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Ordinary Families, Special Children, Third Edition: A Systems Approach to Childhood Disability
By Milton Seligman and Rosalyn Benjamin Darling. Copyright © 2007



CONCEPTUAL FRAMEWORK



Introduction and Conceptual Framework I

Social and Cultural Systems

To put the magnitude of extant disability in the U.S. population into perspective, the year 2000 disability status report from the U.S. Bureau of the Census counted 49.7 million people with a chronic illness or disability. This figure accounted for 19.3% of the U.S. noninstitutionalized population ages 5 and older—or nearly one person in five (U.S. Bureau of the Census, 2003a). These figures do not include infants and children from birth to 5 years of age. Among the population from 5 to 15, about 2.6 million, or 5.8%, had disabilities, with boys representing a larger proportion of the total than girls. Overall, 5.2 million children and teenagers—one out of every 12—have a physical or mental disability. These numbers represent an increase over those in data collected previously. In addition, in this population, disabilities are more common among Native Americans and African Americans than among European and Asian Americans. According to Schonberg and Tifft (2002) and Batshaw (2002), 3–5% of births result in a congenital disability or genetic disorder.

Childhood disabilities range from high-incidence impairments to those that are less frequent in the population. High-incidence impair-

ments in persons 6–21 make up 92% of impairments overall, including specific learning disabilities, speech or language impairments, intellectual disability, and serious emotional disturbance (U.S. Department of Education, 1996; Hunt & Marshall, 1999). Lower-incidence impairments, which for each condition constitute less than 2%, include multiple disabilities, hearing impairments, orthopedic impairments, other health impairments, visual impairments, autism, deafness–blindness, and traumatic brain injury. Furthermore, more than 6.3 million children and youth, ages 3–21, received special education services during the school year (U.S. Department of Education, 2002).

We suspect that these statistics provide a meaningful yet incomplete picture of the portion of the U.S. population that has a disability. In accumulating data from various sources, one should be mindful that there are differences in definitions of what constitutes a disability, differences in how data on multiple conditions are determined and counted, sampling method differences, and decisions that are made about when certain age groups are included/excluded (Olkin, 1999; Shapiro, 1994). This concern does not diminish the validity of the reported figures, but it does suggest that there may be even more people with disabilities than the figures indicate. These numbers indicate that persons with disabilities constitute the largest minority group in the United States (Olkin, 1999), and one that anyone can join at any time as a consequence of illness or accident. Actually, less than 15% of people with disabilities were born with their disability (Shapiro, 1994).

Dramatic improvements in medicine have benefited the existing population of infants, children, youth, and adults with disabilities. Enhanced methods of assessment and diagnosis, along with a greater awareness of symptoms by informed family members have increased the early identification and remediation of disabling conditions. By keeping people alive, and by keeping them alive longer, medicine has contributed to a disability population explosion (Shapiro, 1994). Such medical discoveries as chemotherapy for cancer, insulin for diabetes, and the methods to sustain low-birth-weight infants have kept people with impairments alive and functioning, yet often with disabilities.

Social change has not kept pace with clinical progress. People with disabilities remain at a disadvantage in relation to those without them in virtually every area of life. These individuals are much more likely to be unemployed, to live in poverty, and to remain at home rather than attending social functions. In addition, only 34% of those with disabilities say they are very satisfied with their lives, compared with 61% of those without disabilities (*National Organization on*

Disability/Harris Survey of Americans with Disabilities, 2000). Children with disabilities also experience disadvantages in comparison with their nondisabled peers. For example, they are about twice or three times as likely as other children to be abused or neglected (National Clearinghouse on Child Abuse and Neglect [NCCAN], 2004). Eliminating such disadvantages requires societal-level changes to remove the structural and attitudinal barriers still faced by people with disabilities. Such interventions are often beyond the scope of professionals working with families on a one-to-one basis. Nevertheless, these professionals need to be aware of the effects of socially constructed barriers on the families they serve.

