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Changing Perceptions of Mothers of Children with Disabilities 1960-1992: A Critical Review

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Abstract

A review of theoretical, popular and experimental literature concerning mothers of children with developmental disabilities reveals a change in focus time. In the sixties the focus was on maternal pathology; in the seventies, on partnership with professionals; and in the eighties, on family coping. Relatively little is known about the mother, her needs and coping strategies. Social and educational policies families of children with disabilities have been created with little regard to their impact on mothers. Future policies must be cognizant of maternal needs if we are to support the primary care takers of persons with disabilities.

Changing Perceptions of Mothers of Children With
Disabilities 1960-1992

Current educational and social policies concerning children with developmental disabilities rely heavily on maternal participation. Pressure on budgets is forcing cities and towns to search for ways to educate and care disabled students within both the public school and the community. Fewer students are being placed in residential settings and most remain at home after the age of twenty-two. Because the mother is usually the primary caretaker, the case management of her child's program often falls to her. Professionals who work with mothers of children with developmental disabilities, in educational, social, or therapeutic settings, need to understand these women and their lives if their work together is to be successful. To increase understanding thereby the ability to assess the validity of current views about these mothers, this paper will examine how mothers of children with developmental disabilities have been characterized over time, the lessons learned, and the implications for current educational and social policies

Before beginning this review, it is important for reader to understand that little research has been done on mothers of children with disabilities. While

much has been written about disabilities and the disabled, very little has been written about the mother of the disabled child and even less has been written about the mother of the older child. Those few writings that do study these women usually focus on the mother effect on the child or the effect of a particular intervention on her mothering. Or, the mother is embedded in the family and her needs are not differentiated from those of other family members. Thus relatively little has been said about her needs and goals, and how the child influences her personal and life. In addition, as Wolfensberger and Kurtz noted 1969,p. 227 "when some writers refer to parents, they do not mean parents at all, but mean mothers to the exclusion of fathers". Frequently, in society, mothering and parenting are taken as synonymous. Fathering is included as an afterthought if at all. Conversely, writers refer to "parents" despite the fact that mothers report greater responsibility for the care of children with disabilities with a resulting increase in fatigue and stress than do fathers (Bristol, Gallagher and Shapler,1988; DeMyer,1979; O'Moore 1978 . In fact the confusion among mothers, fathers, and parents is so great that sometimes writers will change subjects in the middle of a sentence. While this imprecision is most likely unintentional and could be excused on stylistic

grounds, too often it serves to obscure the mother
her special role and her special needs

Method

This review covers theoretical, popular and experimental literature concerning mothers of children with developmental disabilities, written between 1960 and 1992. The sample is limited to books readily available to future professionals and parents. Thus the books reviewed are from a city library in New Hampshire, and the libraries at three schools of education: the Harvard Graduate School of Education, Lesley College in Cambridge, Massachusetts, and the Rivier College in Nashua, New Hampshire. The theoretical literature consists of books and articles by authors who attempt to understand maternal behavior and its causes. The popular books are books written by parents, and texts intended for future professionals, as well as books intended to teach parents and professionals how to cope with stresses or how to instruct. Quantitative and qualitative studies relating to mothers of children with disabilities are included in the experimental category

The Theoretical Basis

In 1964, Ayroult noticed that most of the books and manuals written for both future teachers and parents of

mentally retarded children assume that the mother feels guilty about having produced a "defective being". Many authors writing about various types of disabilities suggest that the mother represses her guilt feelings about the child and then overprotects him/her. Therefore, the discussion must begin with the theoretical basis of this guilt.

Although Freud wrote little about women, in his article on female sexuality (1932) he contributed three ideas that form the basis for the construct of reality concerning mothers of children with disabilities. First, after identifying the subconscious, Freud noted that conflicts within the subconscious influence daily behavior. Second, he theorized that the instinctual desires within humans are in conflict with society. Third, he theorized that the nuclear family is the central stage on which the subconscious is developed and emphasized the intrapsychic roots of problems.

