

Chapter 2

Family Dynamics and Caregiving for People with Disabilities

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Caregiving is at the heart of family life. Parents care for children, spouses care for each other, and, when illness or disability occurs, family members care for each other. At least 80% of primary caregivers for individuals with severe disabilities are family members (U.S. Census Bureau 1997; National Alliance for Caregiving (NAC) and AARP 2004). Families affected by a disability experience a host of relational opportunities and challenges. In this chapter, we will discuss factors that shape family dynamics in caregiving for individuals with disabilities related to chronic illness, trauma, or congenital conditions and how clinicians, educators, researchers, and policymakers can promote health family dynamics.

The study of caregiving and disability naturally lends itself to a systemic approach (McDaniel et al. 1992; Rolland 1994; Lyons et al. 1995). All people in relationships depend on one another; disability makes interdependence explicit. Medical decisions, hygiene routines, and residential choices directly affect the caregiver as well as the disabled person. Domains that would otherwise be private become open to relational scrutiny and negotiation. For example, Manuel, an adult with quadriplegia, prefers manual, intermittent bladder catheterization to an indwelling catheter that continuously drains to a leg bag or other device. Under most circumstances, the mode and frequency of voiding is a personal, unilateral choice. But for Manuel, his personal assistants, his family, and his healthcare team must decide with him because the decision to catheterize several times a day requires significant commitment on the part of caregivers. Families such as Manuel's must strike a balance between autonomy of the individual and the sometimes competing needs of caregivers. This is a tension that exists in every family but disability highlights and amplifies these relational intricacies.

Disability is also an inherently systemic concept because it resides in the fit between the individual's needs and the physical, social, and legal environment.

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Problems related to a disability often have as much to do with deficiency in the environment as with physical or mental impairment. Similarly, some of the challenging interpersonal dynamics that arise among individuals with disability and their caregivers are sometimes more accurately attributed to failings in larger system supports, rather than to the disability, *per se*. This contextual view of disability should inform any discussion of family dynamics and caregiving.

The “family” of an individual with disabilities often extends beyond those who are biologically related. Healthcare providers, friends, personal assistants, and community agents form an identifiable system that interacts around the disability. Anderson et al. (1986) argued that the most helpful focus of attention for family therapists is the “problem-determined system,” that is, the group of people that are involved in shaping each others’ experience of a presenting issue. This is certainly true when it comes to discussion of family dynamics and disability. The most meaningful focus will almost always be on the person living with disability, plus those inside and outside the family who care for and about that person. Thus, we intend our discussion of family dynamics to apply to the relationships and structures of this system as well as to the nuclear or extended family as traditionally defined.

The Biopsychosocial Model

The biopsychosocial systems model (McDaniel et al. 1992) provides a comprehensive framework from which to understand the needs, desires, and interactions of the person with disability and the family, broadly defined. Internist George Engel (1977, 1980) first described the biopsychosocial model, an alternative to the traditional biomedical model. Engel’s model takes into account different levels of a problem, ranging from molecular, genetic, and organ systems, to the individual’s psychology and belief systems, family functioning, community responsiveness, and federal policies that impact the daily lives of people with disabilities and those who care for them. Biopsychosocial theory sprang from the same roots as family systems theory, that of General Systems theory from the early twentieth century (Wynne 2003). Integrating biopsychosocial and family systems theory, biopsychosocial systems theory encourages assessment of any problem at the most relevant levels of the biopsychosocial hierarchy. For people with disabilities, this always means the biological, the psychosocial, and the relational. It includes community and policy levels when disparities or discrimination are apparent. Intervention is targeted for levels that are most relevant and most likely to produce useful change. Most often, any intervention involves the family—either directly by targeting relationship problems, or indirectly as part of the care system.

The dynamic interplay between physical factors, individual psychology, and relational dynamics is the purview of the professional healthcare team, especially the medical family therapist¹ (McDaniel et al. 1992) who may provide consultation to

¹ In this chapter, we often refer to “illness and disability” together. These terms are not technically interchangeable. Illness does not always lead to disability, and many disabilities are not a result of

physicians, nurses, and other professional providers, as well as to the person with the disability, the family, and others caring for the disabled person. Drawing from the literature on psychology and theology (Bakan 1969), the general goals for medical family therapy are to increase both *agency* and *communion* (McDaniel et al. 1992). These goals offer a useful framework for considering the individual and family factors that influence outcomes for people with disabilities.

