

## POSITIVE ADAPTATION IN LATINO FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES: AN INITIAL TEST OF POSITIVE ADAPTATION THEORY

### L'ADAPTATION POSITIVE DES FAMILLES LATINOS AVEC UN ENFANT AYANT UNE DÉFICIENCE INTELLECTUELLE: UNE PREMIÈRE VUE DE LA THÉORIE DE L'ADAPTATION POSITIVE

S.I. Aldana, G.H.S. Singer, C.A. Maul, A. Magaña, & S.I. Esparza

#### Abstract

Historically, research on disability and family dynamics drew from Psychology and Medicine. Consequently, eugenics models, grief theory, and other largely decontextualized frameworks of stress and coping were used to explain families of children with disabilities. This is a report of an initial test of a set of ideas the Singer research team has combined in order to explore the cognitive and problem-solving approaches of families of children with disabilities. Our purpose is to propose a contextualized theory for explaining how cultural diversity has an impact on positive adaptation to a child's disability. This theory addresses the following: 1) attachment; 2) internal and external cultural resistance to stigmas about disability; and 3) perceived informal (family/friends) and formal (professionals) sources of support for positive views about disability and parenting. Sampling Latino families demonstrated how cultural contexts demonstrate a different flavour from majority culture interpretations of these cognitive terms of our proposed theory. Transcripts of the interviews were coded using grounded theory analysis, specifically, the constant comparative method. We discuss the goodness of fit for themes emerging from the coding process with the proposed theory terms. Results confirm attachment, social supports, and cultural resistance as terms for future development of this proposed theory.

*Keywords: Disability and parenting, positive adaptation, Latinos and disability, culture and disability*

#### Abstrait

À travers l'histoire, la recherche sur les handicapés et les relations intrafamiliales utilisait comme sources la psychologie et la médecine. Par conséquent, les modèles de l'eugénisme, les théories sur le deuil, et d'autres cadres analytiques sur le stress et les stratégies d'adaptation, plutôt décontextualisés, étaient utilisés afin d'expliquer aux autres comment fonctionnaient les familles avec un enfant handicapé. Ceci est un reportage sur un test initial d'un ensemble d'idées qu'a combiné l'équipe de recherche Singer afin d'aborder les approches cognitives et méthodes actives des familles des enfants handicapés. Nous proposons une théorie contextualisée afin d'expliquer comment la diversité culturelle aurait un effet sur l'adaptation positive de la famille face à l'handicap de leur enfant. Cette théorie aborde les idées suivantes : 1) l'attachement; 2) les résistances culturelles internes et externes aux stigmates sur l'handicap; et 3) les sources d'information sur l'handicap et le parentage liées à l'adaptation positive perçues comme informelles (famille/amis) et formelles (les professionnels). En utilisant un

échantillon de familles Latinos, nous démontrons comment les contextes culturels démontrent des interprétations différentes des termes cognitifs de notre théorie, et non l'interprétation de la culture majoritaire. Les transcriptions des interviews étaient codées selon la théorie ancrée, plus spécifiquement la méthode de la comparaison constante. Nous discutons la concordance des thèmes venus via le processus d'encodage avec les termes clés de la nouvelle théorie proposée. Les résultats de cette recherche confirment que l'attachement, le soutien social, et la résistance culturelle seront des termes clés dans le développement de cette théorie proposée.

*Mots clés : Handicap et parentage, Adaptation positive, Latinos et handicap, culture et handicap*

## Introduction

Previous ways of assessing families of children with disabilities are evidence of inappropriately applied theories, when the task is to understand these families in an increasingly multicultural society. In particular, the framework of stress and coping does not specify the critical terms and processes necessary to explain positive outcomes in families of children with disabilities. Dr. George H.S. Singer of the University of California at Santa Barbara and his research team of graduate and undergraduate students in special education, disabilities, and risk studies, developed a theory that is contextualized by the family's response to a child's disability and explains how families from different cultures adapt positively to a child with a disability. Specifically, research in positive adaptation provides a vehicle for altering the types of support available to families. This qualitative study elicited support for our theory's cognitive and problem-solving terms: attachment and stigma, cultural resistance, social supports, reliable alliances with key sources of support (professionals), and the establishment of sustainable daily family routines congruent with family's cultural expectations for family life. This paper addresses the cognitive terms of our proposed theory: attachment and stigma, cultural resistance (internal/external resistance to disability and persons with disabilities), and perceived social supports (informal/formal) are presented, as is the confirmation or disconfirmation of each term. The problem-solving terms will be defined in future work.

### *Attachment and Parenting Involving Children with Disabilities*

Several paradigms address family functioning for families that have a child with a disability. Historically, services were primarily designed in response to negative subtext rather than positive frames. Professionals and the community assisted families with grieving rather than encouraging attachment and facilitating growth and development because having a child with a disability could lead to divorce, behavioural problems of siblings, maladjustment, and stress on the family (Risdal & Singer, 2004). Several researchers, including Bailey and Wolery, Blancher, and Collins-Moore, cite appearance, negative or lack of responsiveness, delayed smiling, medical frailty, and lack of eye contact as contributors to lack of attachment between mother and child (as cited in Seligman & Darling, 1997). However, in spite of these obstacles, parents actually do bond and attach to their children with disabilities (Seligman & Darling, 2007).

There is emerging evidence that most parents view the experience of parenting a child with a developmental disability positively, and that over the long term, families are best described as resilient (Hastings, Allen, McDermott, & Still, 2002; Seltzer, Greenberg, Floyd, Petee, & Hong, 2001; Turnbull, Patterson, Behr, Murphey, Marquis, & Blue-Banning, 1993). As the number of parents of children with disabilities in academia increased, so too did questions related to the lack of investigation on resilience in families with children with disabilities (Risdal & Singer, 2004). Furthermore, many parents were found both to associate disability with positive meanings and to have the power to create environments conducive to having a good quality of life (Risdal & Singer, 2004).

