

Intervention Strategies for Families Having Children with Developmental Delays: Prospects for the 21st century

Abstract

A family systems model is presented for understanding, adaptation, and coping with children having a developmental disability. The importance of a systems approach, emphasizing reciprocal interactions, in working with children and families is stressed. These interventions provide the entire family techniques through which effective adaptive coping strategies, increased self-esteem, more positive parent-child interactions, and appropriate strategies for educating the child with disabilities are achieved. Centre-based child programs for children with developmental disorders can no longer function in isolation, rather emphasis and support for a family systems and social-ecological model is presented.

Résumé

Nous présentons un modèle de système familial cherchant à comprendre les enfants souffrant de troubles du développement, à s'y adapter et à traiter avec eux. Nous insistons sur l'importance de ce type de système et sur les interactions relatives au travail auprès des enfants et des familles. Ces interventions fournissent à toute la famille des techniques grâce auxquelles il est possible d'arriver à mettre en application des stratégies d'adaptation, d'accroître l'amour-propre, de rendre plus positives les interactions parent-enfant et de mettre en application des stratégies sur l'éducation des enfants souffrant d'invalidité. Les programmes des établissements destinés aux enfants présentant des troubles de développement ne peuvent plus fonctionner en vase clos et notre présentation met l'accent sur un modèle socio-écologique et un système familial.

Although past researchers have generally focused upon individual and dyadic relational patterns of adaptation, a family systems theory emphasizing reciprocal interactions, intersystem influences, and the complexity of relational networks form a natural conceptual bridge between developmental psychopathology and family systems theory (Cicchetti & Howe, 1991). Successful therapeutic interventions, by necessity, require a family-based organizational and transactional model. These interventions can provide the entire family with techniques through which effective adaptive coping strategies, increased self-esteem, more positive parent-child interactions, and appropriate educational strategies for educating the child with disabilities can be achieved. The importance of incorporating an intervention model considering both the spousal and parent-sibling subsystems remains crucial for the well-being of the entire family and is consistent with Minuchin's (1985) family systems theory.

The past two decades have seen a trend in research and clinical programs toward an emphasis and examination of the effects of childhood disorders on the entire family. This is in marked contrast to earlier efforts that traditionally focused on negative parental effects upon children, merely incorporating a dyadic (mother-child) model (Konstantareas, 1991). Five contributing, overlapping factors, may have accounted for the shift in paradigms: (1) a more systematic and widely accepted perspective of the transactional nature of interactions in family situations (Minuchin, 1985); 2) the growing body of research delineating the effects of children's behaviour on parents (Lamb, 1976); 3) a view of family functioning which perceives the child as an equipotential family member; 4) the absolute necessity for parental input for the long term treatment and education of children with disabilities and special needs; and 5) the recognition that many parents are frequently unable to meet the multiplicity of demands of having a disabled child (Konstantareas, 1991). This changing paradigm has influenced and had a direct impact upon service delivery models. For example, innovative intervention programs have begun to include the handicapped child, parents, and siblings (Caro, 1990).

Although numerous traditional home-based and centre-based clinical interventions are available for children with developmental disabilities and their families they remain problematic for a number of reasons. Many attempt to serve families with a multitude of psychological and medical needs, they remain atheoretical in orientation, and have staff with varying degrees of training. Nevertheless, most programs attempt to provide at least some modicum of parental training as well as individual treatment programs for the disabled child (Tjossem, 1976). While staff members may have different theoretical orientations and varying skills and sophistication in dealing with children with multiple disabilities, the programs themselves frequently subscribe to some general conceptual philosophical and/or psychological model (Derevensky, 1981).

While most intervention programs strongly advocate and incorporate parental training (e.g., Abidin, 1980; Caro, 1990; Caro & Derevensky, 1991; Derevensky, 1981; Derevensky & Wasser-Kastner, 1984; Derevensky & Baron, 1986; Tjossem, 1976) its efficacy has recently been questioned (e.g., White, Taylor, & Moss, 1992). More recent research efforts have begun to focus upon the entire family unit incorporating a family systems model.

