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# Understanding the Parenting Issues of Adults with Mental Retardation

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Alexander J. Tymchuk, Ph.D.  
Linda Andron, M.S.W.  
Stephen J. Bavolek, Ph.D.  
Anne S. Wuattrociochi, M.S.W.  
Hester I. Henderson, Ph.C.

## The Right of Retarded Adults to Become Parents

Although there continues to be an effort to ensure that the rights of individuals who are mentally retarded are protected and that they enjoy adequate opportunities to express those rights, the right to be a parent continues to be an elusive one (Hertz 1979). The reluctance to allow people who are retarded to procreate stems from a historical fear that they will have retarded children (Hathaway 1947). This attitude is best exemplified by Justice Holmes when he stated that "three generations of imbeciles are enough" and upheld a state law that was the basis for forced sterilization (*Buck v. Bell*, 274 U.S. 200, 207: 1927). Although laws for the indiscriminate involuntary sterilization of persons who are mentally retarded are no longer on the books, the attitudes that parents who are retarded will have retarded children, or that they are incapable of caring for children, continue to prevail (Bass 1973; Hall 1974) despite the inadequacy of the evidence on which they are based (Payne 1978). On the other hand, equal rights for persons who are retarded in the area of sexuality and marriage are being advocated (Andron and Sturm 1973; Budd and Greenspan 1985). The concern regarding the inability of parents who are retarded to care for their children is an appropriate one, but it is unclear whether in fact they are capable of doing so, or whether there are circumstances under which they are capable (Fotheringham 1971).

There are several problems in relationship to the information being reported so far on the parent who is mentally retarded of which the reader must be aware. First, the applicability of information gleaned from early and even from more recent writings on parenting by de-institutionalized adults with mental retardation to adults with mental retardation raised in the community, is questionable. These people lived in very restricted environments and, even when placed in the community, they lacked adequate social supports. A caution must be raised therefore not to judge the parenting capabilities of people who are mentally retarded when only based upon historical information. These data can only provide us with some direction. In fact, it may not be until a whole generation of retarded parents has lived in the community during which time accurate diagnostic criteria have been applied and supports given, that we can truly understand their capabilities.

A second major problem with past, as well as present, studies has been the manner in which samples to be studied have been selected. The parents with mental retardation who have been reported upon have not been representative of the general population of retarded parents. In addition, studies have used limited sample sizes: some have been court-referred (e.g. Shaw and Wright 1960), followed after leaving an institution (e.g. Borgman 1969), or after graduation from a special education class (e.g. Feldman et al 1985). Furthermore, all samples have been from lower socioeconomic groups; to get a representative sample studies are needed to determine the extent of the universe of parents who are retarded and to make comparison with intellectually normal parents of the same socioeconomic status.

A third methodological problem that exists with this evidence is that of a general lack of sophistication, plus a lack of comparability of methodologies. Some reports are little more than case studies based on the author's observations of a parent, without consideration of

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observer bias or measurability of the observation (e.g. Bowden et al 1971). It is also unclear who are the people being studied, as many of the studies report on parents with a history of mental retardation (e.g. Peterson et al 1983). Despite these limitations, a number of conclusions have been made regarding retarded adults as parents: that they will have retarded children; have larger families than the norm; that these children will be poorly cared for; and that retarded adults cannot be trained to be adequate parents.

### Do Mentally Retarded Parents Have Retarded Children?

The major concern regarding whether adults with mental retardation should have children has always been that they will have retarded children. The concern emanated in a large part from the early descriptions of the Kallikak (Goddard 1912) and the Jukes (Dugdale 1920) families. More systematic studies have shown that the incidence of organized etiologies among offspring of retarded parents is equal to that found in the general population. However, it is unclear whether the IQ's of offspring of retarded parents are similar to those found in the general population (Laxova et al 1973). There is evidence that the adequacy of the environment in which they are raised, can influence the intellectual functioning of these children.