Research shows that attachment is not instinctual but rather a process of parent-child interaction. This explains why most parents form strong bonds with their children with disabilities by interacting with them and by receiving the encouragement of

supportive individuals (Seligman & Darling, 2007). Further, Bowlby and Ainsworth identified that a secure base figure encourages exploration and safety for the attached person (as cited in Vaughn, et al., 2007). In addition, internal working models change as the child matures and is open enough to be influenced by changes in the attachment relationship; in the case of a child with a disability, there may primarily be physical or intellectual changes (Vaughn et al., 2007). Bowlby believed this process to be true across cultures because the secure base relationship was a behavioural process resulting from a co-construction (as cited in Vaughn et al., 2007).

A major criticism of this position is that Bowlby's research has been vetted only among European-American populations, discounting other cultures such as the Latino culture, which values interdependence more than autonomy (Vaughn et al., 2007). For example, Latino children are socialized to learn from caregiver activities and to coordinate with the group (Rogoff, 2003). This simultaneously develops autonomy and group engagement (Rogoff, 2003). In order to understand Latino families, one must account for community aspects of caregiver relationships to each other, the community's health and economic circumstances, and cultural provisions for family life and infant care (Rogoff, 2003). The agency by which social, economic, and other societal influences affect families must be identified with more clarity (Bernheimer, Gallimore, & Weisner, 1990). Unfortunately, the effect of culture is a dimension that has been largely left out of previous ways of discussing family processes.

#### *Current Approaches to Parental Adaptation to a Child with a Disability*

Recent eco-cultural approaches mediate the family in terms of social, cultural, and familial interactions and experiences. As a contextualized approach, it optimizes family functioning (Gallimore, Weisner, Kaufman, & Bernheimer, 1989). Since Anthropology, Sociology, and Developmental Psychology are steeped in an understanding of culture and how it interacts with family adaptation to disability, they are particularly useful for understanding a family's positive and negative responses to a child with a disability (Bernheimer, Gallimore, & Weisner, 1990). Gallimore and colleagues (1989) cut across cultural differences by using eco-cultural niche theory to assess families. A niche is both the proximal home environment and the cultural features by which families organize their daily lives. The proximal home environment is defined as parenting style, sibling interaction, and extended family resources; cultural features reflect cultural values and beliefs that pervade everyday activities and organization of the home (Gallimore et al., 1989). Families organize themselves according to patterns and meanings they inherit or adopt from their surrounding culture. Their socially constructed actions are responses to competing cultural demands. Therefore, family accommodation influences and modifies the niche as necessary so the interaction between individual goals and culture shape the broader ecology (Gallimore et al., 1989).

This explains how families adapt to conflicting meanings and actively construct new, reasonable meanings. For example, previous cultural conceptions of disability may be blended with current dominant culture norms. These meanings are satisfying and sustainable within their eco-cultural niche (Gallimore et al., 1989). Therefore, congruency and sustainability are key components for positive family outcomes. Flexibility in achieving them is likely the result of sustaining activities across time

(Gallimore et al., 1989). Eco-cultural theory dispels assumptions of homogeneity in that it reveals the lived texture of family life much better than simple measures of molar variables like socioeconomic status (family income, parental occupation, and social status in the community), education, and levels of stress (Bernheimer, Gallimore, & Weisner, 1990). The Singer research team's proposed Positive Adaptation Theory extends the eco-cultural ideas beyond sustainable daily routines and into cognitive terms including attachment, internal/external cultural resistance to stigma, and perceived sources of support; their theory is meant to increase our understanding of family functioning in a multicultural society.

### *Latino Cultural Norms*

The application of eco-cultural niche theory to parental response to a child with a disability defines culture's role in family cohesion. Generally, culture helps establish social and behavioural expectations of a group. These extend beyond thoughts, emotions, and norms into actions. Both knowledge and behaviour represent culture meaningfully and are "constructed both at a collective and personal level" (McNaughton, 1996, p. 173). In addition, the nature of one's social roles and choices are associated with predetermined sets of behaviour that reinforce that role in their culture (Gardner, 2003). The variability in personal and collective cultures provides an opportunity to examine parenting (McNaughton, 1996). Therefore, an eco-cultural framework facilitates examining Latino families with children with disabilities in their adaptation and family functioning.

Despite nuances among cultures, Bailey, Skinner, Rodriguez, Gut, and Correa (1999) found that most Latino communities have shared political experience, shared language, similar levels of education in their country of origin, and similar socioeconomic challenges. Specifically, Zuniga offers an excellent overview of Latino cultural norms in Lynch and Hanson's (1998) guide on cross-cultural competence. She reviews a variety of contextual variables that influence Latino families, including demographics, familialism, and communication style. There are high rates of underemployment and a significantly younger population among Latino communities compared with those of European-Americans (Zuniga, 1998). In addition, undocumented status, acculturation, social supports, values, education, beliefs, familialism, and child-rearing practices all provide influences on cultural identity. Mistrust of institutions by undocumented immigrants may contribute to a family's ability to respond effectively to the needs of their child with a disability (Zuniga, 1998). In addition, social support networks with others of the same ethnicity facilitate adaptation in terms of learning new socio-cultural norms and developing acceptance of the dominant culture (Zuniga, 1998).