The family's adaptation to the presence of a disabled family member is predicated upon the quality of the relationships achieved among all family members. An understanding of the family's communicative patterns with their disabled child remains critical to understanding family functioning and the potential efficacy of specific types of intervention strategies.

Family Systems Model

A family systems model represents a conceptual framework through which individuals can focus on the various subsystems within the family unit. The reciprocal effects of each family member's behaviours on the other members emphasizes the importance of examining marital (husband-wife), parental (parent-child), and sibling (child-child) interactions.

As a means of ascertaining the existing mental health status of the family unit, an essential starting point for clinical intervention may be determined by systematically observing interactions among its members, assessing the degree of closeness and communication skills, and examining both verbal and nonverbal behaviours (Skrtic, Summers, Brotherson, & Turnbull, 1984; Turnbull, Summers, & Brotherson, 1986). On a more pragmatic level family functioning reflects the nature of the family's ability to cope with cultural, environmental, economic, and psychosocial stressors (Fewell, 1986). Key factors found to influence the family's functioning revolve around basic needs, levels of stress, and perceived support. The individual's ability to deal effectively with each of these factors significantly affects their level of adaptation. The level of social support, and perceptions of this support, serves as a significant predictor of potential family crisis (Nihara, Meyers, & Mink, 1980). Not unexpected, specific resources, especially financial resources, have been found to mitigate the level of stress (Wikler, 1986). Similarly, close relationships with extended family members and religious groups serve as potential sources of support (Cohen, Agosta, Cohen, & Warren, 1989; George, 1988).

An understanding of both parent and child perceptions are paramount for the intervention team. Whether these perceptions are accurate or inaccurate, they continue to influence the manner in which parents respond to their children.

Relationship between parents and young disabled children

Central to the issue of the family's level of functioning as a unit is the quality of the relationships achieved by its members. This is particularly important for children with developmental disorders. Interactions between parents and children with developmental delays require an accurate interpretation of behavioural and nonverbal cues. Parental behaviours and interactions reflect an understanding of the cognitive abilities and affective needs of their children. Typically, nondisabled children demonstrate behavioural cues that are more easily and accurately interpreted, resulting in adult feelings of efficacy and self-worth (Goldberg, 1977). Conversely, young children with developmental delays frequently exhibit behaviours that negatively influence parental interpretation of their needs and, in turn, the quality of parent-child interactions. Children's passivity and lack of responsivity has been shown to elicit fewer positive parental reactions and behaviours (Brooks-Gunn & Lewis, 1984; Hanson, 1984). Interactions between parents and children with moderate to severe developmental disabilities consist of less enjoyment, pleasure, and reciprocity, when compared to parents having nondisabled children (Gallagher, Beckman, & Cross, 1983; Wasserman, Shilansky, & Hahn, 1986; Yoder & Farran, 1986). As well, the frequency of maternal and paternal responsivity has been shown to increase as a function of the children's enhanced repertoire of communicative skills (Frey, Fewell, & Vadasy, 1989). Increased communicative competence by children with disabilities is similarly indicative of their improved cognitive skills, resulting in higher frequencies of parental responsiveness and interaction (Brooks-Gunn & Lewis, 1984).

Although considerable research on parent-child interaction has centered upon maternal behaviour, the importance of paternal behaviour has recently received attention. Fathers have been shown to display varying levels of child care and emotional involvement with their nondisabled and disabled children (Bristol, Gallagher, & Schopler, 1988). In comparison to mothers, fathers are more effective in obtaining children's compliance to requests and present more socially interactive games (McCollum, 1988). Equally important is the essential role they play in supporting their spouse.

Interactions between nondisabled and disabled siblings

Within a family systems model the examination of sibling interactions becomes important. This becomes particularly acute when one of the siblings has a handicap. The sibling subsystem has characteristics that are unique, is influenced by family interactions, is dependent upon the developmental level of the children, and is reflective of individual differences and needs (Brody & Stoneman, 1986; Brody, Stoneman, & Burke, 1987; Dunn, 1988).

