Deinstitutionalization and the movement towards "least restrictive alternative" has meant that persons with retardation are increasingly living in the community. Adults with retardation are marrying and having children. Unmarried women with mental retardation (those with moderate and severe retardation as well as those classified as "mild") are having children. Research indicates that fertility rates of women with retardation are similar to or slightly higher than fertility rates of the general population with a mean of 2.8 children per mother with retardation (Accardo & Whitman, 1990). It has been estimated that at least 120,000 babies are born each year to mothers who are mentally retarded (Keltner & Tynmchuk, 1992).

Mental Retardation is defined by the American Psychiatric Association (DSM-IV, 1994) as significant subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning. Adaptive functioning includes the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, academic skills, leisure skills, health and safety. The onset for Mental Retardation must occur prior to age 18.

DSM-IV (1994) further delineates subaverage intellectual functioning as an IQ of about 70 or below (approximately 2 standard deviations below the mean). Four degrees of severity are specified: Mild (IQ 50/55 to 70), Moderate (IQ 35/40 to 50/55), Severe (IQ 20/25 to 35/40) and Profound (IQ below 20/25).

The prevalence rate of Mental Retardation has been estimated at approximately one percent of the population. Etiology is heterogeneous and may be primarily biological or primarily psychosocial or a combination of both. Heredity accounts for approximately five percent of cases.

Citizens who have mental retardation need to have the same guarantees of freedom as any other citizen. At the same time citizens with mental retardation need to follow laws, including specific laws that require adequate care for children. All children need to have basic needs met regardless of parenting and regardless of the limitations of the parent. (Forder, 1990)

**INCIDENCE OF MALTREATMENT**

Are children of parents with mental retardation at increased risk of maltreatment? This question has been researched in a number of studies (Accardo & Whitman, 1990; Feldman & Walton-Allen, 1997; McGaw & Sturmy, 1993; Schilling, Schinke, Blythe, & Barth, 1982).

For example, Schilling et al. (1982) reviewed 14 studies investigating the adequacy of parents with mental retardation. The studies were published between 1947 and 1979. The sample sizes were 17 to 342 and with four studies having samples over 100, seven with samples of 50 to 99 and three with samples under 50. All but one of these studies found that persons with retardation were over-represented for incidence of maltreatment or were more likely to demonstrate unsatisfactory parenting. The single dissenting study had a sample of only 20 with a mean IQ of 75.5 (relatively high IQ scores above the range of retardation). Schilling et al. cite many methodological problems in these early studies, as do other reviewers (Dowdney & Skuse, 1993).

A 1983 study in Sweden (Gillberg & Geijer-Karlsson) traced all women with retardation born between 1943-54 and living in Gothenberg. Of these, 15 women had given birth to 41 children. The ages of the children ranged from 1 to 21 years. One child had died. The psychosocial living conditions of the families were judged unsatisfactory in 85 percent of the families. Despite having been "offered maximum help from society" (p. 893), only two mothers lived in acceptable conditions.

In a 1989 study, a retrospective review was undertaken of comprehensive assessments of 107 children from 79 families in which one or more parents were diagnosed with mental retardation (Accardo & Whitman, reported in Accardo & Whitman, 1990). Of the 107 children, 71 (66.4 percent) had suffered child abuse, sexual abuse, failure to thrive and/or child neglect. In general, children who were cognitively brighter and who could talk better appeared more likely to be maltreated.

Still, actual numbers of affected children are difficult to obtain. According to Ray, Rubenstein and Russo (1994), in 1992 at least 2000 children placed in out-of home care by New York’s State Social Service system had at least one parent with mental retardation and an additional 800 children in the child protective service system were living with a parent with mental retardation. These numbers are not especially helpful, because the total number of children served was not reported.
Parents with Retardation
continued from page 1

It is important to emphasize that some parents with mental retardation provide satisfactory care to their children. For example, a very early study (Michelson, 1947, reported in Tymchuk & Andron, 1990) found 38 (42 percent) of 90 families were providing satisfactory care. In evaluating 33 consecutive admissions to a parenting project, Tymchuk & Andron (1990) found about half had abused or neglected their children and half had not. This is similar to findings of McGaw and Sturmy (1993) where approximately half of parents with retardation were reported for child maltreatment. Unfortunately, parents with mental retardation who are being successful have not been identified and studied by researchers. The parents who are involved in programs are generally those whose parenting has been identified as deficient.

Some parents who are successful in retaining custody of their children and providing adequate care are assisted by family members. The mother and child(ren) may live with a sibling or parent or family may check on the mother and assist with finances, homework or other aspects of parenting. Although frequent mention of family support was made in the literature, no data was offered concerning how many successful parents with mental retardation were receiving assistance from, or living with family members.

TYPE OF MALTREATMENT

Concerns about the parenting of persons with mental retardation center upon physical and psychological neglect, rather than upon physical abuse or sexual abuse (Feldman, 1998).

Tymchuk (1992) is careful to distinguish between child abuse and child neglect. He maintains that IQ, by itself, is not a predictor of either the occurrence or of the nonoccurrence of purposeful child abuse in parents with mental retardation. Indeed, Tymchuk states that physical abuse is rarely perpetrated by the parent with mental retardation but rather, when present, is the result of another person associated with the mother who may be either emotionally disturbed or substance-abusing.

In contrast, Tymchuk notes that for child neglect, an IQ below a certain level, usually 60, can be a predictor of neglect. This assertion is similar to conclusions of Dowdney and Skuse (1993) who reviewed the literature and concluded that "parenting is less likely to be competent in retarded mothers whose IQs fall below 55-60 on standardized tests" (p. 43). However, Tymchuk maintains that the best predictor of child neglect by persons with mental retardation is the absence of suitable societal or familial supports.

It should be noted that advocates maintain that many parents with mild mental retardation (sometimes termed "educable") can acquire both the knowledge and the skills to perform similarly to other parents living in poverty (Llewellyn, 1997; Tymchuk, 1992). Since persons diagnosed with moderate retardation vary greatly in their general abilities, it can be expected that individuals falling in this IQ range will vary in their competence as parents. There is less information about those individuals falling in the severe and profound ranges.

SPECIAL RISKS

What parenting problems have been documented for those with mental retardation? Available literature suggests that problems can be grouped according to several broad categories: lack of reading skills; communication problems; concrete thinking (leading to limited problem solving); limited ability to provide cognitive and emotional stimulation; impaired learning and memory; social skills deficits; lack of internal control; and motivational problems (Espe-Sherwindt & Kerlin, 1990; Schilling & Schinke, 1984).

Lack of reading skills.

For those parents with limited or no reading ability, parenting is more difficult for several reasons. These parents are unable to read books or magazines about raising children and are unable to consult printed material for help in parenting tasks. They are also unable to read directions on medicine bottles, increasing the likelihood of misadministration of medicine. Likewise, a baby may be fed inadequately because the parent cannot read the mixing instructions on formula. Parents without reading skills can not read to their children, thus the children fail to receive this important source of stimulation. For those parenting older children, lack of reading means that notes and announcements from school can't be read, that report cards may not be understood, that opportunities for child activities may be missed, and that homework assignments are a mystery.

Communication problems.

Communication problems may include limited use of language or speech. Some parents with mental retardation may not talk interactively with their infants.

Whitman, Graves & Accardo (1990) provide an example:

"Watching Nellie change his diaper was like watching a clerk wrap a lumpy package. There were no words or comforting sounds, no eye contact; it was just a matter of getting the job done. When Janet, the parent aide assigned to Nellie, began modeling more appropriate diapering behavior, Nellie said to Janet, 'Why do you talk to him? He don't understand and he don't say nuthin.' The aide responded briefly that babies need attention and that hearing people talk to him would encourage him to make sounds and eventually talk. Nellie was unconvinced." (p. 55).

Concrete thinking.

Concrete thinking may limit the parent with mental retardation to only a few child management techniques. The ability to adapt the technique to the situation or the ability to apply a technique to a new situation may be limited. For example, Tymchuk (1992) cites a lack of knowledge and problem-solving for health care, safety and emergency situations. Parents with mental retardation may not understand the significance of symptoms and too often suggest responses that "if implemented would even be more harmful to the child or to themselves" (p. 170).