### *Familialism as a Social Support*

Family is culturally important and has historically been defined by static traditional roles, including female submissiveness, male dominance, strict sex roles, and care-giving assignments to females only (Zuniga, 1998). It organizes itself around cultural frames with more flexibility depending on class variations, decision-making necessary for the child with a disability (empowerment/advocacy), and maternal employment (Zuniga, 1998). Additionally, higher levels of education and advocacy

efforts in service systems play a role in how families communicate with professionals in these systems and in their need for specialized responses congruent with emotional aspects related to their child with a disability (Zuniga, 1998).

The degree of familialism influences the degree of acculturation since it is a value immigrant families do not give up (Zuniga, 1998). Their collective sense provides valuable support through extended family networks, including godparents (padrinos), and close friends (compadres) who help in child-rearing activities (Zuniga, 1998). Furthermore, the child-rearing style is predicated on a relaxed attitude and a lack of push for independence. This highly acceptable cultural norm is incongruent with child-rearing values of European-American families (Zuniga, 1998). The field dependant cognitive style emphasizes identity with the family, respect for authority figures, and compliance with conventional thoughts and practices (Zuniga, 1998). Another way cultural values influence Latino parents is through medical folk beliefs characterized by evil eye (mal ojo), evil hex (mal puesto), and fright (susto), which influence parents to take the child to a healer (curandero) for a cure (Zuniga, 1998). It is important to note these influences are moderated by social class and education levels (Zuniga, 1998). Forms of communication used by Latinos are varied since many use both Spanish and an indigenous language, with differences in idioms from one county to another. Lastly, this is a high-context culture in that its communication is based on words and the affect that accompanies the personal delivery of the message (Zuniga, 1998).

Given the convergence of these ideas, the authors attempted to answer the following questions about Latino families with children with disabilities: 1) Does cultural background and experience affect attachment to a child with a disability?; 2) Do internal and external resistance to cultural stigmas characterize parental views toward disability and parental adaptation to a child with a disability?; and 3) Do informal (family/friends) and formal (professionals) sources of support create and sustain positive views about disability and parenting a child with a disability? The levels of these questions extend beyond making sense of lived experience and address how cultural contexts take on a different flavour from dominant-culture interpretations of the key terms identified.

### Methods

When embarking on the task of theory development, this team began with a qualitative study to test the goodness of fit for themes that emerged from extensive practical and academic work with families of children with disabilities. In order to address the breadth and depth associated with the research questions identified in this study, this team developed an extensive interview guide. Parents of children with moderate-to-severe developmental disabilities were recruited and interviewed to provide the qualitative data necessary to explore attachment and stigma, internal/external cultural resistance, and informal/formal sources of support. This study has undergone an ethics review and has been approved at an American university.

### *Inclusion and Exclusion Criteria*

We used the State of California Department of Developmental Services (DDS) definition of developmental disability that includes mental retardation, cerebral palsy, epilepsy, autism, and disabling conditions closely related to mental retardation or requiring similar treatment (California Department of Developmental Services, 2007).

The children were 0 to 12 years of age. Mothers and fathers participated. Further inclusion criteria were the following: a) language spoken in the home (English or Spanish) and b) permanent residence with the child. Exclusion criteria were based solely on inability to meet all four inclusion criteria.

### *Subjects*

Twenty participants were recruited through agencies providing services to the families. These agencies include, but are not limited to, Head Start, Regional Center, and schools. Participants were mostly married couples. There was one single mother whose common law partner did not participate and one single father. For the 18 remaining couples, two husbands indicated that they did not want to participate because it was the woman's role to take care of everything to do with the children.

### *Recruitment*

Participating agencies made initial contact with the parents. The initial bilingual recruitment letter included the statement that there would be no negative consequences if a parent chose not to participate. This mailing included a self-addressed envelope and a form indicating that the participant wanted to learn more about the study and requested address, email, telephone number, and best contact times. It was clear that students and a faculty member at the University of California, Santa Barbara would conduct the research. Recruitment materials were translated by the bilingual, bicultural primary researcher. They were sent for review of idiomatic expressions and back translation by translators at the school district.

### *Data Collection Procedures: Interview Protocols*

Participants took part in in-depth qualitative interviews. We used successive passes through the memory, or cultural knowledge, of the "consultant", in this case a parent (Werner & Schoepfle, 1987, p. 318). The interview guide was designed for the interviewer to elicit information from participants about the following key elements: cultural resistance to disability, development of attachment and reciprocal positive relationships, reliable alliances with key sources of support, and the establishment of sustainable daily family routines congruent with the family's cultural expectations for family life.

Questions were open-ended with a combination of grand tour and mini-tour questions to elicit as broad a response as possible. They were clear and directed in the content they were designed to draw out for each term of our proposed theory. The Spanish version of the interview guide can be found in Appendix 1 with the English version found in Appendix 2. Researchers conducted semi-structured interviews that were conversational in nature and lasted 90 minutes. Participants were given the choice of interview language (Spanish or English), and all but one requested Spanish. The interview with the couple that requested English was actually conducted using what is commonly referred to as Spanglish (Zuniga, 1998). Incentives were provided, mostly to defray the cost of childcare.

Three doctoral students were trained for 6 hours in interview techniques, coding, transcription, and writing. There were minimal risks, though it is possible that the interview evoked difficult emotions or memories, and some participants may have

developed a negative mood as a result. Measures to address threats to validity were implemented, reliability checks were conducted, and data were analyzed using both open and closed coding methods. Validity becomes quite complex in interview research so as transcripts were translated, the meaning of the ideas behind participant responses was kept intact. In addition, the theoretical elements being tested provided external validity (Marshall & Rossman, 1989). Transcriber reliability was maintained by having two bilingual and bicultural researchers review and discuss the transcriptions for Spanish language accuracy. Both researchers compared translations of the interviews for correctness. The co-principal investigator conducted all interviews since she is a native Spanish speaker with a bicultural background. This interviewer was raised abroad and was sensitive to the upbringing of the Latino participants. In addition, her visible disability contributed to the development of rapport. However, researcher bias was controlled for by audio-taping the interviews and having an additional bilingual researcher transcribe them, as well as providing the non-Spanish speaking principal investigator with translations of the transcripts.

