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▣ FAMILY

In a rapidly changing world, there is no longer an easy answer to the question "Who is the family?" Yet it is a profoundly important question for people with disabilities and their families. Governments around the world are committed to policies that support citizens with disabilities and their families, often under the banner of community care. But we know that most care in the community is care by the family, and that families "who care" save governments billions of dollars. Support and care between family members are the product of many forces—love, duty, obligation, reciprocity, altruism, custom—but it is a vital form of support that is primarily unpaid. As far as is known, it is also the norm in all societies. Who, then, is the family that takes on these responsibilities? How do families organize support of disabled relatives? How is this experienced? And what should families expect from governments to assist them in their endeavors?

WHO IS THE FAMILY?

Governments come and go but, taking a traditional view, the family as an institution is supposed to be a constant, even a stabilizing influence on society. In countries where major economic, political, and social changes have taken place, the family as an institution has endured but family structures, family forms, and the boundaries of families are being reshaped (Silva and Smart 1999). In many postindustrial societies, people are marrying later, having fewer children, and becoming parents later in life. Women are realizing improved educational opportunities, control over their fertility, and greater participation in paid employment. Changing demographics such as these will continue to affect the supply of people within families who are theoretically available to undertake caregiving

responsibilities, but government policies can foster or restrain conditions that make this possible.

More significant than banner statistics about the family is the growing consensus that diverse patterns of family life exist. Perhaps the most major change in the concept of the family is that it can be represented in terms of the subjective meanings of intimate connections as well as formal, objective blood or marriage ties. This means that it is subjective experiences that can create ties between people living in separate households for part or all of the time, as well as people who choose to belong as a family.

What a family is can be closely linked to what it does, including, for example, support of disabled relatives, child care, sharing of resources and skills, and the meeting of demands and responsibilities. Within this context of changing definitions of *family*, there is little evidence to suggest an abandonment of commitment or obligation, much as those with more conservative views might argue. Newer family forms generate their own rules and norms to regulate exchanges and responsibilities so as to address the same commitments as other, more traditional, families. Though some of these arrangements are recognizable—families of choice, parenting across households, parenting by people with disabilities, single-parent families, and stepfamilies—many do not yet have names. Gene therapy and sperm donorship are making sure of that. Hence, there exists not solely one kind of family capable of producing moral, autonomous, caring citizens or of supporting in a sensitive manner family members with disabilities.

Values and beliefs that are culturally rooted, and long established, have a powerful influence in the setting of hierarchies of responsibility within families. Who ends up caring for whom therefore is likely to be a direct or indirect product of this. This may also affect who is defined as being part of the family and how help-seeking is negotiated. Currently, little is known about relationships between disabled people and their families from different ethnic and racial groups, especially outside of North America. Constructs of "the family" in developing countries, and how they organize their affairs, are likely to provide important lessons about effective ways of supporting disabled relatives, and how disabled people in

turn can make valued contributions within the family and the community.

It is self-evident that “the family” is more than the sum of those individuals who live in the same home. Steady improvements in health and survival together with social and geographic mobility lead inevitably to the dispersal of families, though not necessarily to their fragmentation. More recent technologies such as the Internet, e-mail, and cell phones are means by which physical barriers to communication between family members can easily be accommodated, and responses to demands and crises dealt with. Indeed, these technologies represent one way in which care and support “from a distance” can be brought into play. By definition, they cannot replace requirements for more hands-on support and care where direct contact, intimacy, or constancy is necessary. This illustrates one of the fundamental divisions in how families fulfill their caregiving responsibilities toward those with disabilities or high support needs, that is, by accommodating responsibilities toward “caring for” persons while maintaining a commitment to “care about” them.

FAMILIES SUPPORTING DISABLED RELATIVES

Many ways of describing how families “do their caregiving” have been discussed in the literature. One of the more enduring approaches is to distinguish “caring for” from “caring about” responsibilities. Early social policy research tended to focus on caring-for responsibilities depicted largely in terms of highly personal care (e.g., helping someone with bathing, toileting, dressing) or homemaking (e.g., assisting with laundry, ironing, gardening). These activities can be regarded as task-based or *instrumental* in character, and clearly important as such. This is sometimes referred to as direct work. At the same time, families express how they care about their disabled children and relatives in other ways. These are rather less tangible, but no less important, and include things such as planning and anticipating, negotiating, problem solving, and case managing, all of which can be regarded as kinds of indirect care. With both direct and indirect care (caring for and caring about), there

is typically an integral affective or emotional dimension reflecting the strength of ties that bind family members together.