Agency is a sense that one can make personal choices in dealing with illness and the healthcare system. In the West, we struggle with the relationship between individual responsibility and illness: we hold people responsible for their emotional problems, while believing they are *not* responsible for physical illness. Framing a problem as “physical” can lift the burden of blame from a person’s shoulders but it can also encourage a passive-dependent patient role that is socially acceptable. For patients and families facing illness and disability, agency means not remaining passive. It means coming to grips with what they must accept while discovering what action they can take. Agency is a sense of activism about one’s own life in the face of all that is uncertain. Dealing with this uncertainty is part of the challenge of facing illness and disability.

Communion refers to strengthening emotional and spiritual bonds that can be frayed by illness, disability, and contact with the healthcare system. It is the sense of being cared for, loved, and supported by a community of family members, friends, and professionals. Serious illness or disability is an existential crisis that can isolate people from those who care for them with significant health consequences. Research shows lack of good social support is a stronger risk factor for illness and disability than cigarette smoking (House et al. 1988). At the same time, serious illness or disability provides opportunities for resolving old conflicts and forging new levels of healthy family bonding.

Taken together, agency and communion describe individual autonomy in a relational context. Helgeson (1994), in a review of research on agency and communion, concluded that both are required for optimal health. Unmitigated agency, or unmitigated communion is associated with increased morbidity. When illness or disability challenges functioning, individuals or families may be high on one of these dimensions and low on the other. For example, a family caregiver may be high on her sense of competence (agency) in the face of disability but low on support (communion). Unbalanced agency and communion also puts people at risk for mental health symptoms. As professional caregivers, we want to assess, increase, and balance agency and communion for people with disabilities and their caregivers. To do so, it is helpful to be aware of the patterns that define human interactions.

illness. We have chosen an inclusive stance toward defining our focus of study for several reasons. First, many of the family dynamics we address pertain to circumstances in which one or more individuals in a family experiences a change in physical functioning, irrespective of the source. Second, from a conceptual and political level, we believe there is much to be gained for families when those with caregiving needs unite around common concerns. Finally, much of our clinical experience and previous writing has focused on families and chronic illness and we wished to draw from that knowledge base.

Understanding Family Systems

“Family dynamics” is a broad term that encompasses the myriad processes, which together constitute the family system. Walsh (2003) has identified three basic domains of family functioning: organization patterns, family belief systems, and communication processes. These domains help to organize any assessment of family dynamics.

Organizational Patterns A family is more than a collection of individual members. Families are systems that have distinct structures. Roles, boundaries, hierarchy, and connectedness yield patterns of interaction, expectation, and support. Family caregiving for an individual with disabilities challenges families to evolve patterns that are flexible enough to adapt to demands created by the disability but stable enough to provide some predictability, continuity, and room for growth. Because kin and social networks support successful family caregiving, boundaries between the family and the outside world ideally are semipermeable, allowing a system of care to develop, while protecting and demarcating core family members.

Family Belief Systems Just as individuals have distinct identities and worldviews, so families have shared beliefs that shape how they adapt to stress and change (Rolland 1994). Families living with disabilities must make meaning out of the challenges they face. What seems overwhelming and difficult for one family may be embraced as a valuable difference in another. Health professionals should attend to the meaning and value families assign to any difference or disability. Resilient families are able to increase agency by gaining a sense of coherence, maintaining hope, focusing on growth, and forging a group identity that includes but goes beyond the disability. For some families, spiritual beliefs and practices unite the sometimes painful realities of disability with a larger purpose or story.

Communication Processes Communication connects and empowers stressed families. Walsh (2006) regards clarity, open emotional expression, and collaborative problem solving as the key elements of healthy communication. Direct messages delivered in an open and collaborative environment result in increased communion for the individual and the system. Sharing care among family members often requires frequent information exchange, decision-making, and cooperation. Some disabling conditions (especially those that require physical accommodation) demand that families and care providers engage in intricate planning and coordination in order to pursue an activity that would otherwise be spontaneous. A simple outing like a family picnic, for example, can require extensive planning for transportation and access. Empathy for all involved is useful oil for the communication system that is needed to anticipate and plan for the future needs of its members.

The Dynamics of Disabilities Like families, disabilities have unique features that influence caregiver experience. Rolland (1994) proposed a typology of illness and disability with four key dimensions: onset (acute or gradual), course (progressive, constant, relapsing/episodic, predictable/unpredictable), incapacitation (presence or

absence and severity), and outcome (fatal, shortened lifespan, or nonfatal). The matrix formed by combining these dimensions helps to predict the pattern of psychosocial and caregiving demands created by a particular disability. Cystic fibrosis, for example, has a gradual onset, progressive relapsing course, varying levels of incapacitation, and shortened lifespan. The caregiving demands and family dynamics of this disabling condition would be quite different from those associated with traumatic brain injury, which has acute onset, constant course, and nonfatal outcome.

