied in distinguishing the need to support from the need to intervene. In those homes in which responsibilities were considered satisfactorily handled, minimal support was provided. When incidents arose that warranted additional assistance, for example, Debbie’s need to return home after her separation, appropriate accommodations were made. And when the situation necessitated intensive intervention, as in the cases of Ken and Arlene and Rich and Marilyn, extended family members responded accordingly.

Such is the case with other sample members as well. In those extreme cases, when mothers were judged by family members to be incapable of providing adequate care for their children, as with Penny (case no. 13) and Willa (case no. 12), custody was not permitted. Penny’s three children, all severely retarded, were immediately institutionalized or placed in foster care. In Willa’s case, her parents assumed responsibility for the child and even now after 10 years, dismiss the possibility of Willa ever caring for her.

In those instances in which sample members reside with their parents, even within this supportive environment, differing levels of assistance are perceived necessary and subsequently provided by the parents. In the case of Sandy (case no. 11), her mother assumes most of the responsibility for caring for Sandy and her four children, including handling her money, overseeing the care of the children, and dictating who she can and cannot socialize with. She believes Sandy is a good mother when she wants to be but frequently needs to be reminded to do routine things like dress and feed the children. Her mother has stated that while she hopes Sandy will marry some day, she has no intention of allowing her to take the children with her, as she does not believe she will take proper care of them on her own.

In the case of Mary (case no. 10), her relationship with her mother is somewhat different. While her mother responds to her need for help with financial matters and in making decisions pertaining to her three children, she discourages Mary from being too dependent and tries to minimize the amount of assistance she provides. She intervenes only when Mary has been too lenient or has forgotten to do something with regard to the children (e.g., to give her son his daily dosage of medicine) or shows poor judgment when other people try to take advantage of her. She looks forward to the day when Mary will no longer be a burden to her and wants Mary to return to school to learn more skills to prepare for living on her own.

For some sample members, for instance, Manny and Stacey (case no. 7), the provision of a suitable place to live in their parent’s home and assistance in money management are the only areas in which intervention is perceived necessary by the parents and thus provided. Childcare is performed totally by the sample members and is apparently considered sufficient, as no intervention is deemed necessary.

Similarly for sample members living on their own, when specific deficiencies in self-management are detected by family members, as-
assistance is provided. In the case of Alene (case no. 9), her mother recognized the difficulty she was experiencing in handling money and assumed responsibility for managing her banking and paying her bills. The same is true for Dan and Laura (case no. 6). Both their mothers agree they are wasteful and frivolous with what little money they have and on different occasions have had to step in and pay overdue bills and purchase necessities for their grandchildren.

In the case of Chrissy and Lonnie (case no. 3), Chrissy's mother acknowledges that neither are good managers and so has taken over the task of budgeting their money for them. She also visits three or four times a week, drives Chrissy shopping, as she complains of the difficulty of managing groceries and her toddler son on the bus, and is available for the numerous phone calls she receives from Chrissy or Lonnie seeking advice. Nonetheless, the mother views Chrissy and Lonnie as capable, attentive parents and contends that if they were not, she would immediately assume responsibility for her grandson's care.

And finally for Marinda (case no. 8), who like Faith and Debbie is considered resourceful and self-sufficient, family members respect her independence and are available for companionship and occasional advice.

5. A Study of Parenting by Retarded Persons

as in the case of Dan and Laura. Both Debbie and Faith were aware of the amount of work involved in rearing a child and so wisely planned to allow a sufficient amount of time to pass before considering a second pregnancy.

In those homes in which three or four children very close in age were being reared, extensive intervention by grandparents was a necessity. In all these instances, while the grandparents recognized their retarded child's desire for a child and thought they could possibly handle the responsibility for one child, all were concerned over the multiple pregnancies, especially so closely spaced. Sandy's mother had suggested a tubal ligation after the first child, and again after the second and third; sterilization was finally arranged after the fourth child was delivered. In the case of Rich and Marilyn, both Rich's mother and Marilyn realized three children were enough, if not too much, for the couple to handle and encouraged Rich's vasectomy. Arlene's and Mary's family also insisted that three was enough, and tubal ligations were subsequently performed.

Finally, a most crucial element to the success of these individuals appears to be the willingness and sensitivity of their parents to react to the demonstrated or perceived needs of their retarded offspring and grandchildren. By carefully matching assistance with need, specifically in those areas that warrant intervention, the parents are able to ensure that both their retarded offspring and grandchildren will be maintained at an acceptable level of adequacy. Judgments as to needs are based on implicit standards that the family members have developed from cultural and/or social class experience, which serves as mechanisms for judging behavior as falling within or outside what they consider to be an acceptable range.

