

# Empowering Culturally Diverse Families of Young Children with Disabilities: The Double ABCX Model

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Many culturally diverse families and their young children with disabilities or delays are not provided appropriate early intervention/early childhood special education services, especially not in a culturally sensitive and meaningful context. Families with diverse backgrounds often feel helpless and stressful because their values are not respected, concerns are not identified, and therefore their needs are not met due to the lack of support from appropriate resources. The purpose of this article is to provide a positive strategy to empower families of young children with special needs and who are from culturally diverse backgrounds through a family-centered, strength-focused family system model: Double ABCX model. Procedures of implementing the double ABCX model was described and discussed. Supported by previous research and the current case studies, the double ABCX family adaptation model has found to be an effective approach to serving diverse families of children with disabilities.

**KEY WORDS:** family empowerment; cultural diversity; coping strategies; ABCX model.

## BACKGROUNDS

The population of children and families in the United States who receive early intervention or early childhood special education services is becoming increasingly diverse. Families nowadays in the United States are diverse in ways such as culture, sexual orientation, economic status, work, religious beliefs, and composition. Take the composition of families as an example: single-parent families, families of divorce, blended families, multigenerational families, extended families, homeless families, migrant families, and gay and lesbian families as well as non-biological kin rearing children represent some of the diversity in families (Christian, 2006; Cartledge, Kea,

& Simmons-Reed, 2002). Integrated with the diverse family composition is the cultural/ethnic aspect of family characteristics. It is estimated that by the year 2050, half of the U.S. population is projected to be of Latin American, African American, Native American, or Asian/Pacific descent (Cartledge et al., 2002). Working with young children with disabilities and their families from culturally and linguistically diverse backgrounds can be very challenging for early interventionists and early childhood special education teachers. Because of the complexity of family composition and sensitivity of cultural issues, it is risky or even dangerous to over-generalize about family needs, priorities, values, and beliefs. Even for families from the same cultural backgrounds, no two families are exactly alike (Cartledge et al., 2002).

In collaborating with families from culturally and linguistically different backgrounds, so often early interventionists/early childhood special education teachers move from one end of the continuum to the other: either playing as the authority to step in and make all decisions for the child and the family or withdraw from the family in fear of making mistakes

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due to the lack of communications and understanding. Either approach has left the family in a powerless and often desperate situation.

As a result, many culturally diverse families and their young children with disabilities or delays are not provided appropriate early intervention services, especially not in a culturally sensitive and meaningful context. Families with diverse backgrounds often feel helpless and stressful because their values are not respected, concerns are not identified, and therefore their needs are not met due to the lack of support from appropriate resources. Yet no matter how different families appear to outsiders, all families have at least one common characteristic: they all develop their own coping strategies to deal with the stress or crisis caused by having a child with disabilities and related issues. Culturally diverse families, despite some potential communication obstacles, are known to be adaptable in family roles, especially through strong kinship bonds, work ethics, and religious belief (Cartledge et al., 2002). It is true having a child with disabilities could (almost always) create stress to parents and other family members. However, family caregiving involving children with disabilities is not necessarily a negative experience (Abbot & Meredith, 1986; Saloviita, Italinna, & Leinonen, 2003). Research has shown that how a family effectively adapts to a stressful situation relates to factors such as how the family defines a stressor event, what resources are available, and how these factors interact with each other (Saloviita et al., 2003; Winton, 1990). Additionally, cultural differences play a critical role in how families define stress and how comfortable families are in seeking resources for help. Examining these strengths will promote effective early intervention/early childhood special education that fosters optimal child development and functioning.

#### **THEORETICAL BACKGROUND OF FAMILY SERVICE MODELS**

Traditionally family involvement was limited in a way that families were treated as passive recipients of early intervention services, and early interventionists were the decision makers. During the past three decades since the first special education law was enforced in 1975, a movement has been shifted from the model that emphasized family deficits to a model that emphasized family empowerment and strength (Cartledge et al., 2002). Empowering and enabling families as a system has been the goal of early intervention services with family in the center

and the child with special needs as the focus. As defined by Allen and Cowdery (2005), empowering families is to carry out "interventions in a manner in which family members acquire a sense of control over their own developmental course as a result of their own efforts to meet needs" (p. 168) and enabling families is to create "opportunities for family members to become more competent and self-sustaining with respect to their abilities to mobilize their social networks" in order to get their needs met and attain goals (p. 168). Therefore, the purpose of this article is to provide a positive strategy to empower families of young children with special needs and who are from culturally diverse backgrounds through a family-centered, strength-focused family system model.