A parent with retardation may apply learning inappropriately, even if that parent is highly motivated to be successful. Rosenberg and McTate (1982) provide an example. A mother who learned how to play interactive games with her nine-month-old infant was observed a year later still attempting to engage the child in the same games. The mother failed to recognize her child's growth and adjust her approach to the child's needs. Others (Llewellyn et al., 1997) have commented that parents with retardation seek to "know exactly what they should do" (p. 250) rather than appreciate the dynamic, growing, changing nature of child rearing.

Inadequate judgment and lack of ability to foresee consequences can compromise safety for the child. Rosenberg and McTate (1982) mention a young mother who failed to realize that her 2 1/2-year-old son was in danger if left in the bathtub unsupervised while she visited with friends outside the apartment. Kaatz (1992) labels safety issues as an "enormous concern" (p. 215) in parents with mental retardation.

Limited ability to provide cognitive and emotional stimulation.

A subtle but important aspect of child rearing is the ability to provide cognitive stimulation for the child. This requires understanding child development and the ability to notice as the child matures into new capabilities. It requires planning for the child's growth so that opportunities are available when the child is ready for them. Such longer-range planning and preparation may be beyond the capability of parents with mental retardation and their children may lack appropriate stimulation for normal growth and development.

Nurturing is also vital to the developing child. Parents with mental retardation have been found to be less interactive, less
affectionate, and less likely to use praise and other positive reinforcement than mothers without retardation.

Some research suggests that parenting stress escalates as the child matures (Feldman, 1998). Children’s needs become more complex and varied as they grow. Parents who are able to meet the basic physical care needs of younger children may not be able to assist school-aged children with skill development or maintain a steady course for an unruly, acting-out teenager. Some parents with retardation are overly permissive, do not supervise or set limits, and instead allow their children to run the household. Indeed, one investigation (Feldman, Leger & Walton-Allen, 1997) found that mothers with intellectual disabilities who had school-aged children reported significantly more stress than mothers of infants, toddlers or preschoolers. Unfortunately, little attention has been paid to the parent with mental retardation who is parenting older children (Llewellyn et al., 1997). Ray, Rubenstein & Russo (1994) note that older children had often been removed.

Impairments in learning and memory.

Impairments in learning, memory, concentration and interest may limit the amount and type of parent training that can be offered to parents with mental retardation. Enrolling in a class with a group (even a group of other parents with retardation) may not be feasible as the pace or type of teaching will not likely be able to be geared to the learning abilities of each parent.

Even if material is learned, difficulty in remembering may limit the application of skills. For example, Kaatz (1992) notes that infants and young children with parents who have mental retardation are at risk for inappropriate nutrition and/or failure to be fed in a timely manner. Inconsistent feeding, inability to adjust feeding to the child’s growth, and attempts to feed foods inappropriate to the child’s developmental level all contribute to medical problems. Such infants may then come to the attention of the medical community because of failure to thrive. Similarly, parents with retardation may simply fail to recognize medical needs of their children and fail to acquire needed medical care in a timely fashion (Kaatz, 1992).

Social skills deficits.

The past experiences of persons diagnosed with mental retardation may not have provided optimal socialization. Some persons with retardation have been institutionalized either in special education programs or in special vocational programs outside society's mainstream (Tymchuk, 1992). “Institutional living does not prepare a person to be an adequate parent” (Booth & Booth, 1994, p. 13). Limited contact with others means many of those with mental retardation lack practice in asking questions, seeking services and obtaining what is needed for both themselves and their children. The isolation frequently continues into adulthood (Llewellyn, 1995).

Many persons with mental retardation have a history of being abused or neglected themselves as children (Booth & Booth, 1994; Feldman, 1998). A personal history of maltreatment increases the likelihood that the parent will maltreat their own children. In addition to being misused by key individuals, persons with mental retardation may have negative experiences with service providers or agencies. In these cases, parents may avoid potential sources of support due to memories of the “bad” experience (Whitman, Graves & Accardo, 1989).

Lack of internal control/motivational problems.

Some parents with retardation may experience difficulty adhering to schedules. Parents must rise each morning and assist children in getting ready for school and meeting the school bus. Such persistence and self-direction may be more difficult for those with retardation. Some parents with retardation are unable to tell time, drive a car, or use public transportation independently, further complicating the task of maintaining regular school attendance.

Many adults with mental retardation have been taught through methods of external control. Self-direction and internalization of rewards have not always been stressed in special education programs. Thus, adults with mental retardation may daydream, procrastinate, forget or passively look to others rather than take responsibility themselves for daily, necessary tasks (Espe-Sherwindt & Kerlin, 1990).

Additional factors.

In addition, parents with retardation are likely to have low incomes, unskilled jobs or no job, inadequate housing and poor health. All of these factors complicate parenting.

One recent study (Feldman, Leger & Walton-Allen, 1997) found that parents with mental retardation experience clinically significant levels of stress. Stress has been shown to correlate with child maltreatment. Adding to this social isolation, poor self-esteem, self-held expectations of failure, inability to make judgements about safety, and lack of knowledge about child development, all common to parents with mental retardation, it becomes clear that most parents with retardation will need additional help and support to maintain minimal or adequate levels of care for their children.

Another area of risk has only recently been considered. That risk is the higher probability that adult persons with mental retardation living in the community will have the experience of being a crime victim, a victim of domestic violence and/or a victim of sexual assault or abuse. Children can also be injured during such incidents and are negatively affected by witnessing such events. Also, when someone is exploited, the entire family suffers.

According to Ticoll (1999), persons with retardation are vulnerable to being victimized because they are perceived as powerless and as “good victims” who are unlikely to marshal help. She places the risk of victimization at 150 percent of the non-disabled population. A recent study by Luiselli, Lisowski & Weiss (1999) found that 50 percent of their sample of adults with mental retardation had experienced maltreatment during adult years. Over 58 percent of females had experienced sexual assault as adults. According to Catriona Johnson, director of training and development at ARC of Maryland (1999), the risk of becoming a crime victim is four to ten times higher for adults with retardation than for the general population.

More subtle forms of exploitation also exist. Male “friends” of a mother with retardation may “borrow” and not return her money. They may also be subject to repeated sexual activity that is unwanted and which could result in unintended pregnancy.

Some authors (Tymchuk, 1992) maintain that an important source of risk of physical and sexual abuse to children of those with mental retardation comes from partners. “Live-ins”, acquaintances or even family of the parent with retardation rather than directly from the parent. Often the perpetrator who is associated with the mother is emotionally disturbed, addicted to substances, or criminal in behavior.

An example is provided by Ronai (1997) in an account entitled “On Loving and Hatting My Mentally Retarded Mother”. She describes physical abuse of both herself and her mother by Frank, her father. Frank also sexually abused his daughter and manipulated his wife into active sexual abuse of their daughter as well.

Child factors.

The above discussion has considered only factors about the parent. It is well known that child factors contribute to the
The combination of risk factors (parent risk factors and child risk factors) increase the likelihood of persons with retardation neglecting or abusing their children. Sometimes, extended family support can lower these risks, but other times, extended family may be of little help. For some parents with retardation, their family background was chaotic and abusive with their own parents showing a history of court involvement due to neglect, abuse, or inadequate supervision (Seagull & Scheurer, 1986). For others, the family is functional and wants to be supportive, but the parents with retardation are ambivalent towards or rarely tolerate offered assistance (Llewellyn, 1995). Still others have overtaxed the supportive people available to them (Forder, 1990; Rosenberg & McTate, 1982). For those parents with supportive family and a network of community support, risk for abuse or neglect decreases if the parent uses the support (Accardo & Whitman, 1990), as does risk of having children removed (Espe-Sherwindt & Kerlin, 1990).

It is important to note again that risk factors do not necessarily apply to all individuals within a given category. Researchers such as Llewellyn (1997) include a view that “parenthood for persons with intellectual disability is automatically beset with problems” (p. 256). Rarely are the experiences of parents with mental retardation who are doing well shared with professionals or with the larger community.

EFFECTS ON CHILDREN

Short-term Effects

There is some information about short-term effects on children due to inadequate parenting by those with mental retardation. However, no literature was found which systematically examined the overall growth and development of children being raised by a parent with retardation. Therefore, it is not clear which effects are most typical and how severe the consequences are.