Seaburn and Erba (2003) found that the time of onset in the history of a family also influences family dynamics. A disability that predates the inception of the family, such as when a person has epilepsy before he marries, become “nested” in family life such that roles and relationships accommodate the needs of the disabled individual and caregivers. Caregiving routines become part of the rhythm of normal family life. When a disability occurs after a family is formed, such as head trauma after a biking accident, families must reorganize and redefine themselves. Often, families have difficulty making these adjustments. They can become stuck in chronic state of crisis, so that individual and family development are disrupted or even frozen around the time of the disability.

Disabilities and the Family Life Cycle Individuals develop within the context of family and other systems. These systems, in turn, adapt over time in response to the developmental needs of individual members and to pressures exerted on the system from outside. Thus, families of disabled individuals experience their roles and relationships in continuously evolving context. This fluidity means that the dynamics of caregiving will be different at different times in the life cycle of a family.

Key transition points in the family life cycle include: leaving home, coupling, pregnancy and childbirth, raising young children, raising adolescents, launching children, middle-age reevaluation, retirement, and end-of-life issues (Carter and McGoldrick 2005). Obviously, many families do not follow this sequence in order; for example, many circle back to the coupling stage after a divorce while also raising adolescents. The stages in the family life cycle are influenced by culture, opportunity, and preferences and should not be viewed as prescriptive. Nevertheless, the family life cycle provides a useful lens for viewing developmental issues and family dynamics at a given point in time.

This lens may be particularly salient for families with disabilities because caregiving demands may be out of phase with the family’s life cycle stage. For example, the parents of an adolescent with cognitive disabilities may need to arrange social opportunities or help with grooming during a time when other families with adolescents are preparing to launch their children and move on. This asynchrony with expected life stages can seem more pronounced if the family has other children who progress “normally.” Likewise, as we will see in the case example below, physically disabled parents often need help from their children in ways that the life cycle model does not predict, such as caring for their hygiene, performing daily household tasks for them, or acting as liaison to a society that is often not equipped for their needs. (For a thorough review of disability and the family life cycle, see Marshak et al. 1999).

“Things Aren’t As They Should Be:” A Family Struggles with the Effects of Serious Illness and Disability²

Mr. White, a 54-year-old German-American man, had Parkinson’s Disease, which is a chronic, progressive illness. He was sick for a number of years. He lost his ability to speak, so went to communicating by laptop. His wife of 24 years requested a medical family therapy consultation with Dr. McDaniel because she was concerned about the effects of her husband’s long-term illness and disability on her three daughters: Denise, 22; Jessica, 19, and Barbara, 16. At the time of the consultation, Mr. White was bed-ridden, had a feeding tube down his throat, and his tremor was so significant that he could no longer communicate by computer. Prior to his illness, Mr. White had been a prominent community leader with a highly visible counseling and consulting practice.

Mrs. White and her daughters were articulate about many of the family dynamics they experienced. The dialogue³ from this session illustrates some of the family dynamics common to so many families facing chronic illness and disability.

Shifting Family Roles

Barbara: . . . It isn’t fair that he should be going through all this. . . . It isn’t fair for him to just stay home and not lead a normal 54-year-old life. . . . It’s not fair that he can’t go on vacation. . . . Denise said it isn’t fair for me not to be able to lead a normal 16-year-old life. Mom, you don’t have a husband. . . well, I mean you do have a husband, but you can’t do normal things with him.

Disability can challenge long-standing family roles and patterns of family organization. In this case, the daughters express concern that their mother has lost her “companion” and all that means. Likewise, the mother set up the session because of her concern about the girls losing a functional father.

Mother: . . . I noticed the other night that. . . when he wanted to communicate and would have difficulty, he would end up crying, you know, and that is very hard. He was never the one to cry. . . . That was my job. It still is.

Denise: I know the first time that I ever really saw him cry was the second time he was in the hospital. . . . We hadn’t made it in all day to visit him. . . and we got there pretty late at night. . . . He was very upset because he was expecting us and then we didn’t come. . . . He just broke down. That was the most disconcerting thing I have ever been through because he was. . . always, you know. . . he was the person in control when the rest of us fell apart.

Mr. White’s role shifted with his increasing disability, from being the “rock” of the family to the vulnerable patient. The family finds the fact that he now cries

² Medical family therapy is an approach to working with families, rather than a distinct profession. A medical family therapist may be a social worker, psychologist, psychiatrist, or family therapist—anyone trained to do psychotherapy with families in medical settings.

