ABSTRACT. Children with disabilities, their families, and the social workers who provide services are faced with navigating complex social and institutional environments in their quest for developmental, educational and daily living supports. Models of disabilities provide conceptual frameworks for understanding and action that can inform the decision-making process of parents and social workers. A new ecological model of disability, the systems model, is proposed that integrates the medical model, focused on individual deficits, the social model, focused
on disabling social environments, and the transactional model, focused on person-environment interactions. Diagnostic, institutional, and practice implications of the new model are discussed. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2004 by The Haworth Press, Inc. All rights reserved.]

**KEYWORDS.** Disability models, ecological, children, systems

Children with a disability may be described as a “minority within a minority” (Munn, 1997) who face unique challenges because of their status as dependents and the special needs of both child and family. These challenges stem from the child’s impairments and related developmental challenges, on the one hand, and inadequate social services and societal barriers, on the other (Brett, 2002; Dowling & Dolan, 2001; Ellis, Luiselli, Amirault, Byrne, O’Malley-Cannon, Taras, Wolongevicz, & Sisson, 2002). The challenges that children with a developmental disability and their social workers confront require integrated services and dynamic multilevel interventions that support both child and family (Heiman, 2002; Middleton, 1998; Reiter, 2000; Ward, 1999). However, social services and intervention programs are often based on relatively simplistic assumptions regarding the experience of disability and its consequences for children with disabilities and their families (Brett, 2002; Middleton, 1998; Reiter, 2000). These assumptions can best be understood in the context of models of disability.

**MODELS OF DISABILITY**

Models of disability can provide social workers with the basis for a systematic approach to understanding the causes and contexts of disability (Imrie, 1997). As the lens through which a child’s disability is comprehended, models of disability selectively bring into focus some factors to the exclusion of others (Fougeyrollas & Beauregard, 2001). This suggests a strategic use of models by social workers, depending upon the salient challenges facing the child in the context of his or her age, developmental disability type, and social environment.

Models of disability have generally been used to illuminate the experiences and goals of disabled adults (e.g., Marks, 1997a, 1997b).
These experiences and goals may be quite different than those envisioned for their children by parents of children with disabilities. Most of these parents are not themselves disabled, have little or no knowledge of the “disability community,” and certainly begin the process of parenting a child with a disability through interaction with the medical health care system. Parents enter the medical health care system with the intention of “fixing” their child, at least to the extent possible. Over time, as parents gain knowledge and come to realize that many disabilities are lifelong, this goal shifts from a medical intervention focus to an adaptive environment focus.

The role that models of disability can play, over time, in providing both theoretical and practical support for the interventions and services chosen by parents in consultation with social workers and other professionals for children with developmental disabilities are examined in this paper. In addition, we discuss some of the implications of models of disability for diagnosis of developmental disabilities and for educational and health policy. The term “developmental disability” is often used as a pseudonym for mental retardation, but in fact its definition is broader. Developmental disabilities have been defined by the federal Developmental Disabilities Assistance Bill of Rights Act (P.L. 101-496, section 102, 1990) and include conditions such as autism, cerebral palsy, hearing impairment, and vision impairment as well as mental retardation.

Models of disability refer to frameworks for understanding the causes of disability and, by implication, the means to ameliorate them (Altman, 2001). For children with a disability, their families and social workers, the stakes in the choice of intervention program (and therefore, disability model) are very high. Developmental disabilities challenge the resources of child, family and community with multidimensional and developmental stage-sensitive needs. Successfully addressing such needs requires a coherent plan or vision of the kind that a model of disability can provide by indicating which facets of the situation are important, how they fit together, and how an optimal outcome might be achieved. Models of disability implicitly describe not only the disability, but also those conditions under which the negative effects of disability on functioning are attenuated. Thus, different models of disability imply different intervention approaches; no single model provides an adequate basis for the entire spectrum of intervention approaches. However, the path toward lessening the impact of disability implicit in each model also bears a unique, and necessarily limited,
These limitations argue for the strategic use of models as tools, rather than as stand-alone road maps for action. Unfortunately, parents often choose an intervention for their child without a clear understanding of the model on which the intervention is based. A better understanding of the disability model underlying most interventions would doubtless improve both the decision-making capacity of parents and social workers and the design of interventions by providers. There are four major models of disability of particular utility for children with a disability, their social workers, and service providers: the medical model, the social model, the transactional model, and the ecological or systems model. Each model will be discussed in application to the issues facing children with disabilities and their social workers.