Freudian theory has been widely criticized for its emphasis on personal responsibility to the neglect of societal causes. In the case of mothers of children with developmental disabilities, Freud's particular construct has led to the creation of a reality that has denied the validity of maternal feelings and perceptions, and slowed the search for social solutions. It has justified providing psychological help, when mothers have begged professionals of all types for

practical assistance. This justification was welcomed by professionals, in part, because the dispensing of psychological assistance is far more lucrative than the giving of practical aids, such as babysitting or laundry help (Ehlers, 1966). It also justified the vending of the wares which the professional helper had to sell. By correlating services offered and finances, the author does not mean to suggest intentionality; but rather to introduce the complexities in the relation of theory to practice and economics. More importantly these theories were slow to be questioned, in part, because they required only the individual to change and, thus relieved the policy makers and society of responsibility.

Until the 1970's any theories relating to mothers of children with disabilities were either extensions or elaborations of the Freudian notions above outlined. While these theories are out of fashion now, it is important for us to remember that any mother of a teenage or older child with disabilities, was subjected to the power of these theoretical models. Any professional trained before the late seventies was schooled in their wisdom. Therefore, these theories have had a profound effect on the advice given the majority of today's living mothers, and the vestiges of these ideas still influence professional thinking. Moreover, Freud's ideas

have entered the cultural consciousness and influenced our attitudes about the role of mothering.

A Critical Review of the Literature

A brief critique of these ideas will show how they added to maternal pain. Helene Deutsch (1973), who wrote extensively about motherhood, pregnancy, and childbirth suggests that unresolved feelings about masturbation and oedipal conflicts lead the mother to fear having an abnormal child. Furthermore, she states that the mother needs to resolve the conflict between her own narcissistic wishes and the demands of motherhood. Deutsch warns that these tasks are difficult, and made more difficult by the fact that the mother is tired. Although she notes that "exhaustion is not a propitious soil for happiness" (Deutsch, 1973, p 251), she makes no suggestions about how to alleviate this exhaustion. Nowhere does Deutsch validate the right of the mother to have her own needs. In fact, if this theory has any truth, then the work of a mother of a child with disabilities is even more difficult. First, her guilt about masturbation and oedipal feelings will have been substantiated with proof of her own badness; second, the intense conflict between self-love and object-love will be increased since the child usually requires more care and the care extends over a greater period of time than is usual for most mothers.

While Helene Deutsch applied Freudian concepts to all mothers, Maud Mannoni (1972), a French psychoanalyst, theorized about the specific difficulties of mothers of children with retardation. She suggests that for the mother the child represents all that is and lacking within herself, and that the mother uses child to avoid facing herself and her own negative feelings. As a result, she thus overprotects the child and talks to no one about the child

A further extension of this theory was expressed by Polansky, Bomme, DeSaix, and Sharlin (1971), when they listed several ways in which the mother uses the child to deny reality. This list includes the use of the child as a spite weapon, the use of the child to express her own impulses, and the use of the child to make herself feel special. They suggest that using the child in these ways is "testimony to the ego's expertise at wringing salvage from life's disaster" (p. 649).

Nowhere does anyone suggest that the mother's own strength and courage enable her to overcome sorrow and disappointment and even to find some joy in the situation. Nowhere do the theorists hint that coping is a tribute to the mother's conscious striving, rather than a manifestation of intrapsychic wars.

In addition, none of these theories incorporates later notions put forth in Carol Gilligan's study of women's moral decision making (1977), which suggests

that women, perhaps more so than men, are able to integrate the wishes and demands of self with the wishes and demands of others. Nor do they consider, as Jean Baker Miller (1976) has suggested, that serving others might not be in conflict with serving the self, but rather might help satisfy one's own needs for affiliation.

In advising these women, neither theoreticians nor therapists suggest that their feelings about the kind or lack of options mothers perceive for themselves or for their children might influence their behavior and feelings. No one considers that the mother of a child with disabilities, in order to find services for her child, may be forced into an aggressive role and that may put her in conflict with a more passive notion of femininity with which she was reared. Much less does anyone recognize that the mother may be surprised and delighted by the pleasure she feels in the accomplishments from this more aggressive role.

