Recognizing the Role of Parents in Developmental Outcomes: A Systems Approach to Evaluating the Child with Developmental Disabilities

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When developmental concerns arise in children, a clinical assessment focuses on the child’s developmental profile to achieve three goals: (1) determine diagnosis, (2) develop interventions, and (3) evaluate progress. Parents often have needs during this time that are not addressed by professionals because of the exclusive focus on the child during the evaluation. In this article, we suggest that clinicians take a “systems” approach to the assessment process by recognizing how the well-being of family members can impact a child with a developmental disability. We review systems theory and its conceptualization of individual functioning and discuss how parental well-being differs according to child diagnosis. Finally, we suggest a systems-based model to use during the assessment process.

Key Words: assessment; systems; families

Language delays, problems in gross motor development, difficulties in participating in reciprocal social interaction, significant behavioral challenges, the possibility of an autism diagnosis—these and other concerns about their children’s development are among the reasons that parents seek professional help [Simeonsson and Scarborough, 2001]. When such concerns arise, parents often turn to their pediatricians to provide initial guidance in establishing an explanation or obtaining confirmation of their child’s delays. However, a more comprehensive clinical assessment, often conducted by a multidisciplinary team (e.g., clinical psychologist, speech-language pathologist, occupational therapist), is typically necessary to address questions about the origins of existing delays, their nature and extent, treatment options, responses to treatment, and anticipated outcomes for the child [Simeonsson and Scarborough, 2001]. In this article, we make recommendations for further broadening of this assessment process.

For many parents, reactions to initial suspicions and then confirmation of an existing developmental disability are similar to those reactions experienced in response to a trauma or crisis [Sanders and Morgan, 1997; Seligman and Darling, 1997]. In some cases, elevated levels of psychological stress lead to marked and sustained impairments in functioning among parents and other members of the family. In contrast, some families deal effectively and even thrive in the face of the challenges associated with a child’s developmental disability. The factors that lead to these differences in family response are not fully known [Hassall and Rose, 2005]. Family responses, however, can play an important role in their ability to implement recommended treatments for the child, to seek out additional resources for the child, and generally to support the child’s development.

It can be difficult for professionals to fully appreciate and address the needs of parents and other family members because the assessment process is traditionally child focused. Current assessment practices often limit a clinician’s or evaluation team’s ability to expand their clinical evaluation services beyond establishing a diagnosis for the child and providing a set of recommendations for treatment and care, again, focused on the child [Greenspan and Meisels, 1996]. Large case loads and lengthy waiting lists have become the norm as increasing numbers of children are identified as needing evaluations to investigate developmental concerns. Add to this the financial and staffing restrictions in many healthcare environments, and it can be difficult for clinicians and multidisciplinary evaluation teams for envision and expansion of the assessment process [Greenspan and Meisels, 1996].

We believe, however, that, despite these challenges, clinicians and evaluation teams should take a systems approach to the assessment process and thereby acknowledge that the well-being and experiences of other family members can impact a child with a developmental disability. In the systems approach, the “patient” is no longer simply the child with suspected developmental delays, but his or her family system and its individual members, including parents and siblings, each of whom has an important role in the child’s development and well-being.

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whom presents with unique needs and challenges to be assessed, interpreted, and ultimately treated.

In this article, we describe systems theory, how parental well-being differs according to child diagnosis, and a model for clinicians to use in applying a systems approach to the clinical assessment process. Because of space constraints, we limit our discussion largely to parents, but it is important to recognize that siblings and other extended family members (e.g., grandparents) also are affected by, and can affect the child with a disability, and thus they too should be considered in a systems-based assessment.

SYSTEMS THEORY

Until relatively recently, relationships among family members have been viewed as comprised of associations between two individuals, such as mother and child or husband and wife, independent of any other relationships within the family [Seligman and Darling, 1997]. However, family systems theory asserts that relationships among family members are interdependent and that the family is more than the sum of its individual members. Individuals assert influence on other family members while being influenced by other family members, and the contexts in which interactions among all family members are occurring [Minuchin, 1974]. Relationships are thus described as a “system” [Minuchin, 1974], operating so that all members are affected in some way by the experiences of any one individual in the system, in much the way that a machine’s function “emerges” from the mutually dependent actions of its various parts.