DEFINITIONS AND MODELS

The terms *impairment*, *disability*, and *handicap* have been used at various times to describe conditions that deviate from the norm. The most recent version of the International Classification of Functioning, Disability and Health—Second Edition (ICIDH-2; World Health Organization, 1999) no longer includes the term *handicap* because of its pejorative connotations. The document acknowledges that not all impairments limit or restrict participation in life activities; that is, they are not *disabilities*. Consequently, such limitations and restrictions are included as variables in the resulting classification scheme.

The ICIDH-2 still includes what is often called the *medical model* of disability. This model is based on an equation of, or analogy between, disability and illness. In short, disability is viewed as a negative condition requiring treatment, rehabilitation, or cure. A newer model that has become popular during the past few decades has been called the *social model* by Oliver (1996) and others. This model suggests that, although impairments may involve health-related conditions, disabilities are socially caused; that is, because society stigmatizes people with disabilities and creates physical and social barriers to their full participation in society, they are at a disadvantage in relation to more typical individuals.

Oliver and others have argued that disabilities are not inherently negative. In fact, many now speak of “disability pride” (see, e.g., Linton, 1998). Swain and French (2000) have suggested an “affirmation model” of disability, in which disability is viewed as a normal (and positive) form of human diversity. Russell (1994) and others have suggested an analogy between “black pride” (i.e., the positive identities of

African Americans) and disability pride. Many individuals with disabilities today recognize a vibrant disability culture of shared writings, performances, meanings, and values that sets them apart from the mainstream in a positive way.

Whereas the medical model is based on professional dominance (Freidson, 1970), or control by physicians and other medical personnel, the social model places the locus of control in the hands of individuals with disabilities and inspires self-help movements based on obtaining rights and choices. Expertise based on lived experience thus replaces expertise based on education and training.

Finally, whereas the medical model views disability as a personal tragedy, the social model views it as a social problem. The proposed solution to the problem involves social change and social policy change, such as the passage of the Americans with Disabilities Act, rather than the treatment or rehabilitation of the individual.

Although the social model has been gaining adherents, not all individuals with disabilities have rejected the medical model (see Chapter 6 for a further discussion of the range of orientations toward disability in today's population). Many parents of children with disabilities continue to focus on treatments or interventions that will improve their children's ability to function in society. While recognizing the diversity in orientations among families and individuals, in this book we adopt the terminology of the ICIDH-2 and the social model by using the term *impairment* to describe an anatomical or physiological trait or condition, which sometimes may be ameliorated by appropriate professional intervention, and the term *disability* to describe conditions with social consequences.

We also adopt two perspectives that characterize recent trends in human services by espousing a model that is both *family-centered* and *strengths-based* (partnership). The family-centered care movement developed within the field of pediatrics (e.g., Hostler, 1991). Brewer, McPherson, Magrab, and Hutchins (1989) wrote: "Within this philosophy is the idea that families should be supported in their natural care-giving and decision-making roles by building on their unique strengths as people and families" (p. 1055). This perspective also has been adopted in special education legislation, such as the Individuals with Disabilities Education Act and its amendments.

Like the family-centered model in the fields of medicine and education, the "strengths-based" approach in social work (e.g., Lee, 1994) assumes that clients are capable of acting in their own best interest and that they understand their own concerns and life situations better

than professionals. Unlike earlier deficit models, this approach focuses on family resources such as support from extended family member or from a church or other type of organization. In this book we reject the notion that the needs of families of children with disabilities can be met only by professionals. Similarly, we reject the notion, found in some of the early literature in this field, that all such families are pathological and in need of therapy. *All* families, whether or not they have children with disabilities, need a little help from time to time, and some need considerable assistance. This need is a normal aspect of family life and is met by most families in informal ways, with the help of family and friends. However, sometimes families' informal support systems are insufficient to address their concerns, and professional help is required. Although we focus on such instances in this book, we take the position that professionals need to work *in partnership* with the families they serve, rather than as powerful experts. The partnership approach is discussed in greater detail in Chapter 11.