#### **THE ORIGINAL ABCX MODEL**

A family includes interconnected members and each member influences the others in predictable and recurring ways (Van Vesor & Cox, 2000). Because of the diversity and complexity of families of young children with disabilities, a comprehensive, dynamic approach that focuses on the whole family as a system is needed. The Double ABCX model of family adaptation is an integrated framework that links the steps of assessment, outcomes, and implementation in a way that emphasizes family strengths as the starting point for intervention.

Theories on families' coping with stress began with the ABCX family crisis model of Hill's (1949), which in modified form remains the most influential view of family stress today. The original ABCX model postulates that a stressor (A) interacts with the family resources for dealing with crises (B) and with the definition the family makes of the event (C) to produce the crisis (X). Individual differences among families in their adaptation to stressful events would be explained through this model. This ABCX model suggests that how a family adapts to a critical event is shaped by the interaction between family resources and family perceptions. In other words, the stressor(s) may not necessarily lead to a crisis when a family appropriately and effectively utilizes their resources and thus they would perceive the stressor in a more positive way. As a result, the family would develop appropriate adaptations to deal with the stressful event and become stronger as a unit through this process.

## THE DOUBLE ABCX MODEL

The focus of the original ABCX model was on factors preceding the crisis that determine the capacity of the family to cope with the stressful event, and thus the extent to which the outcome constitutes a crisis. In order to consider the behavior of families after a crisis, and in particular their efforts at adaptation, Burr (1973) developed the double ABCX model of family crisis. The subsequent refinement of this model by McCubbin, Patterson, Bauman, and Harris (1981) and modification by Heflinger, Northrup, Sonnichsen, and Brannan (1998) treat coping as the central process in the family's efforts to adapt to a crisis. Coping follows the accumulation of demands on the family, and involves an interaction of resources and perceptions. The double ABCX model adds four post-crisis factors, each of which corresponds to a factor in the original model. Components of the Double ABCX Model of family adaptation include family crisis (xX) that results from the family demands associated with the child (aA), family adaptive resources (bB), and family definition of the situation (cC). In this process, the capitalized letters ABCX refer to factors preceding the crisis and changes in those elements over time are depicted as a, b, c, and x. When the ultimate outcome is an adaptive response, parents and other family members may experience less or manageable levels of stress and therefore the crisis may not be a negative one. However, when the response is maladaptive, excessively high levels of caregiver strain and psychological distress may be experienced and result in additional stressors (e.g., child maltreatment, out-of-home placements, difficulty fulfilling parental responsibilities, sibling behavior problems, divorce, etc.).

### Family Demands: Pile-up (aA factor)

The aA factor reflects the observation that families rarely deal with only one stressor at a time. A substantial literature exists on the variety of family stressors imposed by having a child with a disability. For example, the extra time, money, and efforts involved in early intervention, special education and related services could create more stressors (pile-up) because of the disability (primary stressor).

### Family Resources (bB factor)

McCubbin and Patterson (1982) argued that the resources that a family may bring to the management of a crisis consist of three basic kinds: the personal

resources of individual family members, the internal resources of the family system, and social support from resources external to the family. Personal resources include financial well-being, physical and emotional health, education, and personality characteristics of individual family members. Education contributes to cognitive abilities that influence a family member's capacity to solve problems and appraise crises realistically. Pearlin and Schooler (1978) found that family members with high self-esteem and self-efficacy coped better with social stress.

McCubbin et al. (1981) found that the most significant internal family system resources to be member self-esteem, open communication, mutual support, problem-solving ability, physical and emotional health, and a sense of mastery over the events they experienced.