Martin Seligman, Ann Turnbull, and others have argued that families with a child who has a disability can be best understood through family systems theory application [Turnbull et al., 1986; Turnbull and Turnbull, 1990; Seligman and Darling, 1997]. However, little empirical research has been conducted on families raising a child with a developmental disability within a systems framework. Further, there have been few studies focused on the functioning of family systems according to the nature of the child’s diagnosis [Turnbull and Turnbull, 1990; Patterson and Garwick, 1994].

Translating a systems approach into clinical practice requires incorporating “family-centered” policies and practices into healthcare services throughout the diagnostic and treatment process [Mink et al., 1983; Mink and Nihira, 1986; Hauser-Cram et al., 2001]. In a series of studies examining the role of the home environment on the development of children with disabilities, Mink et al. [1983] focused on 115 families of children with mental retardation, 48% of whom were diagnosed with Down’s syndrome. Results indicated that children raised in families that were cohesive and harmonious or child-oriented and expressive in nature demonstrated higher levels of adaptive behavior, fewer behavior problems, and experienced less peer isolation compared to families lower in these qualities.

Mink and Nihira [1986] extended these findings to the prediction of a child’s later social and emotional development and functioning. Using a sample of 218 children identified as having mild to moderate intellectual disabilities and their families, these investigators found that higher levels of family cohesion or harmony along with high levels of parent involvement resulted in children subsequently demonstrating higher levels of independent community functioning and increased understanding of their role and responsibility in social situations [Mink and Nihira, 1986].

In a study examining the relationship between home environment and child functioning utilizing data samples from the Early Intervention Collaborative Study database [Hauser-Cram et al., 2001], increased levels of family cohesion reported at age 3 predicted fewer behavioral problems in children with disability when measured at age 5 [Warfield, 1995]. Similarly, preschool children raised in environments with higher levels of family cohesion were also found to demonstrate improved social interactions with peers [Hauser-Cram et al., 1999].

These studies demonstrate that positive, cohesive, engaging family relationships can lead to better family functioning and positive development in children with developmental disabilities. When parental functioning is compromised, the negative effects can be seen within the family system as changes in parenting style and the emergence of interactions that are increasingly negative or disengaged [Mink and Nihira, 1986; Hauser-Cram et al., 2001]. Already compromised due to medical, congenital, and developmental difficulties, the child with a developmental disability is particularly vulnerable to the effects of a less than optimal family environment. Therefore, identifying the needs of parents and families and determining how those needs can be met should be an important goal for professionals [Seligman and Darling, 1997].

FACTORS AFFECTING PARENTAL WELL-BEING

Parents’ ability to process diagnostic information, seek out resources, participate in their child’s course of treatment, and support the child’s development can be compromised if they experience stress or mental health challenges of their own as a result of the child’s disability. In fact, many parents with a child with disabilities report higher levels of stress and perform poorly on measures of individual emotional well-being and family functioning compared to families raising a typically developing child [Olsson and Hwang, 2002; Baker et al., 2005; Singer, 2006], although some report adjusting well to caregiving responsibilities and having positive outcomes or benefits [Taunt
and Hastings, 2002]. The factors explaining why some individuals and families fare better than others, including parental gender, coping style, and parental genotype in explaining response differentiation [Hasall and Rose, 2005].

The differences between mothers and fathers and their experiences in raising a child with a developmental disability have been reasonably well-documented across different child disabilities, with those differences being grounded in gender roles, particularly in relation to caregiving responsibilities [Seltzer et al., 2001; Hasall and Rose, 2005; Herring et al., 2006]. In comparison to fathers, mothers of children with disabilities typically report higher levels of stress [Herring et al., 2006], higher levels of depression [Olson and Hwang, 2001], and increased caregiving responsibilities [Simmmerman et al., 2001]. Some studies, however, have demonstrated that parental well-being is similar for both mothers and fathers [Heller et al., 1997; Hastings, 2003; Keller and Honig, 2004].

