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Abstract

The main responsibility for caring for their children belongs to women. This article examines the underlying assumptions about the roles of mothers of children with disabilities and how stereotypical gender roles influence the caring of a child within a family. With family support programs being provided on the basis of these cultural stereotypes there are possible conflicts between disability issues and gender issues which will have an effect on the success of full community inclusion of people with disabilities. **Keywords: Inclusion, Women**

Women, disability and caring

by Rannveig Traustadottir

This article is based on a two-year qualitative study of families of children with disabilities and the services that provide support to these families. In these studies I have challenged the traditional view of families and tried to explore how stereotypical sex roles influence the caring for a child within the family. I have also examined how traditional ideas and values about the roles of men and women influence the way in which family support services are provided. This perspective has allowed me to identify and examine issues that traditionally have remained out of sight. In this short article I can only touch briefly upon a few of these issues, but I hope the article will encourage people to look more closely and more critically at some of the new practices that are now being developed within the disability field. The research methods I have used are qualitative and the article is based on (1) a case study of one family support program, (2) in-depth interviews with families (including mothers and fathers) and service providers and (3) participant observations in a parent support group and at training events for parents of children with disabilities.

Traditional studies and attitudes toward families

Traditional studies of families who have children with disabilities living at home report that the mothers typically have the primary responsibility for caring for the child. This literature reflects the cultural stereotype of mothers as "natural" caregivers and assumes that women's primary orientation is toward family and motherhood. This both reflects and constructs how we see, understand and interpret the lives of mothers of children with disabilities. These studies are based on traditional ideas and values about the roles of mothers and fathers. These studies have not questioned that women are the primary caretakers of people with disabilities. When studying families, researchers usually interview mothers. But when summarising the studies, the authors most often refer to the "parents" views and experiences, even if their findings are mainly, or solely, based on information from the mothers. One author, who reviewed the research literature on families reports that, "... mothers of handicapped persons were grossly over represented in comparison to fathers." (Wolfensberger, 1983: 9).

This has at least two consequences. First, even if mothers are over-represented in research samples, the research reports hide the mothers and their experiences by constantly referring to "parents" or "families". Second, the under-representation of fathers leaves us without knowledge and understanding of the fathers' views and experiences. This under-representation of fathers is so serious that the author quoted above suggests that "Much of the research leaves one wondering whether handicapped people have fathers." (Op. cit.).

Today the social policy of community integration has become widely accepted within the disability fields, and many countries are developing a variety of services that have the goal of supporting people with disabilities in the

community. Family support programs are one of these new ways of delivering services, and there is now a growing consensus within the field that family supports are one of the essential parts of a new service delivery system. Without family supports it can be very difficult for families to keep their children with disabilities at home. At the same time there has been very little attempt to look critically at how family support services may influence the lives of the families or the different influence these services may have on different members of the family. Most family support services seem to operate within a framework that accepts, almost unquestionably, and sees as appropriate, the traditional view of women as the "natural" caregivers.

Two main rationales for family support

Families of children with disabilities have historically been faced with two options: they can either place their children out of the home or take care of them at home with little, or no, external assistance (Agosta & Bradley, 1985). The third option, keeping the family together with the assistance of family support services, is now slowly emerging, and there is a growing understanding and commitment to devote more attention and resources to support families in caring for their children with disabilities at home. But because family support programs are a fairly new way of delivering services, both authorities and service providers have to be convinced that family support is a better way of delivering services, and more resources should be directed to develop new family support programs. When considering the most common arguments in favour of developing family support services, there seem to be two main rationales that people use: Economical and ideological (Taylor, Racino, Knoll & Lutfiyya, 1987).

The economic rationale

When researchers compare the cost of residential placements and the cost of home care, they find enormous savings when the care is provided at home (e.g., Bradley, 1988). Thus, one main argument in favour of providing family support services is that it saves money because it prevents costly out-of-home placements. In addition, adequate family supports may encourage families to take their children home from institutions and nursing homes.

The ideological rationale

As an ideological rationale, people point out that besides being grounded in the ideology of normalisation and community integration, family support services support traditional family values. Without family support services, families experiencing the additional stress of having a member with a disability are more likely than other families to break up. The goal of family support services is, by definition, to support the family as a unit, keep families intact and help families in their traditional roles of "taking care of their own".