Brandon (1957, 1960) in one of the few systematic descriptive studies, reported on all of the women who had children and who had been admitted to an institution in England. Where the mother's mean IQ was 61.1 on the Terman-Merrill (range 38 to 84) or 83.1 on the Wechsler-Bellevue (range 49 to 113), 99 (91 percent) of the 109 live children were normal intellectually. One woman who had the highest IQ (113) had a child with the lowest (44), while a woman with the lowest IQ (55) had a child with the highest (132). There were differences in the IQs of the children depending upon where they were raised. While the 30 raised by their mothers in the institution had a mean IQ of 98.7, 25 raised in foster care had a mean IQ of 96.8, and 38 in orphanages had a mean IQ of 87.6. Charles (1953, 1957) also reported that the IQs of the children of the retarded parents in his study were in the low range with two children being institutionalized and two others requiring special education.

In contrast to these studies, others (e.g. Shaw and Wright 1960; Priest et al 1961; Reed and Reed 1965) have shown that the incidence of lower IQ among offspring of retarded parents is higher than what would be expected in the general population. However, because many of the retarded parents studied live in impoverished environments and because there are no longitudinal studies of their offspring, it is difficult to determine what the effects upon the child are of poverty on the one hand, or being raised by a retarded parent on the other. Based on a sample of 40 (Tymchuk and Andron 1986), there has not been a significant relationship between the mother's IQ and that of the child. For example, three mothers with IQs in the 60's have children tested in the above average to gifted range.

Etiology has to be considered. If the parents' retardation is the result of birth injury or post-natal injury or illness, the hereditary factor would not be involved. However it should be noted that one of the families above has a pattern of retardation over several generations and yet now has a child testing at a very high IQ.

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### **Do Mentally Retarded Parents Have More Children?**

The second issue that emerges when discussing the parent who is retarded is whether they have more children on the average than the norm. As there are few studies which provide a contrast group of the same socioeconomic status as the retarded parents, it is difficult to make a precise determination of this issue. Based on current studies, it seems apparent that retarded parents have the same number or fewer children than the norm.

In an early study, (Ainsworth et al 1945) studied 50 women who had been institutionalized – of whom 47 were married with 115 living children (64 boys, 51 girls), an average of 2.3 percent woman. This figure was corroborated by Charles (1957) who was able to locate 127 people who had been originally studied by Baller (1936). He reported that the group averaged slightly more than two children per family, which was slightly less than the national average for the age group at that time. Although these data have been substantiated by others (e.g. Peck and Stephens 1965; Mattinson 1979; Craft and Craft 1979), still others (e.g. Priest et al 1961) have shown a higher number of children in comparison to the norm. In this latter study, however, the selection of the sample may have accounted for this finding.

### **Do Mentally Retarded Parents Provide Inadequate Child Care?**

The third concern when we speak of retarded adults is the adequacy of the care that they provide for their children (Schilling et al 1982). Available evidence shows that, while some parents provide inadequate care, others do provide adequate care. However, just as there are design and definitional problems with the literature related to the understanding of the intelligence and the number of offspring, so too there are problems in this area. The major shortcoming after subject selection bias is the concept of adequacy of childcare. The majority of studies provide a limited definition of what constitutes adequate care and only anecdotal evidence as to how it was measured. Peck and Stephens (1965), for example, reported on a group of five families only one of which was doing “reasonably well.” Bowden et al (1971) reported on one retarded couple’s marriage and commented on the couple’s difficulty in caring for the child. Similarly Crain and Miller (1978) reported on one couple.

Although these data are not overwhelming, other data from Scally (1973), who reported that 62 percent of the children of 342 people with retardation in Ireland were not being cared for adequately, support the contention that parents who are retarded do not provide adequate child care. These and other data, however, also show that some retarded parents can provide adequate care. Floor et al (1975), for example, reported on marriages of previously institutionalized people who are mentally retarded, some of whom had children. The authors concluded that, although the care of some of the children was questionable, others were receiving adequate care.

Borgman (1969) has suggested that one of the identifying factors regarding who can provide adequate care is IQ – especially below 60 – while above 60, other factors may play a greater role. Michelson (1947) suggests that adequacy of care is related to the number of children, to marital harmony, to additional problems (e.g. alcoholism or personality disorders) and to adequacy of income. In this study (1947), Mickelson reported on 80 families in rural Minnesota where the wife (74 percent), the husband (9percent), or both (17 percent) were retarded. Forty-two percent were rated as providing satisfactory care, 43 percent questionable care, and 26 percent unsatisfactory care. The average number of children was correlated with care rising from 5.4 to 6.2 for the three groups. Where

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mothers had IQs between 30 to 49, 80 percent of them were rated as giving questionable or unsatisfactory child care. With higher IQs, there was no relationship between IQ and level of care.

