

**A Model of Stress in Families of Children with
Developmental Disabilities:
Clinical and Research Applications**

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Abstract

This paper presents a theoretical model for understanding stress and related issues in families of children with developmental disabilities (DD). It first describes the theoretical underpinnings in the literature on stress and coping in individuals and on family stress. The proposed model includes Stressors (Child Characteristics and Other Life Stressors), Resources (Individual's Personal Resources and Family System Resources), Supports (Informal Social Supports and Formal Supports and Services) and both Positive and Negative Parental Outcomes. Each domain of the model is described, together with suggestions for future research and clinical implications pertinent to each domain. Some evaluation of the model is provided, it is contrasted to other models, and several empirical illustrations are provided.

The notion that parents of children with developmental disabilities (DD) experience "stress" is almost self-evident. Over the past 20 years or so, researchers and clinicians from several disciplines have brought tremendous diversity to the understanding and measurement of stress, as well as to clinical work with families. However, in research there remains a lack of consensus regarding the conceptualization of stress, the criteria for distinguishing independent from dependent variables, and the selection of measures that reflect our conceptualization in an unconfounded way. In practice, there is generally a lack of reciprocal influence between research and clinical experience and, thus, poor translation of knowledge gained from research into practical applications that really make a difference for families.

This paper presents a theoretical model of stress and related constructs, intended for use in both research and clinical practice. The initial model (Perry, 1989) was based on clinical experience with families and a thorough

review of a number of bodies of literature, including different conceptualizations of "stress" (described below). In addition, five other bodies of literature influenced the development of the model: family systems theory as applied to families of children with DD (e.g., Turnbull, Summers, & Brotherson, 1986), ecological theory (Bronfenbrenner, 1979), social support theory (Cohen & Syme, 1985), sociological family stress theory (McCubbin & McCubbin, 1987), coping theory (Folkman, Schaefer, & Lazarus, 1979), and developmental psychopathology (Cicchetti & Lynch, 1993). Each of these is a large body of work with its own theories and methodologies. Perry (1989) reviewed them in some detail, as they pertained to the development of the proposed model. It goes well beyond the scope of the present paper to do so here, but key highlights are noted throughout.

In the present paper, different understandings of stress will be reviewed first; then the model itself will be described. Second, research and clinical implications pertinent to each domain of the model will then be discussed. Third, strengths and weaknesses of the model will be suggested and it will be contrasted to other available models. Finally, several applications of the model in empirical research will be presented as illustrations.

Conceptualization of Stress

Four different conceptualizations or definitions of stress can be distinguished, each with its own body of literature, and each has been applied to families of children with DD. First, in one of the earliest theories (Selye, 1980), stress is understood as the physiological and psychological reactions that an organism goes through, usually in stages, to adapt to a stressful situation. Although not universally accepted by parents or professionals, this definition has been quite widely applied clinically with families of children with DD in terms of "grieving models" (e.g., Siegel, 1997) in which parents go through stages of shock, denial, anger, bargaining, working through and acceptance (Perry & Condillac, 2003).

A second conceptualization of stress is referred to as the "stressful life events" paradigm. This paradigm suggests that stressful life events have a negative impact on mental and physical health. This model has been extensively researched in many health areas and, generally speaking, the relationship between any particular stressful event (e.g., loss of job) and any particular outcome (e.g., depression) is weak because there are many intervening variables (e.g., what social supports the person has, what the job loss "means" to them, what coping strategies they use, and so on). In the case of families of a child with DD, it is evident from research and clinical practice

that there is tremendous heterogeneity among families, with some coping very well and articulating positive effects, while others report significant stress and strain (e.g., Turnbull, et al., 1986; Wilgosh & Scorgie, 2000).