These two rationales have been widely accepted as two of the most powerful arguments in favour of family support services. But a critical examination of

these two rationales raises some concerns related to the underlying assumptions about the roles of mothers of children with disabilities. The first concern is related to the cost-savings of family supports: Why do family support services save money? The most obvious answer is, because the mothers stay at home and provide the services at no public cost. Another concern relates to the idea of "traditional family values". Traditional family values bring to mind the culturally sanctified female role of caretaking and selfless giving. Traditional ideas and values about men's and women's roles within the family assign the responsibility for housework, child care and other caring work to women. Women have traditionally been expected to work for no pay within the family. Traditional values also assume that women's primary orientation is toward family and motherhood. The reality today is that the majority of women work outside the home while trying to negotiate their caring role within the family (Fox & Hesse-Biber, 1984, Berg, 1986). An uncritical emphasis on traditional family values as one major rationale for family support services may lead to some serious dilemmas or conflicts and raises questions like: Are we basing family support services on an outdated understanding of women's sex roles? Do present family support services assume and depend on substantial and consistent input of women's unpaid work in the home?

The meaning of care

The concept of care is central to the way people talk about families of children with disabilities and how the families themselves talk. Caring is seen as women's responsibility, and the mothers in my study all had the main responsibility for caring for their children. Some of the fathers provided care too, but the division of labour assigns far more responsibility for care to women than to men. Caring for a child with disabilities can be very hard work, and some of the mothers described it as a burden. For others, caring has been a source of deep satisfaction and pride, even if the caring has required the suppression of other capacities and desires.

Women's informal caring work has rarely been the centre of focus within the disability field. The sexual division of caring has primarily been studied by feminist scholars who have shown a growing interest in what they most often refer to as "community care" (Finch & Groves, 1983, Finch, 1984, Bullock, 1985). While there has been some attempt within this scholarship to look at community care of people with disabilities, this literature has mainly focused on care for elderly people (Ungerson, 1987, Waerness, 1987). The sexual division of caring for people with disabilities is largely an unstudied topic. Thus, at the same time caring is central to the way people talk about families of children with disabilities, there have been very few attempts made to examine and understand caring in all its complexity. Most researchers use, and assume, a common sense understanding of caring; everyone "knows" what caring is and what it means. Therefore, they have not seen the need to explore the topic further. Because of this lack of inquiry into this central issue, I decided to treat caring as a problematic topic and tried to rid myself of my own common sense understanding.

I listened carefully to what mothers, fathers and service providers said about caring. I paid particular attention to mothers, who as the primary caregivers, should be regarded as the expert witnesses. It was apparent that the informants defined "care" in at least three different ways. The first, and most common description of caring, was that of caring for (or taking care of) the child. This definition of care refers to the caring work. The second way of describing caring was caring about the child, i.e., loving the child. These two meanings of care refer to how the parents (especially the mothers) relate to their own children. The third way of describing caring transcends these personal relations to a broader community or societal concern, i.e., caring about what happens to people with disabilities in general and the way society as a whole treats them. I have chosen to call this third definition of care "the extended caring role". Naming this "the extended caring role" reflects my attempt to make visible aspects of the complex caring roles of mothers of children with disabilities. The activities that compose "the extended caring role" are traditionally referred to as "advocacy work". I think that seeing these activities as a part of the mother's caring role provides a better way of understanding the lives of mothers of children with disabilities and their complex caring role. This analysis is grounded in the way the mothers themselves talked about their lives. Many of the mothers described these activities, and the attitudes and feelings behind the activities, in terms of caring.

The three definitions of care

1. Caring for: The work

The first and the most common way of talking about care was in terms of caring for the child. This description of care refers to the caring work. This can be extremely hard and demanding work which often requires specific knowledge. Part of this work is the same kind of caring work that all mothers do when they care for their children. But when caring for a child with a disability, the caring work often requires specific knowledge and techniques that are usually associated with professional work, beyond the skills of housework or traditional "mothering-work". This is especially true when mothers are caring for children who are referred to as technologically dependent or medically fragile.