What data are available on the adequacy of child care provided by retarded parents suggest then that some parents can provide adequate care. Because of the lack of control groups, it is unclear whether this number is similar to that found among the non-retarded population of the same backgrounds. The data also suggests that there are predictors of adequate child care – namely mother's IQ at least between 50 to 60, the number of children, marital harmony, the extent of additional difficulties, and the adequacy of income. Clinical reports, unpublished papers, and professional communications from those currently involved with this population, support the finding that, above 60, the IQ of the parent is a poor predictor of ultimate parenting success – particularly if removal of the child from the home is used as a measure.

### **Can a Mentally Retarded Person Learn to be a Parent?**

The fourth problem related to adults with retardation as parents is whether they can learn to be parents. This issue has been of more concern recently because the courts have been asked to decide on who is an adequate parent (Hertz 1979). Although a determination of the adequacy of child care provided is one aspect of whether a parent is adequate or not, it is still only one determination. More importantly, there is a need to determine whether the person with retardation can be trained to be a parent, as most often, he or she has lived in circumstances which provided only limited training or role models. Gillberg and Geijer-Karlsson (1983) found in Sweden that 55 percent of their retarded mothers themselves came from deprived backgrounds. For Mattinson in 1971, the figure was similar.

Training programs for retarded parents are a relatively new phenomenon and their results are promising; however, there is some earlier evidence that training and/or extensive support does allow retarded adults to function better as parents. Mickelson (1949) in the second part of his study, found that where increased agency support was most needed, it was least accepted. This suggests a circular effect of doing poorly, being identified, refusing help and doing more poorly. Some of the parents, particularly in the group which provided adequate child care, were institutionalized; during which time they were sterilized and provided with some training. After this period, apparently some families did better than before institutionalization. Because sterilization occurred after the fourth child in the satisfactory group, after the fifth child in the questionable group and after the sixth child in the unsatisfactory group, the number of children seems to impact on the adequacy of care.

Although Mickelson suggested that IQ was not the critical factor in determining parental adequacy, an interpretation could be that the lower the IQ, the less likelihood of a job and therefore less money and poorer care. Alternatively the lower the IQ, the greater the need for additional efforts at training, particularly as general counseling had limited usefulness. Mickelson's study also suggested a need for the identification of the characteristics of those parents who require such additional training.

Several studies have shown parents who are retarded rarely praise, usually punish, and have limited cognitive interactions with their children, although they do not seem to differ from other parents of the same socioeconomic group (Mira 1982, 1984). Peterson et al (1983) provided specific behavioral training to six retarded parents on four behaviors:

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describing, praising, reflecting, and interacting non-directively with their child. After training, these behaviors changed significantly, but on follow-up one month later, only the decrease in directiveness was maintained. The parents who were mentally retarded were similar on follow-up in praising in comparison to a normative comparison group. The authors suggested that further training was required in order to continue gains.

### **Factors Influencing Adequacy of Child Care and Ability to Learn**

Over 30 specific training programs for parents with retardation or other developmental disabilities, as well as many others integrating them into high risk service models, have recently sprung up across the United States. Networking has become a major effort in our need to gain some understanding of the parameters that impinge on the functioning of this population and the best ways to provide intervention. A series of external factors and personality dynamics are beginning to emerge as significant parameters. The discussion which follows represents the conclusion of our own work with 40 families, as part of Project Parenting at UCLA. Much of this information has been corroborated by the numerous others involved in the national network we have coordinated.

#### **Judgment**

What then are those significant factors? To begin with, we must restate that IQ above 60 does not seem to affect parenting success if we measure this either by the eventual removal of the child from the home, or by the child's development on both cognitive and emotional levels. Even judgment, which is presumably greatly affected by IQ, does not seem to follow. For example, Grace (IQ 50) was raising her grandson. When a second story window broke and the management of her building took no action to fix it, she put a chair in front of it, presumably to block it off. In fact, Alan, aged two, used the chair as a way to climb up to see what was outside. He fell two stories, was amazingly unharmed, and was subsequently removed from her custody. The group of mothers (with IQs in the 60's and 70's) then participating in Project Parenting, were well able to see the poor judgment involved and spoke of what their responses would have been, such as calling the Health Department or placing wood or cardboard over the window.

