

## **Acculturation in Women with Mental Retardation and Its Impact on Genetic Counseling**

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*The provision of genetic counseling to women with mild mental retardation poses many challenges, some directly related to their developmental and cognitive disabilities. Traditional genetic counseling models, in which decision-making is largely based on the understanding of factual information, are particularly affected by the intellectual limitations which characterize this population. Equally important, however, are these women's attitudes, perceptions, and behaviors related to their involuntary inclusion into a highly stigmatized social group. Common themes among these women which surface in the genetic counseling setting include the denial of mental retardation, a hierarchical perception of their own and others' disabilities, and a strong motivation to conceive and parent a child. Such attitudes and behaviors may be symptomatic of acculturation, as these women struggle to take on accepted social roles while rejecting the stigma of intellectual disability. In contrast to factual information, the counselee's ability to discuss emotions and perceptions is not necessarily hampered by her intellectual limitations. A focus on the recognition and discussion of psychosocial issues provides a more meaningful approach than traditional genetic counseling models for facilitating informed reproductive decisions among women with mental retardation.*

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### **INTRODUCTION**

Numerous articles have been published in recent years on the need to sensitize genetic counselors to the concerns of a variety of culturally-

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distinct populations within American society (Rapp, 1993; Punaless-Morejon and Rapp, 1993; Paul and Kavanaugh, 1990). Both geneticists and social scientists have recognized the importance of including cross-cultural issues when counseling Asian, African-American, and other ethnic groups (Wang and Marsh, 1992; Sue and Sue, 1990). A fair amount of work has also been done to educate counselors about the deaf culture and its unique perspectives on genetic risk (Israel *et al.*, 1992; Nance, 1977). Another group that has been steadily gaining momentum in recent years is comprised of women with mental retardation who, in ever-increasing numbers, are making important reproductive decisions. Such women share many parallels with other recognized subcultures in American society; however, the genetics literature offers only minimal insights into their growing numbers, history, and the factors that motivate their reproductive choices.

The need for strategies to address reproductive and genetic counseling issues among women with mental retardation has become more urgent over the past three decades. In contrast to a general decline in the birth rate among women in Western societies, the birth rate among women with mental retardation continues to grow each year (David and Morgall, 1990). Many factors have contributed to this increasing birth rate. For example, there is a growing recognition that people with intellectual disabilities have the same sexual emotions, desires, and rights as other people in society (Kempton and Kahn, 1991). Changes in social policy (e.g., inclusion and deinstitutionalization), have allowed more opportunities for women with intellectual impairments to develop sexual relationships. Whereas in the past, normal procreative drives in such women were effectively squelched by repressive societal attitudes and forced sterilization, today's more tolerant atmosphere brings with it a mixed bag of new opportunities and freedoms along with a host of ethical, legal, and social dilemmas (Whitman and Accardo, 1990). As the number of pregnant and preconceptional women with mental retardation rises, genetic counselors will increasingly need to familiarize themselves with the cognitive, developmental, and "cultural" features which characterize this challenging population.

This article addresses the sociological phenomenon of acculturation and its application to the study of reproductive decision-making in women with mild mental retardation. Common themes identified within the mental retardation "culture" are based upon both published literature and more than a decade of my experiences as a genetic counselor at Elwyn, Inc., a nonprofit organization providing services to people with developmental disabilities in Pennsylvania and elsewhere. At Elwyn, I have had the opportunity to counsel at least 45 women with mental retardation, 12 of whom were extensively interviewed as part of a Jane Engelberg Memorial Fellowship project to develop genetic counseling strategies for this population.

Three illustrative case reports are presented. While the perceptions and attitudes of women with mild mental retardation significantly affect their reproductive choices and should be explored as part of the genetic counseling process, specific strategies to address these issues are described elsewhere (Finucane, in press) and are beyond the scope of this article.

### CULTURAL ASPECTS OF MENTAL RETARDATION

A commonly cited definition by Grossman (1983) describes mental retardation as "significantly subaverage general intellectual functioning, resulting in or associated with concurrent impairments in adaptive behavior and manifested during the developmental period" (p. 1). In other words, a person with mental retardation not only shows intellectual deficits but also demonstrates a lower than expected capacity to adapt and function within his or her environment by age 18 years. According to this definition, over 4,000,000 people in the United States have mental retardation. The vast majority of those affected have mild retardation, defined by an IQ between 55 and 70, and lead semi-independent lives. Genetic factors, alone or in concert with environmental influences, play a significant role in the etiology of mental retardation at all IQ levels, and mildly affected parents are at particularly high risk for recurrence in their children (Bregman and Hodapp, 1991).