The most frequent mention was of “developmental delay”. Authors noted that most of the delay was attributable to environmental and parenting factors, rather than genetics. Lack of stimulation leading to lack of language and cognitive development was specifically mentioned. Tymchuk (1990) states there is a significant risk of cognitive delay for children being raised by parents with mental retardation.

One piece of evidence supporting the idea that delays are due to environment and to parenting comes from a study by Seagull & Scheurer (1986). This study found that children removed from parents with retardation and placed in foster care showed gains in all developmental areas (physical, intellectual, social and emotional). This is similar to findings of Gilberg and Geijer-Karlsson (1983) who followed 41 children born to 15 mothers with mental retardation in Sweden. Their findings were that of the living children, 85 percent had severe psychosocial problems. Those who had entered foster care experienced rapid physical, intellectual and emotional development.

Other authors mention health problems, sometimes due to lack of care such as failure to immunize or failure to seek medical care for illnesses due to not appreciating the seriousness of the symptoms (Fheighway, 1992; Llewellyn, 1999). Inadequate nutrition is also a concern. Some children have experienced malnutrition or failure to thrive. Others attend school having had no breakfast and bringing no lunch. Poor budgeting may mean there is no money for food or parents may have the food but lack the skill to prepare it.

Children may suffer from isolation from others if the parent has no friends. Lack of interaction with others results in low self-image and poor social skills. As children grow older, they may be embarrassed by

FACTORS ASSOCIATED WITH CHILD MALTREATMENT FOR PARENTS WITH RETARDATION

- absence of support systems
- more than one child
- child(ren) with medical or other disorder
- a partner with an emotional disturbance or substance abuse problem
- abusive partner
- low motivation
- problems in addition to mental retardation (such as depression, alcoholism or physical problem)
- no or low reading recognition
- IQ below 60

(taken from Tymchuk, 1990; 1992)
Long-Term Effects

There is scant literature addressing the long-term impact on children being raised by a parent with mental retardation. As children begin to mature, they realize more about their parent's limitations. Some children use this information to "trick" the parent into allowing them to skip school, avoid curfews and generally choose their own activities and do as they please. Other children try to protect the parent and limit the parent's negative experiences.

Almost all children eventually try to "come to terms" with their parent's disability. This can be an ongoing process, extending throughout the child's adult years. Ronai (1997) writes, "I betrayed her by growing up. Year after year we grew further apart...She was not growing with me; and as time went by, she became an embarrassment and a liability...She was strong and weak in the strangest ways...There is no final answer...only ambivalence...I feel ambivalent, one moment protective of my mother, the next furious and the next profoundly sad. I want to avoid her and control her life for her, all at the same time" (p. 430).

Other than Ronai's account, the only published literature about adult children of parents with retardation is a recent book by Booth & Booth (1998) (See review, this issue "Growing Up With Parents Who Have Learning Difficulties").

Booth & Booth (1998) located and interviewed 30 adults who had grown up with one or more parents with mental retardation. Of the 30, all but three expressed some positive feelings towards at least one parent and 24 specifically voiced positive feelings towards their parent with retardation. Most (22) felt close to their mother with retardation, while only 11 felt close to their fathers (12 had a distant relationship and the remainder had had no contact or did not know their fathers). Every person in the study had maintained close contact with at least one of their parents.

Only 3 of the 30 regarded their childhood with uniform unhappiness. Over half (16) reported physical or sexual abuse as a child with the most usual perpetrator being the father. Half of the 30 themselves had mental retardation. Children with retardation experienced many problems, both in childhood and as adults. Those without retardation were able to establish adult status with minimal difficulties.

RESEARCH FINDINGS

Comparisons with Matched Samples

There have been some more recent studies designed to compare parenting by those with mental retardation to matched socio-economic status parents without disabilities. Feldman (1998) examined competence on 9 tasks such as feeding, bottle cleaning, crib safety and hair washing. Across all skills observed, the parents with intellectual disabilities scored significantly lower than parents without disabilities.

Children raised by parents with mental retardation have also been studied. These children, compared to matched controls, are significantly more likely to have lower IQ's. In one study (Feldman & Walton-Allen, 1997), 59 percent were in special education, compared 12 percent of matched controls. Also, 40 percent of the children of mothers with mental retardation had clinically significant behavioral disorders and not one school-aged child of parents with mental retardation was problem-free.

The study by Feldman & Walton-Allen is also significant because it addresses the question of the effects of poverty. Poverty is frequently mentioned by advocates for those with retardation as a possible causative factor in poor outcomes of children. Some researchers (Tymchuk, 1992) maintain that parents with retardation can acquire skills and knowledge to perform similarly to other parents living in poverty. Results of Feldman & Walton-Allen's study suggest, in contrast, that being raised by a mother with mental retardation can have detrimental effects in the child's development that can not be attributed to poverty alone.

Problems with Studies

It is difficult to interpret and apply the research literature. Studies suffer from several problems. One difficulty for researchers is identifying samples of parents with mental retardation. There is no easy way to identify which parents have mental retardation. Advocacy groups maintain that parents who have come to the attention of the system are those with particular problems. This subsample, advocates maintain, are not necessarily typical of parents with retardation who are managing on their own and who are unidentified.

Only one study was found where an entire group of children with mental retardation were followed into adulthood to determine the incidence of parenting problems (Gillberg & Gejer-Karlsson, 1983). In this study only 2 of the 15 mothers with retardation were living in "acceptable conditions". An English study by Booth & Booth (see book review, this issue, "Growing Up With Parents Who Have Learning Difficulties") is the next closest study. While this study does not follow children with retardation, it does attempt to examine long-term effects of having a parent with mental retardation. Thus, the literature is lacking accounts about parents with mental retardation who are successful without intervention or extensive support from family members.

Many published studies are based upon small samples or even single subjects and are biased by factors such as poverty, the existence of multiple risk factors, and lack of adequate follow up. Many programs do not assist parents with retardation after the children enter school, some time-limit intervention, and most concentrate upon parenting in the first three years. Success rates during early years may be overly optimistic, since some literature indicates that parenting older children is the most problematic stage.

The most difficult part of interpreting the literature, especially recent literature, is the lack of limiting the population studied to persons who fit the definition of mental retardation.

Studies prior to the late 1970's often used an early definition of retardation developed by the American Association on Mental Deficiency (AAMD). This definition included those one standard deviation or more below the norm on an IQ test (below 85). Those with IQ scores between 70 (two standard deviations from the norm) and 85 were considered to be in a category of "borderline mental retardation" and comprised approximately 13 percent of the general population. In the late 1970's the AAMD changed the definition of mental retardation to require significant subaverage general intellectual functioning, eliminating those in the range of 70 to 85, and causing the theoretical population of those with mental retardation to decline from 16 percent to less than 3 percent.

Thus, early studies often included "parents with retardation" who do not fit current criteria because their cognitive functioning is considerably higher than the cur-
Parents with Retardation
continued from page 5

tal retardation? There is much disagreement in the literature.

Seagull & Scheurer (1986), citing experience from over 1500 families, found that "those families in which a parent was significantly intellectually limited failed to improve in the care and protection of their children despite elaborate, lengthy treatment plans" (p.494).

Budd and Greenspan (1985) report results from a survey of behavioral-oriented therapists. A total of 52 questionnaires from 16 parent training programs that served parents with retardation were returned. Training for parents with retardation was judged to be more intensive, more directive and longer than training offered to those without disabilities. The treatment length varied from one month to four years (median 30 weeks) with one-third of cases being ongoing. Training occurred mainly in the home (83 percent) rather than the clinic (17 percent), although 44 percent of families received both clinic and home services.

Slightly less than half of the parents with retardation made substantial improvements on referral problems, and in one-third of cases therapists were optimistic about the family's ability to function adequately without extensive continued assistance. Despite comprehensive treatment, often there was little generalization of effects beyond the specific problems and settings treated.

The authors report that while outcome levels are lower than for those who are not impaired, some parents with mental retardation made considerable improvements as a result of the intervention. Parents who benefitted the most were those with the highest adaptive levels prior to intervention and those where the parent was actively involved in the treatment.