#### **Family History**

Family History clearly seems to be one of the most significant factors. Those who had parental role models that provided some nurturing are clearly more nurturing of their own children in spite of other environmental difficulties. Those with histories of physical and even sexual abuse are more inclined to show rough handling, though they speak of a great desire not to repeat what their parents did to them. However, even those who grew up in intact families with some type of parent role models had little in the way of programming for parenthood. All relate that their families never thought they would become parents and so did not provide the covert messages about what one does as a parent as they grew up, that are normative in other families.

#### **Independent Living Skills**

As with many developmentally disabled adults, the parents we have worked with have been socialized to be highly dependent. They have been given little chance to learn to make decisions or discover the consequences of varying actions. Many have also entered parenthood without the benefit of training for adulthood, i.e. any independent living skills training. Often they have not come to the attention of the service system

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until they became parents. Once parents, the focus has been on parenting skills, often without evaluation of their ability to care for themselves.

Many of the lacks we have seen in parents' ability to provide for their children came from a lack of ability to perform basic skills of independent living. Joan, for instance, had few cooking skills and no confidence in those she did possess. She and her son ate breakfast out every day and brought in fast food or prepared sandwiches for themselves and her husband for dinner. This was compromising both their nutrition and their budgeting. When an independent living skills instructor was sent into her home, Joan was able to learn to prepare many dishes, shop appropriately, and budget for this. Their family began to eat together and nutrition and budgeting improved. The most dramatic effect was on her self-esteem. This was markedly demonstrated when she was able to make hors d' oeuvres and a three-layer cake for her son's third birthday.

### **Relationship with Professional Agencies**

The most complicating aspect of this is the multiple messages parents must attend to from the varying "authorities" in their lives. As parenting is not a black and white issue and professionals bring their own personal and cultural biases to their work, advice about the same issue often differs from one to the other. Also, the parents must prioritize in regard to which agency's demand and suggestions take precedence. Dependency seems also to increase with so many people involved.

In understanding the parents' response or lack of response to service, we must look at the constant boundary invasion they experience. What may seem to be resistance may in fact be their way of trying to shore up these boundaries. Few people are required to open their homes to the type of scrutiny these families are exposed to. They are clearly judged on a more stringent standard than the general population and are very aware of being constantly watched. In the early months of our program, one mother brought her children in a new outfit each week. When asked how many they had, her reply was, "How many weeks will we be coming here?" While we protect people's reproductive rights with regulations against sterilization, we have public laws stipulating that children can be removed from parents because parents are developmentally disabled. All this leads to reluctance on the part of parents to utilize services. Because of the stringent reporting laws, families know that if they reveal serious difficulties, the service provider will be forced to report them. This makes trust very difficult to build. Service providers must be honest about the role they play.

Mentally retarded parents live in constant fear that someone will come to take their children away. For some, this seems to account for the over protectiveness they demonstrate. Some of the "paranoia" would appear justified. There seems to be little rhyme or reason about which reported case the Department of Children's Services (DCS) takes action on and even less reliable criteria on which to measure what actions the judges will take. When Grace's (IQ 85) severely retarded daughter gave birth to a son, Grace took responsibility for raising the child. She was repeatedly warned about the dangers of leaving the child with her daughter and how he would surely be taken away if anything happened. One night she did and he was harmed. The story is unclear, but the child was found to have a severe abrasion with the skin literally rubbed off the elbow. The judge returned the child one week later with no court order for any particular evaluation or service. On the other hand, Carol lost both her children after pinching the younger one when she could not control her crying. In spite of the

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following through of all the counseling requirements and demonstrating her ability to handle the older child, the system resisted the return on the grounds that no one could guarantee that her anger would not be expressed inappropriately with this child.

Similarly, when the police were called after a previously well-functioning mother had a paranoid episode, the child was taken into custody without any effort to find the stepfather or to see this as a crisis rather than a representation of her global inability to parent. No psychiatric care was ordered. The mother was judged on her current psychiatric status rather than on any comprehensive evaluation. On the other hand, when the police were called to the home of an alcoholic mother they did nothing as they said she could still walk. This mother was reported to the Department of Children's Services on many occasions before the children were removed.