THE MEDICAL MODEL

The medical model of disability is probably the most influential and pervasive model today (e.g., Gregory, 1997; Imrie, 1997; Llewellyn & Hogan, 2000) due to the power and prestige of the medical professionals, insurers and institutions on whose perspectives, expertise and influence the medical model is based. The medical model couches disability in context of pathology and impairment (e.g., sensory, neurological, cognitive) from a trauma or disease process (Danforth, 2001; Hughes & Patterson, 1997). The medical model is sometimes cast as devaluing or dehumanizing because of the focus on deficiencies (Imrie, 1997; Bax, 1998). However, a more thorough examination of the medical model in its application to advocacy for children with a disability is warranted if the limitations are to be meaningfully assessed in this context.

The medical model assumes that the impairment arises from symptoms due to a disorder, syndrome, disease, or condition that is subsequently categorized and classified. Prevention, treatment, and management of disease processes and traumas in service of reducing or eliminating the pathology associated with disability, as well as secondary conditions, are its goals (Drake, 2001). Interventions based on this model have much to commend them from the standpoint of the child with a disability and his or her social workers. For example, strength training in a child with a primary disability of cerebral palsy will likely decrease the physical challenges faced by that child at each developmental stage (Damiano & Abel, 1998). Meanwhile, by choosing an intervention that lessens the impact of the child’s disability, the family may, over the long run, have
more available affective and material resources than it would otherwise have. In addition, the capacities and potential outcomes for the child have been enhanced.

Despite these advantages, a disability model that is grounded in the diagnosis of individual pathology provides a useful framework for intervention only to the extent to which there is some indication of underlying pathogenic process. With developmental disabilities this is not always the case. Some developmental disabilities, such as mental retardation resulting from identifiable genetic anomalies (e.g., Down’s syndrome or Fragile X syndrome) are based on a clearly measurable medical diagnostic procedure. Others, such as autism spectrum disorders, are based on observation of behavioral attributes of the child while in a clinical setting, and often result in an unclear or tentative diagnosis. For many developmental disabilities, even when a clear medical diagnosis is established, there is no single, demonstrably effective medical intervention to alleviate the cause or the symptoms of the disability. Thus, parents often have a diagnosis but don’t know what to do next.

These examples raise the important issue of adaptation to disability, which brings into focus the interaction between the person and environment as each evolves over time. The medical model is particularly unsuited to considerations of person-environment interaction as factors actively shaping disability (Fougeyrollas & Beauregard, 2001). Disability in this context extends beyond the condition of disability to encompass the experience and consequences of disability, both of which are intimately tied to another concept—“functioning,” or, what the individual is able to do irrespective of diagnosis. The distinction between level of functioning and diagnosis is not a trivial one for several reasons. First, some studies have shown that diagnosis may not be the best predictor of functioning for people with a disability (Pelkonen, Marttunen, Pulkkinen, Laippala, Loennigvist, & Aro, 1998; Simeonsson, Bailey, Smith, & Buysse, 1995). Furthermore, as Ustun, Chatterji, and Rehm (1998) point out, diagnosis is not a good predictor of service need—rather, functioning mediates the impact of diagnosis on need. “(T)he missing link between diagnosis and need is functioning” (Ustun et al., 1998, p. 1146). This observation is particularly true for children with developmental disabilities. Developmental disabilities tend to be “spectrum disorders” in that functional impairment may range from mild to severe for children with identical medical diagnoses. Even within the mild category, the functional abilities of children may be differentially impaired. This means that a child’s physical or psychological functioning, as well as his or her social functioning at home or school,
will directly affect that child’s self-perceived needs, as well as the perceptions of parents, siblings, teachers, or peers vis-à-vis the child’s needs. Another model of disability, the social model, takes functioning into consideration and provides a framework for understanding how the social environment has an impact on functioning and, consequently, service needs.