### Family Perceptions (cC factor)

The cC factor refers to the meanings the family attributes to the crisis (xX), the accumulation of stressors and demands (aA), and their resources to deal with them (bB). These perceptions interact with the resources available to produce the coping response. Patterson and McCubbin (1983) pointed out that giving meaning to the situation clarifies the issues for the family, suggests potential solutions to the problem, renders the emotional strain associated with the crisis more manageable, and enables the family to re-establish its equilibrium.

### Family Adaptation (xX factor)

The xX factor is the ultimate product of the double ABCX model. Studies have been conducted to examine the process by which families reach an adaptation to the disability that the child has. For example, Watson (1989) surveyed a group of rehabilitation professionals on the family variables thought to be important for a successful adaptation to a disability, and concluded that the double ABCX model is particularly appropriate for understanding the family response to a disability in a family member. Family adaptation is a positive response to family stressor(s) using effective coping strategies.

As mentioned earlier, although family caregiving involving children with disabilities is not necessarily a negative experience (Abbot & Meredith, 1986; Summers, Behr, & Turnbull, 1989), previous research did suggest that caregiver stress is a more common phenomenon among family members having children

with disabilities than it is among other families having children without disabilities (e.g., Friedrich & Friedrich, 1981; Beckman, 1991; Singer & Irvin, 1991; Scott, Atkinson, Minton, & Bowman, 1997). It has been apparent that family outcomes following the impact of a stressor event, such as the discovered severe disability of a child, are the result of multiple factors interacting with each other (Patterson & McCubbin, 1983; Singer & Irvin, 1991). Therefore, a multivariate approach such as the double ABCX model is needed to examine psychological, intra-familial and social variables simultaneously. The stress and coping theory of Lazarus and Folkman (1984) applied the double ABCX Model by adding the factor of time into the model, and expanding it to also comprise a post-crisis adaptation.

The cultural difference makes each family unique in terms of how they define their stress, what resources they are seeking for help, and how they perceive their stress. When working with culturally and linguistically diverse families, the double ABCX Model is an effective approach to viewing multiple variables from different perspectives.

### IMPLEMENTING THE DOUBLE ABCX MODEL

The double ABCX model of family adaptation provides interventionists with a conceptual framework that promotes a focus on strengths rather than deficits. It highlights the differences between implementation strategies and outcomes, a differentiation helpful in promoting the concepts of individualized early intervention/early childhood special education programs (Landesman & Ramey, 1989). It also involves helping parents to assume their parental role in hospitals, home, child care centers, and schools; and developing appropriate interactions with their children. The model provides an integrated framework for directly linking assessment information with outcomes and implementation strategies.

The two critical variables in the double ABCX model interacting with each other to create adaptation are family resources and family definitions. These two variables are similar to two components of family strengths identified in the literature (Olson et al., 1983): (a) external resources and (b) internal coping strategies. External resources refer to the importance of planning interventions in ways that promote and enhance the family's existing external resources, such as friends, neighbors, and extended family (Dunst, Trivett, & Deal, 1988). Internal coping strategies can be defined as the perceptual ways that

families adapt to crises. One important strategy in using internal coping strategies is reframing (Winton, 1990), which is to redefine the family needs and priorities and to identify a family strength to meet the needs. This concept is particularly helpful with families who seem to have multiple crises. The following is the procedure of using the double ABCX model with two families of young children with disabilities (See Table 1).

#### *Smith's Family*

Mr. and Mrs. Smith have three children. Both Mr. and Mrs. Smith worked full time until one year ago when their youngest son, Ian (3 years old), was diagnosed as having autism with moderate mental retardation. Since then Mrs. Smith has only worked part-time because she needs to take Ian to receive therapy 3 times a week. Six months ago Mr. Smith was found to have Parkinson's Disease, which deprived him from his work at the post office.

#### *Chang's Family*

Mr. and Mrs. Chang have two children, a 7-year-old son and a two-year-old daughter. Their daughter, Helen, was born with Down Syndrome. Helen receives physical therapy three times a week. She also attends a childcare center three mornings a week. Both Mr. and Mrs. Chang attend graduate school and work part time off campus, and they live in the same house with Mr. Chang's parents.