A third approach to conceptualizing stress is the "daily hassles" paradigm, which suggests that it is not necessarily a major life event that is stressful but all the everyday frustrations and hassles associated with it. In the case of families of children with DD, this theory has been used extensively. It leads to the assumption that it is not the single life event of having a child with difficulties that is stressful but, rather, the cumulative effect of smaller day-to-day annoyances and hassles associated with caretaking (e.g., changing diapers on a big child, taking the child to various appointments, etc.). In fact, measures of parenting stress such as the Parenting Stress Index (Abidin, 1995) and the Questionnaire on Resources and Stress (Friedrich, Greenberg, & Crnic, 1983; Holroyd, 1974) include many items that are really parent perceptions of relatively factual child characteristics (e.g., my child needs help getting on the bus to school) as opposed to measures of the extent to which parents find events stressful or upsetting. Some studies have measured perceptions and facts separately and found them to be correlated but separable (Bebko, Konstantareas, & Springer, 1987; Freeman, Perry, & Factor, 1991). Thus, it is important to discriminate between stressors (stimuli) and appraisals of stressors.

A fourth definition of stress involves the concept of a "resource imbalance" between the demands of a situation (stressors) and a person's resources or coping ability. In the case of families of children with DD, this approach implies that stress is not simply a function of child characteristics (stressors). It is more than a single stressful life event or even a series of daily hassles. It depends to a large extent on the individual parent's coping abilities, the resources in the family, and the supports the family receives from others. Furthermore, certain factors discussed below such as coping, social support, and so on, may act as buffers or protective factors, moderating negative outcomes (e.g., Dunn, Burbine, Bowers, & Tanteleff-Dunn, 2001; Hastings & Johnson, 2001).

The four measurement approaches to stress discussed so far have focussed on stress at an individual level. Some work based in systems theory and sociology has taken quite a different approach, attempting to measure "family stress". There have been some interesting and helpful studies of parents of children with DD conducted using McCubbin & Patterson's (1983) Double ABCX Model or variations on it (e.g., Bristol, 1987; Minnes, 1988; Wikler, 1986). In the original form of this model (Hill, 1949), A represents

the stressor or crisis-provoking event (child with DD), B represents the family's resources, C represents the family's definition of the event, and X represents the "crisis". Later versions of the model added other variables in an attempt to describe the process of adaptation over time. In the Double ABCX model, for example, there is also a "pile-up" of other stressors (aA), the family's new and existing resources (bB), and a slightly modified meaning of the stressor (cC) which are used to predict family adaptation to the crisis (xX). More recent versions of this model are more sophisticated still, including constructs such as problem solving/coping, family typology, and resiliency.

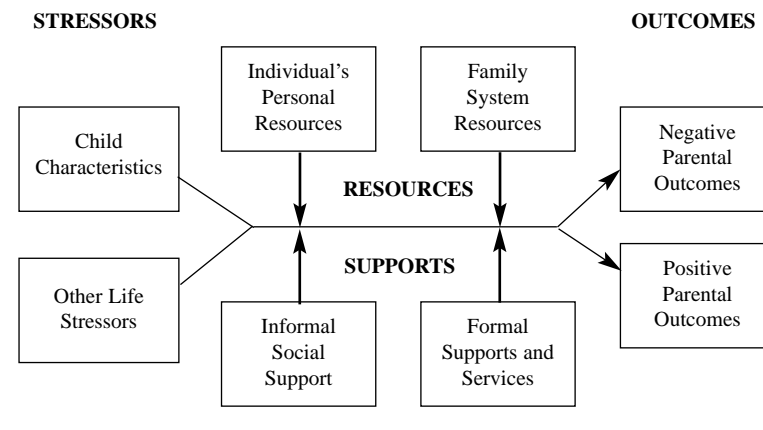
However, there are, in my view, a number of significant limitations to these models and the way they are typically used in research on families of children with DD. First, the X factor is inappropriately conceptualized as a crisis or even as adaptation (xX) to a crisis or stressful life event, as is often assumed. For the reasons discussed earlier, this does not appear to be the only or most helpful assumption to make regarding families of children with DD. Second, there is considerable confusion between C and A in studies using these models. Are parent reports of child difficulty part of A (the stressor) or the meaning they attribute to the stressor (C)? Meaning, in a deeper existential sense, is not typically studied, and if it were it is likely that it would differ across individuals in the family. Third, the B or bB factor is excessively broad and needs to be broken down much more specifically. It includes new and old resources of the family, but does not make the crucial distinction between individual resources of parent(s) such as beliefs and coping styles versus family system resources such as cohesion and family harmony. Furthermore, it does not separate these within-family resources from social supports and professional services received from outside the family. More fundamentally, there is the issue of whether a family or individual model is most useful. These models purport to be family models, but typically individual measures are used to operationalize the domains. Finally, the very recent versions of this model are so elaborate, including a number of variables that cannot be readily measured, that they are of dubious practical utility in applied research (see Perry, 1989 for a more detailed critique).