These parents do not have the savvy to screen what they tell the professionals who are judging them, especially those they are not voluntarily involved with. Thus, Anita called the worker to say her five-year-old said he hated her. Without understanding the developmentally appropriate, if not pleasant, nature of this comment any better than the mother, the worker saw this as proof that the child needed to go back to foster care.

### Family Involvement

In respect to familial involvement, we have been surprised to see how little physical support many of these parents get from their extended families. Parents of retarded children speak often of their fear that their children will have children whom they will have to raise. In fact, this is only the case in multigenerational families. In a few instances, families are providing minor financial support. In others, they have much to say about how things should be done, but are not available for actual child care. Almost none of the parents are able to have time to themselves due to the lack of money for baby sitters and the reluctance of family members to care for their children.

However, the extended family, even if dead or living far away, has a powerful influence in terms of the clients' desire to win their approval. This is especially problematic when the advice of grandparents is in direct conflict with the advice of doctors or professionals. An example of this was the mother who fed her baby solids at four weeks because her mother told her to do so. The professionals involved were saying that giving him solids too soon was resulting in his "failure to thrive." Both the involved agencies and the family were threatening to have the baby removed but for opposite reasons.

The multigenerational family poses an interesting challenge. Usually the mother in such a situation is referred by her own mother, who asks for help in improving her daughter's parenting skills. However, if she does not learn new skills, this seems to upset the family equilibrium. This has led, at the benign end, to mothers being withdrawn from the program to the more serious consequence of verbal or even physical abuse directed towards the mother and/or her children. Things have become extremely difficult when the mother speaks of moving out. Unfortunately, some of this need to keep the mother in her parental home seems to be motivated by the SSI checks involved.

When we consider assessing the success of parenting in multigenerational families, we are faced with another challenge. If the child or children are developing well, can the parent be seen as successful or is he/she by definition inadequate because he requires

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or chooses the support of the multigenerational family? Among the families we have known, multigenerational families appear to be normative to some minority cultures. In many of these families, siblings without retardation are also raising their children in these family units.

### **Cultural and Religious Factors**

This leads us to the cultural issues operating for many of these families. When a mother was seen using a great deal of physical punishment, this was felt to be the result of her difficulty with anger control. In fact, probing further, we discovered that this is the norm in her family which has dealt with disobedience with a physical response for as long as she can remember. On a home visit, we found another grandmother with a folded belt on the table and we were told clearly that this was culturally normative. We, of course, had to be honest regarding the law's definition of its use as abusive.

Cultural issues have been seen in respect to nutrition education as well. Our staff became alarmed when a mother spoke of chewing her child's food before giving it to him. Further exploration revealed that this was a normative practice in her culture and posed no real danger to the health and safety of the child. While children sleeping in bed with their parents or fed on their laps may cross mainstream middle-class standards, they are normative for many cultures.

Religious factors also play a role. While one mother was having amniocentesis because "my Regional Center worker told me to," she assured us that she would never have an abortion no matter what the results were, due to her Catholicism. This belief also sustained her hold on life when her depression became intense and she considered suicide.

### **Marital Relationship**

As for "normal" couples, marital issues have a strong influence on parenting. Much of the marital discord we see centers around issues of extended family. This often further complicates the difficulties parents who are mentally retarded have in deciding whose messages to attend to. The mother may be the one interacting with the agency personnel and then having to defend this against her husband's family's input or vice versa.

Several of our families fit what might be called the "Jack in the Beanstalk" syndrome. The wives in these families complain that their husbands are ogres and to listen to the men the illusion is there. But, like the ogre in the story, these men feel very inadequate and use their bravado as a cover up. Their wives, like the ogre's wife, play a role in supporting this behavior. In some cases, the "ogre" is actually physically violent. These men speak of the intense effort they exert not to allow their anger to affect their children; perhaps their wives are a safer target for their frustration. One of these men was essentially totally uninvolved with his son except to yell at his wife to keep him quiet. His wife had only negative things to say about any effort he made to change. Following an angry explosion on his part, she went to a shelter with their son. The husband became depressed and contracted to try to play a major role if she returned. She in turn agreed to be more supportive of his efforts. With this new focus, he began to venture to play with his son and demonstrated some excellent interactive skills previously masked by the severe discord and his painfully low self-esteem.