RECENT CHANGES IN DISABILITY RIGHTS

The social model of disability shifts the focus away from treatment and care toward a demand for rights. This shift reflects changes that have come about as a result of a growing disability rights movement (DRM) as well as activism by parents of children with disabilities. Like other civil rights movements, the DRM has taken the position that people with disabilities are a minority group that is oppressed by the more powerful majority (e.g., Shapiro, 1994). Early disability legislation in the United States, such as workers' compensation insurance, created programs to support individuals with disabilities who were deemed unable to work. As a result of DRM activism, the more recent Americans with Disabilities Act (ADA), passed in 1990, promotes changes that enable individuals with disabilities to work and participate fully in other ways in society. Whereas earlier legislation resulted primarily from the efforts of nondisabled individuals, the ADA and similar laws in other countries resulted directly from the activism of people with disabilities. A DRM slogan that reflects this change is "Nothing about us without us" (Charlton, 1998).

Parents of children with disabilities also have engaged in activism, primarily in the area of education. Recent legislation, such as the Individuals with Disabilities Education Act (IDEA; 1997, originally enacted as the Education for All Handicapped Children Act in 1975)

and its amendments, has reflected parent demands for education in “the least restrictive environment” and supports services that enable children to attend public schools with their nondisabled peers (Darling, 1988; Seligman, 2000). Parent activism is discussed further in Chapters 5 and 11.

Thanks to the efforts of the DRM and parent activism, changes in legislation, improved treatment, better educational alternatives and resources, along with more progressive social attitudes, the quality of life for many families of children with disabilities has improved. Community services and financial help, such as supplemental security income (SSI), have greatly contributed to the ability of some families to provide for their children at home.

However, along with these positive developments, many social and cultural obstacles remain, and the birth of a child with a disability still poses formidable challenges to the family: from the strain on available financial, time, and emotional resources to learning how to negotiate complex educational and medical systems, from dealing with dashed hopes and expectations to worries about what the future holds, these families face an uncertain journey. This edition of *Ordinary Families, Special Children* is dedicated to addressing this journey and to providing assistance to professionals who encounter these families along their way.

SOCIAL SYSTEMS AND FAMILY SYSTEMS

The concept of systems is a leading perspective in the social sciences. However, earlier conceptions of disability within the family contained scant reference to the family unit/system or to other social structures that surround the child and the family. In psychology, this approach has been marked primarily by the development of family systems theory and the social ecology model. In sociology, all theory relates to models of interacting individuals and groups or systems.

This edition of *Ordinary Families* focuses on systems models, as supported in both psychology and sociology, in relation to families of children with disabilities. Both disciplines have offered complementary theories to facilitate an understanding of the family in the context of childhood disability.

Conceptions of family systems theory are incorporated in the theoretical grounding of contemporary psychologists and other professionals who conduct research on, or provide services to, families con-

taining a member with a disability. But this has not always been the case. Early theoretical formulations saw the child or the child and the mother as the central focus in both theory and practice. A drawback of this focus was that other implicated family members were neglected as important contributors and respondents to family events. The singular focus on the family member with a disability is also shortsighted in that it neglects the dynamic nature of family functioning. A problem experienced by one family member affects the entire system and, in turn, affects the family member with a disability.

In the past there was a grudging reluctance to embrace a broader, or ecological, perspective, which may have been partially a consequence of psychoanalytic theory and practice, which focuses on individual and intrapsychic rather than interpersonal processes. Early psychoanalytic theory focused on the mother, with a particular focus on the mother-child relationship. Fathers were discounted as nurturers because of the assumption that they were less important than mothers in influencing the developing child (Parke, 1981). Extant theories reflected the traditional conception of the remote, uninvolved father. Furthermore, the mother was seen as the first and most important object of infant attachment, and fathers were seen as playing a supporting role for the mother (Bowlby, 1951). Another contributing factor may be that, with few exceptions (Minuchin, Rosman, & Baker, 1978), family theorists and family therapists have not studied or shown a particular interest in childhood disability within the context of the family. Others implicate professionals who narrowly define the unit of care as the individual with a disability (McDaniel, Hepworth, & Doherty, 1992). Whatever the reasons for this narrow perspective, there is considerable interest in integrating theories of family systems with the available information on children with disabilities and their families (e.g., Elman, 1991; Ramsey, 1989; Rolland, 1994; Seligman, 1991b; Turnbull & Turnbull, 2001; Berry & Hardman, 1998; Marshak, Seligman, & Prezant, 1999; Marshak & Prezant, 2007). The marriage of family researchers and practitioners with professionals knowledgeable about childhood disability turned out to be a fortuitous merger in that it serves both parties. Chapter 2 provides an in-depth exploration of the value of family systems theory and related theories in the field of psychology for an understanding of families of children with disabilities.