**THE SOCIAL MODEL**

The social model of disability posits that disability is a social construction, which is to say that society creates “disability” by imposing hindrances to the full participation of persons with different abilities (Hughes & Patterson, 1997; Harris, 2000; Swain & French, 2000). Such hindrances include negative attitudes, physical impediments, and institutional, communication, and social barriers. In the social model, disability is differentiated from impairment by exclusionary societal practices that isolate and stigmatize individuals with a disability (Goodley, 1997; Hughes & Patterson, 1997). This model adopts a civil rights perspective on the social and civic participation of persons with a disability (Marks, 1997a, 1997b; Munn, 1997). The term “minority model of disability” may be used interchangeably with “social model of disability.” The term “minority model” underscores how civil rights, to offset the pernicious social construction of disability rest on minority status-based legal protections (e.g., Batavia & Schriner, 2001; Schriner & Batavia 2001; Scotch & Schriner, 1997). The social, or minority, model of disability thus reflects the value base that undergirds the Americans With Disabilities Act (ADA), the Rehabilitation Act (Rehab Act), and the Individuals with Disabilities Education Act (IDEA), all of which trace their moral precepts and anti-discrimination language to title VII of the Civil Rights Act of 1964 prohibiting discrimination on the basis of race (Batavia & Schriner, 2001; Danforth, 2001). Proponents of the social model of disability observe that society unjustly privileges certain appearances, levels of functioning or needs as “normal” over others, resulting in social exclusion as well as economic and political marginalization (e.g., Imrie, 1997; Dowling & Dolan, 2001). Those who do not conform to the behaviors, needs or aesthetics expected of nondisabled people are treated as inferior and considered to have a subnormal status.

Similarly, society weighs the rights of the individual and the responsibilities of the community differently depending on the consequences
to the dominant, nondisabled group. For example, a school district may fund counseling for several families following an incident of widespread school violence but refuse to fund counseling for a family whose child has just suffered an acute head injury. This difference in resource allocation is paradoxical; both events disrupt family functioning and require additional supports, but only one, school violence, is deemed worthy of scarce counseling resources. In the first case, school violence is considered to be a “community concern,” whereas in the second case, disablement is considered to be a “family concern” and, subsequently, ineligible for community funds.

Within this framework, the appropriate accommodations needed for persons with disabilities to participate fully in society are recast as rights (Asch, 2001). In practice, however, the boundaries of such rights have been the subject of heated debates when public and private entities have been challenged with costly alterations to standard practices or services. For young children with a disability, this debate may take shape when mainstreaming children diagnosed with cerebral palsy or Down’s syndrome requires additional teacher training and a teacher’s aide for every integrated classroom.

The social model puts the accommodation needs of children with a disability on an equal footing with those of their nondisabled peers (Ravaud & Stiker, 2001). The social model also recognizes the importance of the institutional (e.g., educational system), social and political environment in facilitating or impeding conditions that vouchsafe such rights (Barton & Armstrong, 2001). Perhaps even more than the medical model, the social model requires the knowledge and participation of parents and social workers in order to craft an appropriate, child-specific intervention for each child with a disability. The federal government acknowledged the importance of informed parental input into the intervention process when it included a mandate for state-sponsored parent training organizations in the IDEA.

The social model permits consideration of social class, ethnic- and cultural-based biases and discrimination. Thus, the unique barriers to information faced by members of racial and ethnic minorities (children and parents) can be taken into account, even when their impact is upon the quality of medical care, ostensibly the domain of the medical model, but foreign to the disease focus of that model. In fact, members of racial and ethnic minorities may not receive the services they need (Brookings, 1993; Sloper, 1999). Moreover, differences in physical health and in the incidence of disability between White Americans and
African-Americans, Hispanic-Americans and American Indians begin at birth (Brookings, 1993). Disparities in access to care, service provider lack of familiarity with ethnic minority cultural beliefs, and cultural barriers to understanding increase risk factors for aggravating the condition and consequences of developmental disabilities over the life span (Brookings, 1993). Families with disabilities tend to have greater financial need than other families (Sloper, 1999; Porterfield, 2002), a critical factor relevant to the equitable receipt of services. This is a factor that the social model makes particularly salient to social workers. Thus, the social model can add a needed dimension to the treatments and services that are usually thought of as the exclusive purview of the medical model. Just as the medical model emphasizes prevention and timely remedial intervention, the social model espouses proactive measures to anticipate and reduce barriers to full participation in the institutional, social and political environment as the young child transitions from home to preschool and preschool to school environments. The social model complements the micro (individual) focus of the medical model with a macro-level perspective. Unfortunately, neither the medical nor the social models properly account for the meso-level activities that mediate both the effects of physiological or psychological impairments and the effects of institutional policies or practices.