Description of Model & Domains

The present model (shown in Figure 1) is intended to be conceptually clear and comprehensive, yet practical for applied research and clinical practice. It includes four major components: Stressors, Resources, Supports, and Outcomes, each of which is divided into two domains. Stressors are the

major and minor stressful stimuli in the life of parents of Children with DD, including those associated with the child, as well as other life stressors. The Resources area consists of the personal resources of the individual parent(s) and family resources. The third major component of the model consists of the Supports the parent or family may receive from outside the immediate family, from informal social networks and from formal support services. The Outcomes in the model, in keeping with the "resource imbalance" tradition, may be thought of as what is left over after considering the primarily negative (but also potentially positive) impact of the Stressors, mediated and/or moderated by the primarily positive (but also potentially negative) influences of the various Resources and Supports available. This residual quantity consists of emotional states and cognitive appraisals and attributions about those emotional states, and can be positive and/or negative. A more detailed description of each domain with clinical and research implications follows.

Figure 1. A model of stress in families of children with DD



Child Characteristics

Potentially relevant Child Characteristics that may be stressor variables in this domain include level of dependency in self-help tasks, cognitive or developmental level, frequency and severity of maladaptive behaviour, diagnosis or type of DD, age, and gender. A distinction should be made between "objective" variables such as age or IQ and parents' perceptions of child difficulty or "stressfulness", which is probably more relevant. There is

widespread conceptual confusion in the literature and overlap in measurement between subjective parental perception of child characteristics (considered here as stressors) and parenting distress (or stress response or outcome). It is crucial that future research not confound outcome measures with stressors.

Clinically, it is important that the objective characteristics of the child are not allowed to create false assumptions by clinicians about the family's experience (e.g., he's high functioning so they won't be very upset). Another clinical implication of this idea is that interventions designed to alter the child characteristics (e.g., decreasing maladaptive behaviour) will not necessarily bring about the effect we might expect on the family. The parental perceptions and expectations themselves may be a fruitful avenue for clinical intervention, however. Further, the effect of the stressors cannot be meaningfully understood without considering intervening variables. Some families (especially those seen clinically) can be overwhelmed by a child whose disorder seems relatively mild, whereas other families with much more seriously affected children can cope in a healthy manner and describe positive benefits from their experience. It is this heterogeneity in families that is the subject of much current family research.

Other Life Stressors

Families who have a child with a DD may, of course, experience other types of stressors, just as all families do. Other Life Stressors include those related to employment, those pertaining to illness in other family members, financial problems, and so on. It is important for researchers to incorporate (and/or develop) measures of life events stress, since it has a well demonstrated (though not strong) relationship with depression/malaise in the general life events literature, and some support in the DD literature. In addition to the typical items included on a life events measure (e.g., moving, death in family), it is important to consider the not uncommon reality that there are other family members with a DD, as well as other stressors related to having a child with DD (such as costs of special treatments, need to renovate house). Researchers are encouraged to measure life events separately from child-related items so that their effects can be assessed independently.

It is also important to take these stressful life events into account when working clinically with parents. A refugee family living in one room may need assistance in finding accommodation initially, rather than services related to the child with DD specifically. The mother of a child with autism

who is also coping with a senile parent may not have much energy to work at a home language program with her child every night. We can assist families dealing with these other stressful life events by appropriate referrals, by sensitivity to other demands on their time, and by offering appropriate direct services, such as emergency respite care for the child at the time of a death in the family.