Such ways of mapping how families express their support and care of children and relatives with disabilities dominate in the literature. They typically show that mothers are responsible for most direct care, with male partners playing a more secondary or even discretionary role. Indeed, it is the mothers who continue to occupy the role of what might be termed *primary caregivers*. In these regards, their commitments parallel those of mothers of nondisabled children. There is further evidence to suggest that when caregiving needs are most intensive or prolonged it is mothers who will be on the front line. At lower levels of caregiving intensity, contributions from male partners are more apparent. Gender divisions are not quite so clear-cut in relation to indirect care, not least because responsibilities do not fall so readily into the hands of any one person.

In relation to disabled children, grandparent support has been tacit but only recently formally studied in a systematic way. Maternal grandparents have been found to provide more support than paternal grandparents, grandmothers typically provide more support than grandfathers, and grandparents living closer to the family of the child with a disability seem to provide more support than those living farther away. Current research is exploring whether such support truly complements parent support and how it ameliorates or contributes to parental stress and adaptation. Support from siblings of the child with disabilities can similarly complement that of parents and may be particularly important at times when parents are under pressure. The impacts of such obligations on younger siblings, especially those of school age, require special attention given the formative stage of their own development.

Support and care within families are generally presumed to be positive in their effects, but this is not always so. The intent is one thing; the experience may be another. This makes it imperative to draw distinctions between motivations for caregiving, delivery of care, and the actual experience and outcomes of that care from the perspectives both of family members and disabled people in the family. Through careful

and ethically sensitive research, representations of the views and experiences of disabled children about aspects of personal and family life are now emerging that will shed further light on supportive arrangements within families.

Family caregiving has also been studied with reference to its intended purposes with a focus on motivations and outcomes rather than tasks. Such research highlights caregiving that is anticipatory, preventive, and protective as well as supervisory and instrumental. Indeed, there is evidence to suggest that family caregivers tend to think more readily along these lines. This has the advantage of sensitizing those with responsibilities for supporting families to the goals to which families aspire, to what families achieve, or to what frustrates them along the way. It therefore shifts the focus from a purely process-based orientation to one that embraces both processes and outcomes.

A linked conceptualization sees disability and its consequences for families constructed from four dimensions: onset, course, outcome, and incapacity. The *onset* of a disability may be immediate or gradual, expected or unexpected, with the particular circumstances creating challenges and demands for families. The *course* of a disability may be progressive, constant, or relapsing/episodic. The character of the course therefore affects the ability to predict when and how supports need to be put in place. The *outcome* of a condition relates primarily to the expectation of death or shortened life expectancy, which may lead to the tendency to overprotection by families. *Incapacity* is the final dimension, characterized in five areas: cognitive, sensory, mobility, energy, and stigma. Different types of incapacity are seen as requiring differing responses from individuals and families, mediated in turn by values, expectations, and available coping resources. The four dimensions within this model are united by what has been called a “meta-characteristic,” namely, predictability. Evidence suggests that families find it more difficult to deal with things when conditions remain less predictable. To some degree, this can be overcome by having access to good information about the onset, course, outcomes, and incapacities likely to be encountered.

These are examples of medical model thinking that views the person’s disability as *the* challenge to be

addressed or overcome. They do not fully explain oppressive forces that people with disabilities and their families face on a day-to-day basis. On the other hand, the social model redefines disability as the product of how the institutions of civil society exclude, disadvantage, or oppress people, rather than viewing impairment as a personal tragedy with the individual as victim. It addresses the lived experiences of people with disabilities and their families. Potentially, then, the social model has the capacity to see the interests of disabled people and their families as being united in a struggle to overcome the environmental roots of disadvantages that bar people from participating in community life on an equal footing with others. A critique of the social model is that impairment per se cannot and should not be marginalized on the grounds that it does in fact play an important part in their everyday experiences as disabled people.

EXPERIENCES OF FAMILY CARE

After many years of research about how families experience disability, most of the accounts are from the primary caregivers—principally, mothers of disabled children, spouses or partners of disabled adults, or children of older people with disabilities. Multiple accounts from different family members within studies are still rare, so controlled comparisons of the roles, reciprocities, experiences, and outcomes of supporting disabled relatives remain a priority for prospective research.

Family caregiving of children and relatives with disabilities is frequently portrayed as a stressful experience. Images of burdened or even burned-out family members who need respite from their caregiving roles continue to dominate the professional and academic literature. These perspectives depict family carers as being physically and emotionally stressed, with limitations placed on fulfilling social relationships, employment prospects, and quality of life. This view is based on a deficit model, which presumes that supporting someone with a disability must be burdensome or unduly challenging and that burden and challenge lead inevitably to negative experiences within the family. Nevertheless, there is a lot of evidence showing that perception of potential stressors

and how these are appraised in relation to available personal coping resources are important keys to understanding how family members adapt to the pileup of demands they face.