**THE TRANSACTIONAL MODEL**

At the meso level where children with disabilities and their families interact with institutions such as schools and social service agencies, transpersonal factors, such as interpersonal, family, and organizational dynamics influences the child’s quality of life (Ferguson, 2001). The transactional model provides a framework for conceptualizing how these dynamics affect the experience of disability, for the child and his or her support system (Llewellyn & Hogan, 2000). The transactional model posits multiple feedback loops between the behavioral patterns, beliefs and emotional reactions of the child with a disability and his or her immediate social environment. Thus, it takes into account the way in which the interactions between a child with an autism spectrum disorder and her parents produce reciprocal responses that shape the child’s self-presentation and self-esteem with clear implications for the child's experience of disability when she or he enters the school environment. Applied Behavioral Analysis (ABA) or Lovaas therapy is (though per-
haps not purposefully) congruent with the transactional model (Lovaas & Smith, 1989; Cattell-Gordon, 1998). These intensive methods of intervention train children, who are otherwise oblivious to social cues, explicitly how to act appropriately in each social setting through techniques such as role-playing and social stories (Gray, 1998). The child’s response to behavioral management techniques, as well as the manner in which the parent or therapist uses those techniques, will have profound implications for the teacher’s use of such techniques in the classroom context. The parent-child interaction will also influence the child’s self-presentation with implications for the initial impression of the child by both teacher and classmates, and for the tenor of subsequent interactions of the child with them. Hence, the transactional model of disability views the interactions between the child and his or her social environment rather like ripples spreading across a pond; reinforcing or interfering with important growth processes and thus altering the perceived impact and experience of disability. It is complimentary to both the medical and social models—inasmuch as psychology and physiology affect behavior, cognition, and emotion, so too does society through the mechanisms of socialization and social cognitions such as stereotypes. However, the transactional model’s emphasis upon “reciprocal relations” can lead to false assumptions about putatively equal influence on the part of individual and society. It fails to consider the power of society through moral and legal sanctions, and the distribution of information and resources, to shape the agenda and the context in which transpersonal transactions take place.

PUTTING IT ALL TOGETHER: THE SYSTEMS MODEL

In order to consider all three elements—individual (medical model), societal (social model), and transpersonal (transactional model)—simultaneously, an ecological approach is required. In their search for ecologically valid models of disability for research and clinical applications with children, Llewellyn and Hogan (2000) suggest a “systems analysis” model guided by Bronfenbrenner’s (1992) process-person-context model. Bronfenbrenner’s model attributes individual characteristics to the joint effect of personal traits and environmental factors over the life span. Bronfenbrenner’s ecological or systems theory was based upon the earlier work of Kurt Lewin (1947), who devised the Field Theory approaches to human behavior. Lewin observed that explaining human
behavior by reference to the action of the human psyche acting alone constituted an unwarranted solipsism:

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\ldots \text{behavior could not adequately be understood simply in terms of cognitive structures, wishes, and expectations, and that some way would have to be found for dealing with the constraints, opportunities, resources, and pressures that originate in the social, political, and technological environment. (Cartwright, 1978, in Schwartz, 1993, p. 267)}
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The basis of Lewin’s Field Theory posited a “life space” at the intersection of person and environment. This “life space” was the “region,” partly accessible and partly not, in which the individual interacted with his or her environment and structured the individual’s psychological experience. Thus, Field Theory placed outcomes in the context of a structure and process.

Bronfenbrenner added another dimension to Lewin’s Field Theory: change over time. Whereas Lewin insisted that person-environment interaction research focus on a snapshot in time, Bronfenbrenner was interested in the changing interaction over time, for which he introduced the concept of “chronosystem” (Berry, 1995). Although he supported the application of Field Theory to macro-level environments, Lewin was focused chiefly on individual behavior as shaped by small group social interactions, rather than on larger social problems (Gold, 1992). Bronfenbrenner, by contrast, devoted his energies to developing a framework suitable for conceptualizing the environment in concentric circles of influence from its most proximal relationship with the individual to its most distal, and in-between. Specifically, Bronfenbrenner conceived of person-environment interactions as nested structures spatially arranged by their distance from the individual. He began with the most proximal structure, the microsystem (e.g., family), then described the mesosystem (e.g., direct relationships such as neighbors), followed by the exosystem (e.g., indirect relationships such as school systems), and finally considered the most distal structure, the macrosystem (e.g., overarching influence systems such as cultural influences).