Individual's Personal Resources

Individual's Personal Resources consist of personality variables and cognitive coping strategies and beliefs, as well as more demographic factors (such as education and employment status). This is perhaps the domain most ripe for research efforts aimed at discovering the particular internal resources, beliefs, and coping abilities (e.g., hardiness, optimism, religious faith, task-oriented coping, etc.) that are most effective for reducing stress. Research should focus on whether these resources function in an additive way, whether they mediate stress or interact with the level of stressors in a moderating effect pattern, or operate in some other way(s). The question of how these operate in fathers versus mothers is also pertinent and largely unstudied. There will, no doubt, be direct clinical implications of this line of research investigation in future.

As clinicians, we frequently deal with parents' beliefs and personality characteristics, directly or indirectly. We need to value and respect certain religious and/or philosophical beliefs that we may not share. We have to be careful about whether, when, and how we address parents' denial and "irrational" beliefs (e.g., that the child will be cured), since these may be necessary coping or defence mechanisms, and/or they may generate considerable energy to work with the child. The other major clinical implication to be drawn from this section is that professionals' dealings with parents should be conducted, as far as possible, in such a way as to enhance parents' self-esteem and sense of control over their situation. This proviso could affect the way we present diagnostic information to parents, explain assessment results, demonstrate treatment techniques, and so on. Again, coping abilities and internal resources may be appropriate targets of individual or family intervention in some situations.

Family System Resources

Family System Resources are comprised of variables that tap family functioning, marital satisfaction, and demographic variables (such as SES and marital status). The family stress literature and the theoretical models

mentioned earlier look at the family as the unit of analysis, as do many clinicians taking a family systems perspective. However, in empirical studies, the family variables are typically based on one or more individuals' perception of the family and it is unclear whether these really differ from individual variables. Furthermore, there are a substantial number of single parents, for whom these variables may not make sense, and research has not necessarily addressed this reality sufficiently. In future research, efforts should be made to untangle family variables from individual variables as well as, in couples, marital from family variables, if possible. Note that, in the present model, these marital and/or family measures are considered as independent variables not outcome measures, as outcomes are conceived of as necessarily individual variables.

The obvious clinical implication in this domain is that it is extremely important that parents be encouraged to maintain and, if necessary, strengthen their family and marital relationships. In certain cases, this could include offering marital or family therapy, though most families may not need or want such services. Facilitating family functioning may involve provision of respite care as many parents of children with developmental disabilities find it impossible to get babysitters. As professionals working with these parents, we must be careful not to prescribe interventions (with the child's needs in mind) that require so much parental time and energy as to be harmful to the marital relationship or the family as a whole. Also, we should make every effort to involve both parents in meetings, conferences, and programs (even if inconvenient for us), in an attempt to produce a common goal and understanding, thereby minimizing one potential source of marital difficulties.

Informal Social Support

Informal Social Support is emotional sustenance and/or tangible help actually received and/or perceived to be available from extended family members, friends, neighbours, social organizations, and religious communities (Perry, 1989). There is a large body of literature on stress and social support in families of children with DD and it is clearly a crucial concept. However, there are significant conceptual and measurement issues that require further clarification. These include: the quantity versus quality issue (small but supportive networks may be best); the utility of the concept of perceived support (versus actual support obtained); the valence of contacts with the social network (helpful or stressful); and the issue of a threshold model of support (social isolation is harmful, but beyond that, more is not necessarily better).

In terms of clinical intervention, it may be appropriate to encourage parents to make use of and develop their social support network if they report feeling socially isolated. Other parents of children with DD can provide a unique type of support and, consequently, parent support groups may be helpful. Another area worth exploring with parents is the nature of their support network. If they are giving more than they are receiving, it may be appropriate to help them learn to set limits with people. If there are issues with extended family or significant others, particularly disagreements around the child with DD, it may be appropriate to help parents learn to cope more effectively with this. This could even involve including those other individuals (e.g., grandparents) in some form of clinical intervention with the parents.