2. Caring about: The love

The second way of talking about care was in terms of relationships and emotions. Sometimes the mothers interviewed did not distinguish between the "love" and the "work". In other cases they clearly differentiated between the two definitions of care. When describing these two types of caring, it is evident that both parents and professionals saw the mother as the "natural" caregiver, both in terms of doing the work and giving the love.

Using one word to describe the many and varied components of caring can create confusion. It can also create some unfortunate consequences for mothers of children with disabilities. For example, if a mother feels that it is unfair that she bears the main responsibility for caring for the child (doing the

work) and wants others to share some of the work, it can be inferred that she does not care about (love) the child. Other people can use this as leverage to influence the mother to do all the work. And the mother herself may be burdened with guilt, particularly when she is unable to distinguish between these two definitions of care.

3. The extended caring role

What probably makes mothers of children with disabilities unique is the complexity of their caring role. This caring role works in at least two ways. On one hand, the extremely hard and consuming work involved can limit the mother's other roles and activities. And on the other hand, the role can provide more flexibility than that of the traditional mother. Having a child with a disability can mean that one is allowed to extend the caring role to activities that can be compared to professional career-work rather than traditional mothering-work. An example of this situation is when mothers of children with disabilities extend their "caring" to become advocates for change on behalf of all people with disabilities. Many mothers of children with disabilities are active (some as leaders) in the parents' movement and spend much of their time advocating both on behalf of their own children and on behalf of people with disabilities in general. These mothers often set the agenda for other parents and act as catalysts for making changes within the disability field. These mothers go to meetings, lobby the legislators, pressure the school boards, testify at public hearings, organise parent groups, etc. These are not typically considered to be traditional female activities, but when performed by a mother of a child with disabilities, they are seen as an extension of the mother's caring role - an expression of the mother's devotion to her child - which benefits the whole family. Thus, while caring roles for mothers of children with disabilities can limit, they can also provide opportunities that are much like a professional career. To some degree, these mothers have made having a child with disabilities their careers.

Traditional values: How they influence family support services

Cultural stereotypes of men and women seem to have significant influence on the way family support services are provided and service providers seem to have different views and expectations of mothers and fathers.

What the mother should be like

The mothers play a central role within the families in terms of doing the caring work for their children with disabilities. The mothers are also the main contact persons for the service providers. The mother usually initiates the first contact with the family support services, and the professionals focus mainly on working with the mother.

What the father is like

Family support programs see the role of the father as being different from the mother's and have different expectations of the fathers. The service providers, as well as the mothers and fathers themselves, seem to have a similar view of what the father's role should be. A father is expected to be supportive of the mother. His role as supporter is at least twofold. First, the father is supposed to support the family and provide the economic resources needed to keep the child at home. Second, the father is expected to be supportive of the mother's dedication and devotion to the child and her caring work around the child and the family.

The professionals tend to use different language when discussing fathers versus mothers. They tend to describe the father in terms of what he "is like". For example, if the father is involved with the child, participates in the caring work, has contact with, and co-operates with the professionals, they typically speak in glowing terms and praise him for his involvement with the child. But if the father is not involved with the child, has no contact with the service program and refuses to work with the professionals, then that is seen as what the father "is like". The professionals take the attitude that, "We cannot force the fathers."

The service providers therefore see it as their role to impact the mother. They demand a certain level of co-operation and performance and try to influence what the mother does and how she does it. At the same time, they do not see themselves as having the same authority over the fathers and are reluctant to put any serious demands on the fathers. This raises some legitimate concerns about the way family support services influence and control the lives of mothers of children with disabilities.

Conflicting interests?

Two of the most influential social movements which surfaced after the 1950s are the disability rights movement and the women's movement. The disability rights movement demands full social and societal participation of people with disabilities, and the women's movement has drawn attention to the unjust and inferior status of women and has demanded greater equality between the sexes. A critical examination of the current reform efforts within the disability field seems to suggest that there may be some serious conflicts between the interests of women and the interests of people with disabilities. Now is a critical time to explore the extent to which social policy of community integration may conflict with the political aim of greater equalities between the sexes. The disability field has not been aware of this possible conflict between disability issues and gender issues. It is essential that we look more closely at these issues, because if the disability field does not develop a sensitivity which gives equal consideration to women's issues, the field as a whole may face serious dilemmas which could damage the current reform efforts and attempts to pursue the full community integration of people with disabilities.

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