Sociologists commonly classify theories into those that are “micro level” and those that are “macro level.” Macro-level theories try to explain the workings and effects of larger social systems. These systems consist of *structures*, or forms of social organization, and *cultures*,

or the operating principles of those organizations. Micro-level theories attempt to explain the workings and effects of interactions between and among individuals who reside in larger social systems. Family systems theory, as described above, is a micro-level theory. The remainder of this chapter (1) explores the sociocultural framework within which family systems operate and (2) describes two theoretical perspectives in sociology that are used in later chapters to further our understanding of families of children with disabilities. We begin with sociological systems theory because individuals and families operating at the micro level are affected by macro-level cultural factors (e.g., norms, values, beliefs, attitudes) and structural factors (e.g., social inequality) that are present in the larger society in which they live.

THE SOCIOLOGICAL PERSPECTIVE

Because we represent two different but not unrelated disciplines, namely psychology and sociology, we felt that it would be helpful to reflect on what each discipline brings to the field of disability and the family. In some ways sociological theory is similar to psychological theory. In other ways it is very different. In this section we provide a brief overview of two major sociological approaches that are applied in later chapters: structural–functionalism and symbolic interactionism. We will also suggest similarities and differences between these approaches and the systems perspective in psychology. Finally, we examine the differing foci of the psychological and sociological perspectives and suggest why both are valuable in understanding and working with families of children with disabilities.

Social Structure

The “structural–functional” school of thought in sociology is a macro-level body of theory that has been most closely identified with the systems concept. In the perspective of this school, which traces its American roots primarily to Talcott Parsons (1951), society is regarded as a network of interconnected groups. The structure is held together by shared values that shape the roles people play.

Each part of the system has a *function* that contributes toward the working of the whole. Functions may be *manifest*—generally acknowledged—or *latent*—not known or acknowledged. For example,

the manifest function of a preschool program may be to provide an early educational experience for children; its latent function may be to provide a few hours of respite for parents.

In the structural–functional view, the actions of individuals are explained by their place in the social structure, and society has certain expectations about the behavior of people in different roles. Some of the determinants of these culturally based expectations include age, gender, ethnicity, and socioeconomic status (SES), among others. The values of the larger society, then, shape the ways in which parents relate to their children, husbands relate to their wives, and employers relate to their employees.

Much of the literature in the field on the sociology of the family looks very much like recent literature from the family systems perspective in psychology. Writings in both fields share a concern with family roles and functions, and with life-cycle stages and transitions between stages. A structural–functional perspective is used later in this book in discussions of “opportunity structures” and the socially structured barriers that limit individuals and families in the achievement of their goals (Chapters 5 and 6) and of the social expectations inherent in professional and parent roles and in the organization of services for families (Chapter 11).

Because individuals are shaped by the social structures in which they live, people from different societies or different groups within a society may view similar situations differently. Thus the perspective of parents of children with disabilities may not be shared by the professionals who provide services to them. Some (Mercer, 1965; Marshak et al., 1999; Naseef, 2001b; Seligman, 2000) have described conflicts between parents and professionals based on their differing life experiences. These conflicts are explored in greater detail in Chapter 11. Moreover, not even all parents view their life situations and their children’s disabilities in the same way. For example, because of their beliefs and values, some Native American families may be less distressed by the birth of a child with a disability than families of other ethnic backgrounds. Family diversity with respect to reactions to childhood disability are discussed further in Chapter 3.