The strength of ecological or systems models of disability is that they put the child with a disability in the context of an environment that can produce developmental changes (Llewellyn & Hogan, 2000). For example, a peer support group or a “circle of friends” can provide a buffer between the child and her environment, helping the child to negotiate difficult situations and providing a context for social interaction. These
are the peers who think of the child as a friend rather than someone with a label (Gold, 1994; Taylor, 1997). The chief challenge in articulating a systems model of disability is to specify its parameters. Whether guided by Bronfenbrenner’s theory, as were Llewellyn and Hogan (2000), or by Lewin’s (1947) theory, an ecological or systems model, much like ecological theory, does not permit predictions, but rather maps out general relationships.

**DIAGNOSTIC ISSUES**

The diagnostic criteria for developmental disabilities vary by country. In the United States they are found in two separate diagnostic manuals, the World Health Organization’s International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10), and the American Psychiatric Association’s Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR). Developmental disabilities such as cerebral palsy are considered “medical” disorders and are diagnosed by medical doctors according to criteria delineated within the ICD-10; those such as autism are considered “pervasive mental” disorders and are diagnosed by mental health professionals according to the criteria delineated within the DSM-IV-TR. One consequence of not having a unitary or unified classification scheme is inadequate provision of capacity building and ancillary services, such as special equipment, personal assistance, and social work services (Benedict & Farel, 2003). Another consequence is inadequate insurance coverage. Although there is some overlap among the roles played by various medical professionals (for example, autism may be diagnosed by a neurologist or a psychiatrist/psychologist), for insurance purposes these disabilities tend to be covered as “medical” if the diagnosis is contained within the ICD-10 and as “mental health” if the diagnosis is contained within the DSM-IV-TR. Many insurance plans provide lower levels of coverage with higher co-payments or coinsurance for mental health diagnoses than they provide for medical diagnoses (Sturm & Pacula, 2000; Pacula & Sturm, 2000).

Internationally, the World Health Organization recognized the need to include environmental factors in reciprocal relation to personal factors and organic systems in the design of the International Classification of Health, Disability, and Functioning (ICF), yet they have yet to be truly integrated into the diagnostic criteria or adopted by medical professionals and social workers in the U.S. (Gray & Hendershot, 2000).
Meanwhile, environmental and personal factors provide the context for functioning and personal or life activities. Body functions and structures are assessed with regard to significant deviations from the norm. Activities constitute observable, culture-specific person-level tasks or activities that are limited by the degree to which the individual has difficulty performing them—with or without the use of assistive technologies or personal assistance. Participation, characterized by involvement in life activities such as social relationships, work, social and civic life (e.g., Drake, 2001), is, by contrast, generally not included in diagnostic criteria, and is restricted to the degree that external rules, such as social rules limit participation. The environment includes natural, social, technological, material, institutional, political, and belief-system-based factors impinging on an individual’s life, and is subject to barriers and facilitators of different degrees.

Despite its sensitivity to the multidimensional character of disability, even the ICF places the individual squarely at the locus of the process. This has the effect of minimizing the impact of sociocultural and historical factors shaping services for children with a disability and their families, and puts the onus of intervention primarily on the individual in the environment (Szymanski, 1994). Environmental interventions are overlooked, beginning with the proximal care environment of service providers and moving outward to the more distal environments of institutionally and nationally sanctioned policies and practices. Indeed, families as agents of socialization and social control are excluded from individual-focused models of intervention. Moreover, the labels and classificatory schemes used to designate ‘disability’ may have a negative impact on the services and support received by children with developmental disabilities. Both “official” labels and classificatory schemes are inherently power laden, and shaped by the values and purposes of powerful groups (Gregory, 1997; Szymanski, 1994) whose interests are not those of children with disabilities or their social workers.