³ This description is of an actual case. Details of the family have been camouflaged to protect their confidentiality.

“disconcerting.” Mom said, “That was my job. Still is,” as she wiped her eyes. Progressive disabilities require family members and the disabled person to reorganize and take up new roles with regard to affective communication, instrumental chores, and functions in the family.

Of course, family dynamics shift depending on which member is disabled or ill. When a primary family caregiver becomes disabled, family roles must shift to redistribute the tasks she is unable to perform (McDaniel and Cole-Kelly 2003). Both instrumental and emotional work must be distributed across other family members, who must develop the ability to project strength in the face of adversity. It requires flexibility for a family to accommodate new realities in a respectful, unintrusive way that preserves the previous caregiver’s remaining sense of agency.

When a parent is disabled, the challenge for the family is meeting the children’s developmental needs while also caring for the disabled adult. Mrs. White expressed concern about striking this balance when she requested a medical family therapy consultation for herself and her daughters. Barbara also referred to this dynamic when she said it was not fair that she cannot lead a “normal” life.

When a child is disabled, from congenital defects, chronic illness, or an accident, parents are absorbed by the typical tasks of raising children *and* caregiving for someone with disabilities. Healthy siblings may also feel the strain, often feeling they must be perfect to accommodate. Maturity and caregiving come early to these children. With proper support for their developmental challenges, caregiving can be an enriching experience. If, however, their needs are overlooked or undetected, these children may develop symptoms of their own at some point.

The Confluence of Coping Styles

Jessica: I talk to Barbara about. . . my Dad. . . . I don’t really talk to Denise about it, and that sort of bothers me.

Dr. McDaniel: Somehow the illness has come between you, and you’re kind of missing Denise.

Jessica: I think it’s like Denise has a different way to deal with it.

Denise: I think sometimes I bury it so far down. . . . Something happens or. . . I react immediately, but then it gets buried and I don’t even realize that it’s still bothering me. . . on a conscious level.

Jessica: Sometimes it bothers me that it doesn’t look like it’s bothering her.

Denise: . . . That’s where the tension arises for us because sometimes people. . . look and think I don’t care, because in an effort not to fall apart I just push it further down.

Patients and family members have to find a way to cope with chronic disability and with each other’s coping styles and conflicting health beliefs. Family members often accept serious illness or disability at different points in time. It’s almost as if someone in the family needs to deny the illness or disability and advocate for life to go on, and someone else needs to help the family grapple with the hard realities associated with the disability. Of course, people can get polarized and move into major conflict

over this. Successful families respect each others' coping styles, and allow space for each person to grieve with his or her own rate and style.

In the White family, Denise is near the denial end of the continuum, pushing down her feelings, while Jessica is at the other end of accepting the illness. Jessica, who was very expressive and let her anger and frustration out, misinterpreted Denise's behavior as "not caring." In response, Denise described herself as just trying to get through a difficult situation. Airing these differences and normalizing them can be useful. It is also important to understand that when the coping styles of one individual changes, it may have implications for others in the family.

The Isolation of Illness and Disability

Barbara: It would be nice to be able to talk to someone, like one of my good friends. I mean, it is my father [and] none of them know. . . a lot of the stuff. . . I am sure I am going to go through this whole week and none of them are going to know about what is going on. . . . Everybody says that I'm so happy. . . . It's all a front.

Dr. McDaniel: If it was one of your good friend's fathers who were in the hospital, would you want to know?

Barbara: Yeah.

Illness and disability can be a singular, lonely experience for the patient. It can also be isolating for the family, diminishing their sense of communion and community. Barbara, whose typical interpersonal style was extroverted, did not tell her friends about her father's recent decline and hospitalization. She felt that her life experience was foreign to them. At the same time, challenging this belief was easy. When she left the session, she did communicate with her closest friends and received the support she needed from them. When stressed, it is natural for a family unit to close ranks and hunker down but they then can become depleted. The community and professionals involved with patients and families with disabilities must help them access the support and resources they need for the long haul.

Managing Anger and Guilt

Jessica: My main problem is. . . a major guilt complex. . . . Like [my father] will ask me to do something and I'll get frustrated. . . and go off stomping into my room. [I wonder] why did I yell [at him]? It's not really fair. He just asked a simple thing, and I could have said, "Well, I don't have time" and walk away. But instead I yell and stomp around and slam something down on the table because it seems. . . like you have to go and do so much out of your way. But he can't do it. . . . It's always something.