Research has generally focused upon a reciprocal interactional model, whereby each child influences the other. A number of critical factors seem to influence this relationship including birth order, gender, age, type and severity of disorder, family size, and socioeconomic status (SES).

Gender differences appear to be an important determinant. Older female siblings experience greater adjustment problems presumably because they are frequently required to assume many of the child-rearing roles for disabled children (Stoneman, Brody, Davis, & Crapps, 1988). Siblings of the same gender have been reported to be more adversely affected due to their close identification with their disabled siblings (McHale, Simeonsson, & Sloan, 1984). Still further, Pfouts (1976) concluded that nondisabled children displayed ambivalence toward their brothers with mental retardation, while disabled siblings remain more hostile toward their nondisabled brothers. Young male siblings seem to exhibit greater adjustment problems than females and assume a more dominant role in the sibling relationship (Crnic & Leconte, 1986).

Siblings from larger families appear to adjust better as parental expectations can be shared amongst all the children (Stoneman *et al.*, 1988). It has been found that children from low SES homes assumed greater child care responsibilities, while middle-class children exhibited greater concern with the negative stigma associated with having a disabled sibling (Seligman, 1983). The level of competence of the disabled sibling appears to significantly influence the perceived quality of the sibling relationship (Begun, 1989).

A common finding throughout these studies was that the adaptation and attitudes of the siblings greatly reflected parental attitudes (Brody & Stoneman, 1986). These attitudes are thought to be transmitted in an indirect manner through the roles they assign and the demands they place upon their nondisabled children (e.g., being a teacher versus a playmate) with the disabled child (Brody & Stoneman, 1986). Gallagher and Powell (1989) found that siblings' adjustment problems increased as they became more cognitively aware of the full extent of the effects associated with their siblings' handicapping conditions, regardless of the handicapped child's functional level.

Negative effects displayed by siblings include competition for parental attention and resources, compensation for the disabled child's limitations, confusion regarding parents' inconsistent behaviour and coping ability, exclusion from the parent-disabled child dyad, and being the recipient of "bribes" to compensate for diminished parental attention and time (McHale *et al.*, 1984).

School-age children and adolescents frequently experience difficulty in answering peer questions about their siblings' developmental delays and embarrassment from people's stares (Skrtic *et al.*, 1984). Similarly Grossman

(1972) found that adult siblings expressed fear about bearing a child with a disability and/or guilt concerning the burden of care that rests with the parents.

Without appropriate intervention, nondisabled children have been shown to engage in negative behaviours toward their disabled siblings (e.g., verbalizing or performing cruel or angry acts and statements) (Wellen & Brown, 1982). Siblings having a brother or sister with a disability report lower self-concepts and increased anger (Harvey & Greenway, 1984), anxiety, embarrassment, guilt, conflictual patterns with their parents, and decreased amounts of interpersonal relationships (Breslau, Weitzman, & Messenger, 1981; Skrtic *et al.*, 1984).

On a more positive note, siblings of children with cognitive handicaps have been shown to have large networks of friends (Stoneman *et al.*, 1988), indicating considerable sources of social support rather than social isolation (Crnic & Leconte, 1986). Although harmonious relationships between siblings may be difficult to establish and maintain, the incidence of interactional problems remains no more frequent than in other groups (Dunn, 1988). Sibling relationships in families with disabled children fail to maintain a consistent pattern. Their adaptations range along a continuum from inadequate coping to positive satisfactory adjustment (Simeonsson & Bailey, 1986). Nevertheless, within a family systems model an understanding of the sibling's perceptions, needs, and behaviours is paramount.