Parental coping style is also a determinant of differences in parental psychological well-being [Glidden et al., 2006]. Parents who use a problem-focused coping approach, defined by the use of cognitive and behavioral problem-solving strategies and the seeking of social support to address stressful issues, display relatively high levels of emotional well-being [Essex et al., 1999; Abbeduto et al., 2004]. Parents who employ a problem-focused coping style demonstrate lower levels of depression, less pessimism and increased positive affect in comparison to reliance on an emotion-focused coping style, which is characterized by the use of strategies to manage emotion of psychological distress through avoidance, denial, or escape [Abbeduto et al., 2004].

Some parents and other family members may be at risk for lower levels of well-being by virtue of their genotypes. In light of the genetic bases of autism, for example, other family members can display the “broader autism phenotype,” which includes language impairment, limited social reciprocity, difficulties establishing relationships, behavioral rigidity, and the presence of obsessive and compulsive behaviors [Piven et al., 1997; Piven, 1999]. Similarly, biological mothers of children diagnosed with fragile X syndrome, who are carriers of either the full mutation or premutation of the FMR1 gene, are at elevated risk for executive functioning difficulties, higher rates of depression and anxiety, and social interaction difficulties, as well for physical health problems, such as premature ovarian failure [Sobesy et al., 1994; Franke et al., 1996]. In each of these conditions, genetic variations may contribute to differences in parental well-being, which may in turn prevent parents from implementing preferred adaptation strategies compared to parents without such predisposing genetic variations [Piven et al., 1997; Abbeduto et al., 2004].

Findings regarding the lower levels of well-being, on average, for parents of children with disabilities and the factors responsible for individual variation in well-being illustrate the need for clinicians to recognize the ongoing experience of adaptation and how a systems approach to evaluation considers the changing needs of the family in this process [Seligman and Darling, 1997].

PARENTAL WELL-BEING AND SYNDROME-RELATED VARIATION

Considerable research has demonstrated that disabilities of differing etiology often vary in their profiles of behavioral/psychological strengths and weaknesses, as well as in the probability of comorbid psychiatric conditions [Hodapp and Dykens, 2001]. These child behavioral phenotypes may tax parents and families to different degrees and in different ways, resulting in condition-related differences in mental health and well-being outcomes in parents and other family members [Seligman and Darling, 1997; Hasall and Rose, 2005]. To illustrate, we present four different conditions each posing unique challenges to the adaptation process for parents and to assessment for professionals.

Autism

Autism is a neurodevelopmental disorder characterized by qualitative impairments in communication and social reciprocity, and the presence of restricted and perseverative behavioral features [Piven, 1999]. A comprehensive longitudinal study conducted by the U.S. Centers for Disease Control and Prevention suggests 1 in 150 children in the United States have an autism spectrum disorder, including autistic disorder, pervasive developmental disorder not otherwise specified, and Asperger syndrome [Kuehn, 2007].

Parents of children with autism report higher levels of stress [Sanders and Morgan, 1997; Herring et al., 2006], increased levels of pessimism regarding their child’s future [Abbeduto et al., 2004], and increased levels of depression in comparison to parents raising children with other types of neurodevelopmental disorders [Olson and Hwang, 2001; Hastings et al., 2005]. Mothers report higher levels of distress than fathers [Hastings, 2003; Hastings et al., 2005]. Although fathers consistently report lower levels of stress in comparison to mothers of children with autism [Herring et al., 2006], corresponding father reports of stress remain significantly higher in comparison to other disability groups [Hastings et al., 2005]. Hastings [2003] further indicated that the greater caregiving responsibilities assumed by mothers, coupled with traditional household activities and the somewhat poorer mental health outcomes of fathers, is responsible for the higher levels of stress and symptoms of anxiety in mothers. The child’s behavioral difficulties are also a critical factor in predicting parent mental health in this group [Baker et al., 2002; Hastings et al., 2005]. Children with autism typically display higher levels of behavioral difficulties in comparison to children with other disability conditions [Herring et al., 2006], with mothers being particularly vulnerable to child behavioral difficulties [Hastings, 2003].