### **Step 1: Observing Primary Stressors (A) and Related Pile-up Stressors (a)**

Observing the primary stressor was often obvious, however, the reality is that rarely only one stressor was the case. Very often the primary stressor(s) may lead to more related stressors which are called pile-up stressors. For Smith family, the primary stressor started when Ian was diagnosed as having autism. Later on, another primary stressor arose from Mr. Smith, who had been the main income winner for the family, broke down with Parkinson's Syndrome. These two primary stressors were piled up with other stressors such as financial stress because of the cut of incomes, energy stress because of the attention and treatment that Ian and Mr. Smith need, and emotional stress due to all these stresses.

For the Chang's family, the primary stressor was the fact that Helen was born with Down Syndrome. Cultural conflict was the second primary stressor related to the first stressor. For example, Mr. Chang's parents (Helen's grandparents) were actually the authority and decision makers of this three-genera-



**Table 1.** Steps in Implementing the Double ABCX Model to Families

Steps	Smith family	Chang family
Step 1: Stressors (aA)	Ian's disability (A) Mr. Smith's disease (A) Pile-up stressors resulted from the primary stressors: financial, time, energy (a)	Helen's disability (A) Cultural conflicts (A) Pile-up stressors resulted from the primary stressors: emotional stress, time (a)
Step 2: Family resources (bB)	External social support (B) Financial support through organizations and government (B) Intra-personal support (b)	Extended family support (B) Intra-personal support (B) Social support (b)
Step 3: Family perceptions (cC)	Feeling comfortable in seeking external help (C) Valuing independent functioning (C) Changed perception: mother's role model has changed her children's perceptions on values (c)	Feeling more comfortable in seeking internal help within the family system (C) Valuing caring and attention (C) Changed perception: grandparents' belief in Helen's disability (c)
Step 4: Coping Strategies(xX)	Initial (X): Seeking social support and professional help Adapted (x): empowering individuals and the whole family: Mrs. Smith going back to school through a scholarship; Mr. Smith taking classes; focusing on positive impact on children	Initial (X): Child caring within family system and financial support from grandparents Adapted (x): Supporting other families through networking; focusing on developing functional, meaningful skills for Helen; Valuing social interactions

tion family. Immigrated to the U.S. as teenagers in early 50s last century, Mr. Chang's parents held a very different view toward individuals with disabilities because of the influence of their home country culture. They did not think intervention would make a difference; instead, they viewed a disability as an inborn deficit and the only way to make up for this deficit was to provide care for their child instead of expecting the child to take care of herself. Therefore, they tended to do everything for Helen with very little opportunities being provided for Helen to explore with the environment and interact with her typically developing peers. These stressors caused additional pile-up stressors such as emotional stress of Helen's parents being caught in the middle of cultural conflicts: They could not openly disagree with their parents although they had very different opinions towards educating Helen.

### **Step 2: Identifying Existing Family Resources (B) and Obtaining Access to Potential Family Resources (b)**

The second step is to identify existing resources that the family has already utilized in coping with the stressors. Through the process of identifying the family strengths in coping strategies, resources that potentially are accessible also can be obtained. It is critical for professionals to realize that each family has a very different approach to obtaining resources.

For Smith's family, both Mr. and Mrs. Smith are African Americans and they feel comfortable to seek early intervention/early childhood special education services for Ian (under the protection of IDEA) and facility service for Mr. Smith (under the protection of Section 504 of the Rehabilitation Act). Based on these family resources (strengths), more resources were identified such as obtaining scholarship for Mrs. Smith and taking online classes for Mr. Smith.

For Chang's family, however, the access to resources was different. Since Mr. and Mrs. Chang were the first generation Asian Americans, Mr. Chang's parents valued education and have high expectations for their children. They would provide as many supports as they could, yet they were not comfortable to seek external help or professional support. They saw the fact that having a child with a disability was a family issue rather than a societal issue. In their home country, it was the family's responsibility to take care of the child with disabilities rather than outside agencies. Therefore, the comfort level that they were willing to seek help was limited within extended family members and relatives. Since Mr. Chang's mother was a retired kindergarten teacher, she volunteered to take care of Helen when Mr. Chang and his wife went to school. She also volunteered at the child care center where Helen stayed for three mornings. Beyond that, Mr. Chang's

parents helped pay the tuition for Mr. Chang and his wife as well as the cost for child care. These supports (family strengths) allowed Mr. and Mrs. Chang to obtain more resources through establishing networking with other families.