Dr. McDaniel: So, you have normal feelings that anybody would have in this demanding situation, but you don't really feel like you have a right to

them because your dad has a terrible illness and is very disabled. So, what do you do with your anger? Where does that go?

Jessica: I take it out on him.

Each family develops a style of managing uncomfortable feelings. Some family cultures are loud and expressive; others are quiet and conflict avoidant. Many styles can work. But illness and disability can inhibit the normal expression of feelings because people like Jessica feel they must treat the ill or disabled person with such care. Generally, this response becomes unhealthy because it inhibits the natural development of the relationship, including corrections that come from honest feedback. Negative feelings can accumulate over time resulting in a blowup or in depression or psychosomatic problems in the patient or family member. Normalizing anger, frustration, and sadness is important for everyone involved when someone's functioning deteriorates. It can be useful for the family to realize that these feelings are more about the illness or disability rather than about the person with diminished functioning him/herself. It is possible to share negative feelings about the illness or disability without mistaking the feelings for anger at each other.

Disruption of the Individual and Family Life Cycles

Jessica: Our lives are totally different than they should be. . . .

It is a major challenge for families to tend to its members' individual developmental needs *and* meet the caregiving demands of a serious illness or disability. It is impossible during an acute or crisis phase. Some families then become frozen around the family organization at the time of the crisis, rather than being able to shift and reorganize to care for the chronic demands of an illness or disability. During the chronic phase, the family needs to be able to care for the illness and still have energy, resources, and space for the patient and other family members to meet developmental challenges that face each stage of the life cycle (Penn 1983).

Managing Loss

Another challenge for families with people with disabilities is managing the loss at the onset of disability or when functioning deteriorates. It can be an ambiguous loss (Boss 1999) in the sense that Western culture has no clear rituals to handle lost dreams. When chronic illness or disability is progressive, anticipatory loss becomes another member of the family. In the White family, the children and mother have watched Mr. White's functioning deteriorate over a period of years. They know that he will die prematurely. This awareness can offer the possibility of intimate, meaningful moments between family members. However, it also puts pressure on individuals and the family so that they are at risk for other individual and relational problems. Ideally, health professionals and a caring community provide support for people with serious illness and disabilities during this time. Hospice is a wonderful example of a social response to a problem not handled well by the cure-focused traditional medical community.

The Response of the Extended Family

How much family members share care can predict the degree of caregiver burden. Negotiation of shared caregiving is complicated. Some caregivers have difficulty sharing the role, even when they are exhausted. Some family members distance themselves in response to fears about an illness or disability, leaving one family member with all of the responsibilities.

Relationships can become skewed because of conflict related to caregiving tasks. These tasks need ongoing renegotiation as the demands of a disability, wishes of the disabled individual, or capacity of caregivers change. Unacknowledged feelings of sadness or anger are sometimes acted out through withdrawal—or its counterpart—smothering and infantilizing the person with disabilities. Family meetings with primary care or medical family therapy professionals can be useful at points when disability tasks are neglected or family relationships become strained. Videotaping the family meeting can be very useful for family members who are unable to come to the meeting, so that they too have the relevant information to decide how they want to respond.

Special Issues for Families

Genetics and Family Caregiving

Genes play a role in many disabilities. In some cases, such as Huntington's disease, a single inherited gene causes the disease that leads to disability. In other cases, such as cancer or heart disease, genes interact with environmental variables to increase the risk of illness and disability in some affected family members. In either circumstance, the genetic link adds a layer of complexity to the family caregiving experience (Miller et al. 2006).

First, the family may have prior experience with the illness or disability. This familiarity can equip family members to understand and anticipate the needs of the disabled individual. Caregivers can draw on collective family wisdom; extended family members can counsel each other based on their successes and struggles. Conversely, prior experience can evoke painful memories of suffering or strife related to an illness or disability. Without conscious intervention, problematic dynamics developed in previous generation of caregiving may be transmitted to the next. For example, a mother who watched her parents coddle or infantilize a sibling with sickle cell disease may replicate that dynamic in caring for her son who develops the disease.

Second, genetic disorders can evoke caregiver fear about future experiences with a heritable condition. When caregiver and disabled person share (or might share) genetic risk, the relational dynamics can be complicated and intense. One can imagine the thoughts that run through the mind of a young man as he washes and feeds his father, the most recent in a line of close relatives disabled by early-onset Alzheimer's disease. Knowledge or suspicion of genetic risk can have ripple effects in the caregiver and family system. For example, the wife and children of this young man

may respond in a variety of ways—compassion, withdrawal, anger—to concerns about their own future with him.