### *Data Analysis Procedures*

This investigation identified initial questions that would focus and test variables within socio-cultural contexts with complexities not easily addressed by traditional quantitative social science research (Marshall & Rossman, 1989). Interviews were transcribed by an undergraduate bilingual researcher who was instructed to type the interviews in Spanish verbatim, but to leave out tangential discussions (Kvale, 1996). However, long pauses or serious distractions were noted. The transcripts were then reviewed by the first author, who retyped sections that were necessary for intensive analysis. English translations of the transcripts facilitated data analysis for non-Spanish speakers on the research team. The undergraduate bilingual researcher and school translator were both included in the review of the translated documents.

Transcripts were analyzed using both closed and open codes. Maternal and paternal responses were categorized for easy retrieval and identification of specific statements. A constructivist approach to grounded theory analysis allowed the authors to include "preconceptions and assumptions" (Charmaz, 2002, p. 683). Closed codes were used as a priori categories in the development of the interview guide so as to ensure that the interviews elicited information about development of attachment, internal/external cultural resistance, and informal/formal sources of support. This conceptual framework maintained flexibility and allowed for the incubation, reorganization, reconstruction, and evolution of ideas (Marshall & Rossman, 1989). Subsequently, an open coding procedure was used to examine the transcripts with as little inference as possible. Initial coding was conducted in a line by line format (Charmaz, 2002). Meaning units were assigned to descriptive codes and these meaning units were then collapsed into larger intermediate level codes. These intermediate codes were collapsed into emergent themes. Group discussions examined divergent interpretations of parents' statements. Findings from open ended coding were compared with and contrasted to identify contrary and supportive evidence for each element of the theory. Emergent themes were identified as supportive of the theory element they reflected.

## Results

All participants were from Mexico. No specific data were kept on their duration in the United States, their immigration status, or related issues in order to ease their verbalized levels of anxiety about potential deportation for their participation in the study. Many casually indicated that they had been in this country as long as or longer than the date of birth of their child with a disability. All were educated in Mexico with 35% completing a sixth grade education, and 21% had varying degrees of a high school education. The following results are for resistance to stigma and development of attachment, internal/external cultural resistance, and formal/informal sources of support.

### *Attachment Transcends Shock of Diagnosis and Stigma*

Development of attachment was meant to identify parental preconceptions of disability. It was anticipated that attachment and reciprocal positive interactions would help parents counter negative meanings about their child. As such, internal and external sources of resistance were analyzed. We expected developing a loving relationship with the child would serve as a buffer against stigma. In terms of negative views or images about people with disabilities prior to their child's birth, most participants did not directly say that they have ideas associated with stigma; however, they described a change in their thinking from seeing disability as something distant and strange, possibly stigmatized, to viewing people with disabilities as equals. Specifically, one response was the following:

Father: No. Cambio mucho mi concepto sobre todo esto. Empezamos a valorizar más a todas las personas por medio del niño. Empezamos también a atender programas de muchos niños que nacen también así, empezamos aprender mucho, empezamos a valorar más a la gente. (Translation: No. My concepts about that changed greatly when he was born. We began to value all people because of our son. We began to attend programs for children born that way and we learned a lot; we began to value people more.)

Since cultural norms are transmitted in typical daily occurrences, we asked parents if they encountered negativity from other people about their children with disabilities. We assumed stigma would be communicated through negative comments or interactions over time. Parents were asked to recount specific instances in which they had experienced external sources of stigma. Many described these negative encounters with strangers in Latino neighbourhoods or their country of origin:

Mother: Si nos han dicho de que, "¿Oye porque tu hijo es así?" Y te sientes mal...Decimos, no es que tiene un problemita pero se ve normal. Dicen dale unas nalgadas y se le quita. Y luego a veces te hacen sentir mal porque hay ciertos niños que, "Ay, yo no quiero jugar con el." (Translation: Yes they have said to us, "How come your son is that way?" and you feel bad. We say he has a problem but he looks normal. They say spank him and he'll stop. Then there are other children who say "I don't want to play with him.")

We also asked if their relationship with their child changed over time (distance/closeness). One couple responded:

Mother: La relación con mi hijo siempre ha sido igual de cariñosa. ...estaba un poco triste de haber tenido un hijo con discapacidad, pero luego lo superé...Le damos mucho cariño. (Translation: My relationship with my son is as caring as it always has been. ... I was a little sad to have had a son with a disability, but quickly moved beyond it. We give him much affection.)

Father: La relación siempre ha sido igual...teníamos un poco de recelo de porque el nació como nació...Brindarle todo el apoyo que necesite a mi hijo. (Translation: My relationship [with him] has never changed...we had some misgivings because he was born the way he was born. We extend to him all the support that he needs.)

Several parents had similar responses indicating that they had always felt an attachment and deep love for their child and that this had not changed over the course of time. Feelings of fear about having the ability to provide for the child's needs were common, but appeared to be a reflection of parental responsibility rather than a contributor that would impede attachment.