**INSTITUTIONAL IMPLICATIONS**

Although the ICF takes a step in the direction of considering both the etiology and the functional reality of disability (e.g., Bricout, 2002)—more accurately pinpointing where on the spectrum a child with a disability lies—its use conflicts with the current structure of health care provision in the U.S. In point of fact, the social workers, medical professionals, educators, and service organizations that serve children with
disabilities will not provide services until a formal diagnosis (medical or educational) has been made. Some service organizations do include evaluation and diagnostic services, but many rely on the medical or educational communities for these services. Diagnostic procedures are codified into laws governing access to services from each of these institutions as well as financial support through other government agencies (such as state “birth-to-three” programs, Medicaid, and social security or supplementary security income cash assistance for the disabled).

Advocacy-minded organizations also provide skills and resources for ameliorating aspects of the child’s condition and environment, such as therapeutic skills and advocacy training for parents. These organizations, perhaps more than any others, integrate the social and medical models. However, the degree to which this integration takes place is limited by the scope of the organization’s purview and mission. The organization’s charge and scope of activities may be circumscribed by the way that the ‘problem’ has been defined, for example, either as an issue of access to care, or in terms of denial of rights, making it difficult to address both needs and rights. Organizational change aimed at broadening the advocacy-minded agency’s mandate may be required to implement a systems approach, and here social workers may provide the catalyst for change (see Cherin, 2000).

PRACTICE IMPLICATIONS

The Internet. One of the most exciting developments in recent years has been the rapid increase of parent support groups and practice information on the Internet. The Internet serves as a medium for communication, support and information. As a medium of communication and support, the Internet has allowed parents of children with fairly rare disorders, such as apraxia of speech or autism, to “chat” and learn from the experiences of other parents (Finn, 1999; Waltz, 1999). Parents can find information on the nature and quality of remediation, compensatory or rehabilitative practices on the Web (Cook, Rule, & Mariger, 2003). Similarly, the Internet provides valuable information for social workers and others in the helping professions related to resources and practices for children with disabilities (Holden, 2002; Sabella, 1998). The Internet can even provide information for parents of children with disabilities desiring so-called alternative and complementary therapies falling outside traditional Western allopathic therapies, such as Chinese medicine and herbal therapy (Rosenberg & Stewart, 2002).
For both parents and professionals vetting information on the Internet it is a critical task: a challenge to the user and a limitation of the medium (Cook et al., 2003; Holden & Rosenberg, 2003; Rosenberg & Stewart, 2002). Another limitation of the Internet, its ‘inaccessibility’ to children with disabilities due to a paucity of software for making both online (Web-based) and standard computer software applications responsive to the needs of children with learning disabilities, visual and speech impairments, is decreasing with the creation of new programs (Amberg, 2001). The ADA provides legislative impetus for making the Web accessible for students with disabilities (Bricout, 2001).

Although the Internet has begun to bridge the medical-educational gap for parents, and created additional forums for discussion among some groups of professionals, its use does not yet appear too widespread or sophisticated enough to address the dearth of communication between professional groups, particularly between physicians and service providers. While the Internet has facilitated a more open dialogue between parents and professionals, it has yet to translate into widespread integration of medical and educational services. In the meantime, a good deal of work has yet to be done in improving the quality of face-to-face dialogues between parents and professionals. Perhaps the most important part of this work at enhancing both the quality and the efficacy of the dialogue lies in creating new partnerships between social workers and parents, and in forging face-to-face parent support groups.

Client-Professional Partnerships. Parents and social workers can be most effective at providing supports for a child with a disability if they understand the underlying models and develop partnerships to secure ecologically sound services that meet the emergent needs of developing children. Although medical diagnosis (e.g., medical model) is necessary for access to services, for most children with developmental disabilities there is no medical “fix” for the functional challenges faced by the child. Developmental disabilities are, by definition, lifelong in nature. One can maintain flexibility and strength in a child with CP, teach a deaf child to speak, educate a child with mental retardation, and teach appropriate social behavior to a child with an autism spectrum disorder, but one cannot “cure” children of these disabilities, the goal of a medical model approach to disability. Thus, the medical model has a place in the intervention process; it is not, however, a panacea.

The focus of the social worker-family partnership needs to be on providing parents with the appropriate skills and knowledge to successfully anticipate and negotiate predictable challenges arising from transitions between developmental stages (Quinn, 1999). These skills and knowl-
edge empower parents to guide the child through interpretation and eventual adaptation to their changing social environment. The partnership involves an iterative process of action and assessment grounded in the families' and most especially, the child's experience of accommodations, treatments, and supports. In the context of such a partnership parents, children and their social workers are better equipped to make choices regarding accommodations to reduce the functional limitations arising from the interaction between the child's disability and his or her social environment. For instance, a wheelchair or system of braces and canes is provided for the child with CP, a TTY system is provided for the deaf child, and a circle of friends is initiated for the child with mental retardation or autism.