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### Support Groups

We have found that mothers have drawn a great deal of support from the peer support and discussion groups they participate in. They are frequently surprised to find that their problems are shared by other women. Through discussions and role plays they often gain new insights into their rights to resist verbal and physical abuse. They also develop friendships that they can pursue outside of group time. This gives them someone to call and often a place to retreat to when they fear abuse. While this would at first glance seem very positive, it often has much the same effect as intervening in multigenerational family systems. As the equilibrium in the relationship shifts, the men become disturbed and either attempt to "forbid" their wives from attending or become more abusive. While their situations often seem quite desperate to program staff, compared to the physical and sexually abusing environments in which many of these women grew up, their current lifestyle represents a major improvement.

### Poverty

Poverty, of course, also has a major effect on the lives of these families. With the high cost of rent and food, there is little money for anything else. They are unable to afford baby sitters or any type of entertainment for themselves. They must constantly skimp to make ends meet. As they are unable to pay for day care, the only way they can get respite is to become part of the program designed to provide day care to children at risk of abuse or neglect. Many have been raised in more opportune economic conditions. Their disability has left them either on SSI or in the entry level jobs and so living a culture of poverty that is foreign to them.

Those who try to make it on their own are actually penalized for their efforts. A family can make less than the income level that would qualify them for aid, but be ineligible because the number of hours the father works renders him "fully" employed. Marginal employment leaves a family also ineligible for WIC and food stamps (nutrition programs and medical aid). We have yet to understand how families receiving identical income levels seem to manage in very different ways. Some of them provide for themselves and their children in an almost miraculous way on infinitesimal incomes.

### Social Isolation

Their poverty as well as their sense of being different leads to severe social isolation. Marriage and/or parenthood have rendered them incompatible if not ineligible for social groups for retarded adults; while merging with the greater community is difficult. Several families trying to live in middle-class neighborhoods have attended "Mom and Me" programs, but felt out of place. Distance and cost of transportation preclude them from getting together with those people they know.

### Personality Factors

Having isolated these largely external factors, we also turned our attention to what personality factors might emerge as predictors of the variability of parenting abilities in clients with similar IQ. Low self-esteem with its attendant depression seems to be one of the most debilitating influences on successful parenting. While this would seem to be an intrapersonal factor, in fact it has its roots in the way these people are dealt with interpersonally. From their earliest years they remember being spoken to and of negatively or at best being ignored. They have never been reinforced for success and have not

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experienced positive reinforcement from their social environment. Their eligibility for all of the services they utilize is the result of their weaknesses and their performance is constantly scrutinized for failure rather than success. The very fact of becoming parents, a life status lauded for others, is criticized, even by the would-be proud grandparents.

### **Personal Childhood Experiences**

Many studies have shown that parents with retardation have difficulty praising their children. These parents will often relate the fact that they themselves received little or no praise or at best an occasional "good girl." Having never experienced positive reinforcement, they have little understanding of what it is. Their lacks in the area of stimulating imaginative play also have roots in their own childhood. In order to engage in imitative play, one must operate at a child's level; many of these parents have been either so deprived of play themselves that they become personally engrossed in the activity, or they are so fearful of seeming "retarded" that they avoid such interaction and tend to be overly directive in their children's play. Having had so few successes in their own lives, they often look to measure their own self-worth by their children's progress.

### **Health**

Their depression has also usually been lifelong; therefore measures of depression, such as the Beck, may not reflect their feelings as this instrument tests "recent onset" depression. Other medical problems, such as seizures, have a strong influence on their abilities as well. Psychiatric disturbance, particularly of the characterological nature, seem to have a profound effect on functioning. Alcoholism has also been a major factor here.

### **Expressive and Literacy Skills**

Specific language disorders, often previously attributed to their low IQ levels, have gone ignored and untreated. These have a major effect on their ability to provide cognitive stimulation. Many have not learned to read, in spite of IQs in the 60's that would predict the ability to learn to read at the fifth or sixth grade level. Mothers in our program have recently been involved with volunteers trained in the use of the Laubach Literacy System. All have made significant progress and speak of great gains in self-esteem related to this. Even those who know how have expressed great fear in confronting written materials, due to their long history of school failure.