#### *Cultural Resistance Exists in Certain Contexts and Families are able to Counter it with Positive Meanings*

We posited that in order to develop and maintain positive views of their child, parents might need to find ways to buffer negative views of disability common within their culture. One question in particular clearly demonstrated that culture has an impact on interactions with persons beyond extended family. We asked, "Do you think people in your culture support you in your positive views about disability?" Several of the couples lived in areas that were readily accessed and influenced by the dominant culture, and therefore, they had little opportunity to experience higher levels of stigma, but indicated awareness that it existed in their culture. One couple emphatically stated:

Mother: No pues, por eso nos cambiamos. O sea allí donde vivíamos habían mucho Latinos y se lo quedaban viendo. (Translation: Well, that's why we changed [moved]. Or rather, where we lived there were many Latinos and they would stare at him.)

Father: Estamos bien ahora porque casi no hay Latinos, hay mucho americano allí. Pues no hay fracasas y cosas así. No, no para nada. La comunidad Latina, por lo regular es la mas discriminatoria. Niños, los entiendo porque son niños. Pero la gente grande que ya sabe y piensa, ya es diferente. (Translation: Today we're fine because there are hardly any Latinos, there are many Americans there. There are no altercations and things like this. The Latino community for the most part is more prejudiced. Children, I understand because they're children; but, adults who have knowledge and think, that's different.)

For many stay at home mothers, their interactions in the social context were limited to experiences with service providers, educators, or local merchants. Fathers primarily spent most of their time outside the home and were better able to explain the cultural differences between their current environment and their country of origin in relation to resistance, or lack thereof, toward persons with disabilities.

*Social Support is Culturally Bound and is Formal/Informal*

To examine the role of social support in families, we asked, “Do informal and formal social supports help in creating and sustaining positive views about disability and the parenting of a child with a disability?” and “Do you have people you can count on to be supportive of your positive beliefs about disability?” Many parents believed there were friends who were supportive, but some indicated that they were not sure these individuals made positive comments. For instance, one couple stated:

Mother: Si hay personas, pero solo nos brindan amistad y apoyo, pero no se si brindaran comentarios positivos. (Translation: There are some people, but they give us friendship and support only; I don't know that they make positive comments.)

Cultural support as a source of informal support resonated when participants were asked, “How have people in your culture supported you in your new beliefs?” Though many did not view their attachment to their child as a new belief, they were grateful and eager to share their positive experiences with friends and loved ones who were protective and tried to facilitate understanding of their child with a disability:

Mother: Yo tengo gente que me apoya siempre, por ejemplo, en un cumpleaños de mi hijo, él estaba en una caja de arena jugando, y le echo arena a una niña que estaba con una señora, y ella se enoja y lo regaña, entonces unas amigas fueron y se pararon peleando con la señora con tal de defender a mi hijo, y eso se siente bien. (Translation: I have people that always support me. For example, at one of my son's birthday parties, she was playing in the sandbox and he threw sand on a young girl who was with a woman and a woman began to scold him. Then my friends went over there and began to argue with the woman in order to defend my son; that was nice.)

Father: Aquí en Estados Unidos no ven tan mal a las personas discapacitadas, por ejemplo, yo voy en la calle, y todas las personas me saludan y le dan poca importancia a la enfermedad de mi hijo, y yo pienso en broma que lo voy a sacar más seguido para que me saluden más. (Translation: Here in the United States they don't look at persons with disabilities that badly. For example, I'll walk down the street, and all the people greet me, and they don't pay much attention to my son's illness; I think, jokingly, that I'll take him out more often so that they'll greet me more.)

Specifically, when asked “Who helps support positive perceptions of your child?”, many referred to close friends or family:

Father: Yo creo que la misma familia, por ejemplo, mis niñas lo quieren mucho, y juegan con él y todo de lo más tranquilo. Yo lo cuido igual que a mis otros hijos, ni más ni menos, y yo creo que eso es lo que nos mantiene fuertes, el apoyo que nos damos adentro de la familia. Estos vecinos pasan enfrente de la casa, y solo dicen que lo traen después y se lo llevan a jugar, eso nos alegra mucho...a veces llevo a mi hijo al trabajo y lo saludan y lo tratan bien, nada más. (Translation: I think it's our own family, for example, my daughters love him very much and they play with him and all that in the most tranquil way. I take care of him the same as my other children, not more or less, and I think that that has kept us strong, that support that we give ourselves within our family. Some neighbours pass in front of the house and they just say they will bring him back later and they take him out to play, that makes us very happy...sometimes I take my son to work they greet him and treat him well, but nothing more.)

Another form of informal sources of support comes from family support/giving hope with positive views. Participants were asked, “Did family members help you see your child in a more positive light?” Responses suggest that family was very supportive. Most felt the support they received was unspoken but clear through cultural interactions; some indicated that the support came from conversations specifically related to the issue of their child's disability:

Mother: La familia, la familia es la que siempre lo apoya a uno. Pues ellos también piensan igual que nosotros. A veces llegamos a platicar de eso y ellos también piensan lo mismo que nosotros. O sea, que siempre casi nosotros estamos de acuerdo en los pensamientos. (Translation: The family, the family is the one that supports you. Well, they also think the way we do. Sometimes we talk about these things and they think the way we do. Rather, we are usually thinking the same thing.)

We also examined the people on whom the family depends. Parents were asked whom they can rely on when needed. Most indicated family and a few identified close friends:

Father: Si pues, la familia, como ella dice. (Translation: Yes, the family, like she says.)

Regarding formal social support, parents were asked, “Did professionals help you see your child in a more positive light?” Only one parent indicated a negative response. Her epilepsy may have presented a confounding variable. She was discouraged by her gynecologist during both pregnancies because she discontinued use of anticonvulsants and had the potential to transmit her disability to her children. It is noteworthy that all other parents indicated positive experiences with formal support systems:

Mother: La doctora se porto muy bien con nosotros, y sobre todo con mi hijo.  
(Translation: The doctor was good to us and most of all to our son.)