The result is a pattern of the assumption of responsibility by grandparents that parallels the informal adoption observed in other societies, for instance, in Polynesia (Gallimore, Boggs, & Jordan, 1974; Levy, 1973) and among blacks in some American samples (e.g., Stack, 1974). In Tahiti and Hawaii it is quite common for members of the extended kin, as well as nonrelated families, to take full or partial responsibility for the rearing of children. Typically this occurs when a child is born to adolescent parents who may or may not be legally married and who either will not or cannot assume responsibility for parenting. In Hawaii this may range from a change of residence for the infant or child to the taking up of residence by the mother, child, and sometimes the father in the grandparent's home. The variations in support by parents and grandparents are as diverse as those described by the retarded parents in our sample.

Just as in the case of the retarded families, the most typical pattern

FACTORS RELATED TO PROVISION OF ADEQUATE CHILDCARE

It remains now to identify the factors that are related to the ability of these retarded individuals to cope with the responsibility of parenthood as well as the factors that influence judgments of adequacy by close family members.

While the relative intelligence level of the retarded person might be assumed to be a contributing factor, our data do not support this notion. The IQs of the three mothers who were denied custody of their newborns, Arlene, Willa, and Penny, ranged from 50 to 69. Moreover, Faith, whose IQ was 78, and Debbie, with an IQ of 55, were viewed as managing admirably, while Marilyn, who scored 85, and Arlene, whose IQ was 50, were seen as incapable of coping with their situation.

Family size and birth spacing seemed to account for some of the ease or difficulty experienced by our parents. In those homes in which one child was present, parents were able to handle the routine care of their child with a minimal amount of assistance. When a second child was expected, grandparents expressed concern as to what effect this additional burden would have on their retarded children's parenting skills
in these Hawaiian households is the assumption by grandparents of primary responsibility for functions, such as the provision of resources and shelter, with more or less responsibility for tasks, such as routine childcare, being assumed by the parents. In Hawaii, this division of responsibility represents a kind of parenting apprenticeship with the as-yet-unprepared parent gradually assuming more responsibilities. We cannot, of course, draw a full analogy between the informal adoption in Polynesia and the circumstances of our urban families. However, though many Hawaiian grandparents may complain about the irresponsibility of their children as parents [usually the inability of the young fathers to provide a stable income], they have considerable hope that maturity will come eventually; and so it does, often in the late twenties for the males and early twenties for the females. Our data are too limited and the grandchildren too young for us to know yet whether the struggles of the grandparents and parents will lead to more self-sustaining households; although in at least one case, Alene’s, this sequence of events did occur, resulting in Alene and her daughter’s move out of the grandparent’s home to a more self-sustaining situation. At present, only minimal support in the form of money management and babysitting is necessary from the grandparents. It is probably the case that for some families, the progression to independence will be possible; in others it seems the solution will be continued support; and in the extreme situations, as the children mature and more difficult management problems are posed, the separation of the children from their parents may be the only alternative.

ACCOMMODATIONS TO RETARDED PARENTS:
A COMPARATIVE PERSPECTIVE

The adaptations seen in our sample are unremarkable when framed in a wider cultural perspective. Extended family interdependence and shared childcare support are the norm as well as a sign of strength in most societies throughout the world. For the Polynesians, shared interdependence and shared function are a sign of maturity and success, while independence from family members is perceived as a sign of trouble (Gallimore, Boggs, & Jordan, 1974). It is only the context of contemporary American life, with its normative pattern of nuclear, socially, and familial isolated households, that the sometimes extensive involvement of the grandparents draws so much attention. Indeed, millions of nonretarded parents of young children in America might well envy those families whose ecologies provide for shared care-

taking—a system that can support work roles of women as well as men, provide relief from daily burdens, provide consultation on childcare questions, and insure a reliable backup during times of hardship or crisis. The retarded parents may be considered fortunate in being ahead of the “culturally deprived” nonretarded counterparts, since they occupy an ecological niche that includes shared caretaking.

Most other non-Western societies would not consider our retarded parents need for support in childcare to be deviant or a sign of dependence. Rather, the kinds of ecological and subsistence pressures that trouble these retarded parents are more likely to be seen as (1) events beyond the personal control of parents and families, (2) contrasts that in any case are unrelated to self-esteem and self-worth, and (3) circumstances of family life that children can participate in ameliorating as helpers, rather than as life problems from which children are to be sheltered. In short, it is the requirements of the larger eco-cultural niche surrounding these retarded parents [time-boundedness, separated housing, etc.] that make requirements for support so problematic and troubling in the eyes of others.

The beneficiaries of the retarded parents [grandparents, siblings, neighbors] do not get involved in every area of the parents’ lives. They appear to concern themselves selectively with certain domains and certain times of the day, week, or month more than others. The benefactors selectively mediate between the larger eco-cultural niche and the retarded parents and their children. We can better understand how effective intervention can work in the natural environment by examining these patterns and relating them to parental resources and children’s ages.