### **Step 3: Examining and Re-examining Family Perceptions (cC)**

Family perceptions from the two families were changed throughout the process in coping with their own stressors and seeking resources. Having a child with autism was stressful for the Smith family, but not a negative experience. They saw Ian as a lovely child and accepted him as who he was. The stress was more on the financial part, especially when Mr. Smith was sick. For Chang's family, the crisis was more on the cultural and emotional aspects. In their home culture, having a child with a disability was a sign of punishment due to the wrong doings from older generation or other relatives. Thus they were ashamed even to share their stress with professionals or other people. On the other hand, however, the financial need was seen as a less stressful crisis, because Chang's parents always valued education and their saved money for their children's education for many years.

Perceptions are dynamic, especially where multiple variables are involved. After Mrs. Smith obtained a scholarship and graduated with BA in early childhood education and a teaching license, her children perceived her as their role model. When her son Bob (8 years old) said that their family was poor and could not afford an out of state trip, their 10-year-old daughter commented that they were not poor, they just did not have enough money. They were proud of their mother being the teacher to help them and other children. Mr. Smith started perceiving this crisis as a challenge rather than the end of his health. While continuously fighting with his disease, Mr. Smith searched online for all kinds of resources to help his family. In Chang's family, Mr. Chang's parents started changing their perceptions towards Helen's disability when they were involved in developing meaningful goals and objectives for Helen's Individualized Family Service Plan (IFSP) and witnessed Helen's improvements in adaptive areas.

### **Step 4: Empower Families with Effective Coping Strategies (xX)**

Once families perceived their crises in a manageable way, they started developing positive strategies for coping with the crises. Mrs. Smith decided to

pursue her master's degree in special education in order to help her son and other children. She was able to obtain a scholarship through the local Economic Opportunity Board in support of her formal education from the state university. Inspired by her, Mr. Smith started taking online classes from the community college which he could never have time to do when he worked full time.

For the Chang's family, while grandparents continued to provide child care and support for the family, the whole family has started to network with other families of children with disabilities. Through this networking, Helen's grandparents realized that they should not hide Helen or prevent her from interacting with her peers. Working with Helen's professional team members, her grandparents were actively involved in developing age appropriate functional skills for Helen that were identified as the prioritized goals to benefit Helen and the whole family. In addition, as parents Mr. and Mrs. Chang started to play a more active role in Helen's life by establishing a family organization to support other families under stress. Started with their daughter's physical therapist, they developed a summer camp for children with disabilities and their families. They had family members, special education teachers, college students, as well as siblings as volunteers to help for the camping. The summer camp was extended into a continuous family project and offered on-going support for families of children with special needs.

## **CONCLUSION**

Working with families of children with disabilities can be a challenge for early interventionists because of the lack of effective connections with families, especially when the family has a different cultural background from the interventionists. While traditionally the family service approach to early intervention/early childhood special education was more professional directed that focused on the deficits or problems of the family, the more recent family service models have switched to family oriented that focus on the strengths of the family functioning system. Double ABCX model was examined and applied to work with families with culturally diverse backgrounds. The value of this model is its emphasis on family functioning as a dynamic and interrelated system rather than a static, isolated unit. In addition, the double ABCX model helps link the assessment and intervention through ongoing evaluation of

family's needs and makes changes of family coping strategies whenever necessary.

While it is not and should not be the only approach, the Double ABCX family adaptation model has found to be one of the most effective approaches to serving diverse families of children with disabilities. It helps make each family function effectively as individuals and as a system. The key to this model is to empower families to help themselves in the process of problem solving. As competent decision makers the empowered family will have long-term consequences for the development of the child with special needs and well-being of the family, community, and society.

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