**Face-to-Face Support Groups.** In addition to professional-client partnerships, parents of children with disabilities can also become empowered through involvement in support groups (Adesida & Foreman, 1999; Solomon, Pistrang, & Barker, 2001). For example, a study of support groups for parents of children with hyperkinetic disorders found that voluntary, facilitated groups with parent-led discussions provided useful information, instrumental and social support (Adesida & Foreman, 1999). As social networks support groups have a number of advantages, they spread emotional burdens over a number of individuals, provide a broad repository of knowledge and experience, and alleviate the stigma and marginalization of social isolation. In many respects, they provide a new occasional environment for parents, a prescriptive in keeping with the social model of disability.

**Adapting Persons and Environments.** The social model is important, but it is not definitive. Changing the environment to fit the child (the social model), while an important ideal, is often not a practical goal for children or their parents. Parents cannot change most social environments because they lack the requisite resources and knowledge and societal norms are resistant to change. Even if parents could change their child's immediate environment, they may not want to because of the negative social stigma and discrimination that the child may face for being too different when s/he moves from his or her immediate environment into other social settings that are less adaptable. For example, one would expect the parent of a child with speech and language limitations to attempt to remediate those limitations through speech and language therapy. The child could simply learn to communicate through sign language or through a picture exchange system (PECS), but this is a second-best solution for a child because that support may not be replicable, or even desirable as the child ages and his social environment expands.
Although accommodations provide essential supports to the child’s ability to successfully navigate her world, medical interventions are equally important. Social policies play an important role in providing both resources and mechanisms for creating enabling environments that foster the full participation of children with disabilities and their families in community life, not as dependents, but as equal citizens (Turnbull, Beegle, & Stowe, 2001). Social workers need to be familiar with the role of social policy to incorporate policy advocacy in their change efforts.

Targeting Social Policies. Social policies need to focus simultaneously on the needs of children with disabilities and their families (Benedict & Farel, 2003; Turnbull et al., 2001). Such policies must be focused on the functional consequences of disability and not on the condition itself if the services received are to be capacity building rather than dependency building (Benedict & Farel, 2003; Turnbull et al., 2001). As a social policy of special import to children with disabilities, the IDEA can serve as the basis for a discussion of enhancing social policies to create participation-enabling environments.

It is critical for social policies to allocate resources for services that address the functional consequences of the disability, rather than limit services to those focusing on alleviating the condition as such. In order to provide services for children with behavioral and emotional disorders, for example, the IDEA must target services that address not only cognitive processing impairments to learning but also behavioral and emotional supports (DPN, 2001). The federal government does not appear to be taking this approach in the IDEA Reauthorization of 2002, which focuses on resources for early reading instruction interventions to the neglect of behavioral and mental health supports that increase the capacity of these children to succeed at school and to eschew substance abuse and violence (DPN, 2001). A study conducted by Turnbull, Beegle, and Stowe (2001) identified several core concepts relevant to the current discussion of targeted social policy resource allocation. Using qualitative methods in a participatory action research process that involved 108 individuals including family members, policy experts and professionals, Turnbull et al. (2001) identified 18 core concepts, of which three are germane to the conditions under which services are delivered: (1) individualized and appropriate services, (2) classification, and (3) capacity-based services.

Policies must be crafted that make possible custom-tailored services that meet the individualized needs of families and their children with disabilities, preferably in an integrated and ‘seamless’ fashion.
from provider system to provider system: for example, from school to work, facilitated by IDEA-mandated transition plans (Turnbull et al., 2001). In practice, the IDEA transition plans have failed to achieve their promise of seamless integration, although viable models may be on the horizon (e.g., Hughes, 2001). Classification systems exist in a context of limited resources, and if they are properly calibrated, can serve to protect the needs of both family and child by considering both the severity of the disability and family resources (Turnbull et al., 2001). As we have seen, adequate classificatory schemes for meeting the developmental and financial needs of children with disabilities and their families do not exist. A necessary counterweight to the needs-based focus of the classification system is provided by capacity-based services, which take into account client strengths as well as needs, and seek overall to enlarge the capacity of both child and family (Turnbull et al., 2001). Once again, the IDEA principles of family-directed assessment and multidisciplinary needs evaluations may fall short of the mark, especially for members of racial and ethnic minority groups (Zhang & Katsiyannis, 2002). Social workers and other advocates must lobby for federal policy initiatives that reflect a systems approach and capacity building orientation, particularly in the current political climate that is characterized by devolution and a shrinking commitment to more costly but necessary investments in seamless social and medical services.