Formal Supports and Services

Formal supports and services are professional or paraprofessional interventions, including education/treatment programs for the child with DD and family interventions such as individual, marital, or family counselling, respite care, behaviour management training, parent support groups, and parents' organizations. It seems quite likely that it is not just the number of sources of formal support that should be measured, but also their quality and effectiveness, their suitability for the family's needs and values at the time, and their impact on parental levels of satisfaction. Measurement instruments tend to be developed locally for each study and have unknown psychometric properties. Future researchers will have to construct more effective instruments to tap these variables.

Clinically, it is important to note that many formal support services are (appropriately) oriented primarily toward the child with DD. Education/treatment programs that aim to improve the child's cognitive level or self-help skills, for example, are attempting to alter what have been called objective child characteristics. However, changes in such child characteristics, though worthwhile intervention goals for the child's sake, should not necessarily be expected to reduce parenting distress because all of the other domains in the model are also operating. A second clinical implication of the model is that some services, even those designed primarily to support families, do not, in fact, have a significant impact on parents' lives relative to some of the other domains in the model. Therefore, professionals may need to be more humble about their expectations in this regard. In some cases, from the parents' perspective, "services" conflict with family values, fail to match family needs, or simply compound demands on parental time and energy (i.e., add stress, rather than relieve it). Supportive,

family-centred, formal services must be offered in a flexible way that is sensitive to the self-identified needs of the parents and family and their particular circumstances. One way of using the present model in clinical practice with families is to review strengths and needs in each domain (separately for mothers and fathers possibly) and set goals accordingly, taking into account some of the suggestions made earlier regarding unconventional intervention strategies.

Parental Outcomes

Most family stress research has focused on negative outcomes, including the original version of this model (Perry, 1989), in that the outcome was termed "parenting distress" (depression, pessimism, feeling trapped, burnout, and so on). However, there have been scattered reports in the literature of both positive and negative effects on parents of having a child with a DD. Clinical work and work in the larger system certainly demonstrate that there is the potential for parents to experience considerable personal growth as a result of having a child with DD and/or as a result of their advocacy efforts. There is no doubt this work has resulted in many impressive achievements, as well as considerable personal cost in some cases. Recent research suggests that positive and negative outcomes are not mutually exclusive or even negatively correlated with one another (Trute & Hiebert-Murphy, 2002). Thus, it is optimal for researchers to conceptualise and measure outcome as two separate variables, rather than as one variable (degree of negative reaction) or even as one bipolar variable (ranging from bonadaptation to maladaptation as in McCubbin's model). This task is barely beginning and requires our best efforts be directed to it.

Clinically, this idea has important implications. The notion that there may be independent and simultaneous positive and negative effects requires clinicians to perhaps rethink some attitudes about dealing with families (compared to the stages of grieving notion, for example). We can support and empower parents in their advocacy efforts, while at the same time providing intervention and support to deal with difficulties. We need to acknowledge and affirm strength and competence at the same time as vulnerability and needs.

Advantages and Disadvantages of the Model

The model described here has some advantages and disadvantages. It is meant to be comprehensive in that it borrows from several bodies of

literature (family stress, systems, coping, social support, ecological theory, developmental psychopathology), and yet simple enough to be practical in applied research and clinical practice (i.e., not to have too many domains and too many pathways). The model itself could be tested using multiple regression techniques in a relatively modest-sized sample or using structural equation modelling in larger studies.

The model is essentially a static one; it does not attempt to capture a process over time (such as adaptation to the birth of a child with DD). However, it could be used with a process orientation in mind. Families could be studied longitudinally and families at different life cycle stages could be compared. The effect of macrosystem changes could be studied by examining different cohorts over time.

Although certainly informed by a family systems view, the model is essentially an individual framework. There are three reasons for this. First, many of the important coping resources (beliefs, coping mechanisms, etc.) are inherently individual constructs. Second, even the so-called family measures are really individual perceptions of family variables and it is an empirical question to what extent these are independent. Third, the potentially important differences in the experience of mothers and fathers (and possibly different intervention implications) would be obscured by any model or analysis that routinely combined them.