The increasing availability of genetic testing has similar family implications. Genetic knowledge is inherently relational in that information about one person potentially affects everyone in a family. The ethical, relational, and psychological implications of genetic testing are beyond the scope of this chapter; however, readers should be aware that emerging genetic knowledge is changing practice and family experience of healthcare in the twenty-first century (for a further discussion, see McDaniel and Campbell 1999).

Mental Disability: The Invisible

In the 2006 American Community Survey sample, mental disabilities affected approximately 11.5 million Americans between the ages of 5 and 64 years. This group represented about 43% of the total 26.6 million disabled individuals in that age group (U.S. Census Bureau 2006). This group included those who reported having a “physical, mental, or emotional condition” lasting 6 months or more that made it difficult to “learn, remember, or concentrate.” This heterogeneous group would presumably include individuals with cognitive/intellectual impairment, serious mental health disorders, dementia, some developmental disorders, and other neurocognitive conditions.

Mental disabilities differ from many others in that they are “invisible,” hidden in the brain and intrapsychic experience of the affected individual. The causes of many mental disabilities are unknown and the ways in which they impair can be subtle and unpredictable. Thus, families coping with mental disabilities face the dual stress of social stigma and ambiguous loss. For example, Jonathan and Alexis, the parents of a boy with Asperger’s disorder, routinely hear comments from family members and coworkers that question their competence. “Just give him to me for a day,” Jonathan’s boss recently told him after the boy became nervous and refused to interact with guests at a company picnic. In addition to being hurtful, such comments occasionally cause the boy’s father to question the validity of the diagnosis, leading to conflict with his wife who has become a fervent advocate for the boy and others with his disability. Like many parents of disabled children, Jonathan and Alexis had to mourn the loss of the child they had expected and begin to dream of new possibilities for their family. The invisibility of their son’s disorder complicates this process; even they wonder how a boy who looks so healthy could have so many problems.

Recommendations for Practice, Education, Research, and Policy

Supporting Healthy Family Dynamics in Professional Practice

Most Western healthcare systems are organized to meet the needs of individual patients. Family-oriented healthcare has been espoused by members of the Collaborative Family Healthcare Association (for more information, see <http://www.cfha.net/not.org>) and by various health professionals working in Family Medicine

(Bloch 1983; McDaniel et al. 2003). When one health professional treats the person with disabilities as well as the caregivers, that professional is able to monitor the needs of the patient and caregiver and suggest individual and family-based interventions for prevention, respite, and improved management as needed.

Collaborative Family Healthcare advocates for health professionals collaborate actively with patients, families, and other health professionals. A collaborative, strengths-focused approach to people with disabilities and their caregivers supports individual and family competencies, encourages prevention, and addresses caregiver burden and other problems as early as possible. Having a family-oriented mental health professional working onsite with a healthcare team allows the inevitable stresses and strains of caregiving to be addressed throughout the course of the life cycle of the family (Olkin 2001). A medical family therapist can assist other professionals in assessing and treating problems as they arise (McDaniel et al. 1992).

While this approach to care is not yet widespread, some programs have established interdisciplinary, preventive, strengths-focused care systems. They include many hospice, respite, geriatric, and rehabilitation programs. Several model programs have integrated mental health into primary care clinics.

In summary, health professionals must work together to increase and balance agency and communion for the caregiver and the person with the disability over time. Providers should seek to: (1) deliver family-oriented healthcare, (2) assess and intervene with a family members as a matter of course, (3) focus preventively on family dynamics early in the course of a disability, and (4) assess family dynamics as the needs of the person with disabilities and caregivers change over time.

Supporting Healthy Family Dynamics Through the Education of Health Professionals

Because of the individual bias of current healthcare practice, education and training generally focuses on the needs of the person with disabilities, rather than on assessment, support, and intervention for the family caregivers. However, some medical and nursing programs are infused with family systems approaches to patient care. Psychology and social work programs also exist, but they, too, are not the norm. Caring for the caregiver comes naturally when the family is the unit of care, whether the focus is on the physical or the mental health of family members (McDaniel et al. 1992, 2003).