An example of a successful, intensive intervention is found in Feldman and colleagues (1986) report. They worked intensively with 8 "developmentally handicapped" (IQ less than 85) mothers of infants. Mean IQ was 66. Training was able to remediate deficits (low interaction with infants, low praise, limited vocalizations) to a level equal to non-handicapped mothers and gains were maintained over a 5-10 month follow up period. These results were similar to a subsequent investigation by Feldman et al. (1992) where parent train-

ing resulted in gains in the 90 percent range on a variety of caregiving and child care skills.

A more recent study (Rubenstein and Russo, 1994) reviewed the results of eight programs in New York state that provide parent training and direct assistance to parents who have mental retardation. The programs served from five to 27 families (a total of 86 families). The cost of service delivery ranged from $4670 to $10,710 per family per year.

The study examined a sample of 41 representative families of the 86 in the program. In general, parents were assessed as needing some support or significant training in many basic parenting skills (such as maintaining hygiene, providing supervision, providing adequate nutrition, providing appropriate discipline) and, in 59 percent of families, no adult had the skills to manage household money.

The programs reported that start-up was more difficult than envisioned and six of the eight programs did not begin to serve families until four to eight months after the program began. The programs did not demand substantial experience and training with persons with mental retardation to be considered for employment. Rather, the programs sought employees who were accepting of persons with mental retardation, receptive to new ideas and competent in parenting skills. Programs reported that finding staff was difficult. The three programs that had hoped to utilize senior citizen volunteers quickly abandoned that idea due to identifying only a few suitable candidates who would make the 10 hours per week time commitment. High turnover of staff in the first year was an additional problem.

Enrolling families was not a problem. The programs were designed to be small with six of the eight serving less than 15 families (of the two larger programs, one served 18 families and one served 27). Most programs soon had active waiting lists.

Keeping families in service, however, was a problem. Only 41 percent of the families were rated as "very committed" to the program. Annual drop-out rates were approximately 40 percent. Staff had difficulty with "no shows" (families not being home for scheduled home visits) and some families were noncompliant or inattentive to basic tasks (cleaning, cooking, obtaining regular medical care, administration of medication to children). Easy re-enrollment for drop-outs and willingness to shift workers were standard operating procedures designed to keep the programs attractive to the families.

Although programs started with the idea of training the parents to do the tasks for themselves, staff spent more time than anticipated in direct assistance. Effective parent training was more difficult than originally anticipated. "Transfer learning" or generalization, where an individual applies a skill learned in one specific situation to another, was especially difficult. Many of the parents with mental retardation in

Intervention Studies

Can communities offer support and intervention sufficient to provide proper care for children living with parents with men-
this study experienced difficulty keeping track of multiple tasks. This is similar to findings cited by Tymchuk (1992) where parents with retardation learned skills but the learning was “quickly lost for about half of the small groups of mothers” (p. 173) for a variety of tasks. The parent may have learned to perform a particular task in isolation, but collective parenting demands were overwhelming and some parents were not organized enough to attend regularly to the needs of their children. Some families remained in a “crisis-service orientation” throughout the program.

Whitman et al. (1990) have also reported about the constant “crisis orientation” (p. 59) of some persons with mental retardation. They report on Batrice. “It was a rare day when no crisis loomed on her horizon” (p.59). Batrice was not an exception. During their first years of operation, 46 percent of the families served became homeless (Whitman, Graves & Accardo, 1989). The problem for helping professionals is to know when the crisis is immediate (such as the late night call in frigid weather when Batrice and her two small children were evicted from their home by her brother’s girlfriend) and when a delay of a day or two will make little significant difference. The second problem is staffing and the “burn-out” resulting from dropping everything to respond to real or fake alarms.

Reporting on a center-based parent training program in St. Louis, Missouri, “Parents Learning Together”, Accardo and Whitman (1990) and Whitman, Graves & Accardo (1989) comment about the complexity of serving parents with retardation. Many of their clients had concurrent problems such as psychiatric disorders, hearing and vision impairments, speech disorders, physical handicaps, poverty, large family size and the absence of family support. The parents “did not usually remember their children’s birth dates, were not always able to recall the names of all their children or consistently distinguish one child from another...and would often put the toddler’s shoe on the wrong foot” (Accardo & Whitman, 1990, p.70).

Accardo & Whitman report a “mixed bag of success and failure” (p. 70) where multi-agency interventions often seemed to add to the chaos. While the program achieved “limited success in the preschool years”, “the problem does not appear to be remediable in the case of older children” (p. 70). The authors suggest that parenting fail-

ure in those with significant retardation is not a question of whether, but when.

A program reported by Feldman (1998) offered parenting education as one part of a continuum of services, including counseling, stress management, community living and social skills training, as well as referrals to community services. The program was an early intervention program, with a priority on remediating basic child-care skill deficiencies affecting child health and safety.

“Some of the common problems included failure to clean and sterilize baby bottles; this failure resulted in infant gastric distress and infection. Often, formula (or food) preparation and feeding skills were ineffectual; this led to child malnutrition. The parents did not effectively treat diaper rash and other childhood afflictions. Sometimes they placed the child in dangerous situations by using bath water that was too hot, leaving the baby alone on the changing table, using medication incorrectly, or allowing dangerous objects within the child’s reach” (Feldman, 1998, pp. 407-408).

Once the physical safety issues were ad-

dressed, parents were taught to provide a more stimulating environment in order to foster language, social and cognitive development. Relationship skills were taught as well as problem-solving. Intensive, in-home training was the intervention in this program. Mothers who received training were compared to wait-list mothers and non-impaired mothers. The training group significantly out-performed the wait-list mothers and compared favorably to the comparison group of mothers without impairments. Further, before participating in the program, 82 percent of parents with mental retardation who had a previous child had lost parental rights. After finishing the parenting program, only 15 percent forfeited the child who was the target of the intervention (the four parents who lost custody dropped out of the program).

Feldman cautions that, while parenting education can be a viable and humane alternative to termination of rights, it is not a panacea. The families continued to have multiple problems that could impede parenting. Since the study followed the par-

Continued on page 8
Parents with Retardation

improvements in one or more skills and improvements were noted in 63 percent of skills. Five studies presented data on generalization and reported a low percentage (0 to 89 percent with an average of only 21 percent). When two studies involving generalization from “saying” to “doing” were removed, the rate of generalization improved to 76 percent, suggesting that training must be provided in the home for this population.

FACTORS PREDICTING SUCCESS

Some studies have attempted to identify factors contributing to successful outcome. These include:

- higher IQ (greater than 50, Espe-Sherwindt & Kerlin, 1990; greater than 60, Tymchuk, 1990; 1992)
- being married (Espe-Sherwindt & Kerlin, 1990) or living with the child’s grandparent (Tymchuk, 1992) or daily support from a high functioning adult (Seagull & Scheurer, 1986)
- having fewer children (Espe-Sherwindt & Kerlin, 1990) or only one, healthy child (Tymchuk 1990 & 1992)
- adequate motivation and willingness to accept support from service providers or informal sources (Espe-Sherwindt & Kerlin, 1990; Llewellyn & Brigden, 1995; Tymchuk 1990 & 1992)
- providing training in the home to enhance generalization (Feldman, 1994; McConnell, Llewellyn & Bye, 1997)
- the parent had appropriate parent models during childhood (Tymchuk, 1990 & 1992)
- good physical and mental health (Tymchuk, 1990 & 1992)
- adequate finances and low stress (Tymchuk, 1990 & 1992)
- parent has adequate education and skills such as reading recognition and comprehension (Seagull & Scheurer, 1986; Tymchuk 1990 & 1992)
- parent has not been institutionalized (Tymchuk 1990 & 1992)

SUGGESTIONS FOR SUCCESSFUL INTERVENTION

McConnell, Llewellyn & Bye (1997) surveyed 40 service providers and identified four principles associated with effective services to parents with retardation. First, services need to be responsive to the parents’ individual needs. A family-centered approach is required to ensure that interests of both parents and children are served.

Espe-Sherwindt & Kerlin (1990) also advocate focusing on the needs most crucial to the parent: “Parenting and child development per se cannot be a priority as long as families are overwhelmed by the crisis of day-to-day survival” (p. 25). McConnell et al. note that while the greater proportion of parents (63 percent) identify child care as the area needing the most help, others do not. Help with vocational skills, friendships, and accessing community resources were identified by other parents as more important.

The second principle is for services to be long-term, ongoing support because the needs of children and the parenting skills and techniques need to change as children mature. While experts agree that long-term intervention is necessary, few programs provide services throughout the growing years of the child.