Another formal support is the formation of parent groups. Most respondents indicated positive experiences or a desire to have more significant interaction with other parents. In particular, the desire was to have support from others who can relate to their own experience:

Mother: Si, y mucho, porque ellos también habían pasado por esto, entonces nos ayudaron mucho. (Translation: Yes, a lot because they also have been through this, so they help us.)

Parents were asked, “Are there any people whom you can rely on when you need them?” Respondents identified multiple sources of support when asked the same question of their informal social supports yet only identified the Regional Center system in relation to formal social supports.

### Discussion

Summers, Behr, and Turnbull (1989) took the theory of cognitive adaptation (Taylor, 1983) and applied it to positive adaptation in parents of children with disabilities. These researchers provided a meaningful attempt to address supportive and encouraging approaches to working effectively with parents of children with disabilities. It is unfortunate that this theory largely remains decontextualized. This study began the process of contextualizing all the terms of this theory by asking specific questions in the areas of attachment and stigma, informal/formal sources of support for positive views of the child with a disability, internal/external cultural resistance, reliable alliances with key sources of support, and the establishment of sustainable daily family routines congruent with family’s cultural expectations for family life.

Resisting stigma involved the duality of internal and external resistance. The first assumption was that our society takes for granted that disability is undesirable and has a negative halo. The second assumption was that parents have pre-existing negative views of disability, which would include perceptions about disability as something strange or distant for their lives. Cultural schemas were viewed as negative if their understanding of disability did not include positive coping strategies and positive adaptation. Parents were expected to counter pre-existing negative views about disability with the development of positive perceptions and ultimately would positively adapt to their child with a disability through a process of cognitive adaptation. The findings for this term are inconclusive; this may be due to a confounding variable like social desirability. Most participants did not report they believed their pre-existing views of persons with disabilities were negative regardless of labelling disability with adjectives like pity, obligation, and God’s plan. Although most did not say that they started with negative views, they said their views about valuing people with disabilities changed after having a child with a disability. This process would seem to indicate that there was a shift from negative or neutral valuation to more positive attitudes.

External resistance is the influence of the social environment on individual perceptions of disability. One assumption was that recent immigrants have experienced

a different societal framing of perceptions of disability. Links between folk ideas and religious subtexts influence perceptions of social and cultural beliefs and values attributed to disability. Directly related to that assumption is the fact that efforts in disability rights, social services, and special education have contributed to the creation of a different atmosphere in the United States. There was an expectation that parents would recognize these clearly identifiable differences between their differing social contexts. The findings related to resisting external stigma showed that participants indicated they had experienced a distinction between how people with disabilities are valued in their country of origin and how people with disabilities are valued in the United States. They acknowledged that people from their culture were predisposed to having more negative views while European-Americans had very different and positive responses toward their child with a disability. The Latino immigrant community may have brought these views with them to the United States and that contrast has the potential to influence positive parental adaptation. It follows that this would be more likely for families that have fewer informal social supports (extended family/friends) in their new socio-cultural context.

Initial assumptions about attachment were twofold. Firstly, researchers acknowledged that parents attach to their children, and this process helps buffer against internal/external sources of stigma. Secondly, parents will develop, either independently or in conjunction with sources of social support, the ability to meet the challenges of raising a child with a disability. The current research demonstrated that parents arrived at positive adjustment to their child with a disability. Specifically, findings were that parents responded by treating the child with a disability as they do any of their other children.

In terms of social supports (informal/formal), questions were based in the idea that family and friends may or may not be informal supports for parents' positive perceptions about their child's disability. In addition, formal support systems are culturally foreign ideas to recent immigrants, and therefore their interactions with the system may be limited or tangential. The expectation was that family, friends, professionals, and other parents of children with disabilities provide support of positive views toward disability and the child with a disability. The findings supported these expectations by an overwhelming percent for informal and formal sources.

The initial impression of cultural resistance was that there may be pervasive negative attitudes toward disability among Latinos who may not be educated about tolerance and support for persons with disabilities. Researchers expected to find that families living in the United States would not experience as much blatant prejudice as they would if they were in their country of origin. Participants living in predominantly recent-immigrant Latino communities reported experiencing higher levels of prejudice and alienation; while those living in highly Anglo communities reported substantial instances of acceptance and integration. It may be that because fathers spend much of their time outside the home, they are better able to identify stark differences between the two cultural contexts. Mothers, as primary caregivers, may not perceive cultural resistance because they spend much of their time involved with either Spanish-speaking, culturally sensitive European-American service providers or Latino service providers and recent immigrant social supports. Further research is needed to identify

contributing factors to these differences. Meanwhile, this research project indicates strong support for a contextualized approach.

#### Conclusion

Generally, the findings supported the following key terms: stigma, attachment, social supports, and cultural resistance. It is important to note that these findings apply only to responses from parents and do not include data from siblings, extended family, or social support networks. Future analysis will qualitatively address the practical solving of problems, codified in our theory as sustainable accommodations and professional relationships. Upon completion of this process, this team will embark on a comparative study between the cultural groups that participated in this qualitative work. Additionally the codes and themes in this study will be used to develop quantitative data collection instruments that will then further test the terms of our proposed theory.