Down Syndrome

Down syndrome is the most frequently occurring chromosomal disorder, occurring in ~1/800 to 1,000 births, with ~5,100 children born each year in the U.S. with Down syndrome [Canfield et al., 2006]. Most cases (95%) arise from nondisjunction during meiosis resulting in three copies of all or part of chromosome [Gardiner and Costa, 2006]. Not surprisingly, therefore, the syndrome is associated with abnormalities in multiple organ systems and a characteristic phenotype, which includes physical as well as behavioral features [Roubertoux and Kerdelhué, 2006]. The behavioral phenotype includes impairments in cognitive ability and especially serious delays in language development [Abbeduto et al., in press]. In general, however, individuals with Down syndrome are highly sociable and display low rates of challenging behaviors, such as aggression and hyperactivity, compared to other neurodevelopmental disorders [Antonarakis and Epstein, 2006].
Parents of children with Down syndrome have typically been characterized by higher levels of adaptive parental and familial functioning in comparison to other disability groups, particularly autism [Stoneman, 1997]. This “Down syndrome advantage” has been described as including lower levels of stress and higher levels of positive impact or rewarding uniquely attributed to the experience of raising a child with Down syndrome [Hodapp et al., 2001, 2003; Sellinger and Hodapp, 2005]. The sociability and low rates of challenging behaviors in children with Down syndrome as compared to children with other disabilities have been cited as causal features of the advantage [Hodapp et al., 2003].

More recent evidence, however, suggests that the Down syndrome advantage may attenuate somewhat over time for parents [Hodapp et al., 2001, 2003]. In a study examining the relationship between maternal well-being and syndrome-specific behavior among preschool children with Down syndrome, autism, and cerebral palsy, findings suggested that mothers of children with Down syndrome, on average, reported lower levels of stress, potentially attributed to fewer behavioral problems at the preschool age [Eisenhower et al., 2005]. However, mothers of children with Down syndrome reported increased maternal stress and behavioral problems in their children over time [Eisenhower et al., 2005]. Similar findings were demonstrated in a study examining maternal stress trajectories over three different time points at 12–15 months, 30 months, and 45 months of age [Most et al., 2006].

**Fragile X Syndrome**

Fragile X syndrome is an X-linked disorder caused by an expansion of repetitive sequence of nucleotides in the **FMR1** (Fragile X Mental Retardation 1) gene. The syndrome is the most common inherited cause of mental retardation [Sherman, 1996], with an estimated prevalence of 1 in 4,000 males and 1 in 8,000 females. Virtually all males with syndrome meet diagnostic criteria for intellectual disability [Loesch et al., 2002]. Females are less intellectually impaired than males, with about half of females having an intellectual disability and the remainder having normal range IQs, but often with learning disabilities, especially in math [Loesch et al., 2002]. The phenotype also includes hypersensitivity to a variety of sensory stimuli, hyperactivity, attentional problems, impairments in executive function, and social anxiety [Freund et al., 1992; Hagerman, 1999; Reiss and Dant, 2003]. Social problems are particularly severe and include gaze avoidance and excessive delays in the pragmatic dimension of language [Abbeduto et al., 2007]. There is also a high-rate of comorbidity between fragile X syndrome and autism, with ~10–40% (with a consensus being about 25%) of individuals with the syndrome warranting an autism diagnosis [Feinstein and Reiss, 2001; Rogers et al., 2001; Demark et al., 2003].

The mothers of individuals with fragile X syndrome appear to be at risk for poor psychological outcomes. These mothers report higher levels of parenting stress and lower levels of psychological well-being than normative samples [Franke et al., 1996, 1998; Sarimski, 1997; van Lieshout et al., 1998; von Gontard et al., 2002; Johnston et al., 2003]. Mood disorders, especially depression and anxiety disorders, are frequent among these mothers [Freund et al., 1992; Sobesky et al., 1994; Franke et al., 1998; Abbeduto et al., 2004]. Mothers of individuals with fragile X syndrome also fare more poorly than mothers of adolescents and adults with several other disabilities [Sarimski, 1997; van Lieshout et al., 1998; von Gontard et al., 2002; Abbeduto et al., 2004]. For example, mothers of adolescents and young adults with fragile X syndrome report more symptoms of depression, greater pessimism about the child’s future, and feel less reciprocated closeness from their children than do mothers of matched individuals with DS [Abbeduto et al., 2004; Lewis et al., 2006].