Social Process

Another important current of thought in sociology has suggested that structural–functionalism does not adequately account for the dynamic

nature of society. These theorists suggest that social change is the norm and that social interaction is a process in which “reality” is constantly being renegotiated. In this view roles are not static sets of behaviors based on predefined values and expectations; rather, roles are continually recreated by those who play them, based on situational contingencies. All “fathers” do not always act in exactly the same way, nor do all “mothers,” “teachers,” “doctors,” or “patients,” and the same father may act differently at different times or in different places.

The sociological perspective that has been most concerned with the determinants of these social processes is *symbolic interactionism*, a micro-level perspective that focuses on individuals and small groups such as families, rather than on larger social structures. However, symbolic interactionism is a distinctly sociological form of social psychology, because it connects the thoughts and actions of individuals with the larger society in which they live. Mead (1934) and other early symbolic interactionists accepted the notion that individuals are shaped by society and attempted to explain the process through which social ideas are transmitted to them. The perspective suggests that individuals, in turn, continually reshape society through their interactions. This perspective is used (and elucidated further) in Chapters 4, 5, and 6 to explain the “career” path followed by families from the prenatal period, through the birth of a child with a disability, through the preschool and school years, and into adolescence and adulthood. The symbolic interactionist perspective is used again in Chapter 11 to describe the process of interaction between families and professionals.

A concept that derives from symbolic interaction theory is that of the *self* or *self-identity* and the related concept of *self-esteem*, which is used in both psychology and sociology to describe a positive attitude toward the self. Sociologists believe that a person’s self-concept derives from interactions with other people. Cooley (1964) classically described the self as a “looking-glass self,” to suggest this idea. Thus, if a person is always being told that he or she is a bad person, that person is likely to have low self-esteem. Obviously, the converse also is true: Positive evaluations produce high self-esteem. Because high self-esteem is usually one of the outcomes desired for children with disabilities (and, indeed, for all children), interventions are often directed toward achieving this goal. Chapter 6 explores the identities and orientations toward disability that are commonly found among adults with disabilities in society today and speculates as to the interactional paths that produce these differing outcomes.

The concept of stigma, used in several chapters, also has its roots in the symbolic interactionist literature. Stigma refers to the negative attitude held by others in society toward individuals with disabilities and other devalued statuses. Goffman (1963) classically described stigma as a perceived discrepancy between virtual and actual social identity, which prevents the nondisabled person from recognizing the positive attributes of a person with a disability. Although some early literature suggested that individuals with disabilities internalize the stigma they experience, resulting in low self-esteem, more recent literature has suggested and later chapters will show that, like members of other minority groups, people with disabilities can be “inoculated” against negative definitions through their interactions with supportive family members and friends.

Related Concepts

The concepts of stress and social support, which are discussed in Chapter 2, have received considerable attention in both the psychological and sociological literature. Sociological studies of disability, in particular, have typically regarded social support as a major mediating variable. These studies are discussed in Chapters 4 and 5

How the Perspectives Complement Each Other

Although sociologists and psychologists have developed similar perspectives in trying to understand families of children with disabilities, their focus in practice tends to be different. For psychological practitioners, the object of intervention is usually the “client” (in this case, the family). Intervention, in the form of counseling, therapy, or treatment, is intended to bring about changes in the family system or its individual members. For the sociological practitioner, on the other hand, the object of intervention is often some aspect of the larger social structure. Sociologists generally focus on social change to create more opportunities for families.

Because of the difference in focus, both sociology and psychology (and other helping professions) are important in working with families. The helping professions that operate at the micro level (primarily psychology and social work) are important because family members need to learn to use existing resources and to adjust to, or *cope* with, situations that may be unchangeable. For example, the family that devotes all its time to finding a “cure” for a child’s Down syndrome

may need assistance in redirecting its efforts. Individual, family, or couple counseling can also be beneficial for families experiencing intolerable conflict and stress.

On the other hand, in many situations, the family would be able to cope very well without therapeutic assistance if enough supports or resources were available to them. The sociological perspective encourages the professional to assist families in creating new resources and expanding their “opportunity structures.” For example, if no appropriate classroom for children with disabilities existed in a neighborhood school, the sociologically oriented practitioner might engage in advocacy for families by working with the school to develop the means to establish an appropriate classroom. Sometimes situational factors are so overwhelming that intervention at the family level is not at all helpful. Extreme poverty resulting from larger societal conditions, for example, cannot be eliminated by family counseling; much broader social change is needed in such a case. At other times, needed social structures are in place, yet the family continues to experience stress, marital disharmony, and major communication problems. Such feelings as guilt, shame, embarrassment, anxiety, and depression may be impossible to shake. Again, in such instances, psychotherapy or family therapy may be indicated.