Recent studies of parents with children with intellectual disabilities show that mothers tend to be more stressed than fathers by the behavior problems of the child, possibly because they are more involved in everyday direct caregiving, but that fathers can be more troubled by external factors such as other people's responses to or acceptance of the child. Many mediating factors have been identified in explaining such gender differences, but there is a general acknowledgment of the need for much further carefully designed research here.

Stereotypes are sometimes used to maintain an underlying pathological view of families. For example, it is still common within professional discourses to hear families being talked about as if they were responsible for the difficulties faced by their disabled relative. This is perhaps most prevalent in connection with parents of disabled children where the language of overprotection is commonly used. Similarly, the stress and burden families are presumed to face are sometimes linked to the idea that families are rather passive, unresourceful, and lacking in agency. Alternatively, in other accounts of family caregiving there is a tendency to view families as having agendas and needs that stand in opposition to those for whom they care, this perhaps being more common where disabled family members have reached adulthood with distinctive rights and claims of their own. Then there are families who are depicted as being frozen in time as a result of wanting to remember earlier times before they were engulfed by caregiving demands.

This type of imagery identifies caregiving, most of it undertaken by women, as a part of their oppression or marginalization, the proposed solutions to which appear to be a return to forms of residential or collective group home living by disabled people. This position has been criticized by disabled feminists for assuming that disability equates with dependency, and for also overlooking the voice and subjective experience of disabled people themselves, and what they contribute to collective well-being within the family and beyond.

More recently, there has been growing recognition of the wider complexities of family caregiving, including a fuller appreciation of its associated transformations and rewards. This, in turn, has been leading to a more positive view of how families accomplish their caregiving and of the capacity of families to learn, adapt, and overcome. In families with children and adults with intellectual disabilities, for example, there is undeniable evidence showing how the coping repertoires of families expand through experience. This evidence also shows how mastery increases though the growth of self-confidence and skills. As family members ascribe meaningfulness to their caregiving, the role and position of caregiving are often reevaluated in a positive way. Strengthened ties between the caregiver and the cared-for person are commonly reported arising from a fuller acknowledgment of the layers of reciprocities that bind people together. Love, coupled with the moralities of duty and obligation, is important here.

There is also experience suggesting that rewards and satisfactions accrue from overcoming everyday challenges. These can emerge from dealing successfully with matters that might seem mundane to third parties—helping to lift someone more efficiently, receiving a smile of acknowledgment from someone with a severe cognitive impairment—but they can also occur when families make breakthroughs, especially when their caregiving efforts give rise to a reevaluation of prognoses by doctors, as has happened quite frequently in families with disabled children.

Hence, despite what might at first appear to be multiple limitations in their daily lives as a result of caregiving, many families share hopeful visions and experiences, or what some have called profound personal growth, because of this experience. This “embrace of paradox” as it has been called is a perspective that acknowledges the frustrations, the sometimes dashed hopes, and the emotional troughs of caregiving experiences, but it also suggests the existence of a capacity to bounce back as a result of something more resilient that makes families what they are.

Identifying all the factors that appear to make some families, or some family members, more resilient than others when facing similar challenges remains an important topic for continuing research. Different

theoretical starting points are assumed: some searching for personal qualities that make some individuals more resilient than others, while there is an alternative view that resilience should be viewed as a family-level construct. A number of different starting points have been suggested for further investigation here.

First, there is the theme of identifying capacity rather than incapacity within families. Families are often reminded by outsiders of their deficits rather than their competencies and expertise. Like disabled people, families are often reminded of their dependency status by formal organizations that continually check their eligibility for health or social care services. Newer service models are placing an emphasis on devolved systems of funding and decision making, including the introduction of direct-payment systems.

Second, there is growing evidence of the importance of the search for meaningfulness as a key to understanding successful coping and management. Families can be presented with many unexpected demands or find themselves doing their caregiving under nonnormative circumstances, for example, continuing to look after a disabled child for years beyond what they had predicted. Hence, they typically reframe the meaning of what they are doing, often by adapting their values and beliefs as they proceed. Such evidence can be found within the accounts of many older family caregivers.

Third, the ability of families to maintain a sense of control in difficult situations is a recurrent theme. Problems arise when matters that need control are beyond the direction of the family. This can implicate services as a prime culprit, for services that are designed to support families are often not available, are not synchronized with family routines and structures, are insensitive to family norms and rules, or else fail to involve families as partners when important decisions have to be made. These remain serious challenges for services in many countries.

Fourth, resilient family members need to be able to reaffirm their own sense of identity not only as caregivers but also as persons with important duties and obligations to themselves and to others. These families balance competing claims on their time and energy, giving rise to successful “boundary maintenance”

or “border crossing” between their different identities. The role of culture and ethnicity in cementing, if not underpinning, the resilient qualities of families is not clear. Indeed, features of the “holding environment,” that is, the social and cultural context in which families do their caregiving, are still being mapped. It is important to understand not only how these environments mold the dispositions and values that family members bring to their caregiving but also how the social networks to which they give rise shape the giving and receiving of care.