The third principle advocated by McConnell et al. is for services to consider the special learning needs of the parent. Learning must occur in the natural setting (the home), be repetitive, use demonstration and use resources which require little or no reading. Workers should maintain and reinforce the parents’ skills (Booth & Booth, 1994).

It is important to first establish a trusting relationship and partnership with the parent (Espe-Sherwindt & Kerlin, 1990). Being nonjudgmental and nurturing is also crucial. The emotional needs of the parents must be recognized (Booth & Booth, 1994).

To be effective, parent education therapists need knowledge of both child development and of the impact of intellectual disabilities on adults. Experience in both behavioral training and parent education is needed (Feldman, 1998).

Based on his review of the literature, Maurice Feldman (1994) suggests that the current “best practice” parenting education involves specific skill assessment utilizing direct observational techniques. Training should be performance-based rather than knowledge-based and should utilize modeling, practice, feedback and praise. Providing tangible reinforcers is suggested as a way to promote attendance, rapid skill acquisition and maintenance. Workers need to be prepared for slow and “seemingly minute” changes. Measuring change through case notes, attendance and reaching goals is suggested as traditional methods “may not be optimal” (Espe-Sherwindt & Kerlin, 1990, p. 26).

Fourth, according to McConnell et al., services must assist parents in becoming part of their community. Parents in their study were physically and socially isolated. Access to transportation was lacking as was support from family members, friends or helpful neighbors. Others (Llewellyn & Brigden, 1995) stress that services must be provided in the home, on a one-to-one basis. It is felt that generalization fails to occur if services are center-based. Yet parents with retardation may receive in-home services only rarely due to funding considerations.

Espe-Sherwindt & Kerlin feel that empowerment along with social and problem-solving skills, will allow parents with retardation “to identify their own periodic
SPOTLIGHT ON RICHMOND:  
THE FAMILY SUPPORT PROGRAM

For a number of years, Greater Richmond SCAN (Stop Child Abuse Now) has been offering a family support program to families at risk of child maltreatment. Now, the group is in the process of expanding in order to offer support to parents or caretakers with diagnosed or suspected cognitive impairments. This population could include those with mild or moderate mental retardation, borderline intelligence, or a significant learning disability. The group will be open to expectant parents, parents with custody, and those who are trying to regain custody.

The 12-week group will offer a combination of support and education. Topics will include behavioral management, child safety, child development, nutrition, problem-solving, feelings identification and community resources. A children’s group for those 0 to 13 will meet at the same time as the parents’ meeting.

For more information about The Family Support Program contact Amy Strike, Greater Richmond SCAN, 1506 Staples Mill Road, Suite 203, Richmond, VA 23230, (804) 257-9866, FAX: (804) 257-7109.

The Family Support Program is being supported by a grant from the Virginia Department of Social Services Community-Based Family Resource and Support Program. For more information about grant funding contact Ann Childress, Virginia Department of Social Services, 730 East Broad Street, Richmond, VA 23219, (804) 692-1252, Fax (804) 692-2215.

needs for assistance, to view asking for help as enabling rather than disabling, and to access the appropriate support systems” (p. 27). Parents should be involved in the decisions affecting their children. Booth & Booth (1994) note that a worker may be unable to advocate for the parents for the interests of both parent and child, therefore, separate advocates may be needed. Workers need to demonstrate genuine liking or feeling for the families, understand their points of view and respect them as people. There should be support for the emotional bonds between parent and child.

Llewellyn (1997) has written about the importance of family traditions and childhood memories in determining the parenting techniques of persons with mental retardation. Knowledge of the influence (both positive and negative) of family and friends on parents with retardation is necessary. Still, Llewellyn recommends that providers be aware of the informal learning of the parent and be sensitive to the influence of family systems.

Many researchers stress the importance of social support from family or occasionally from friends in maintaining successful parenting. It is noted that it is most effective if support persons respond to early signs of stress instead of waiting for crises. However, exactly what constitutes suitable social support for parents with mental retardation is not yet determined (Llewellyn, 1997).

An interesting examination of social support for mothers with mental retardation was performed by Tucker & Johnson (1989). They examined 12 families with a total of 25 children who received support from extended family or in 2 cases from a group home operator. These authors found that the mere existence of a support network was insufficient to predict parental coping and competence. They found that some social support promoted competence in parents with retardation and some support actually appeared to inhibit competence in parents with retardation. Support that promoted competence involved providers who believed that the parents were capable of becoming more self-sufficient. These providers directed considerable effort towards training the parents and were able to tolerate or accept the parents’ limitations.

The authors note that competence-inhibitors (who did not try to train the parent but instead did the child rearing themselves) may have been responding to failed efforts to train the parent with retardation. They also noted the negative effects of having more than one child on the system of support and on the performance of the parent with retardation.

The authors raise an interesting question. If the children of the parents with retardation are receiving adequate care, how important is it to maximize the caretaking competence of the parent? Additionally they ask, if children will ultimately receive better care from providers or relatives no matter how well-trained the parent becomes, is it ethically responsible to expect the parent with retardation to provide more direct care?

PARENT PERCEPTIONS

A number of authors have commented upon the need for careful and consistent coordination among various agencies and professionals serving the family. Parents with retardation express much upset about receiving conflicting information from providers and about the intrusion into their lives by multiple providers (Llewellyn & Brigiden, 1995). The importance of offering assistance that fits how the parents want to be helped is paramount (Llewellyn, 1995; McGaw & Sturmy, 1993).

Parents themselves have offered suggestions Continued on page 10
Parents with Retardation
continued from page 9

tions about what strategies they believe are effective. Ultimately, the opinions and reactions of the parents receiving services will be the most compelling force in determining service provision. If parents with retardation are unable to benefit from a particular service or if parents are unhappy with a service and avoid using it, that service approach will fail.

Unfortunately, there are few published accounts of the parents' (consumer's) perceptions of the services designed to assist them. Three resources were found in the literature. Walton-Allen & Feldman (1991, reported in Llewellyn, McConell and Bye, 1998) found differences in the perception of mothers receiving services and the workers providing it. Some mothers felt they did not require services at all, in contrast to the providers' views. Also, mothers reported too much service in some areas and lack of service in others.

Extending the work of Walton-Allen & Feldman, Llewellyn, McConnell & Bye (1998) interviewed 47 parents (40 mothers and 7 fathers). Llewellyn et al. obtained similar findings as the earlier research. Parents reported service gaps in vocational skills training (exploring work options), in accessing community resources (knowing what was available and how to use it) and in assistance in making friends. As in the prior survey, service workers perceived greater needs for the parents than did the parents themselves.

The Wisconsin Council for Developmental Disabilities has been active in seeking input from the consumers of services. Their findings are summarized in the block, "What Parents Want in Support Systems."

HOW MUCH INTERVENTION IS NEEDED?

There are dilemmas as one reads the literature. The first is the question of whether or not persons with retardation require additional assistance in raising children. According to Ingram (1999) “many people who have mental retardation need little, if any, help to raise their children” (p. 2).

For the parents with retardation who do need assistance, Ingram's position is that support should be offered throughout the entire life of the person with mental retardation. Out-of-home placement is “frequently the result of a failure to provide adequate supports to help a family remain intact, rather than the result of the individual’s disability itself” (p. 2).

This sentiment is echoed by Booth & Booth (1998) who state, “The damage model thinking easily gives way to a self-fulfilling prophecy on the part of professionals who, pessimistic about the prospects for the child, fail to support the parents and so bring about the outcomes they fear” (p. 4).

Others present a different perspective. Polly Snodgrass, RN, has devoted much of her life to assisting parents with retardation. She asks provocative questions in her article “How Many? How Much? Scarce Resources and Supported Parenting” (1990). The question is “how many services, at a cost of how many dollars, for how many years and for how many people?” (p. 8). She asks, “Shall we give a few families all the resources they need to succeed or shall we give to many families just enough to stay afloat?” (p. 9). Others, Llewellyn, Bye & McConnell (1997) have written about the need to move from a short-term to a long-term model of service delivery. Limited funding and services may mean more effective individualized programming is not available. We question the wisdom of supporting parents with mental retardation, says Snodgrass, because we are frightened by the relentlessness and magnitude of their needs. “Ignore them and they will not go away” (p. 10). Snodgrass’ Positive Parenting Project has, in the past, offered everything to a small group of families forever. It has been the “secret to success” with the families, but a major reason for failure with funding sources. Recently the Positive Parenting Project has decided to work with parents only until children are three years old.