A number of concepts drawn from sociology research are useful in understanding the cultural characteristics of people categorized as having mental retardation. By definition, *culture* describes the skills, habits, traditions, and knowledge common to a society (Coates and Vietze, 1996). Within a culture there exist categories of individuals who share one or more common characteristics which distinguish them from others. People with mental retardation share the common distinguishing feature of low intellectual and adaptive capability, to the point where their educational, vocational, and residential needs frequently deviate from those of most people in society. Because mental retardation is neither an achieved nor a chosen status, individuals who have this disability are an "involuntary" social group. Other examples of involuntary characteristics defining social groups include ethnic ancestry, sensory impairments, and race. The way society perceives members of involuntary social groups is often stereotypical and frequently results in significant stigma and discrimination against individual group members. Stigmatized groups react to such negative characterizations in a number of ways, both constructive and destructive. *Acculturation* describes one such reaction whereby individuals of stigmatized minority cultural

groups adopt the behavior, values, or viewpoints of a dominant culture from which they are separate and to which they wish to belong.

Mental deficiency remains one of the most highly stigmatizing of all human conditions, not only in Western cultures but throughout the world (Sabornie and Kauffman, 1987; Edgerton, 1970). Consequently, people with mild mental retardation often deny their categorization within this social group and may be highly motivated to dissociate themselves from outward signs of incompetence. They strive to "pass for normal," both in their own minds and in the eyes of others. Thirty years ago, Edgerton (1967) documented this phenomenon of "passing" in a detailed study of 48 mildly retarded adults released into the community from a California institution. Virtually all of the released residents took pains to conceal their past institutionalization from new acquaintances, expressing a desire to put that aspect of their lives behind them. While acknowledging that mental retardation existed, they nonetheless denied their own categorization as "retarded," or explained it away as a mistaken diagnosis. Once in the community, many of the newly independent adults actively surrounded themselves with the trappings of normalcy, proudly displaying unread books, framed magazine photographs, and items of mail in their homes. They also adopted popular attitudes and speech patterns and avoided further contact with their deinstitutionalized peers.

Other researchers have more recently documented self-awareness of social stigma in people with mild mental retardation (Jahoda *et al.*, 1988). In my experience, acculturational behaviors continue to be a common phenomenon among members of this social group. For example, teenage special education students frequently conceal their attendance at Elwyn's day school, which is well known as a mental retardation center, by telling neighborhood friends that they attend private schools elsewhere in the community. The students defensively describe themselves as "just like everyone else," and few admit to having mental retardation. Similar themes have been reported among both institutionalized and community-based individuals with mental retardation (Schurr *et al.*, 1970). The inclusion of special education students into regular classes within their home school districts does not necessarily eliminate their sense of stigmatization (Rucker *et al.*, 1969), and published interviews of people with intellectual disabilities have often reflected their strong desire to blend in with and fully participate in mainstream culture (Schwier, 1994; Anonymous, 1974).

Because of the lifelong dependency of people with mental retardation, their everyday lives are tightly intermeshed with the philosophies and practices of mental retardation professionals. In recent decades, the professional mental retardation field has actively fostered acculturation through its adherence to the concept of "normalization." Normalization of individuals with

mental retardation implies that “as much as possible, human management means should be typical of our own culture; and that a (potentially) deviant person should be enabled to emit behaviors and an appearance appropriate (normative) within that culture for persons of similar characteristics, such as age and sex” (Wolfensberger, 1972, p. 28). While its most positive intent is to create a valued place within society for people with disabilities, normalization has also fueled a pervasive rejection of disability labeling, including etiological diagnoses, within the mental retardation field. The current antidiagnosis trend is epitomized by the description “differently abled,” endorsed by some disability rights advocates, which rejects not only the label but also the notion that a disability exists at all. When applied to the social category of people who have mental retardation then, acculturation is illustrated by the widespread rejection and denial of disability stigma by affected individuals and the professional mental retardation field, and through the adoption of behaviors and attitudes aimed at achieving normalization.

## ACCULTURATION AND GENETIC COUNSELING

Acculturation manifests itself in specific ways among women with mild mental retardation in the genetic counseling setting, and its impact is felt in three main areas: denial and underrecognition of mental retardation; hierarchical perception of disability; and reproductive motivation.