In practice, these theories resulted in the perception that if the mother advocated for her child, her motives were suspect and her character called into question. If she found mothering difficult, she was blamed rather than validated. No one acknowledged that her difficulties might be due to lack of social supports, to lack of schools and programs for her child, or to the excessive demands and isolation that caring

for a child with disabilities placed on her. Blaming the mother added to maternal anxiety and even caused her shame since the assumption was that she, as all women, should wholeheartedly love mothering.

Mothers Voices as Agents of Change

During the time when these theories were popular, parents of children with various types of disabilities wrote fondly of groups where they met others in the same situation - people who had "been through it." There they found a sympathetic ear and good advice from others who had coped. They also wrote books complaining about poor treatment they received from many different types of professionals who would not listen seriously to their notions of their own children. They also described family lives with remarkable coping skills. They talked of their despair and how they went on with their lives and sought to get the best help for their children how eventually they found joy in their coping and in the small achievements of their children. Two of these books in particular not only informed other mothers, but also added to the professional literature The Siege by Clara Claiborne Park (1969) is an excellent clinical description of autism, although the author is an English teacher, not a clinician. This book is one of the first to acknowledge the role of the mother's work outside the home in maintaining balance in her life and demonstrates

a mother's resourcefulness The other, A Difference in the Family, by Helen Featherstone (1980), foreshadowed the emphasis that would be placed on families and family coping skills.

Throughout the seventies, most textbooks written for future teachers therapists, counselors and doctors warned that maternal feelings would be projected on the helper and advised the professional to remain distant "How to" books made no suggestion of shifts in family roles to alleviate some of the mother's exhaustion or enable her to be less isolated. Most experimental studies at the time focused on the mother's effect on the child or the effect of a particular intervention on her mothering. Only a few, notably Farber (1969) Lloyd-Bostick (1976) and Ehlers (1966), emphasized family needs and the maternal desire for practical help

In sum, by focusing on maternal idiosyncracies these theories blinded practitioners from looking at themselves, the environment, or cultural myths The theories and, in turn, those who applied them, discounted or discredited maternal perceptions and the alleviations the mothers suggested by labeling them pathological or crazy. There is a long history in many fields of labelling women crazy when they talk of the reality they experience (Chesler,1972). They gave little hope for mothers of children with disabilities to lead mentally healthy lives. These theories created a

reality which was more real than actual experiences described by parents in books and personal interviews (Buck, 1950, Frank, 1951, Heisler, 1972, and Featherstone, 1980).

Changing Views

Wilson (1972), was one of the first to suggest that societal structures and attitudes, not maternal anxiety

be changed if the child is to be helped. It was her opinion that the small nuclear family maximizes maternal suffering because it isolates the mother. She also said

asking mothers to be the sole caretakers of these children is a disservice to women and "a reflection as in a distorting mirror of the role of mother in our society" (p. 7)

As the seventies moved along, a major change in the field was brought about by a confluence of factors: the civil rights movement, the women's movement, and finally the passage in 1975 of PL-94142, The Education for All Handicapped Act, which required parental participation in the educational planning for each of their children. The angry, projecting, avoiding mother was now a partner. Her image was reconfigured. Theories and attitudes began to change.

Elizabeth Kubler-Ross (1969) popularized theory of stages of dealing with death. Soon they were adopted in modified form to assist with dealing with all sorts of

disappointments in life -- including facing cancer and producing children with disabilities This served to place maternal emotional reaction within the realm of normalcy, something which parental books had described much earlier Mothers who had moments of sadness anger, or depression were no longer crazy pathological or denying of reality, but rather were exhibiting normal reactions to disappointments. Equally important, this developmental theory gave some hope of triumph over adversity. The major descriptive theory previous to this was Olshansky's (1962) concept of chronic sorrow While this theory granted normalcy to sad feelings, it did not give much hope for happiness. Kubler-Ross's provided a giant step forward in professional thinking and allowed mothers to feel their pain with the knowledge that it might lessen someday.

