



# Mental health and positive change among Japanese mothers of children with intellectual disabilities: Roles of sense of coherence and social capital



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## ABSTRACT

We investigated predictors of mental health and positive change among mothers of children with intellectual disabilities in Japan based on the concept of the Double ABCX model. We used variables of having a child with autism spectrum disorder (ASD) and dissatisfaction with systems as stressors, availability of social support and social capital (SC) as existing resources, sense of coherence (SOC) as appraisal of the stressor, and mental health and positive change as adaptation. A self-administered questionnaire was distributed to 10 intellectual disability-oriented special needs schools in Tokyo, and obtained 613 responses from mothers of children under age 20 attending these schools. The results showed that our Double ABCX model explained 46.0% of the variance in mothers' mental health and 38.9% of the variance in positive change. The most powerful predictor of this model was SOC, and SC may be directly and indirectly related to maternal mental health and positive change through mothers' SOC. Increasing opportunity for interaction between neighbors and family of children with disabilities may be one effective way to enhance SOC through SC. Since maternal SOC, SC, mental health, and positive change were significantly correlated with each other, synergy among these elements could be expected.

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## What this paper adds?

The Double ABCX model was applied to adaptation among mothers of children with intellectual disabilities in Japan. Although sense of coherence (SOC) was the most powerful predictor of their mental health and positive change, social capital (SC) also predicted their positive change. Since SC was positively correlated with mothers' SOC, developing rich SC may be effective way to promote SOC, mental health and positive change in practice.

## 1. Introduction

Having children with intellectual disabilities (IDs) impacts parents' well-being. IDs can be defined as disabilities characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and

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practical adaptive skills that are present before age 18 ([American Association on Intellectual and Developmental Disabilities, 2010](#)). Raising children with IDs alters parents' lives and negatively affects their health in ways such as increased risks for stress, depression, and anxiety ([Emerson, 2003](#); [Gallagher, Phillips, Oliver, & Carroll, 2008](#)). Particularly, mothers have difficulty finding or keeping jobs, experience isolation, feel a lack of fulfillment, and have low self-esteem ([Shearn & Todd, 2000](#)). In Japan, there is a social expectation regarding a mother's traditional role, and most parts of caring for children with disabilities place a burden on mothers ([Fujiwara, 2002](#)). At the same time, raising children with IDs also provides parents with positive experiences such as an increased sense of purpose, priorities, spirituality, tolerance and understanding, personal growth and strength, expanded personal/social networks, and community involvement ([Stainton & Besser, 1998](#)). Previously, we investigated positive change among parents of children with IDs in Japan and confirmed that, although 46.7% might have some form of mental health problem, 79.9% reported positive changes after a child's diagnosis ([Kimura & Yamazaki, 2014, 2015](#)). These studies illustrate that raising children with IDs may have both positive and negative effects on parental well-being.

The ways in which raising children with disabilities impacts parents have been explained by various models. The classic ABCX family crisis model was established by [Hill \(1958\)](#). In this model, A (the stressor event) interacting with B (the family's crisis meeting resources) interacting with C (the definition the family makes of the event) produces X (the crisis). [McCubbin and Patterson \(1983\)](#) added this classic model to a post-crisis adaptation called the Double ABCX model of family adaptation. In the Double ABCX model, stressors and accumulation of demands (aA) can be moderated by two variables (existing and new family resources [bB] and appraisal of the stressor [cC]), and its outcome is reflected in family adaptation (xX). The Double ABCX model of family adaptation has been widely applied to examine how variables of stressors, resources, and appraisal explain adaptation among parents of children with disabilities worldwide. For example, [Saloviita, Itälänna, and Leinonen \(2003\)](#) explored the stress of parents of children with IDs in Finland using the Double ABCX model (e.g., child's adaptive behavior, challenging behavior, aA; marital relationship, informal/formal support, instrumental support, negative coping strategies, locus of control, bB; and definition of situation as a "catastrophe," cC). These variables explained 72% of maternal stress and 78% of paternal stress. [McStay, Trembath, and Dissanayake \(2014\)](#) also examined the predictors of parental stress and family of quality life (QOL) among parents of children with autism spectrum disorder (ASD) in Australia. In the study, 57% of maternal stress and 61% of those family QOL, 58% of paternal stress and 59% of those family QOL were explained in their model (child externalizing behavior, aA; family hardiness, family environment, marital support, bB; family sense of coherence [SOC], cC; coping strategies, BC). The results indicated that higher levels of child externalizing behavior, having less ability to see stressors as a challenge, and lower levels of family SOC predicted mothers' higher stress, and lower levels of child externalizing behavior and higher levels of family SOC and coping predicted mothers' family QOL ([McStay et al., 2014](#)). In the United States, [Manning, Wainwright, and Bennett \(2011\)](#) assessed how life stress, severity of autism symptoms, behavior problems (aA), social support (bB), religious coping (BC), and reframing (cC) impact family functioning and parental stress (xX) and found that 28% of family functioning and 46% of parental distress were explained by these variables.

The impact and relationship among variables in the Double ABCX model also have been explored in various ways. [Pozo, Sarriá, and Brioso \(2014\)](#) investigated family QOL and psychological well-being (xX) among parents of children with ASD in Spain using a multidimensional approach. In their path analyses, behavior problems (aA) had a negative indirect effect on family QOL and psychological well-being (xX) through SOC (cC), and disorder severity (aA) and social support (bB) were significantly related to family QOL (xX). On the other hand, [Pakenham, Sofronoff, and Samios \(2004\)](#) explored meaning-making (benefit-finding and sense-making) by content analysis and examined the relationships between the meaning variables and the double ABCX model variables among parents of children with Asperger syndrome in Australia. In the study, the meaning variables were positively related to social support, self-efficacy, problem-focused and emotional approach coping strategies. Additionally, [Paynter, Riley, Beamish, Davies, and Milford \(2013\)](#) studied the applicability of the double ABCX model among parents of young children with ASD attending early intervention in Australia. They reported that higher symptom severity (A), greater pile-up of life demands (aA), negative appraisals of caring for a child with ASD (C), and greater use of active-avoidant coping styles (cC) would be related to increased parental psychological distress. These studies indicated that the Double ABCX model can be a useful tool to assess the roles of resources and appraisal of parental adaptation in various ways.

In Japan, family adaptation has been partially explained by a different model. For example, [Makiyama \(2011\)](#) assessed the QOL model, which focused on factors to promote mental health of parents of children with disabilities. They found that sense of authenticity and subjective happiness strengthened QOL through SOC and social support. In other cases, [Kojo and Fukumaru \(2015\)](#) investigated depression and related factors among parents of children with spina bifida and concluded that stress about parenting and escape-avoidance coping were positively related to maternal depression whereas support from grandparents, patient, and family support groups; age; and social capital (SC) were negatively related to maternal depression. On the other hand, [Irie and Tsumura \(2011\)](#) developed a family intervention model to facilitate resilience in families of children with IDs through qualitative research and found that intervention of "linking the family with community" improved the stress coping capacity of these families. Furthermore, we focused on mothers of high school students without disabilities and confirmed that mothers living with a higher level of SC were more likely to be higher in SOC ([Kimura, 2011](#)), though the relationship between stressors of raising disabled children and parental SC, SOC, and adaptation have not been explained by a theoretical framework. How we explain the relationships between these factors?

The present study aims to investigate predictors of adaptation among mothers of children with IDs by applying the concept of the Double ABCX model ([McCubbin & Patterson, 1983](#)). As a result of inadequate systems and support, mothers

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