There is considerable variation in well-being, however, among mothers of individuals with fragile X syndrome. Much of this variability is related to differences in the behavioral challenges displayed by the child with fragile X syndrome, with more extensive autism symptoms being associated with greater risk to maternal well-being [Abbeduto et al., 2004; Lewis et al., 2006]. Contextual factors, including the number of affected children in the family, also influence the well-being of mothers of individuals with fragile X syndrome. Maternal genotype may also contribute, however, as there is evidence that some women who carry the FMR1 premutation (i.e., an expansion of the FMR1 gene beyond normal but smaller than needed to cause the syndrome) may at risk for poorer mental health outcomes independent of having an affected child [Franke et al., 1996; Johnston et al., 2001; Hesel et al., 2005].

**Multiple Disabilities**

Families raising a child with multiple disabilities involving physical limitations potentially in addition to cognitive and behavioral impairments, such as cerebral palsy, spina bifida, or other neuromuscular disorders, may also experience higher stress levels than families raising children with typical development. Among families with a child with spina bifida, for example, increased psychosocial difficulties and family distress have been reported [Holmbeck et al., 2003; Greenley et al., 2006]. Further, increased stress levels in individual members of families that include a child with spina bifida are associated with less cohesive, less engaging patterns of interaction among family members, including between parents and their child with spina bifida [Franke et al., 2002; Greenley et al., 2006]. In contrast to the case for autism and fragile X syndrome, there is not a genetic basis for spina bifida [Greenley et al., 2006].

**Summary**

Each of these four neurodevelopmental disorders is associated with a different child phenotype, a different level of parent vulnerability to stress and mental health challenges and thus, a very different adaptation experience for families.
Although there is considerable variability even within a disorder, clinicians working within a systems approach to assessment can nevertheless use knowledge of the child’s diagnosis to guide the assessment process. They can probe those dimensions of child functioning that are part of the disorder’s phenotype and that have special relevance to parent adaptation. At the same time, they can be sure to assess those dimensions of parental well-being and perceptions that are most likely to be problematic for the disorder and consider the ways in which those dimensions might affect reactions to the diagnosis or to planned treatments and follow up for the child. Moreover, because the phenotype of each disorder emerges and changes with age, a systems approach would require that clinicians help families cope with such changes.

A Model for Clinical Practice

The diagnostic evaluation process is an opportunity to evaluate a child’s developmental progress and determine what interventions and resources might be useful in facilitating and supporting his or her continued growth. A systems approach would address this goal by broadening the concepts of assessment, interpretation of findings, and development of treatment recommendations [Seligman and Darling, 1997; Rosenthal et al., 2001; Hassall and Rose, 2005]. The systems approach would expand what has traditionally been regarded as a child-focused practice and enable clinicians to consider intervention options against the broader context of the family’s needs and expectations [Seligman and Darling, 1997; Rosenthal et al., 2001]. Further, understanding the variability among parents and families with regard to their psychosocial circumstances is an important step in this process. Clinicians would maximize a family’s ability to implement interventions in support of the child’s development if they approach the diagnostic evaluation process with greater sensitivity to each family’s circumstances and their ability to “digest” and implement evaluation results and recommendations, which would minimally require an appreciation for the current psychological circumstances and well-being of the parents and other family members [Patterson and Garwick, 1994; Rosenthal et al., 2001].

In the following sections, we briefly sketch a systems model of clinical practice. By integrating information gathered through clinical interview, existing records, self-report questionnaires, observational tasks, and diagnostic testing, clinicians can develop an assessment protocol that ebbs and flows with the needs of the family and their needs as professionals in implementing a systems approach. Clinicians must be flexible and willing to use existing materials while still recognizing the need to probe further and ask additional questions and consider other issues that will assist in establishing rapport, but most importantly, facilitate information gathering and create a comprehensive picture of the family’s experience.