Empirical Studies Illustrating the Model

Perry (1990) conducted an empirical test of this model in a sample of 61 parents of children with autism. Hierarchical multiple regression analysis (with variables entered in a predetermined logical order according to the model) was used to see which variables accounted for significant amounts of variance (controlling for all others entered previously). The dependent measures of Parenting Distress included: a score derived from 4 subscales of the PSI (Abidin, 1995; Depression/Guilt, Attachment, Restriction of Role, and Health), Factor 1 of the QRS-F (Friedrich et al., 1983; Parent & Family Problems), and a composite of the two. It was found that Child Characteristics, entered first, accounted for the largest proportion of variance (27 to 34% of the variance in three different outcome measures). However, it was not the "objective" variables related to the severity of the child's developmental or diagnostic status that were important. Rather, it was the parents' perception of the child's level of difficulty, based on certain subscales of two stress measures. Other Life Stressors, entered second, contributed significant additional variance (4 to 11%), but it was events and

stressors specific to having a child with DD (such as excessive professional "runaround") not the traditional life events measure from the PSI that was predictive. In the Resources area, Individual's Personal Resources was entered third and accounted for a significant but rather small amount of variance (5 to 7%). In particular, this reflected parents' sense of competence. Family System Resources, entered fourth, accounted for a substantial amount of variance (20 to 24%), especially the spousal relationship ("family harmony" did not add independently). Then, examining the effect of Supports, Informal Social Support was entered fifth, accounting for 1 to 7% of the variance, based not so much on the presence of social support but, rather, the lack of social isolation. Formal Supports (simply a list of services received) was entered last and did not add at all to the variance accounted for. The overall models ANOVA analyses were highly significant and the Adjusted R^2 for the three different dependent variables ranged from .61 to .80, suggesting that the model was extremely successful in predicting the dependent measures. Cross-validation remains to be done to confirm these findings, however.

Other studies currently in progress or recently completed can be seen within this framework, as well. The degree to which Child Characteristics such as type of disability, severity of disability, and age are related to family harmony (a Family System Resources construct) has been investigated in a study that includes parents of children and adolescents with Down syndrome, Rett syndrome, fragile (X) syndrome, autism, and DD with unknown etiology (Perry, Harris, & Minnes, this issue). A longitudinal study of parents of young children with DD is examining the moderating effects of family coping and supports and services in moderating future parenting distress and depression (Perry, Condillac, Hundert, & Niccols, 2004).

Research involving a sample of 120 families of children with autism is underway which includes several projects relating to some or all domains of the model. One study involves exploring several interesting variables (such as self-efficacy and advocacy) as predictors and moderators of positive as well as negative outcomes in parents (Diamond, Perry, & Muller, 2003). Another involves examining prosocial behaviour as well as psychosocial adjustment in siblings, as a function of sibling and family factors (Smith & Perry, 2003). Other studies focus on particular domains of the model more fully, in particular the Individual's Personal Resources. These include a study investigating "emotional intelligence" as a possible moderator of distress in mothers and fathers of children with autism (Perry, Morris, & Harris, 2004). Furthermore, a study is exploring the nature of coping (and its measurement) in individual parents versus "family coping" to see whether

these can be distinguished empirically and to assess whether they correlate differentially with measures of stress in couples who have a child with autism (Perry, Harris, & Flynn, 2004).

Conclusion

The model described here is intended to be reasonably comprehensive (i.e., to include the important factors emerging from the various bodies of literature) yet pragmatic (i.e., not so complicated that it cannot be operationalized). It represents a serious effort to address the conceptual and measurement issues in the literature by explicitly defining stress, stressors, and distress; by clearly distinguishing between dependent and independent variables; and by using constructs for which reasonably sound measuring instruments are available. The model was conceived and has been nurtured within the scientist-practitioner tradition and is, above all, meant to be useful to the field clinically and in applied research.

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