Some families need both counseling and advocacy; some families need neither. What the family “needs” is increasingly defined by families themselves rather than by professionals. In the field of early intervention, for example, “family centered” is coming to mean “family driven.” As one of us has described elsewhere (Darling & Darling, 1992), early intervention has shifted dramatically from a clinical or professionally directed field to one in which *parents* generally determine the desired outcomes of intervention for both the child and the family (see Chapter 13 for a further discussion of the process of outcome determination). Similarly, in the field of medical care for children with special health needs, legislation and policy have dictated a more family-directed approach (see Darling & Peter, 1994, for an in-depth discussion of models using this approach in medical education). Social work, education, and other fields have also been moving toward family-centered models (e.g., Adams & Nelson, 1995).

Both psychology and sociology, therefore, are now using a family-centered perspective in relation to families of children with disabilities. Both fields have also moved beyond a simple family-centered approach to a consideration of the larger social system within which families live. Professionals working with families need to be aware of

the various levels on which intervention can occur. Those counseling families need to be sure that the problem lies within the family itself, not in the family's larger (and perhaps changeable) social situation. Conversely, professionals who focus on social change and advocacy need to have the skills to help families cope with limited opportunities (or to refer them to professionals who do have these skills). In either case, successful intervention requires an understanding of the systems perspective and an ability to provide broadly based interventions.

OVERVIEW OF THE BOOK

This chapter has attempted to introduce the systems perspective on families of children with disabilities. The approach to be taken in the following chapters is a systems approach. Derived from both the psychological and sociological literature, this approach views the child as part of a family system of interacting units and a social system of interacting families, individuals, and social institutions.

This book has been organized into four sections. The first, encompassing Chapters 1–3, presents the conceptual framework for the remaining chapters. Chapter 1 has introduced the definitions and models that are used throughout the book and presented a brief overview of the sociological perspective. The relevant concepts from this perspective are explained in greater detail as they are used in later chapters. Chapter 2 presents an in-depth overview of the systems perspective in psychology. Chapter 3 completes the discussion of the book's conceptual framework by addressing family diversity. Although diversity is addressed primarily in a single chapter, readers should keep its importance in mind and think about its relevance for the ideas and situations explored throughout the book.

The second section of the book, consisting of Chapters 4–6, explores the “career paths” of families of children with disabilities. These chapters broaden the reader's understanding of the family experience by tracing it sequentially from the prenatal period through adulthood. Chapters 4 and 5 employ a sociological perspective to look at how family reactions to the birth and rearing of a child with a disability are socially shaped. Chapter 6 explores the possible outcomes of family careers by considering children as future adults.

The third section of the book, Chapters 7–10, based on the conceptual framework outlined in Chapter 2, presents an in-depth exploration of the family as a system. Using the principles of family systems

theory, Chapters 7, 8, 9, and 10 explore the effects of childhood disability on various members of the family system and on the family as a whole.

The final section of the book consists of the last three chapters and focuses on applications of the material covered in the preceding theoretical and conceptual, chapters. Chapter 11 discusses the parent-professional relationship, beginning with a theoretical discussion of the sometimes opposing roles of parents and professionals. The chapter then presents the current strengths-based or “partnership” model of practice as the approach that guides the interventions suggested in the last two chapters of the book. Chapter 12 focuses on counseling as a family-based intervention practice rooted in family systems theory. Finally, Chapter 13 illustrates the application of a social systems perspective to assisting families in identifying their resources, concerns, and priorities and in using these family-defined elements in the development of a service plan to achieve the outcomes that they desire. By combining the systems literature from sociology and psychology, we hope to provide the reader with a broader and deeper understanding of families of children with special needs and to offer some tools to assist these families in achieving a higher quality of life.