### Denial and Underrecognition of Mental Retardation

Many people with low intelligence who are considered to have mental retardation in today’s technologically-advanced societies might not have been so classified in the pre-industrial cultures of earlier centuries. Standardized screening tests used in schools throughout the United States since the 1960s now virtually ensure the early detection of children with significant developmental disabilities. In noneducational settings, however, mental retardation is not always obvious without formal evaluations, particularly among the mildly affected women who typically present for genetic counseling services. Once out of the special education system, these individuals are often anxious to be perceived as “normal” and may be reluctant to volunteer information about past educational experiences, sometimes denying a disability altogether.

In my experience, the majority of adult women with mental retardation who present for genetic counseling services do so without a known etiological diagnosis, and in most cases, having never undergone a formal genetic

evaluation. This is probably due to a combination of the recency of genetic diagnostic technology and the rejection of diagnostic “labeling” by professionals in the mental retardation field. For example, much of the current mental retardation literature reflects a lack of awareness about reproductive genetic issues among affected women, and frequently, a trivialization of the role of genetic factors in the etiology of developmental disabilities (Drash, 1992). Compounding this situation is the fact that severe and profound intellectual impairments, while accounting for less than 10% of all mental retardation, are disproportionately represented among people with diagnosable genetic syndromes. As a result, genetic counseling professionals may develop a skewed perception of the severity of mental retardation and may not adequately recognize its presence in a counselee with mild intellectual deficits. For instance, when I contacted regional genetic counselors to solicit participants for the Jane Engelberg Memorial Fellowship project, few acknowledged ever directly counseling women with mental retardation, although most said they at least occasionally encountered women who seemed “slow.” In retrospect, it is likely that some of those counsees may have had mild mental retardation, based on the subtlety with which this disability can manifest itself.

The combination of a counselee’s efforts to “pass for normal” and a counselor who underestimates the significance of her client’s “slowness” is particularly important when, as in many cases, the woman is referred to a genetic counselor for reasons unrelated to her own retardation. A pregnant woman with mild mental retardation referred because of advanced maternal age or an abnormal marker screen may face additional prenatal risks due to her own disability. Yet the genetic counselor’s ability to address those additional risks may be limited by his or her ability to recognize mild mental retardation and by the woman’s willingness to discuss these issues. Additionally, a counselor may overestimate her client’s ability to provide accurate historical and pedigree information, further affecting risk assessment. Traditional genetic counseling formats, which rely heavily on teaching factual information, are often ineffective for counsees with intellectual impairments. Obtaining informed consent for prenatal diagnostic procedures may be especially difficult when the counselee has mental retardation and is intent on hiding her inability to grasp the information provided.

### **Hierarchical Perception of Disability**

The term “mental retardation” encompasses a wide range of deficits in intelligence and adaptive behavior ranging from mild disability to the most profound levels of cognitive impairment. People with mild mental

retardation appropriately view themselves as more like, rather than unlike average people, and distinct from those with severe intellectual disabilities (Jahoda, 1988; Edgerton, 1967). Consequently, a social hierarchy exists within the group of people categorized as having mental retardation. In my experience, rarely do mildly disabled people describe themselves as having mental retardation, even when it is technically true. Most are far less reluctant to use inaccurate but socially acceptable terms such as “slow learner” or “learning disabled.” They perceive some people to have mental retardation, typically those with obvious physical impairments and minimal verbal abilities. Gan *et al.* (1977) reported positive and realistic attitudes about “the mentally retarded” among 33 mildly affected adults who completed a questionnaire; however, the issue of whether those respondents actually considered *themselves* to be retarded was not addressed. I have observed that mildly disabled individuals tend to be sympathetic toward people they view as mentally retarded, but often react negatively if the term is used to describe them personally. In special educational settings, it is not uncommon for students with mild retardation to taunt each other using the derogatory term “retard,” just as they in turn have been teased by unaffected peers. Such hierarchical distinctions may allow students with mild disabilities to psychologically distance themselves from those they perceive as truly retarded. Their imitation of “normal” teasing behavior may further serve to elevate their social status in the classroom by focusing stigma on less capable peers.