## References

- Bailey, D., Skinner, D., Rodriguez, P., Gut, D., & Correa, V. (1999). Awareness, use, and satisfaction with services for Latino parents of young children with disabilities. *Exceptional Children, 65*(3), 367 –381.
- Bernheimer, L. P., Gallimore, R., & Weisner, T. S. (1990). Ecocultural theory as a context for the individual family service plan. *Journal of Early Intervention, 14*(3), 219 –233.
- California Department of Developmental Services (2007). Information about Developmental Disabilities. Retrieved from [http://www.dds.ca.gov/general/info\\_about\\_dd.cfm](http://www.dds.ca.gov/general/info_about_dd.cfm)
- Charmaz, K. (2002). Qualitative interviewing and grounded theory analysis. In J.F. Gubrian, & J.S. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 675 –694). Thousand Oaks, CA: Sage.
- Gallimore, R., Weisner, T. S., Kaufman, S. Z., & Bernheimer, L. P. (1989). The social construction of Ecocultural Niches: family accommodation of developmentally delayed children. *American Journal on Mental Retardation, 94*(3), 216 –230.
- Gardner, R. (2003). Identity frames. Beyond intractability. Retrieved from [www.beyondintractability.org/m/identity\\_frames.jsp](http://www.beyondintractability.org/m/identity_frames.jsp)
- Hastings, R.P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(3), 269 –275.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. London: Sage.
- Marshall, C., & Rossman, G. B. (1989). *Designing qualitative research*. Newbury Park, CA: Sage.
- McKeever, P., & Miller, K. L. (2004). Mothering children who have disabilities: A Bordieusian interpretation of maternal practices. *Social Science and Medicine, 59*, 1177 –1191.
- McNaughton, S. (1996). Ways of parenting and cultural identity. *Culture & Psychology, 2*, 173 –201.
- Risdall, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities, 29*(2), 95 –103.
- Rogoff, B. (2003). *The cultural nature of human development*. Oxford: Oxford University Press.
- Seligman, M., & Darling, R.D. (2007). *Ordinary families, special children*, (3<sup>rd</sup> ed.) New York: Guilford Press.
- Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Petee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal of Mental Retardation, 106*(3), 265 –286.
- Summers, J.A., Behr, S. K., & Turnbull, A.P. (1989). Positive Adaptation and coping strengths of families who have children with disabilities. In G.H.S. Singer, & L.K. Irvin (Eds.). *Support for caregiving families: Enabling positive adaptation to disability* (pp. 27–40). Baltimore, MD: Paul H. Brooks Publishing.

- Taylor, S. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 83(11), 1161 –1173.
- Turnbull, A.P., Patterson, J.M., Behr, S.K., Murphey, D.L., Marquis, J.G., & Blue-Banning, M.J. (1993). *Cognitive coping, families, and disability*. Baltimore MD: Paul H. Brooks Publishing.
- Vaughn, B., Copolla, G., Vermissimo, M., Monteiro, L., Santos, A., Posada, et al. (2007). Coordination between organization of mother's secure base knowledge and children's secure base behavior at home in three socio-cultural groups. *International Journal of Behavioral Development*, 31, 65 –76.
- Werner, O., & Schoepfle, G.M. (1987). *Systematic fieldwork: Ethnographic analysis and data management*. London: Sage
- Zuniga, M. (1998). Families with Latino Roots. In E.W. Lynch, & M.J. Hanson (Eds.). *Developing cross cultural competence: A guide for working with children and their families*, (2<sup>nd</sup> ed.) (pp. 209 –250). Baltimore, MD: Paul H. Brooks Publishing

## Appendix 1

**Guía para la entrevista**

¿Qué sintió al saber que su hijo/hija tenía una discapacidad?

¿Antes de que su hijo/hija fuera identificado/a como discapacitado/a, qué opinaba Ud. sobre personas con discapacidades?

¿Tenía Ud. imágenes o pensamientos negativos sobre discapacidades?

¿Otras personas hicieron o dijeron algo que le hizo pensar que otros individuos tienen una opinión negativa su hijo/hija? ¿Si es así, quién y bajo cuales circunstancias?

¿Sus opiniones han cambiado?

¿Tiene Ud. a personas que apoyen sus nuevas opiniones?

¿Cómo le hay ayudado las personas de su propia cultura en sus nuevas opiniones?

¿Quién ayuda en apoyar sus nuevas opiniones?

¿Los miembros de su familia ayudaron par ver su hijo/hija de forma más positiva?

¿Los profesionales ayudaron con esta labor?

¿Y los amigos?

¿Hay otras personas que ayudaron/ayudan a enseñarle y mantener una perspectiva positiva?

¿Los padres de otros niños con discapacidades ayudaron en la adquisición de un punto de vista mas positivo?

¿Conoce Ud. a personas de las que puede depender en caso de necesidad?

¿Estima Ud. Que alguna vez la crianza de su hijo/hija crea estrés? ¿En caso afirmativo, considera Ud. que su hijo/hija es la causa principal de ese estrés?

¿Ha cambiado Ud. sus costumbres diarias y las de su familia debido a su hijo/hija y su discapacidad?

¿Si es así, de qué forma?

Preguntas adicionales para Pregunta numero 6 de la Investigación de Ajusto de padres con niños con discapacidades.

Preguntar sobre rutinas específicas: Alistarse par ir a la escuela, comidas, tiempo libre en la casa, hora de dormir, excursiones o paseos familiares, salidas a restaurantes, celebración de cumpleaños.

Declaración de intrevistor: Algunos padres encuentran que hacen cambios a la rutina diaria para ajustar a las necesidades de su hijo con discapacidad. Por ejemplo, podría ser que se levantan más temprano para ayudarle as su hijo a alistarse para irse a la escuela. En las siguientes preguntas quiero pedirle que me explique aspectos de su vida diaria y si ha tenido que hacer cambios debido a las necesidades de su hijo. También quiero saber como le han funcionado esos cambios y quien participa en ellos y porque. El enfoque de estas preguntas es mas sobre el impacto que han tenido en su familia tantos antes que despues de los cambios.