Assessment

Evaluating the Family Context

The clinical interview is an excellent tool for clinicians to examine the attitudes, expectations, personal traits, levels of stress and emotional well-being, and coping mechanisms of parents and siblings individually and as they pertain to the greater family unit [Patterson and Garwick, 1994; Rosenthal et al., 2001]. Although the assessment process traditionally begins only after the child has been born and demonstrated developmental delays, parental diagnosis is now possible and allows clinicians to identify and assess the needs of families during pregnancy rather than waiting until the child has been born to begin providing support services to assist families in the adaptation process. In any event, establishing a relationship with parents that is sensitive to their experiences and to the challenges they have encountered prior to the evaluation appointment is important. Doing so ensures that parents feel comfortable within the interview and are willing to respond openly to questions that are individual and family-focused [Berman and Shaw, 1996; Rosenthal et al., 2001].

Developmental and background history forms are often completed by parents prior to a child’s evaluation appointment and used to inform clinicians of a child’s development, medical and educational history, psychosocial experiences, and description of behavioral problems. Self-report questionnaires assessing important facets of parent functioning may also be administered prior to the appointment. If reviewed during a clinical interview, this material can be an avenue for rapport building between parents and clinicians, creating the opportunity for increasingly focused questions about individual and family functioning [Greenspan and Meisels, 1996; Sattler, 2002].

Individual Psychological Well-Being

The assessment of families should be designed to allow the clinician to evaluate parents and other family members along the dimensions of stress, coping, and other variables reflective of psychological well-being, such as depression and anxiety. The format of the clinical interview allows parents a voice in describing how they feel in response to the challenges of raising a child with a developmental disability and is an opportunity to share how those challenges are experienced within the context of their everyday lives [Seligman and Darling, 1997].

Interview questions should also address parental perceptions about the role children assume within the family and feelings of acceptance towards the child with developmental concerns. Assessing parental perceptions of competency to execute parental tasks, particularly as they pertain to caregiving of the child with developmental concerns and to balancing the needs of other family members, also provides insights into the family climate. Examining how parents view the child in relation to expectations for their growth, development, parental caregiving, and the child’s participation within the family can also provide a useful context for understanding parent and family adaptation and parental locus of control.

Self-report measures are also useful as a supplement to the clinical interview and provide quantitative measures of many important dimensions of parental well-being to better understand the parent’s current psychological state, response to the child with the disabilities, and the degree to which necessary supports are in place. Although not a complete list of those used by clinicians, Table 1 includes a sampling of self-report measures that are available to assess individual psychological well-being, parenting perceptions, and functioning within the family context.

Family Environment

The assessment should also address the family’s environment and the nature of family interactions. Obtaining information from family members during the clinical interview that describes how warm and supportive they feel towards each other will help clinicians understand the types of support that are available for individuals within the family unit and the extent to which interventions designed to change patterns of
The clinician using a systems approach can now consider how the child’s diagnosis and even more importantly, his or her phenotypic behavioral profile, is eliciting particular responses from parents and other family members. This approach examines how the child’s diagnosis and phenotypic behavioral profile is affecting individual and family well-being and functioning and how the various processes are shaped by other contextual variables, such as the family’s socioeconomic status and resource availability and access. By integrating the information collected, the clinician can begin to anticipate how the family might respond to being told the diagnosis and the supports that need to be established, including interventions targeting parents and other family members, to ensure that the family can follow recommendations for follow up or treatment.

Adapting to a child with a disability is often a slow and, perhaps, even lifelong process, and clinicians have an opportunity through assessment to evaluate where the family is in that process, what their needs are, and how to address those needs. For example, clinicians can identify families or family members who may be at risk for increasingly significant problems in coping and/or the development of psychiatric issues (e.g., clinical depression). Families may also require assistance in seeking external support networks, particularly over time. Contextual changes in raising a child with a developmental disability, such as changes in parental perceptions of child functioning, access to social supports, and employment changes can impact parents’ ability to sustain effective coping mechanisms. In a longitudinal study examining coping strategies used by parents of children with autism, it was found that parental use of problem-focused coping mechanisms declined over time, with a corresponding increase in emotion-focused coping responses [Gray, 2006]. Possible explanations for the decline in problem-focused coping included changes in social support systems as the child ages, with fewer parents and children having routine interventions available to them beyond the school-age years, and changes in parental expectations for improvement in their child’s overall functioning and behavior [Gray, 2006]. Findings such as those of Gray [2006] illustrate the need for clinicians to recognize the ongoing experience of adaptation and how a systems approach to evaluation considers the changing needs of the family in this process [Seligman and Darling, 1997].

