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WELLESLEY CENTERS FOR WOMEN

## Working Paper Series

### More Different Than Others?: Mothering A Child With Special Needs

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Perhaps the most telling aspect of my title is the question mark. Is a disabled child really more different from her mother than other children are from theirs? Is mothering such a child qualitatively different from mothering any other child? Perhaps I posed the question in the hopes of finding an answer for myself; if so, I wish I'd never asked. Speaking publically about my experience as a mother, stating out loud some of my thoughts on the act of mothering, is more difficult than I anticipated. To speak without succumbing to the tendency to exaggerate both the good and the bad, the positive and the negative aspects of mothering a disabled, or as many advocates prefer, a differently abled child is a challenge. Exaggeration provides a safe cover, it blurs the complexity and makes everything come out neat, simple, understandable. Much that is written about disabled children contains this exaggeration. It is an exaggeration that often places the parents, particularly the mother, of a disabled child in a ring of silence lest she be considered "deviant".

Over the years I have met many disabled children. Each is different. For some the primary issue is physical, as in the loss of sight or hearing or the use of arms or legs; for others a chronic, debilitating disease is the major problem; intellectual or emotional difficulties impede progress for yet another group. But for many of the 10% of our children born with significant disabilities, it is a combination of physical, intellectual and emotional disorders that earn them one of the standard labels: profoundly, severely, moderately, or mildly handicapped. I can speak only as the mother of one particular child, my only child, my daughter Amy. For Amy disabled means moderately retarded and mildly to severely physically handicapped depending on

the year or the week in question. When she was born two months prematurely 16 years ago, Amy seemed healthy and alert. At two months a congenital hip defect that required a body cast was diagnosed. "Simple", I said. "Simple", the doctor said, "a few months of treatment". It has not been so. Amy has spent years in body casts and braces, has had seven major operations for hip and urinary tract problems and more one to two day "procedures" for hip, leg, kidney and now chronic bowel disorders than I care to remember. When she was three, doctors told me she might never walk more than a few steps and might never speak more than one or two word phrases. Amy runs -- with a limp - and Amy speaks -- not always clearly but increasingly so. She reads at a second grade level and she is learning to use the telephone. She will never live totally independently but she is a wonderful, warm person full of potential and power.

Amy is "typical" of disabled children in that her problems are complex and chronic; and she is "typical" in that she has made progress, beyond the gloomiest diagnoses, but not up to the most optimistic. The uncertainty, the ambiguity is always there, no different, really, than the uncertainty of any parent for any child. No different that is, until one considers that for parents of disabled children the ambiguity is between life and death, among minute variations in levels of independence, about whether a child will ever speak or walk or buy an ice cream cone unassisted, uncertainty about things most parents and children assume and never question.

One of the first lessons a parent of a disabled child learns is to appreciate the frustrations of doctors who long to cure and cannot. To understand and accept that they often take refuge in gloomy prognoses.

Doctors can, parents must not. The balance between defeatist gloom, on the one hand, or denial and unrealistic optimism on the other is difficult to achieve and to maintain. But only such a balance can provide a child with a set of options and opportunities that will allow her to be who she really is. This is true for every child, but it may be particularly crucial for a disabled one.

Some things come more quickly and easily if your child has clearly recognized disabilities. You cannot consider your child as someone who may be "just like you" or as someone who may, by her wonderful achievements as judged by traditional standards, validate you and your mothering. You must see her as different and while this awareness is filled with disappointment and grief it is also the source of wonderment and joy and an exhausting but strangely exhilarating challenge. If she is not like me who is she? If her world is not my world what is it? How much of mine can she find? And how can I find pieces of hers? These questions come, I think, more quickly if your child's development differs from the usual expected pattern -- but surely they are every parents' questions. The sequence and timing may be different, the questions are not.

I am a single parent. Amy's father and I made different choices about our lives when Amy was a baby. Her disabilities clearly triggered some of these choices. I do not have reliable statistics on the percentages of families with disabled children who separate but I believe it is high. I know of too many fathers who "tried but couldn't deal with it anymore," the "it" being a daily grind of tending to basic physical needs often with little hope of eventual unemployment. At 16 Amy still wets the bed, wakes in the night

and cannot be left alone in the house for more than a half hour or so. The "it" also involves increased expenses and a mounting anguish as you watch your child suffer physical trauma and painful social rejections. Society allows men this choice but is less permissive with women. Fathering in our culture is an activity you can do or not do, mothering is all too often who and what you are.

Parenting a disabled child is a politicizing activity. Mothering such a child alone is a radicalizing one. Mothering a disabled child requires not only the culturally sanctified female roles of caretaking and selfless giving, but aggressive independent action. You must lobby the legislature, pressure the school board, argue with the doctor and defy the teacher. And, oddly, while these "unfeminine" behaviors might, in other contexts, be deemed deviant, performed in the context of mothering a disabled child they are seen as not only appropriate but laudible.

But for a single mother, even this culturally permissible deviance is insufficient. I could not provide emotional, physical and financial support for Amy and develop a life of my own without redefining my life and in a significant sense reconceiving motherhood.