La Mañana – alistándose para el trabajo y la escuela

¿Que cambios han hecho?

¿Le funcionan?

¿Aumentan su estrés?

¿Quien ayuda con esta actividad?

¿Como llego a hacer estos cambios?

Comidas en la casa.  
 Comidas en restaurantes.  
 Viendo televisión como familia.  
 Ir al cine o eventos de deportes como familia.  
 Ir en el carro como familia.  
 Preparando comidas o meriendas (batanear).  
 Tiempos entremedio de actividades.  
 Salidas los fines de semana. (Incluyendo la iglesia).  
 Que hacer de la casa.  
 Cuidando y jugando con los animales domestico.  
 La hora de bañarse o ducharse.  
 Alistándose para acostarse. (Cambiando ropa, lavar dientes, etc.)  
 Durmiendo durante la noche.  
 Visitando familia.  
 Tener diversión entre familia.  
 Haciendo tarea.  
 Haciendo las compras.

¿Ha cambiado su horario de trabajo para Ud. y su familia (de empleo)?

¿Ha cambiado de vivienda?

¿Han ayudado profesionistas en diseñar cambios para ayudar a la vida diaria de su familia?

¿Estos cambios están teniendo buenos resultados para Ud. y para otros miembros de su familia?

¿Cómo se lleva Ud. con profesionales?

¿Ha recibido apoyo de algunos por sus puntos de vista positivos? ¿Quién (indicar el rol de la persona no su nombre)? ¿En qué consistió ese apoyo?

¿Hay profesionales que no han apoyado sus puntos de vista positivos?

¿Ha sido más difícil obtener la clase de ilusión/esperanza que Ud. Esperaba?

¿Cuáles fueron las organizaciones que no ayudaron o apoyaron? (por ejemplo: escuelas, iglesia, hospital, etc.)

¿Cuáles fueron las organizaciones que no ayudaron o apoyaron?

Hábleme sobre la relación que tiene con su hijo/hija.

¿En el transcurso del tiempo cómo ha cambiado esa relación?

¿Inicialmente se sentía distante de su hijo/hija?

¿Qué ocurrió para estrechar esa relación?

¿Cuáles son los momentos preferidos que Ud. Pasa con su hijo/hija?

¿Cuáles son las conductas que a Ud. más le gustan de su hijo/hija?

¿Qué hace que Ud. se sienta orgulloso/a de su hijo/hija?

¿En general su hijo/hija ha contribuido o ha quitado calidad de vida a la familia?

## Appendix 2

**Interview guide**

What was it like to learn that your child has a disability?

Before your child was identified as disabled what were your views of people with disabilities?

Did you have any negative images or thoughts about disability?

Did other people do or say things that made you think that your child is viewed negatively by others? If so, who and under what circumstances?

Have your beliefs changed?

What helped you to change your beliefs?

Do you have people you can count on to be supportive of your new beliefs?

How have people in your culture supported you in your new beliefs?

Who helps support your new beliefs?

Did family members help you see your child in a more positive light?

Did professionals help with this work?

How about friends?

Others who helped/help you learn and keep a positive outlook?

Have parents of children with disabilities helped you acquire more positive views?

Are there any people who you can rely on when you need them?

Do you ever find a parenting your child is stressful? If so, do you see your child as the main cause of stress?

Have you changed the way your family goes about its day because of your child with a disability?

If so, in what ways?

#### Additional Questions for Parent Adaptation Study

Statement for interviewee: Some parents find that they make changes to the daily activities in their family in order to adapt to their children with disabilities. For example, some parents say that they get up earlier than they might otherwise in order to help their child with a disability get ready for school. In the following questions, I will ask you about different aspects of family life and if you have made changes in them for your child. I will also ask how well those changes are working for you, who is involved and how you chose them. The emphasis here is not so much on the person with the disability but rather the changes that other family members make in their routines.

Morning – getting ready for school or work.

What changes have you made?

Do they work for you?

Do they add to your stress?

Who is involved in the changed activity?

How did you come up with these changes?

Eating meals at home.

Meals at restaurants.

Watching television as a family.

Going to movies or sports events as a family.

Riding in the car with the family.

Preparing food for meals or snacks.

Unscheduled time such as the time between coming home from school and dinner.

Family outings on the weekend. (includes church)

Household chores.

Taking care of and playing with pets.

Bath or shower routines.

Getting ready for bed. ( changing clothes, brushing teeth, etc)

Sleeping at night.

Visiting relatives.

Having fun as a family.

Doing homework.

Going shopping.

Have you changed work schedules for you or your family (for outside employment)?

Have you changed where you live?

Have professionals ever helped you to design changes in activities to make family life go better?

Ask about specific routines: getting ready for school, meals, leisure time at home, bed time, going on family outings, going to restaurants, celebrating birthdays?

Are these changes working for you? For other family members?

How do you get along with professionals?

Have any been supportive of your positive views? Who (role not name)? What made them supportive?

Have any not been supportive of your positive views?

Has it been more difficult to get the kind of help you want?

What organizations have been helpful? e.g. schools, church, hospital, etc.

What organizations have not been helpful?

Tell me about your relationship with your child?

How is it changed over time?

At first did you feel distant from your child?

What helped you get closer?

What are your favorite times with your child?

What are your favorite behaviors your child does?

What are you proud of about your child?

Overall has your child contributed to or detracted from their family's quality-of-life?