### Treatment

Determining and implementing a course of treatment and establishing a procedure for evaluating treatment progress are the remaining pieces of an assessment and the systems approach can help here as well [Seligman and Darling, 1997]. A multidisciplinary evaluation team is very beneficial in this process as each discipline is able to attest to the needs of the child and family and provide materials, resources, referrals, and therapy recommendations that are concrete, specific, and individualized. Further, team members are able to consider the parents and family’s ability to implement services for the child and other family members. Medical care, educational programming, behavioral management, pharmacological support—such interventions can require significant effort on the part of parents to implement and even to monitor. Clinicians who have assessed how parents and family members are coping with current caregiving and adaptation issues are better able to tailor recommendations and treatment options in recognition of the family’s status, their ability to seek out treatment recommendations, and their ability to participate in treatment implementation. In fact, the clinician might make different recommendations for treatment for the child with disabilities based on expectations about the family’s current state of well-being. If possible, recommendations for treatment of family members in addition to the child with a disability can also be suggested.

<table>
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<tr>
<th>Domain</th>
<th>Measure</th>
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<tr>
<td>Individual functioning</td>
<td>Beck Depression Inventory II [Beck et al., 1996]</td>
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<td>Beck Anxiety Inventory [Beck and Steer, 1993]</td>
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<td>Parenting Stress Index [Abdin, 1998]</td>
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<td>Questionnaire on Resources and Stress—Short Form [Friedrich et al., 1983]</td>
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<td>Stress</td>
<td>Multidimensional Coping Inventory [Carver et al., 1989]</td>
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<td>Locus of control</td>
<td>Parenting Locus of Control Scale [Campis et al., 1986]</td>
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<td>Family context</td>
<td>Family Environment Scale [Moos and Moos, 1994]</td>
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<td></td>
<td>Family Impact Questionnaire [Donenberg and Baker, 1993]</td>
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<td></td>
<td>Family Adaptability &amp; Cohesion Evaluation Scale II [Olson et al., 1982]</td>
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<tr>
<td>Family context</td>
<td>HOME Inventory [Bradley, 1994]</td>
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<td>Marital relationship</td>
<td>Dyadic Adjustment Scale [Spanier, 1989]</td>
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<td>Positive engagement</td>
<td>Positive Affect Index [Bengtson and Black, 1973]</td>
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In many cases, treatment recommendations will not be implemented by the clinician(s) conducting the assessment, but instead by outside agencies and professionals. Team members can be incorporated as part of follow-up care to monitor the family’s journey through the treatment process and to provide case management support following the evaluation. Assessment clinics that include a significant social work element or family resource program are especially prepared to do this by maintaining a relationship with the family and assisting them in answering questions and providing contacts as they navigate treatment during this critical period.

IMPLICATIONS FOR SERVICE DELIVERY IMPLICATIONS

Although progressive in its perspective, implementing a systems approach can be challenging and numerous obstacles exist that can impede its acceptance into practice. Clinicians often encounter logistical constraints, including lack of resources, time, and money that make a systems-based assessment process difficult. Changing long-time standards of assessment procedure as well as soliciting professionals from other disciplines to endorse the holistic nature of a systems approach and actually participate in its implementation can also present significant barriers. Thus, although a family systems approach to assessment is comprehensive in its attempts to recognize the needs of the family as a means of supporting the child’s development, implementing social, healthcare, and educational policies and procedures that reflect this approach have only begun to be initiated with the advent of early intervention and special education services [Seligman and Darling, 1997]. These promising new developments encourage professionals to support the use of a family systems approach to assessment.

The Individuals with Disabilities Education Improvement Act of 2004 (P.L. 108-446), Part C, includes the Individual Family Service Plan (IFSP), which is a model early intervention process for children birth to age three that is designed to foster child development by recognizing and supporting the family and their needs, concerns, and priorities. In developing and implementing the IFSP, education professionals and families work together in partnership from the onset of the child’s initial evaluation and entry into services. By identifying the family’s needs and resources, the evaluation process better reflects a complete and accurate picture that include the child’s strengths, needs, and available supports. Recognizing the evolving needs of children as they grow and develop requires that professionals across healthcare, education, and employment settings work together with individuals, parents, and families to establish goals and interventions that enhance the child’s capacity for development by strengthening the family’s ability to participate in that process. The family-centered approach evidenced in IFSP meetings and implemented through daily programming and intervention efforts must be uniformly extended to the Individual Education Program and vocational rehabilitation processes, to further recognize the continued role of families in an individual’s development over the lifespan.