### **Motivation**

Motivation is perhaps the most critical factor in success of both parenting and use of training. Those who are referred by the courts often come with obvious lack of internal motivation to improve and project all problems on others. As in any type of therapy, those who see their own need to learn new things and make changes while not taking responsibility for things that are clearly external, do best. This is also seen in a recent survey of behavioral therapists (Budd and Greenspan 1985). They also identified original adequacy of care (again we do not have an objective tool to measure this) as a major predictor for use of training. There seems to be mothers who instinctively have provided their children with empathy and response. However, we have had two mothers whose anxiety and depression so clouded their abilities that, in the early months, they were unable to handle their babies appropriately or provide good care. With some clearing of this symptomatology and concomitant improvement in self-esteem, they are

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now able to interact well with their children including praise, imitation, and being verbally responsive.

### **Intervention**

Some initial conclusions regarding intervention with these families can be drawn from the experience of the network of programs serving this population. First, it must be stressed that these parents strive to be good parents and learn to improve their abilities. It is important to them that their children have a better life than they did. There seems to be some distinction between those who are court-referred as opposed to self-referred. In working with these families, it is essential to have constant interaction with the myriad agencies they deal with, and have face-to-face contacts as often as possible. It is vital to clarify which agency or person has primary responsibility. It is also essential to establish a trusting relationship. This can often take a very long time because of the many previous negative experiences with agency personnel.

Establishing trust requires honesty. The parents must be told of the legal need to report suspected abuse and neglect. They must feel that the professional is their ally but will do whatever is necessary to protect the child. It helps for them to be able to see that this is their ultimate aim as well. One must have a truly good feeling about these families; they have experienced condescending attitudes, patronization, distrust and outright dislike from various agencies. Such attitudes must be avoided at all costs. A professional must be really committed to working with these families and be able to see both their strengths as well as their problems.

Once a positive relationship is developed, professionals must provide parents both with things to do and those to avoid. We must be reasonable in the amount of change to expect, always keeping cultural and religious factors in mind. Knowing their difficulty in generalizing, material must be presented in a variety of ways. Written materials are rarely useful with this population. Even those who are able to read are often phobic because of so many negative experiences in school. Audiovisual presentations are particularly useful.

The use of models as "like" the parents as possible is essential for motivation for attempt to change and the eventual development of self-efficacy. Peer modeling and feedback is often better accepted than professional input. For this reason, a combination of center-based programming with a focus of peer support and in-home follow-up is very effective. Center-based programming allows the parents to have some respite from full-time care as well. Child care workers can be trained to provide children with stimulation while mothers participate in group sessions. Mother-child interactions are enhanced by the larger facilities and greater number of toys available. In-home follow-up is necessary to attempt generalization of concepts presented at group sessions. Transportation is a major problem for most of the families and center-based programming will only be successful if this is arranged. Careful evaluation of each member before joining the group is clearly indicated. Home visits and individual sessions to clarify goals are also important.

Psychotherapy is not always indicated even when secondary psychiatric disorder is present. This is somewhat analogous to our teaching parenting skills in spite of being unable to change an individual's IQ. The process of insight-based therapy can lead to uncovering of more than can be handled. Group process in a psychotherapeutic rather than parent education or peer support group can be unsettling for many parents. One

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must be particularly careful when therapeutic interventions are aimed at behavior ingrained in a person's life script. It is particularly important to provide the necessary "protection" before permission is given for the client to change (Steiner 1974).

### Conclusions

In this chapter we have attempted to unravel some of the background and factors at issue when persons deemed to be mentally retarded have their parenting ability called into question. The picture is far more complex than once believed. There is still no agreement on what constitutes "adequate child care" and we are still only in the early stages of developing educational and training programs which take into account of the often negative past-life experiences of adults with mental retardation, and which offer them support in their parenting role.

Debates as to whether or not adults with mental retardation should be allowed to have children will continue in ethical and academic forums. The reality of the birth of these children will continue in society and the need to develop appropriate services will remain a priority for clinical settings and relevant agencies. The general community has recently become aware of the issue through extensive media coverage and has shown recognition of the desire of these families to provide and care for and about their children. It is incumbent on professionals in the field to conduct service-based research studies which will serve to clarify further the parameters that do, in fact, predict successful parenting and interventions that will help this population succeed in their goal.

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