Prospects for the 21st Century

The more recent literature in early childhood special education has focused upon interventions with entire family units. A family-focused intervention model which emphasizes the parent-child relationship as well as relationships among other family members, has strong clinical support (Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm, 1986). The goals associated with this approach are to assist family members in (a) coping with the evolving needs of children having a disability; (b) comprehending the child's role both as a family member and as an individual; (c) establishing and maintaining mutually pleasurable and developmentally appropriate parent-child interactions; and (d) designing programs incorporating parental needs and priorities (Bailey *et al.*, 1986). Further, the past emphasis upon the parent-child relationship must be modified to include siblings, thereby ensuring the incorporation of the needs of all family members. Similarly, the family's perspectives, competing needs, and relationships between the various subsystems are included within a family system perspective. Families become empowered and perceived as having the capability to make responsible decisions concerning their children while professionals assume the role of facilitator of family change (Cohen *et al.*, 1989; Darling, 1989; Mahoney & Powell, 1988).

The proposed goals for the disabled child and family members must reflect the cultural, religious, ethnic, educational, and economic characteristics of each family. Ascertaining parental priorities, perspectives, and approval of the proposed intervention plan is stressed. A family-focused model of intervention consists of observations of the family's interaction patterns, the development of hypotheses regarding its needs, and the implementation of techniques to facilitate its growth (Bailey *et al.*, 1986). The success of such a model can only be evaluated by ascertaining the child's progress, the changing relationship patterns among members, and achievement of individual and family goals.

Inherent within this model is the assessment of the parent-child interaction. The strength of the parent-child relationship has a significant impact upon the entire family unit and serves as the basis from which parental feelings of effectiveness and child competence arise. The extent of the bond between parents and their children produces enduring emotions that help them sustain effective family functioning throughout their lives.

A systems perspective is recognized as a framework within which each family member's relationship influences the behaviours of its other members. Although centre-based programs can successfully enhance specific skills and cognitive growth in children with physical and mental handicaps, their potential to influence family functioning remains somewhat limited. Given the unique parameters surrounding family functioning, concomitant with the continued need to modify the handicapped child's program, a more holistic approach seems essential. The family-focused intervention model represents a promising avenue that conceptualizes its relationships as a foundation from which mutual pleasure, appropriate interactional behaviours, and increased child competencies emerge. When professionals are able to successfully facilitate change in all family members, there is an increased likelihood that positive behaviours will endure, more realistic expectations will have been achieved, and progress will continue after services and clinical interventions have been terminated.

Family members exhibit a continuum of both positive and negative reactions associated with living with a young child with developmental delays (Turnbull, 1988). Interventions aimed at improving children's competence and well-being should include explorations of effective coping behaviours and processes utilized by parents and children (e.g., family strategies, integration into community activities). The knowledge ascertained from successful interventions focusing on entire family units can provide a framework for future clinical practice. Centre-based child programs cannot function in isolation; rather they must redirect their efforts and focus upon the entire family.

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Patricia Caro is an assistant professor in the College of Professional Studies at the University of Wisconsin at Stevens Point. Dr. Caro's research and clinical interests are in the area of early childhood special education and parent education.

Jeffrey L. Derevensky is an associate professor in the Department of Educational Psychology and Counselling; associate professor, Department of Psychiatry; and associate professor, Department of Community Dentistry at McGill University. His research and clinical interests have focused upon the development of intervention programs for normal and high-risk children and parents. He remains actively involved in studying a variety of social policy issues.

Patricia Caro est professeur adjoint au College of Professional Studies de la University of Wisconsin, à Stevens Point. Les intérêts cliniques et expérimentaux du docteur Caro touchent aux domaines de l'éducation spécialisée des jeunes enfants et de la formation des parents.

Jeffrey L. Derevensky est professeur agrégé au département de psychopédagogie et de counseling, professeur agrégé au département de psychiatrie et professeur agrégé au département de dentisterie communautaire de l'Université McGill. Ses intérêts cliniques et expérimentaux sont axés sur l'élaboration de programmes d'intervention auprès des parents et des enfants normaux ou qui présentent des risques élevés. Il participe encore activement à des études portant sur des questions de politiques sociales diverses.