An important dimension of the family caregiving experience is the life course of the family. For family members, the life course sets the context for considering tensions around the uncertainties about future caregiving scenarios, maintaining a sense of control of environmental demands, and keeping a balance between the use of private and public time.

Particular tensions arise when individuals have to spend too much of their private time in caregiving when in fact they would prefer to use their time in other ways, private or public. The classic example is the conflict many families of working age face in balancing caregiving demands with employment. These opposing demands are less likely to clash if families can realize tax breaks, welfare payments, flexible working conditions, and job satisfaction, and disabled people can access inclusive education, suitable employment opportunities, or, as necessary, day care. Difficulties can arise for families when they become aware of growing discontinuities between the biological and psychological development of the disabled person. This is perhaps more typical when the disabled person has a cognitive impairment. It is often a signal that caregiving will have to take place “out of time,” that is, beyond the point at which other families would normally end their caregiving. This perception of being out of sync with the rest of society represents another conflict for families, here between private time and social time.

While this is happening, families and disabled people have to manage their time and their activities within the calendars set by services and other institutions of society. With increasing plurality in the supply of services, for example, people with disabilities and their families are likely to encounter many transition

points as they move between health, education, social care, employment, housing, and independent sector services during the course of their lives. Each transition is potentially very stressful since it usually heralds fresh ambiguities and a requirement to adapt to new service philosophies along with their accompanying rules and obligations.

Over the life course, families then are faced with an array of time demands generated by different personal and public calendars. How families manage such competing demands relates to their resilience and capacity, the “family-centeredness” of services, and the degree of continuity and predictability over the life course. How far this is possible given the destandardization and increasing individualization of the life course in postmodern societies remains to be seen.

ROLE RELATIONSHIPS WITH SERVICES

Families supporting either children or adults with disabilities have been described as having an ambiguous role relationship with services designed to help them. This ambivalence seems to be tied to the stereotypes of families described earlier that introduced family members as potential competitors for health and social care services, as well as allies of the disabled people they support. Four tacit models for understanding this ambivalence have been put forward: viewed by services as “resources,” families would be maintained in their role as caregivers; viewed as “co-workers,” they would attract greater recognition of their role from services; viewed as “co-clients,” their needs are likely to be difficult to disentangle from those of their disabled relative; and finally, in the case of the “superseded” family caregiver, services would aim to replace or substitute them.

These are not fixed categories, and it is likely that over the life course family carers may well move between these roles as circumstances change, reflecting the accumulation of expertise, a preparedness to continue caregiving, and the emergence of the family caregiver’s own needs. The implications of perceiving family caregivers in these contrasting ways are quite profound, for each category is associated with different sets of assumptions about what carers bring to their caregiving as well as what they might expect by way of support from services.

Service systems tend to view families largely as resources, and by various means seek to maintain them in their caregiving roles. This commitment seems to predominate over other functions, for example, those tied to enabling families to enhance caregiving enrichment, or supporting efforts by families to abrogate caregiving responsibilities without feelings of guilt when demands become too onerous. The agendas of services and families can therefore be dissimilar in significant respects.

For many years, there has been talk of professionals and services working in partnership with families, but often the rhetoric has not been matched by funding to plug gaps in family support services, by addressing imbalances in power relations, or by providing incentives for families to engage service systems in a more positive way. More recent policy initiatives in a number of countries are at last beginning to tackle these issues. System change at a number of levels is occurring to help make partnership work with families a reality. This change has entailed the following:

- A reorientation of professional activity from individualized casework to family systems approaches where reciprocities and individual autonomy within the family are respected
- A shift from the professional as expert to the family and disabled person as expert and potential case manager
- Adoption of a competency (or *salutogenic*) view of the family rather than a pathological view of the family
- An approach to assessment of family support needs that is committed to enabling families and disabled people to articulate their dreams and strengths
- Recognition that the solution to people’s needs and problems is likely to be found by tapping the natural resources of the family and community with services acting as enabler, rather than by a reliance on services as the solution to everything
- Decision making that adopts a “non-zero-sum” approach, that is, where, as a result of consultation, there is the prospect of multiplying support, expertise, and knowledge that benefits all parties
- Delegation of decision-making responsibility and control of resources to people with disabilities and

families where this is feasible and, where not, to the point closest to them as possible

- A long-term view so that families can realize the kind of transitions that will occur over the lifespan and can plan for these
- New organizational forms that are more responsive, organic, and network driven rather than formal and bureaucratic
- Autobiographies and narratives based on the lives of people with disabilities and their families that act as testimonies to the values and principles to be respected in how they should be supported

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See also Caregiving; Child Care; Family, International; Social Networks.

Further Readings

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