In addition to providing insight into individual and family dynamics, family systems concepts can also be helpful in training the health professional about his/her own role. For example, *triangulation* is an interpersonal process that occurs when two people handle some stressful situation by talking or complaining about a third person. Some venting, especially in the caregiver role, is understandable as a way to support and affirm each other's efforts. However, triangulation can be toxic when it involves serious issues and avoids direct discussion between the most relevant

parties. It is not uncommon for a caregiver to complain to a health professional about some issue regarding the person with the disability. It is very important that the health professional avoids any destructive triangulation, which means avoiding being drawn into siding with one party against another. Instead, that professional should detriangulate and bring the relevant parties together to discuss the problem. Similar interpersonal problems can occur with personal assistants, specialists, or extended family members. Health professionals must be close enough to patients and their families to care, while not becoming inducted into any unhealthy family dynamics. Training in family systems helps to sensitize health professionals to these common difficulties and increase a sense of agency and communion for members of the healthcare team.

Supporting Healthy Family Dynamics Through Research

Research on family factors with chronic illness or disability has been growing over the past decade. A section of the Institute of Medicine report on Health and Behavior, written by the National Working Group on Family-Based Interventions in Chronic Disease, is devoted to reviewing research on families, health, and behavior (Weihs et al. 2002). This review reported that protective factors for health and mental health outcomes include: family closeness, caregiver coping skills, mutually supportive family relationships, clear family organization, and direct communication about the illness/disability and its management. Risk factors include: intrafamilial conflict and criticism, trauma related to treatment of the disease, external stress, lack of extrafamilial support, interruption of family member's developmental tasks, and perfectionism and rigidity. Nonmalleable risk factors include: low socioeconomic status, high disease severity, recent diagnosis and invasive treatment, and prior patient and family member disability and psychopathology. All these protective and risk factors are valuable variables for future research and intervention for people with disabilities and their families. While studies are badly needed for the range of disabilities in every age group, many more studies have been conducted of families of children with chronic illness and disability. Studies of disabled adults are particularly scarce.

Intervention studies to date have focused more on adherence to management plans than on family processes themselves. Preintervention and intervention research on family factors and disability is still in its infancy. Preintervention research has yet to study family characteristics and disability outcomes. Rarely is the *quality* of these relationships examined, a factor that seems crucial in disease and disability management. Research on family psychoeducational programs for a variety of problems offer a hopeful approach to improving family functioning when struggling with physical or mental disability (MacFarlane 2002). A randomized, controlled trial of family psychoeducation for caregivers of Alzheimer's patients offers a model for this approach with other disabilities (Mittleman et al. 1996). The intervention included individual and family psychoeducation groups about Alzheimer's, ongoing support groups,

and crisis counseling by mental health professionals. The results were robust and cost-effective: a significant decrease in caregiver depression, a significant increase in physical health outcomes for the caregiver, and a 329-day delay in nursing home placement for the disabled Alzheimer's patient. More systematic research is needed to learn what individuals and families need and want when they are caring for people with disabilities.

Supporting Healthy Family Dynamics Through Policy

An overarching theme in our discussion has been that caregivers and individuals with disabilities are embedded in a multilayered biopsychosocial system. Policymakers have a unique opportunity to support families by improving how different parts of this system work together. In this section, we identify several legislative and economic priorities that can guide public policy toward developing systems to promote agency and communion for individuals with disabilities and family members who care for them.

Providing care for a disabled family member is often a labor of love. Nevertheless, caregiving requires time, money, and social capital (Coleman 1988). Families and other “informal” caregivers contribute an estimated US\$ 200–300 billion per year in uncompensated labor (Arno et al. 1999; Arno 2006). In addition to their labor, families often finance uncovered healthcare costs, such as disposable supplies, assistive devices, and therapies that are deemed “not medically necessary.” Tax law often requires individuals to reach a certain percent-of-income threshold before medical expenses can be claimed as tax deductions. The time and opportunity costs are equally great. Medical appointments, unexpected care needs, and fatigue can interfere with work performance and reduce outside social opportunities. Recent evidence suggests that poorer women, who disproportionately have children with chronic illness and disability, find themselves caught between their children's caregiving needs and the increasing pressure from social service programs to secure and maintain employment (Patterson 2002).

As we have seen, families of disabled individuals must navigate complex emotional and relational dynamics. Financial strain can sap energy needed for relational work, making family strife more likely. Family-centered disability policy can promote healthy family dynamics by enhancing the economic and community resources available to caregivers.