Challenges. Although a systems approach provides additional benefits by integrating aspects of both the medical and social models, interventions currently available in the United States tend to focus on either the medical or the social model. Medical professionals trained to diagnose the disability may not be aware of intervention programs based on the social model. Educational professionals and public agency case managers, on the other hand, are well aware of therapeutic intervention programs grounded in a social model perspective but may know little about more traditional medical interventions. In other words, there is a disjuncture between the medical, social service, and educational professions. Advocacy organizations can help spearhead efforts at systemic change aimed at integrating the social and medical models. The medical, social services, and educational communities will also be important partners in realizing change at the institutional and societal levels.
FUTURE DIRECTIONS

In the long run, several changes are needed to help achieve the goal of minimizing the pernicious impacts of disability and maximizing the ability of children with disabilities to successfully negotiate their environments. First, the link between medical diagnosis and resources available to support treatment needs to be more clearly identified and developed. In support of this goal it will be important to conduct population-specific, empirical research. The aim of such research would be to create post-diagnosis intervention guidelines appropriate to the child’s age, medical diagnosis, level of functioning, and family resources. A mechanism for linking these guidelines and the resources available to people with disabilities and their families needs to be developed. We envision a computer-mediated interactive decision-making tree, perhaps available on the Internet. This interactive system would constitute a guide for the user who could navigate through state and local area-specific information regarding treatment, advocacy, and both public and private funding resources. User input would be solicited on improving both the substantive content of the guide and the software applications.

Second, low-cost, high-quality education programs explaining the major models of disability and their implications for professional practice, advocacy, and familial problem solving should be made available to service providers, social workers, and parents. The programming content and delivery would be tailored to the intended audience with distinct versions for parents and professionals. Such programs could be ‘modular’ in format and readily disseminated using hard copy and computer-mediated media, such as compact discs, DVDs, or Web pages. Participant feedback on the relevance, utility and content of the educational programs would be part of an ongoing process of evaluation and modification.

Third, online or face-to-face forums where social workers, parents, and professionals can discuss these issues in a less formal setting would help to disseminate cutting-edge medical, therapeutic intervention, and public policy research between these groups. These forums should arise out of partnerships between advocacy groups, parents, social workers, and medical professionals. The common thread running through the proposed strategies is a prominent role for participant feedback, which is then integrated into the development and implementation of services and interventions (e.g., Brett, 2002; Dowling & Dolan, 2001; Heiman, 2002).
CONCLUSION

Improving the “fit” of treatments and programs for children with disabilities will require an ongoing iterative process in which professionals and institutions adapt their responses to accommodate the changing circumstances of the child’s environment and development. At the same time, service providers need to attend to the evolving support needs of both the child and his or her family. This type of iterative process does currently take place to some extent in some local school districts. Links within the process are often quite weak, however (e.g., support of noneducational activities or goals), and medical professionals are often not represented. In addition, schools rarely become involved in family-based supports; rather their focus is on enhancing the child’s educational outcomes. Despite current limitations, the systems model will likely become the dominant model as today’s children with disabilities grow into tomorrow’s adults with disabilities. These children are among the first generations in the U.S. to be included in the general education school and classroom as full and equal participants in the educational process (Ferguson, 2001). Parents are perhaps more aware now of their children’s medical issues and legal rights than at any other point in time. Keeping pace with the exponential growth of knowledge and innovation in medical sciences will, however, continue to be a challenge.

The pieces to enhance the ‘fit’ for children with disabilities are mostly in place, but they are not integrated or sequenced to meet the particular needs of individual clients and their families. What is needed is for these pieces to be organized in a way that is accessible for parents to guide their decision-making process in seeking out appropriate resources and supports. Social workers who are informed about the underlying issues can play a central role in providing relevant knowledge based on the most current medical, therapeutic, and social services research.

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