TERMINATION OF PARENTAL RIGHTS

Feldman notes that, in the U.S. and Canada, about 80 percent of parents with “intellectual disabilities” have their rights to parent terminated, primarily because of actual or potential child neglect (Feldman, 1998). Feldman’s results are similar to a followup by Seagull & Scheurer (1986). In this study only 17 percent of children (11) remained in the care of their parent(s) with mental retardation. The parents had terminated rights for 34 (53 percent), 9 (14 percent) were in foster care, 6 (9 percent) had been relinquished voluntarily, 2 (3 percent) were in the care of the non-retarded parent subsequent to a divorce and 2 (3 percent) had died (one of a beating by the mother’s boyfriend and one from suicide).

Others place the figures for removal much lower. For example, McGaw and Sturme (1993) note that half of parents with retardation are reported for child maltreatment and a quarter have a child removed from their home. The number whose rights are ultimately terminated was not reported.

There is much concern that children may be removed, not because of maltreatment, but simply because of the parent’s retardation. According to Ingram, (1999) parents with retardation have historically been denied the right to parent based on the assumption that their children are “better off” in alternative care.

Few studies have addressed this question directly. One study of 206 seriously abused or neglected Boston children who were court-ordered into services yielded the following information. Of the sample, 104 children had one or both parents with either a psychiatric diagnosis or mental retardation and 46 had parents with a substance addiction. The researchers found that those with retardation were more accepting of services and had less prior court involvement. In regard to ultimate outcome, parents with retardation had children permanently removed at a rate slightly greater than those with no diagnosis (69.4 percent lost custody) and somewhat greater than those with psychiatric diagnoses (75 percent of those with retardation lost custody permanently compared to 63.4 percent of those with psychiatric diagnoses). However, parents with retardation lost custody permanently less often than those with additions (81.4 percent). Thus, this study (Taylor et

WHAT PARENTS WANT IN SUPPORT SERVICES

- A trusting, mutual relationship
- Acknowledgement of the parent as head of the household
- Appreciation for the love between parent and child, despite problems
- Sustained, practical support directed towards building the parent’s skills and confidence
- Genuine liking for the family
- Recognition of the emotional needs of the parent
- Mobilization of community supports
- Integration of formal services with extended family, neighbors and friends
- Allowing the parent to determine the most effective direction for support
- Being the parent’s advocate to the system

Adapted with permission of Howard Mandeville, Wisconsin Council on Developmental Disabilities
al., 1991) would not support a bias towards removing children from parents with retardation. In this study, parents referred to the court for serious maltreatment of children lost custody at similar rates regardless of their diagnostic label or lack of label.

The importance of individual assessment and determination of parental competency is illustrated in a study by Greene & associates (1995). Two families in which the children had been placed in foster care due to abuse and neglect by parents with disabilities were studied. Both were offered similar intensive, individualized services. The two families were a study in contrasts. One parent gradually acquired and regularly applied child rearing skills. She was able to obtain custody of her child. In the other family, functioning deteriorated and the parents’ rights were terminated.

Some researchers (Tymchuk & Keltner, 1991) have begun to delineate risk factors and “advantage profiles” to help predict success in parenting for mothers with mental retardation. Currently, however, those parents with retardation are assessed in a similar fashion to others when questions have arisen concerning parenting competency (see separate article, “Assessing Parental Competency”, next issue; also resource reviews for related books and professional guidelines will be reviewed).

**REEVALUATING INTERVENTIONS**

Many professionals currently working in the field called for new thinking and innovative solutions. “Supported parenting is a philosophy, not a curriculum. It is an attitude, not a clinical specialty,” asserts Howard Mandeville, a Community Resource Specialist with the Wisconsin Council on Developmental Disabilities.

First, policy makers need to acknowledge that support may need to be ongoing and long-term. “We begin with the assumption that parents are capable of adequate parenting and- with appropriate supports that last through the children’s growing-up years - will learn, grow, and change. We view the parent with cognitive limitations as a ‘developing resource’,” explains Polly Snodgrass, Supervisor with the Healthy Families Program in Green Bay, Wisconsin.

Pat Miles, a partner in the Brown-Miles Consulting Group, Portland, Oregon, agrees. “We need to suspend the belief that our job is to ‘fix the problem,’ she emphasizes. Lori Gildersleeve, M.S. of the Central Minnesota Mental Health Center has co-facilitated parenting groups for parents with mental retardation. She comments, “The disability can become the focus and negative attitudes towards disabilities can be a problem.” Both providers stress the need for a mutually respectful relationship and the need to allow the family to determine services.

So what do these professionals suggest to replace the current service delivery? Miles believes that one of the most promising tools is helping the parent to construct a time-line and discussing not problems but the best times. “When was life working well for this individual?” Miles asks. “We are looking for the conditions that were successful, be they physical (such as living arrangements) or social. We then re-create the conditions that worked.” For example, if the mother functioned well when she had “Uncle Steve” living with her, then Miles will find a substitute for Uncle Steve.

Miles is convinced that support persons and even support families can be found, “one person at a time”. By taking dollars from institutional care and paying them to families, support systems can be created. “These families need to be willing to co-parent, allowing the biological mother to contribute as much as she can,” explains Miles.

Fellow consultant John Franz, an attorney from Madison, Wisconsin, agrees with Miles. Franz speaks of “creating a circle of support” and “strength-based planning”.

Continued on page 13
Hennepin County’s Parent Support Project (PSP) began after Child Protective Service workers became aware that cases involving parents with mental retardation were frequently reopened after an initial intervention. The program is a cooperative effort between the Child Protection Division and the Developmental Disabilities Division within the Adult Services Department of Hennepin County. The goal is to reduce the likelihood of further child abuse and/or neglect by helping the parent(s) to recognize their children’s needs and to respond appropriately.

PSP provides intensive home-based services that include assistance with housing, homemaking instruction, teaching of daily living skills, social skills training, health and hygiene instruction, crisis intervention, child-focused services, advocacy and case management. Three workers serve 10 to 12 families each. There are 45 to 50 families served a year. PSP services can remain open indefinitely, but only rarely are they utilized for over three years. The typical family receives services for 18 months.

Services are not limited to parents who have an IQ below 70 but include those with other types of cognitive limitations who score below 80 on IQ testing. Also, entrance criteria stipulate that children need to be under the age of 10. Mark Simpson, MSW, LICSW, Senior Social Worker, notes that the program is receiving re-referrals of families who had been in the program previously and the older children are now in their teens.

When a case is accepted, a thorough assessment is undertaken and a comprehensive service plan is developed. Progress reviews are held quarterly. The referring program must remain active with the family as well, as PSP is a specialized resource and does not accept actual case transfers.

The PSP has a well-developed protocol for assessing parental skills. Competencies are divided into four levels. Level I encompasses concrete tasks and basic self-care skills. Examples of these are the physical condition of the residence, personal hygiene, math and reading skills, cooking and nutrition, medical and dental care, transportation and shopping skills.

Level II skills assessment examines individual psychological development. Competencies at this level include the ability to set and maintain internal limits (for example, in budgeting money), ability to recognize problems, and managing emotions (for example, anger control). The parent’s ability to verbalize feelings and ideas is considered. Mental health stability is assessed (for example, presence of depression, personality disorder, thought disorder or addictive behaviors). Motivation for problem-solving and leisure skills are included in the Level II assessment.

Interpersonal skills and supports are the focus of the Level III assessment. How does the parent manage interactions with others? Does the parent merely react to situations or can they be proactive? What is the level of empathy and reciprocity in relationships? Included is an examination of the parent’s history of exploitation (abuse, sexual abuse, financial exploitation) and attachment with their family of origin. Current involvements with family and partners are considered. The parent’s past interactions with service providers and community resources is examined. Vocational and economic skills are included.

Level IV examines Child Care Skills. Considered in this assessment are the parent’s ability to perceive threats to the child’s safety and to respond appropriately. The parent must be able to place the child’s needs first. Nurturing and discipline techniques are measured. The worker assesses the degree and type of attachment to the child. The worker needs to determine if the parent has an understanding of child development. Can the parent provide consistent daily living routines? Can the parent provide necessary stimulation for the child? Can the child’s physical, emotional and educational needs be met?