In addition to the hierarchy within the mental retardation category, mildly affected individuals also make distinctions between physical and intellectual disabilities. Of six counselees I specifically questioned on this subject, all considered it “worse” to have a physical disability than a learning problem. This may be due to their perception of the relative difficulty of hiding an obvious physical difference as compared to a mild intellectual one. It may also reflect a developmental immaturity that equates physical disability with pain and suffering. All six women interviewed on this subject said they would never end a pregnancy “just because a baby was retarded,” although half said they might consider termination if the child was destined to die or suffer chronic physical problems. This attitude is in contrast with that of many normally-intelligent couples for whom the presence or absence of mental retardation is a key factor in deciding whether to continue a pregnancy (Fonda Allen and Mulhauser, 1995).

A counselee’s perceptions of her own and other people’s disabilities can directly affect her reproductive choices. For example, a woman at risk for having a boy with fragile X syndrome may be unconcerned if she perceives that he will be “just like me,” even though males with this disorder are usually more severely affected than females. On the other hand, a

woman who is told that her child may have "mental retardation" could be overly concerned about the possibility of a severe disability when in fact, the main risk may be for mild intellectual impairment. Pregnant women with mental retardation often express their greatest concern about conditions which affect a child's physical health, including congenital heart defects, oral clefts, and seizures, while seeming relatively unconcerned about the possibility of intellectual disabilities. For some, a "good" outcome is one in which a baby lives, regardless of the presence of a disability, and a "bad" one is when a baby dies. Such concrete, black and white perceptions can be an important source of miscommunication unless explicitly identified and discussed during the genetic counseling session.

### Reproductive Motivation

A variety of different factors underscore any woman's decision to have children. Motivating forces like the desire to nurture and love a child, the need to leave a legacy, a woman's self-concept, and even inherent biological drives may be countered by the perceived and real constraints of child-bearing on her health, finances, emotions, and personal freedom. Among adult women with intellectual impairment these reproductive motivating factors are likely to be similar, although their relative weights may differ from those of women with normal intelligence. Marriage, ideally to a non-disabled spouse, and reproduction are primary goals among many women with mild mental retardation (Schwier, 1994; Sabagh and Edgerton, 1962). Procreation is often viewed as the great equalizer: for a person who has felt different her entire life, who has gone through special education, who continues to be told what to do even into adulthood, the realization that she can become pregnant and give birth can be tremendously motivating. Those who do become pregnant are often pleased by their newly acquired social status and the increased attention afforded them. For these women, to conceive and parent a child is perhaps the ultimate expression of acculturation, far outweighing any perceived negative consequences.

The factors that motivate reproduction among adult women with mental retardation have many parallels among intellectually normal pregnant teenagers, a subset of whom become pregnant by intent rather than accident. Like these adolescents, women with mental retardation have little control over their lives and may be seeking to exert their independence through pregnancy. As a group, pregnant adolescents have been found to be developmentally and cognitively immature relative to their nonpregnant peers, and most exhibit poor decision-making and academic skills (Holden *et al.*, 1993). These characteristics equally describe women with mental



retardation. In both groups, the woman may be driven by the immediate social gratification of pregnancy with little ability to understand its long-term consequences. Pregnant adolescents are more likely than their non-pregnant peers to underestimate the demands of caring for a child (Trad, 1993), as are women with mental retardation. Four of 12 women I interviewed for this project perceived themselves to have *superior* abilities to care for a child with special needs, stating that because they have "been there," they understand the difficulties involved better than other mothers. Parallel examples of "overconfidence" have previously been described among school-age children with mild mental retardation (Schurr *et al.*, 1970). As opposed to low self-esteem, such comments illustrate the women's exaggerated sense of their own parenting abilities, a perception that is unfortunately not borne out by the high incidence of abuse, and more commonly neglect, among children of mentally retarded parents (Seagull and Scheurer, 1986).

The fact that a woman with mild mental retardation may be highly motivated to achieve and maintain a pregnancy has implications for her reproductive decisions. Developmentally, such women demonstrate the egocentric thought processes typical of preadolescents (Phillips, 1969). They generally have great difficulty projecting into the future and tend to focus on the "here and now." For example, potential fetal risks are often far less important than maintaining the woman's newly-heightened social status, and there is little appreciation for the demands of raising a disabled child. On the other hand, many women with mental retardation may be extremely protective of the fetus during pregnancy and may willingly abstain from hazards such as cigarettes, drugs, and alcohol if specifically told to do so. In my experience, women referred for genetic counseling frequently express an interest in prenatal diagnosis "to make sure the baby is okay," even if they would not abort a pregnancy under any circumstance. If they understand that significant procedural risks may be involved however, many decline prenatal testing. Once a baby is born, some women are eager to accept parent training and outside assistance, particularly when this assistance helps them maintain custody of the child.