First, families need better access to and funding for quality home health assistants and respite care. According to the U.S. Census Bureau (2005), seven million Americans have difficulty dressing, bathing, or getting around inside the home. Many more need monitoring and assistance for safety and other reasons. Many families experience frustration with the high turnover rate and lack of experience among some home health workers. Better pay and training could improve the overall quality of the workforce, thereby easing family stress. Regular respite from the demands of caregiving also promotes healthy family relationships. When fully funded, the Lifespan

Respite Care Act (Public Law 109–442 [2006](#)) is a good example of legislation that will address a portion of this need. This bill explicitly recognizes that “the family caregiver role is personally rewarding but can result in substantial emotional, physical, and financial hardship” (Sec 2801a). The bill aims to provide grants to states and other entities to develop lifespan respite programs, to evaluate such programs, to improve planned and emergency respite services, and to train and recruit respite care workers and volunteers. Initial funding came in 2009 when President Obama allocated US\$ 2.5 million in the FY09 Omnibus Appropriations bill for respite care (ARCH Respite Coalition [2009](#)).

Second, family caregivers would benefit from flexibility and security in the workplace. Disabled individuals may require care from family members during typical working hours. For example, a mentally disabled adult, Lucy, needs to be fed and driven to her part-time job each morning. Flexible work schedules (“flextime”) can enable family members like Lucy’s sister, a legal assistant, to provide that care by shifting her hours at the office. Flexible leave policies also support healthy family functioning by allowing a caregiver to care for a disabled family member for an extended period of time without penalty in the workplace. The Family Leave Act of 1993 (FMLA) represented a remarkable step in the right direction. However, many families cannot afford to take advantage of the leave policies provided by FMLA because of the pay and benefits (including health insurance) they would forfeit during an extended leave. Lawmakers should consider remedying this limitation by providing funding for health insurance for full-time family caregivers. A bill with this aim, the Caregivers Access to Health Insurance Act (S. 3179[107]), was introduced in 2002, but did not make it out of committee (Library of Congress [2006a, b, c](#)).

Third, families of disabled individuals need a healthcare system that facilitates interdisciplinary care. It is common for individuals with disabilities to receive treatment from several healthcare professionals. A single individual may work with a primary care provider, several medical specialists, a physical therapist, an occupational therapist, a social worker, and a psychotherapist. Coordination among these professionals is essential for effective care (McDaniel et al. [2003](#); Seaburn et al. [1996](#)). Without it, families are left to integrate complex opinions and information on their own, often leading to conflict when family members hear different opinions from providers. Yet interdisciplinary collaboration is rarely reimbursed. Third-party payors almost never compensate providers for the time and resources required to conduct care team meetings, joint visits, and multilateral written communication. Furthermore, some payors prohibit visits with more than one professional per day. Obviously, these policies are aimed at preventing fraud and abuse. Policymakers and payors should strive to develop plans that achieve that protection without undercutting interdisciplinary cooperation in the care of individuals with disabilities and their families.

Fourth, caregivers need affordable access to mental health services. Lawmakers have moved in recent years to increase parity between coverage for physical and mental disorders. The Mental Health Parity Act of 1996 took an important step forward by eliminating annual and lifetime dollar limits for mental healthcare for companies with more than 50 employees. Unfortunately, the law contains loopholes

that have allowed employers to skirt the spirit of the law, for example, by placing new restrictions that do not exist for other medical conditions, such as additional limits on outpatient office visits and number of days for inpatient care. In fact, the U.S. General Accounting office estimated that 87% of employers that comply with the law have reduced other aspects of mental health coverage. Families of disabled individuals would benefit from a law requiring full parity for all aspects of coverage, including dollar limits, day/visit limits, coinsurance, deductibles, and out-of-pocket maximums. In June 2008, the House and Senate reached bipartisan agreement on a new mental health parity bill that would move the country toward true parity. At the time of writing, this law is awaiting final vote in congress.

Finally, families need comprehensive legislation specifically targeting the needs of caregivers. The National Family Caregiver Support Program (NFCSP), established in 2001 by the Older Americans Act Amendments of 2000 (Public Law 106–501), is an excellent example of such legislation. NFCSP provides money (US\$ 125 million in 2001, US\$ 141 million in 2002, to US\$ 155.7 million in 2005, and US\$ 156.1 million for 2006; Administration on Aging (AOA 2006) to states to work with local agencies and service providers to provide information and assistance to caregivers and counseling, support groups, respite, and other community-based services to families caring for frail older members. Lawmakers should consider expanding eligibility to include caregivers of all disabled individuals, regardless of age.

Conclusion

People with disabilities exist within networks of family members, friends, and professionals. Disabilities present challenges that can strengthen as well as strain individuals and families. Family systems concepts and approaches can help to improve the quality of life of the person with disabilities, caregivers, and the professionals involved in supporting these families. Healthcare professionals will benefit from using a biopsychosocial approach. We need more government and foundation support for research on how to improve support for people with disabilities within the context of their families. And, any policy regarding people with disabilities should include consideration of how it might help or hurt families.

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