DIRECTIONS FOR FUTURE RESEARCH

A family systems approach to assessment affords researchers the opportunity to examine a number of key questions with the goal of understanding how to approach families in this situation in a way that is most effective and one that is more yet sensitive to their unique experiences.

We have learned much in the past three decades about how families respond to raising a child with a disability. Studies have demonstrated that child maladaptive behavior, syndrome-specific behavior, and cognitive and adaptive functioning levels are associated with individual and family dysfunction [Hauser-Cram et al., 2001; Herring et al., 2006]. However, few studies have examined these relationships at the time of initial diagnosis, when specific interventions could be initiated [Hauser-Cram et al., 2001]. Studies are needed to further define variables that contribute to the prediction of parental well-being and family functioning, consider the impact of ongoing developmental concerns on families, and examine contextual factors that differentiate families prior to diagnosis.

In order to do this with increasing specificity, research is needed to determine how to develop new tools to operationalize and assess family systems variables. Although a number of different self-report questionnaires exist and various methods, including use of audiotape, videotaping, and observational coding systems, have been suggested as ways to quantify observed interactions among family members, future investigations into the use of these measures within the assessment process is needed. Development of increasingly sophisticated measures that allow the relational aspects between different family members to be assessed with increased objectivity would provide a tremendous wealth of information that extends beyond the individual perspectives available through self-report questionnaires.

In conjunction with research that examines the impact of diagnosis delivery on parents in terms of specific medical conditions [Garwick et al., 1995; Ferguson et al., 2006], additional research is needed to understand the impact of diagnosis delivery within the clinical setting following an evaluation, with an emphasis placed on identifying the role of a systems approach to assessment within the context of conveying the evaluation’s results and recommendations to family members. Studies are needed to investigate the role professionals play in shaping parent perceptions of their child’s condition and the child’s developmental outlook or prognosis in this process. By looking at variations among the interactions between professionals and families, we can better understand what characteristics have the greatest impact in short-term adjustment and long-term adaptation. These issues become particularly important when working with culturally diverse families whose familial structure often encompasses individuals beyond just parents and siblings to include extended family members. Further, the inclusive nature of a family systems approach suggests that research is needed to examine how culturally diverse families respond to this approach given social norm variations and differences in coping and if adaptations to the approach are needed based on these unique characteristics.

Finally, it is important to consider how a family systems approach to assessment can be integrated into the larger service delivery system to address the needs of families as well as the child can be addressed over time. Adaptation to caring for an individual with a developmental disability is an evolving process with unique considerations at various timepoints in the life of the child and the family’s experience. A family systems approach recognizes that needs exist and change over time. Future research should consider the obstacles to this integration process and examine how a family systems approach to assessment must change with as well to
accommodate the needs of families successfully. Such research will continue to foster an understanding of the variations in the trajectory of the adaptation process and potentially contribute to the development of interventions at the earliest stage of adaptation and as it occurs over the lifespan.

CONCLUSIONS

When concerns arise regarding a child's development, all family members are potentially affected [Seligman and Darling, 1997]. Typically, clinical assessments have been child-focused in an effort to determine a diagnosis and develop specific interventions that target the child's needs. However, parents also have needs that are often not addressed within the assessment process. In this article, we suggested a systems approach as a way of expanding the assessment process to consider family member functioning and its relationship to child development. A systems approach likewise, emphasizes understanding the variation across different disability conditions with which parents and family members respond to the challenges of raising a child with developmental issues. Condition-related differences in mental health and well-being outcomes among parents suggest that clinicians should use the assessment process to recognize and acknowledge the needs of parents and family members and to consider condition-related differences in order to tailor interventions that can effectively meet the child and the family's needs.

REFERENCES


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