In the experimental literature studies began to look at maternal experience-- how the mother copes, what services she would like and which interventions serve her needs (Lloyd-Bostick, 1976) In the popular literature, a rash of "how to" books intended to help parents access and negotiate the system appear. Other books train mothers to be partners in the teaching process. Professionals were now urging each other to listen to maternal complaints, to involve her in planning and to look at their own behavior before accusing mothers of projecting feelings. Mothers were

no longer seen as patients needing care, but as partners in the work of education and rehabilitation. On the one hand this was a great relief to mothers; they were included in the planning for their child's future. On the other hand, this partnership would lead to more work for the mother -- she must be record keeper, advocate therapist, teacher, and case manager as well as mother. Together these books made unrealistic demands on mothers. Books written by parents requested relief and expressed anger that, despite verbiage about partnership, professionals designed the service plans and mothers were expected to comply (Stevens, 1980).

Beginning with Busgaglia (1975), the literature began to suggest that role changes within the family might alleviate the mother's burden. It was usually assumed, however, that it is the mother's job to change those roles since she is the one who has kept the child close to herself and away from other family members. However, experimental literature later in the decade has led us to question the efficacy of giving the mother this responsibility. Help from the child's siblings correlates with help from the father (Bristol, 1979 and Nemzoff, 1979). Thus, the mother may not be the only salient agent in determining family roles.

The Family

The eighties brought another shift in thinking Crnic, Friedrich, and Greenberg (1983) pointed out that there was a "genuine bias in the literature toward expecting deleterious and pathological outcomes in families" (p.132). They criticized the experimental literature for focusing on the mother-child dyad and for assuming unidirectional causality, rather than using a transactional model of development. Moreover, they pointed out that most studies were done in one setting only, without examining the interrelationships of settings, such as, home, community, and school They then suggested looking at how families adapt, focusing on variables which buffer or moderate the effects of stress within the family's ecological system

In the years that followed, studies using a multiplicity of methods and a multiplicity of perspectives, looked at what actually took place in families. Family theory and developmental, ecological, and anthropological concepts were brought to bear on the study of families. There was a recognition of the interaction between cognitive, affective, and instrumental aspects of families The focus of the discourse was now on how best to use the resources available to meet the challenges of daily life.

Antonovsky 1987 introduced the concept of salutogenesis, that is, focusing on family strengths and

healthy coping strategies rather than on pathology In 1989, the Journal of Mental Retardation devoted a issue to studies on family coping and opened the door to the formulation of theories of successful coping Salutogenesis also has led to some focus on the mother, but usually she has been seen as embedded in the family and treated as a member of that unit rather than as an individual with separate needs

The Missing Mother

Relatively little of this literature on healthy coping focuses directly on the mother -- her goals needs and aspirations. Nor is there much that deals with the changed roles of women There are no studies that demonstrate how working mothers manage, despite studies that show there are few after school programs for the child with disabilities. (Seligson and Fink 1989) Also, there is little research on single parent mothering. One study, however, does focus on older mothers. Seltzer and Krauss 1989 did a longitudinal study of coping styles of older mothers of older children with retardation Not only does this research give evidence of maternal skills but also shows that older mothers often find solace and joy in their older children with retardation. The children, in turn, the mothers by reducing loneliness and by helping with household chores They also found that when coping

skills are viewed in a longitudinal study better accommodation is found than when a single period is examined. This discovery calls into question almost all the research on coping that looks at only one time period as doing a disservice to women's coping skills

Implications Drawn from the Literature

In addition to attesting to a dramatic change in the view of mothers of children with disabilities in the period 1960-1992, the literature points out the following:

1. Mothers do develop coping skills (Seltzer and Krauss, 1989).
2. Mothers report less stress and more happiness when they feel supported (Beckman, 1991; Bristol 1979b; Frey, Greenberg Fewell, 1989; Nemzoff 1979)
3. Mothers fare better when they are allowed to make their own decisions and are validated by others in the decision making process than when professionals do it for them (Maistro and German, 1981)
4. As the child ages the mother's support networks diminish -- grandparents age, siblings leave home, and neighbors are less willing to help with a post-pubescent person (Suezle and Keenan, 1981, Nemzoff 1979)

5. Mothers are no longer the causes of problems but are, at least, parts of the solutions. Maternal opinions are no longer viewed as suspect. They are worthy of respect.