All new mothers get advice, but the volume and diversity of the advice given to mothers of disabled children can be quite overwhelming. I was told to 1) have another child quickly 2) put Amy in an institutional setting 3) keep Amy home and devote myself to her education 4) proceed as usual and not get caught up in letting "this" change anything 5) think of my husband and make decisions around his needs and 6) see a psychiatrist to work through the anger and guilt I must be feeling. As a well socialized, "nice" young woman,

I tried to do what "everyone" suggested. They were, after all, either experts or people who knew and loved me, they must certainly have my best interests in mind. I could not, and because I could not, I "knew" I was a failure. I turned to the only source of help and comfort I could think of--I started a women's group. In the group, which I called a consciousness-raising group because it was 1971 and I had just read "Sisterhood is Powerful"<sup>1</sup> and longed for both sisterhood and power, I was able to decide that the advice of experts and loved ones all pointed in only one direction; it was all based on one idea of what a mother/wife/woman "should" do. It was all designed to help me be a "good mother," a wife/mother as prescribed by a middle class, patriarchal society. I probably could have done it but I doubt that I could have found the same joy and wonder in my child and in myself if I had.

The reality was that Amy was not exactly like "other" children. I could not proceed as usual; the reality was that I could not spend 24 hours a day teaching Amy, I had neither the training nor the temperament for early childhood education; the reality was that Amy was not profoundly disabled and did not require institutional care to grow and thrive; the reality was that as much as I desperately wanted to live with my husband I could not force him to make the decisions I wanted, he had to make his own; the reality was that to have another child, when I wasn't at all sure how I could support the one I had, would have precluded most choices other than wife to whomever I could manage to stay with or recruit; and the reality was that I was angry and I did feel guilty but I did not feel incapacitated by it. In fact, I have found working around and through some of the anger, the guilt and the grief, in my own time and in my own fashion, interesting.

Of course in all of this I use "was" but the more precise verb is "is". Motherhood is a lifelong state, but it is a changing one. This is true for all mothers whoever their children are. I watch as my mother worries about me and feels irrational guilt. Her guilt derives, I think, from helplessness in the face of my dilemmas. And I watch as I, in anger and grief, "blame" her sometimes when life seems a little more than I can handle. Why didn't she tell me? Why didn't she warn me? And besides what can she know about my situation, she and her three perfect children? I watch as I protect her and myself and the image of her perfect children of which I am the first, by not sharing the difficult times with her. And as I watch this I know that part of this protection is also punishment. If she doesn't know, she can't help and her inability to help me hurts her. The web of motherhood is infinitely intricate.

Mothering can be lonely. Mothering a "special" child can be very lonely until we learn not only to help others but to ask for help ourselves. Despite difficult times, I have, through Amy, met a world full of people who care about and for others -- nurses, doctors, volunteers, teachers, babysitters, co-workers, friends and strangers, as well as family, and I have learned that I am one for whom they can care as well as one who can care for them. No one has an exclusive patent on worry. Every parent wonders and worries and hurts inside sometimes. No life is without despair. Tragedy strikes with ruthless abandon. We all learn this in our own time. Having a disabled child is only one path to this awareness and to its lesson -- that joy is also a part of every life and that it too can appear with awesome suddenness.

My particular good fortune is in Amy's special qualities of mind that



have helped me to understand this joy. Oliver Sacks, in his new book, "The Man Who Mistook His Wife for a Hat", writes about retarded people whom he calls "simple". "If we are to use a single word here, it would have to be 'concreteness' -- their world is vivid, intense, detailed, yet simple, precisely because it is concrete, neither complicated, diluted nor unified by abstraction." 2 Amy never misses a sunset or a baby or a flower. She notices and she insists that others notice.

My life with Amy is different from the lives of many of my friends and colleagues. I live with a shifting assortment of students, single women and women with children. All living arrangements are prompted by Amy's needs and my financial constraints. Amy has had many "mothers" including young men as well as young women. These arrangements have been less than ideal but they have never been dull and they have always been full of loving care for Amy, some from me but much from others as well. Amy is at the center of my life but she is not the center.

Is mothering a child with special needs different from mothering others? Yes, it's probably more physically draining and more immediately challenging to both personal and societal expectations-- expectations for oneself, for children, for parents and for a just and reasoned society. But no, it is not qualitatively different, for every mother struggles with the two pieces of mothering; one, the expectations of others, the socio-institutional role of "mother" and the second, her own knowledge of her needs and her child's needs. Sometimes the needs of the mother and of the child are the same, sometimes they are not. The issue is, always, balance. There are no individual solutions, but feminist theory has always taught us that personal

decisions are political. I intend mine to be. As an individual, I can work toward a society in which not only power and responsibility, but independence and dependence are equally available to women and to men; where women are able to choose among many things that they may be and do, of which mothering is only one; and where women and men together can create a world in which children like Amy are seen in their joy as well as in their demands.

Notes

1. Robin Morgan, editor, Sisterhood is Powerful, New York: Vintage Books, 1970.
2. Oliver Sacks, The Man Who Mistook His Wife for a Hat, New York: Summit Books, 1985. p. 164.