This comprehensive assessment becomes the basis for the service plan. Interventions are currently executed by the three senior-staff MSW social workers. Historically most of the workers have had prior experience as case managers for persons with mental retardation.

The program measures success primarily by whether the children can remain in their biological home. A secondary outcome measure is positive adjustment of the children. Linking families to community support is attempted prior to closing. However, no followup is done after discharge from the program. Simpson feels the program is successful for most families, but notes that those parents who also have serious mental illness or addictions have the worst prognosis.

Actual intervention efforts are divided between obtaining concrete services for families and direct teaching of parenting skills. Relatively little of the worker’s time is spent in direct intervention with the children. Simpson explains, “A large number of hours are spent finding basic material needs, especially housing which is a tremendous problem in our area”. Simpson notes that teaching parenting skills to those with cognitive limitations is different than working with higher-functioning parents. “There is great difficulty in abstract reasoning and in generalization of skills”, explains Simpson. “Learning the skills is not a natural process. It requires extensive demonstrating, coaching and modelling to explain concepts.”

As an example, Simpson relates his experience with a client who has a temper control problem and has injured her children. This parent lost her first child due to inflicted injuries and has hurt her second child. The system is offering her a chance to learn anger management. Simpson relates, “The client is continuing to experience episodes of losing control because she is not focusing upon herself and her temperament, but instead focuses on the child’s behavior. I’m trying to help her understand the connection.”

While the program is limited in work with the children, the PSP attempts to link children with healthy supports. Simpson comments, “Many of the older children can develop a team relationship with their parent and can help the parent meet the family needs. Persons outside the family can help normalize the experience for children. Many children do struggle, but as a group they are exceptionally competent and can provide the family with some stability.”

For more information about the Hennepin County Parent Support Project, contact Mark Simpson, MSW, LICSW, Senior Social Worker at Adult Services Department, Developmental Disabilities Division, Government Center, 300 South Sixth Street, Minneapolis, Minnesota, 55487-0150, (612) 348-6295, TDD (612) 348-4985, Fax: (612) 348-2856, E-mail: mark.simpson@co.hennepin.mn.us
His assessment scheme is based on six areas: concerns, strengths, goals, barriers, options and an action plan. "Providers must become creative and go beyond the obvious," states Franz. "Look at the overall pattern of each person's life and relationships to determine what is right and build on strengths. A life must be seen as a complex, interacting whole. Seeing the larger picture can help us shift from short-term, incident-based, problem-focused reactions. Instead, we can begin to establish a proactive, multi-domain relationship with people who may need varying kinds and degrees of assistance over time but who are always in need of improved connections with the rest of their communities."

It is unclear whether or not funding and dedicated individuals can be found to offer extensive supports to families headed by a parent with mental retardation. While savings are theoretically possible by reducing the need for institutionalization (of either the parent in question or the child), initially additional funding sources would need to be found. According to Whitman & Accardo (1990), "Potential solutions demand a level of social responsibility that does not appear probable" (p.6).

One possible model for co-parenting is being piloted in areas where foster parents are serving as supports to the entire family rather than respite or temporary care for the child. (See Family Forever, video review, this issue). Open adoptions also allow the possibility for parents with retardation to continue to be involved in their children’s lives while allowing others to assume the primary care for their children.

---

**INTERVENTION PRINCIPLES**

- Staff require training specific to mental retardation
- Services must be provided as long as needed (even for the entire span of the child’s growth)
- Services should be provided within the home
- Services must be comprehensive (cover financial, medical, social and educational needs for both parents and child)
- Services must be of sufficient frequency to prevent neglect
- Services should be coordinated or provided by a single agency
- Interventions need to be individualized and matched to parent learning characteristics
- Training should be highly concrete, incorporate simple guidelines and promote generalization

(taken from Llewellyn, 1997; Tymchuk, 1990; 1992)

---

**IMPLICATIONS**

The problems of families headed by parents with mental retardation are complex. The diversity of situations and needs means that articulating clear-cut policies, laws and agency procedures is difficult and perhaps undesirable. Rigid policies might mean that flexibility and individual consideration is compromised.

A thorny policy issue is “Who is the client?” Is the client the children who require adequate care or is the client the parent with mental retardation? Frequently, the needs of the children conflict with the equally valid needs of the parent.

Communities are just beginning to articulate and discuss options. Anderson summarizes, ”I don’t think we as a society are prepared to tackle this issue. Those who championed deinstitutionalization didn’t foresee that community placement would result in people becoming parents. We have considerable expertise in educating children with developmental disabilities but no preparation for parenthood. Supported parenting is a new idea.”

**CONCLUSION**

Families headed by parents with mental retardation are increasingly common in most communities. In all likelihood their numbers will grow as fewer individuals are institutionalized and more individuals with mental retardation live in the community and use their freedom to develop relationships, conceive and raise children.

Meeting the needs of this growing population of families will not be easy. Many families appear to need relatively intensive services and support over extended or indefinite time periods. Parent training, by itself, does not appear sufficient. Direct hands-on assistance with daily living and child care tasks is needed by many families. Effective methods for working with parents with mental retardation are being developed, but have not been perfected.

When extended family such as grandparents or a supportive spouse can provide most of this assistance, children’s basic needs can be met. If extended family can not provide ongoing support for those parents with mental retardation who require support, then service systems are left to create innovative programming such as foster care for both the child and parent dyad or group home settings where parents can reside with the child. The ongoing, unrelenting needs of this population challenges traditional programming and funding mechanisms which are designed for short-term intervention.

References Available Upon Request

---


Using a narrative method of study, Booth and Booth interviewed 30 adults (16 men and 14 women) who had grown up in a household with a parent with mental retardation. Of the subjects, half were also diagnosed with retardation.

The book is a fascinating account. At times, lengthy interview segments allow the reader to understand the subjects’ personal experiences as well as offering the possibility of interpreting the data directly.

The authors write from a viewpoint that children can be resilient, that family is crucial to children, and that focus must be upon what is right in the lives of children. The authors are enthusiastic advocates for long-term supported parenting and a family-centered perspective "from the point of view of what can be done to support the family rather than how to protect the child" (p.212).

This volume is one of the few examinations of adult children of parents with mental retardation. For that reason, it is a significant contribution to the literature.

The 1999 CWLA Stat Book presents updated state and national data from traditional sources. It also contains previously unpublished information from several CWLA surveys conducted in 1997 and 1998. Not only are data presented about child abuse and neglect, but also about children in out-of-home care, adopted children, children in poverty and child welfare expenditures. The volume comprises the most comprehensive collection of state child welfare data currently available. The volume is enhanced by CWLA's National Data Analysis System (NDAS) now available on line at http://ndas.cwla.org

Little Flower: A Journey of Caring by Laura McAndrew, 1999, $6.95

This touching story tells about a neglected daisy who finds help and a new place to stay. The flower is able to find people to care for her until her family learns how to properly care for flowers. The book includes projects for children who have been hurt. A good resource for children ages 5 to 10 who are in foster care.

VIDEO REVIEW

Family Forever: Reunification Through Family-Focused Foster Care, by Prince Georges County (Maryland) Department of Social Services, 1999, 17 minutes, $39.95.

This video introduces the idea of foster care that serves not only the children in care, but also their biological families. Four birth mothers relate how their children came to be in foster care. They share their experiences with the foster care system. This video should be a good resource for helping new and prospective foster parents learn the feelings and needs of children and their families.

P.A.N.D.A. ORGANIZATION IS FORMED IN VIRGINIA

A new organization has been formed in Virginia to educate and mobilize dentists about the issue of child abuse and neglect. Prevent Abuse and Neglect through Dental Awareness (P.A.N.D.A.) has been formed by the Virginia Dental Association in conjunction with Delta Dental Plan of Virginia and a coalition of organizations that includes the Virginia Department of Social Services, Virginia Department of Health, Commonwealth Dental Hygiene Society, MCV/VCU School of Dentistry, Alliance of the Virginia Dental Association, Virginia Pediatric Dental Association, Virginia Dental Assistant Association and Prevent Child Abuse Virginia. The group plans to train dentists and other dental team members with a goal of preventing child abuse through education, detection and reporting. The group will also train speakers to educate dentists and the general public about child abuse and neglect.