Not surprisingly, once a woman has given birth and takes on an active parenting role, she may no longer be extraordinarily motivated to have children. Statistically, while more retarded women than ever are becoming pregnant, their average family size is similar to that of the general population (Garber, 1988). Exceptional cases can be seen among women who give birth but are deprived of the opportunity to parent their children. Researchers have shown that over 25% of children born to women with mental retardation are removed from the home or placed in foster care at birth (Whitman and Accardo, 1990). Consequently, some women intentionally

become pregnant repeatedly after losing custody of their children, determined to continue conceiving “until they let me keep one.” For these women, the ultimate reproductive risk is the one that prevents them from ever being able to parent a child.

### CASE REPORTS

The following case reports illustrate the attitudes and perceptions of three women with mild mental retardation. These are women who rarely travel independently, have minimal or no reading skills, cannot reliably make change for a dollar, and are not able to independently manage money or run a household. By contrast, they are able to clearly verbalize their opinions on fundamental reproductive issues. Their stories reflect many of the same emotions and attitudes seen in counselees with normal intelligence.

#### Patty<sup>3</sup>

Patty is a young woman with mild mental retardation (full scale IQ: 64). Prior to the birth of her daughter at age 20, she had always lived at home while receiving special education through Elwyn’s day school program. Patty participated in four in-depth interviews during her pregnancy. Follow-up interviews after the birth of her daughter were through informal meetings and telephone calls. She was initially seen in our genetics clinic at age 14, when she and her brother were evaluated to determine the etiology of their mental retardation. Clinical examination and laboratory analyses failed to reveal a specific diagnosis. However, mild to moderate mental retardation segregating with the single physical finding of marked ocular hypertelorism led to the clinical diagnosis of a unique autosomal dominant mental retardation syndrome in this woman, her brother, and her father. While still in secondary school at age 19, Patty became pregnant by her unaffected 27-year-old boyfriend. They subsequently married and she gave birth to a full-term baby girl who, on follow-up at 19 months, had a normal interocular distance and no evidence of developmental delays. Patty continued to receive ongoing support and supervision from her mother, who lived across the street from the couple.

Patty described herself as having a “learning disability.” She did not consider herself to have mental retardation, although she knew people who were affected. She perceived physical disabilities to be “much worse” than

<sup>3</sup>Names have been changed.

learning problems. Patty admitted to lying to unaffected neighborhood friends about going to a special school, although she did tell the baby's father about her disability after they started dating. She described him as very supportive, although overly protective of her and jealous of other men. During one interview, she related an incident which occurred at the welfare office when the couple went there to apply for medicaid benefits. With the disclaimer "I wasn't really embarrassed, but . . .," Patty expressed anger at her fiancé for having told case workers about her "learning disability" after she had initially denied it on her application. She became very defensive about the subsequent line of questioning by the welfare agency personnel. The couple eventually left without filing an application. Patty explained that people treat you differently and "get an attitude" when they know you have a learning problem.

Although she initially claimed that her pregnancy was accidental, Patty eventually stated that both she and her boyfriend had hoped she would become pregnant and were happy and proud about the pregnancy. She enjoyed school and had many "learning disabled" friends, but stated that she would become a full-time mother once the baby was born, just as her older (unaffected) sister had done. Throughout the pregnancy, Patty expressed concern about protecting the baby's physical well-being. She sought prenatal care within 2 weeks of becoming pregnant and was careful to avoid alcohol, cigarette smoke, chocolate, sugar, and caffeine-containing beverages which she perceived as being particularly harmful. Beginning in the first trimester, she refused to attend gym classes and expressed concern about being accidentally jostled in the school hallways, worried that this might lead to a miscarriage. A main fear as the pregnancy progressed was that the baby might be strangled to death by the umbilical cord at birth as had occurred in her older sister's child. While Patty was quite open about her fears for her baby's physical health, none of them included concerns about intellectual disabilities.