6. Mothers, not professionals, have paved the road for innovative thinking about caring for children and theorizing about mothers and families. They were the first to focus on their strengths. They were the first to ask for education for their children and supports for themselves

7. If mothers do not tell about their lives, others will either ignore them or construct a reality for them as was done by those who based their theories on Freudian concepts

8. Advice to mothers is influenced by the prevalent cultural thinking. It changes with cultural mores and thus can be molded to meet many ends.

Further Questions

This review of the literature dealing with mothers of children with disabilities raises two principal issues. First, one must begin to question current thinking in light of the knowledge that the view of mothers has changed in the past and presumably will continue to change along with cultural bias. Currently one must ask if the focus on autonomy colors the advice

given mothers, the hopes for children, and family policy in general? Could it be that it is destructive to expect any caretaker to "go it alone" or all persons with handicaps to work toward relying on themselves? Would energy be better spent on learning how to enhance one's talents and energies by working with others?

The current societal focus on family independence is antithetical to what the parental reports and clinical studies are showing. Parents want help! Perhaps Erickson's notion of working toward autonomy has generalized to families and is inappropriate particularly for families with extra caretaking needs. By holding out autonomy as the ideal, are we adding to the stress of mothers and children? Jean Baker Miller has shown that women yearn for affiliation and that affiliative needs complement other needs. Her new emphasis on women in relationship might inform and change the discussion of families of children with disabilities. Does the notion that all problems are solvable and the search for cures do a disservice to this aspect of nature which does not conform to the norm or to easy solutions? In a results-oriented society, does the definition of results color the treatments? If society primarily values accomplishments, what does that do for those who devote time and energy to relationships?

Second, with mandatory education ending at age twenty-two, and community programs being cut, the care of adult children who need long-term care falls to the family -- and in most cases that means to mothers. Does the current emphasis on family and community care actually function to isolate mothers? By sending children back to the home full-time after schooling ends, are maternal supports being disseminated?

Policy Implications

In addition to these and other questions several policy implications emerge from this review. Future policy must focus on maternal needs. A mother's work is invisible for two reasons. First it is carried out in the privacy of her home; second, it is taken for granted (e.g. arriving at an appointment on time) Because of her invisibility, policy makers do not need to account to or for her. We all need to know more about the mothers. How do they manage to work? Are their job promotions affected by their child care responsibilities? Are mothers of children with disabilities destined to spend their older years in poverty? How does having a child with a disability affect the mother's personal life?

A report by Bradley and Knoll 1991 of the Human Services Research Institute, argues eloquently for allowing parents more control over funding for their

children and for removing the protective and often isolating shield of professionals around the person with disabilities. But it does not discuss how returning the child to the community itself, not just to special programs, will affect the mother. When programs are limited in scope and size, returning a person with disabilities to the community may be a euphemism for returning the child to the mother. This verbiage may be obscuring the fact that little exists to support mothers in their work.

Mothers must be encouraged to talk about their lives and their needs so that educators and policy-makers can listen and learn what the real issues are rather than deciding for themselves what mothers require

Moreover, professionals would do well to respect maternal ideas and innovations since mothers have been the agents of change in the past.

Since mothers fare better with supports, networking opportunities must be encouraged. A practical step is to ensure that every school and community program provides opportunities for mothers to meet each other. After the child turns age twenty-two and has to leave school, the mother must have regular opportunities to connect with other mothers as she begins the search for services for her adult child

Conclusion

This information is not only important for service delivery planning, but also for decision-making in other areas. With technology identifying handicapping conditions prenatally and saving very ill children post-natally, women need information about their own lives as well as the lives of their children as they confront their choices. The decisions they make for their children will affect their own lives. They need to know how other mothers have fared. Because doctors, legislators and judges are currently involved in these decisions they, too, need to understand the long term ramifications of their decisions. Unless older mothers talk about their lives in medical, educational and rehabilitation quarters, in the legislative halls and in administrative offices, neither mothers nor professionals will be able to make informed decisions. We have a lot to learn. Women's voices and experiences must be heard in all places where their futures are decided.

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