We can start by contrasting different needs of retarded parents affected by their niche: (1) survival needs, such as minimum requirements for shelter, subsistence, health, and defense and security [“minimum” being open to some debate]; (2) childcare and childcare task support needs, such as the need for personnel to help parents and to give concrete aid in the specific tasks of child rearing; and (3) the need for quality of child care, that is, provision of social-emotional support and cultural and intellectual advice on how the structure or pattern of life should be carried out. These domains are also represented in current theories of the role of childhood social ecology in influencing development; these models specify family pressures affecting survival, tasks and routines, and beliefs and ideals implemented by families during social interactions with their children (Weisner, 1984). These different levels of environmental influence require different kinds of benefactor support—differently timed, structured, and available for use.
into their styles of interaction with their children. They do hear comments and criticism and ask questions themselves. But the consistent, regular benefactor interventions required for the survival and childcare aspects of parenting are not repeated at the level of interactional styles. For these kinds of families, then, we hypothesize that continuous, direct tuition and intervention is not generally required.

Our parents appeared to have learned to respond to their children and to have adjusted their behavior as their children grew older, by using immediate models and cues, observational learning, and direct reinforcement from their children. Their children learned and adjusted in the same ways. Complex memory skills, elaborate planfulness, and literacy do not seem to be required to meet these immediate, moment-to-moment, day-to-day demands of social life within the family circle. Evolved adaptive skills of both children and parents can come into play to mutually reinforce some appropriate behaviors and discourage others. For example, child activity and hunger reciprocally interact with parent food preparation and meal organization. Such reciprocal interaction effects serve to establish boundaries around a potentially wide behavioral range and shape the retarded parents’ responsiveness to their children in reasonably appropriate ways.

These parents are best able to parent in a local, controlled context with familiar cues from children, spouses, and helpers, with a minimum of situational ambiguity and variability, and without accompanying overt or implied messages labeling them as incompetent or in need of direct retraining and aid in these most personal areas of life. It appears that most of the benefactors have consciously or unconsciously followed many of the implications of this view; they provide security and caretaking aid but without the accompanying provision of direct training and intervention into the content of child rearing and interaction.

CONCLUSION

The lessons of the kind of contextualized and nondemeaning assistance described in this chapter should be carefully reviewed by those in the service delivery system whose goal it is to serve this population. At least for those families who receive support and assistance from grandparents and other family members, policies should be developed that allow service providers to be more responsive to the already-existing support system. Rather than providing an across-the-board, mid-
dle-class-oriented parent education program, which may only interfere with the well-functioning, adaptive family support system, the delivery of services should be matched to survival and managerial needs (e.g., provide personnel for respite for the grandparents and money allotments for grandparents who offer shelter). In many cases, family members already have targeted problem areas and have experimented with various solutions to insure that survival and childcare needs are met. For example, in the case of Ken and Arlene, Ken’s parents first had Ken and Arlene reside in their home, then had Ken’s brother and his wife live with Ken and Arlene, and finally arranged for a cousin to be present for the morning routine; these all were attempts to find a viable solution. It is time for the service delivery system to recognize the resourcefulness of the family and to begin looking to them as innovators.

The principle of normalization has led to the encouragement of mentally retarded adults to behave in a culturally normative manner. This includes the possibility of marriage, which is perceived by these adults as a meaningful status achievement, as well as parenthood, which is also viewed as a desirable social role. Our data, as others have noted before, attest to the heterogeneity in parenting competence present in this population. In some cases, family units manage quite well on their own, and extended family members remain passively in reserve. In other situations, an active unity of management is required by grandparents and retarded parents to maintain an adequate childcare environment. These data are evidence of remarkably diverse levels of ability and should give pause to those who argue for either the blanket right or the absolute denial of the right of retarded persons to have families. Rather, it is a decision to be made, at least in part, by extended family members, based on their knowledge of the retarded individual’s past need for support and their anticipation of and willingness for continued involvement.

While we have primarily attempted to identify (1) whether the child-rearing practices of retarded parents are judged satisfactory by extended family members, and (2) what factors are related to the maintenance of an adequate childcare environment, other questions, pertaining to outcome, still remain unanswered. For the most part, our sample members’ children are quite young, and little can be said as yet about the long-term effects of parenting by retarded persons—the child, on the retarded individual, or on extended family members. As the children mature and present more and more difficult management problems, will extended family members continue to be supportive? What effect will the sharing of childcare responsibilities have on the devel-
opining child? What will be the effect of a household dominated by grandparents and other family members? Our data show that in at least one family, the grandparent is concerned because the children tend not to pay attention to their mother since they have overheard family members describe her as "being slow and different."

There are also ethnic differences evident within even our small sample, which warrant further investigation. Preliminary data indicate that white families are more likely to prejudge their retarded offspring as being incapable of parenting and to insist that either sterilization be a prerequisite for marriage or that an abortion be performed if conception occurs. Those white retarded adults who manage to have children are generally married, in their late 20s or 30s and less tied into a family support system. Black families, on the other hand, are more likely to welcome the first grandchild and tend to become involved in the internal affairs of their retarded child only after a grandchild is born. These births tend to occur when the retarded mother is unmarried, in her teens, and living at home with family members. And most striking, while white grandparents fear being burdened by the care of their grandchild, black grandparents appear hopeful that the grandchild, when older, may in turn provide support for the retarded parent.

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