Over the course of two sessions, we discussed the results of Patty's genetic evaluation and their implications for her pregnancy. Patty acknowledged the presence of disabilities in herself, her brother, and her father, and recognized that neither her sister, mother, nor fiancé were affected. She expressed little concern about the chance for a recurrence of similar "learning disabilities" in her child, accurately describing the 50% risk as "maybe she will and maybe she won't." Patty did ask whether prenatal testing was available, stating that she would like to know if the baby had a disability, even though she would not end the pregnancy under any circumstance. She vehemently rejected the decision by other people to abort a pregnancy because of a prenatally diagnosed disability, stating that children with disabilities are "just like anybody else." While still pregnant,

Patty already saw herself as an expert on raising children with special needs, since she had personally "been through it." On several occasions, she volunteered to give parenting advice to women who felt they couldn't handle a disabled child, even offering to adopt the children herself.

Patty and her fiancé were married in her third trimester of pregnancy. They purchased a small house across the street from the home of Patty's parents, who provided some financial assistance. She subsequently gave birth to a full-term, healthy daughter. When I visited her a few hours after the delivery, she was elated and clearly relieved that her daughter had survived the birth process; she looked forward to taking the baby home. At 3 months, the baby appeared to be thriving and Patty denied any difficulties. Much of the responsibility for child care however was assumed by Patty's mother, who lived within yards of the couple's home. Patty stated that she had less and less contact with former schoolmates and now spent most of her free time associating with her husband's friends.

### Janet

Janet is a 31-year-old woman with spina bifida, shunted hydrocephalus, and mild mental retardation (full scale IQ: 67). She uses a wheelchair and has limited use of her left arm due to spastic hemiplegia; she has excellent verbal skills and an engaging personality, giving an initial impression of being higher functioning than she actually is. Numerous meetings over a 10-year period were conducted to discuss a variety of topics related to Janet's disability. She was admitted to Elwyn's residential program at age 21, after years of unsuccessful foster placements, including one in which she was sexually abused. At that time, she had a poor understanding of spina bifida and its etiology. She expressed a particular interest in knowing if her deceased mother's alcoholism might have contributed to her disability. A subsequent clinical evaluation showed no evidence of fetal alcohol syndrome. Janet was counseled about the multifactorial nature of spina bifida and its association with hydrocephalus and mental retardation. She expressed relief that her mother had not actively caused her to have a disability.

From the earliest meetings, Janet voiced her strong desire to become pregnant. She admitted to engaging in unprotected sexual intercourse with numerous partners. She had a good understanding of female anatomy, reproduction, and was familiar with many obstetrical terms, including amniocentesis. Her doctors had cautioned her that she would unlikely be able to carry a baby to term based on her restricted lung capacity and severe scoliosis. She expressed concern about these obstetrical risks and about the risk for spina bifida in her future children. Nevertheless, she felt these risks

were worth taking. Janet was aware of the availability of prenatal diagnosis for spina bifida as well as the benefits of dietary folic acid supplementation. She further intended to maximize her chances for a healthy pregnancy by "staying in bed" and avoiding drugs and alcohol.

Now 31, Janet has never been pregnant and seems less driven to achieve this goal, even though she currently lives semi-independently in the community. She acknowledges that she will probably never have a child, although she has not totally abandoned this dream. She has become more cautious about getting pregnant in recent years after learning that she probably would "not be allowed" to keep a baby. She views this as terribly unfair, but is frightened to take the chance of having a baby and then losing it. Janet perceives her disability to be primarily physical. She finds it frustrating to be dependent on people "just because I can't walk." She is aware of being classified as having mild mental retardation, a term which she views with contempt. She also believes that if she did not have to use a wheelchair, she would be fully independent. While acknowledging that she is a "slow learner" and has minimal reading abilities, she does not see this as a handicap. She recognizes that some people are "really" retarded, but she does not believe that a child's level of retardation can be predicted at birth. For this reason, she states that she could never abort a pregnancy based on a baby's potential retardation, since he might turn out to be "just slow." While she would feel bad if her baby had spina bifida, she reported she would never end a pregnancy for that reason. In fact, Janet feels strongly that the only reason she would abort a pregnancy is if the baby had a lethal condition that couldn't be treated. She perceives that, with some help to get around her physical limitations, she would be an excellent parent for a child with special needs. However, she feels that other people should be given the option of ending a pregnancy, since they may not be able to deal as well as she could with a disabled child.