Although dentists in all states are mandated reporters of child abuse and neglect, states that track cases by the reporter’s profession indicate that dentists have made fewer than 1 percent of all reports. An analysis of 260 documented cases of child abuse at a Boston hospital found that more than 65% of all cases of physical abuse involved injuries to the head, neck or mouth, suggesting that dentists are in a position to observe signs of maltreatment. To Dr. Lynn Douglas Mouden D.D.S., M.P.H., the founder of the program, PANDA is the perfect symbol for the program because it is an endangered animal, like the abused child, and because its eyes are black, (which could be another sign of abuse).

For more information about the P.A.N.D.A. program or to schedule a presentation, contact Ronya Edwards of the Virginia Dental Association, P.O. Box 6906, Richmond, VA 23239-0906, 800-532-3886 (in Virginia) Fax: 804-353-7342.
Nine case managers at 9 area Community Services Boards (CSBs) were interviewed about their experiences working with adult clients with mental retardation. Caseloads ranged from 30 to nearly 70 with about half the workers having between 30 to 50 clients and the other half having caseloads of 50 to 70.

Of the 409 clients total on the caseloads of the 9 workers, only 22 (about 5 percent) were known to have children. Of the 22 who had children, 17 (77 percent) were raising the child while in 5 cases, the children were being raised by others. In a few cases, a parent was raising a child but also had another child or children who were in foster care or being raised by relatives. Of the 17 raising children, 6 lived with other adults (spouse, friend, relatives) who helped with child care and 11 were single parents living alone.

Given the low numbers of clients with children, it is not surprising that none of those interviewed listed "parenting education" as part of their job description. This finding is also similar to research literature, which indicates that those serving adults with retardation do not see teaching parenting as part of their job description. The case managers spend most of their time helping clients with issues such as housing, employment, finances, obtaining medical care and networking with other services.

Even with limited experience, case managers were well aware of the parenting problems experienced by consumers on their caseload. Problems experienced throughout the child's growing years included difficulty remembering and keeping medical appointments, inability to administer medication properly, and poor judgment about when to seek medical care. Inability to read or to read well also affected parenting throughout the child's years. For example, parents with low reading ability often do not read to their children, can not help with homework, and don't understand notes or newsletters from school.

Throughout the span of development, parents with MR were described as lacking in knowledge of milestones, as not knowing proper discipline methods, and as having unrealistic expectations. Lack of supervision was a problem with all ages of children as well. The risks of inattention and lack of supervision vary with each age group (for example, more accidents for toddlers compared to lack of control and problems with the law for older teens). For some, there were problems with maintaining school attendance.

The lack of cognitive stimulation was a concern. For infants and preschool children, the lack of stimulation was thought to cause or exacerbate delays in language and learning. For school-aged children, poor study habits and little help with homework were mentioned. Emotional and moral development of children was thought to suffer as well.

Even the most basic care appeared to be affected. Lack of properly balanced, nutritious meals was mentioned. Knowing how often and when to change diapers and finding child care or babysitters was a problem for some. Teaching basic living skills such as hygiene was a problem for those parents who themselves lacked the skills.

We asked at what point Child Protective Services (CPS) was willing to intervene in cases of parents with retardation. In general, the response of two-thirds of the case managers was that CPS intervened on the same basis for these families as for others, in other words, there was no difference.

In evaluating the responses of CPS, 4 case managers (44 percent) felt that CPS was very helpful. These respondents noted that CPS developed a clear plan, helped monitor the family and helped link the parent with services. Three case managers (33 percent) felt neutral about the CPS interventions. One commented that she had had both good and poor experiences, another noted a need for better interagency cooperation and the third felt that CPS had provided referrals but not "hands on" assistance. The final 2 case managers (22 percent) felt that CPS was not helpful.

Most communities have a variety of support services available. These include concrete help such as food pantries and housing vouchers, respite services, support groups, programs available through ARC (Association for Retarded Citizens), health department outreach programs and services for children through the CSB (Community Services Boards). Some respondents noted that there were long waiting lists for some services and insufficient funding for others. In-home services and early intervention were thought to be the most effective interventions.

Some case managers (3 or 33 percent) felt that short-term services could be effective for parents with mental retardation. Respondents utilized short-term intervention for handling emergency situations (death or loss, lapse of benefits, or other temporary disruption) and for teaching basic skills, then monitoring the parent. However, the majority of case managers (6 or 67 percent) felt that services must be long term. Respondents noted that children and their needs change over time, meaning that parents with retardation might need increased help at different stages. Others mentioned the need for continued support and reinforcement. Others noted that the retardation is not "cured" and problems are, thus, ongoing.

Services for children of parents with retardation appear to be problematic. Some CSB's provide services to the children only if the children are also diagnosed with mental retardation, serious developmental delay or serious emotional disturbance. Having adjustment difficulties due to the parent's condition is not considered a sufficient reason to be served.

While services appear limited, case managers acknowledged that the children often experience a variety of difficulties. Some are ashamed or embarrassed by their parent. Some develop behavioral problems at home or at school. Some cite pressures of additional home responsibilities such as reading for parents who can't read. Most case managers perceived the children as higher risk themselves for retardation or developmental delay. One case manager, however, disagreed. This person felt the children of parents with mental retardation were no different from the general population.

Virginia's workers emphasized the importance of treating each person individually. A need for more services, better services, and less paperwork was voiced frequently.

**VCPN's correct web address is:**

http://cep.jmu.edu/graysojh/vcpn_home.htm

Artwork reprinted by permission of Martha Parske from PERSKE:

Special Thanks To

Gina Masone
Mark Simpson
Howard Mandeville
Leigh Ann Davis
PREVENT CHILD ABUSE VIRGINIA HOSTS CONFERENCE

“The Power of Prevention Conference 2000” is the title of a statewide conference on child abuse and neglect to be held May 7-9, 2000. Prevent Child Abuse Virginia is organizing the conference, which will also include a day of specialized training seminars on May 10. The conference will be held at the Holiday Inn Select, Koger South Conference Center in Richmond.

The purpose of the conference is to promote strengthened commitment and to increase the capacity to overcome child abuse in Virginia. Conference sessions will focus on selected aspects of prevention, organizational development and building of a network of services at the community level. The sessions will be geared for professionals, volunteers, civic leaders and parents.

Alma Johnson Powell will be the keynote speaker at the conference. Her experiences traveling the world with her husband, General Colin Powell, have greatly influenced her outlook on life. Since his retirement she has embarked upon a “second career” as a nationally-prominent volunteer. She speaks about family values, morals and ethics and about the responsibilities of all citizens in today’s America.

Other featured speakers are Stephen J. Bavolet, Ph.D., creator of The Nurturing Programs for Parents and Children; Naomi Haines Griffith, inspirational speaker on child welfare issues and Barbara Rawn, former Executive Director of Prevent Child Abuse Virginia and currently Director of Programs, Prevent Child Abuse America.

For more information about the conference contact Prevent Child Abuse Virginia, c/o Brenden & Associates, Inc., 6767 Forest Hill Ave., Suite 220, Richmond, VA 23225, phone 804-272-9004, fax 804-272-9006 or e-mail: P.C.Virginia@juno.com

April is Child Abuse Prevention Month both nationally and in Virginia. The Virginia Coalition for Child Abuse Prevention encourages communities to plan activities. Governor Jim Gilmore is this year’s honorary chair.

The blue ribbon campaign is the centerpiece of many Prevention Month observances. The campaign began ten years ago in Virginia as a memorial to children killed and injured by child abuse and neglect. The blue ribbon is also used as a symbol of the need to be the best we can be when it comes to children – to be blue ribbon parents and make our communities blue ribbon communities. This April wear a blue ribbon to show your support for Virginia’s children.

For more information contact Cindy Gricos at Prevent Child Abuse Virginia, 4901 Fitzhugh Avenue, Suite 200, Richmond, Virginia 23230, 804-359-6166, Fax: 804-359-5065 or E-mail: pcav3@juno.com

James Madison University
Department of Psychology
MSC 7401
800 S. Main Street
Harrisonburg, VA 22807
Attn: J. Grayson

Address Correction Requested