### Yvette

Yvette was initially interviewed when she and her husband brought their infant daughter to Elwyn's genetics clinic for evaluation. The couple had been referred by staff members at a parent training program in which they were enrolled. Yvette was 29 years old and had mild mental retardation (full scale IQ: 55) and marked microcephaly. Her unrelated husband had nonspecific familial mental retardation. Their 8-month-old daughter had developmental delay and microcephaly. A clinical diagnosis of autosomal dominant microcephaly was made in Yvette and her daughter, whose delays may have also been compounded by the paternal history

of multifactorial mental retardation. The child was referred for early intervention services to Elwyn's development center, where I maintained family contact.

Prior to her baby's birth, Yvette lived at home while attending Elwyn's day school program. She describes her experience as "good" although she never told neighborhood friends that she attended a special school. At age 16, she became pregnant after being raped. Her child was given up for adoption at birth. She and her husband had been dating when she became pregnant with her second child despite the fact that she was taking birth control pills. She said she was happy to be pregnant, especially after losing her first child. While still pregnant, the couple voluntarily enrolled in parenting classes in order to learn how to care for their baby. They continue to be very accepting of outside help. They maintain their own apartment in the community, supporting themselves through disability benefits and her husband's income from working at a fast food restaurant. They require intensive ongoing support from social workers to address child care needs, money management, doctor's appointments, transportation issues, and other daily activities. Their case workers describe them as loving, devoted parents who know how to utilize outside resources to compensate for their own limitations.

Yvette describes herself and other members of her extended family as having "learning disabilities." She is aware that her daughter has a small head but denies concern, stating proudly, "She's just like me." Despite this, Yvette does not want her daughter to go to a special school and anticipates that she will attend a neighborhood kindergarten. She perceives physical disabilities to be "worse" than learning problems, and using herself and her husband as examples, she states "we did all right." She expresses much affection for her child and exudes great confidence in her parenting abilities. In Yvette's opinion, "No one could be a better mother to her than I am, because I've been there."

In the future, Yvette predicts that she and her husband will have one or two more children. She states that the possibility of an inherited "learning disability," or the chance of a more serious physical or intellectual disability in future children, has no impact on their reproductive plans. She says that she will accept any child, regardless of its abilities. Nonetheless, she expressed much interest in undergoing prenatal diagnostic tests in her next pregnancy "to make sure the baby is okay." When asked what she hoped to gain by such information, she spoke of her desire to prepare for the baby by getting "handicapped tags" (license plates) if the child has a physical impairment. (Neither she nor her husband drives.) She strongly denounced people who choose to end a pregnancy because of a prenatally diagnosed disability, stating that "it's not right to kill a baby." She suggested

instead that they put the baby up for adoption by other people, like herself, who are better able to care for a disabled child.

## CONCLUSIONS

Mental retardation has historically been a highly stigmatizing disability. Its definition and the very words which describe it change continually, as one term after another falls into socially derogatory use. "Mentally retarded," like its predecessors "imbecile" and "moron," will eventually give way to a new, temporarily acceptable term, yet human nature predicts that people with intellectual disabilities will likely always suffer some degree of social stigmatization. Acculturation represents a response to this situation by those affected, particularly among people with mild disabilities who live literally on the edge of mainstream culture.

Acculturation in people with mental retardation has a complex basis which includes developmental and cognitive factors, as well as an active rejection of disability stigma. Because acculturational behaviors and attitudes influence the reproductive choices made by women with mental retardation, they cannot be ignored in the genetic counseling setting. As illustrated by the three women profiled here, the ability of people with mild retardation to express their emotions and perceptions is not necessarily hampered by their disability. The counselee's self-concept, her attitudes about severe retardation and physical disabilities, and her level of reproductive motivation need to be addressed early in the genetic counseling process in order to establish the groundwork for higher level decision-making. A woman who is quite adamant about her intent to protect and maintain a pregnancy under all circumstances has essentially made a decision to decline invasive prenatal testing, even if she is unclear about certain facts related to the procedure. On the other hand, a woman who demonstrates the ability to parrot factual information about amniocentesis, and who even consents to undergo the procedure, may not be making an informed decision unless basic issues of reproductive motivation and perceptions of disability have been adequately explored. The fact that mental retardation is primarily an intellectual disability does not mandate a solely educational solution, and the challenge of providing genetic counseling to affected women will not be solved by probability dice and clever analogies. Approaches which address fundamental psychosocial issues, particularly as they relate to acculturation, may provide a more fruitful avenue than traditional genetic counseling models for facilitating reproductive decisions in this complex population.

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