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“Welcome to Holland:

Characteristics of Resilient Families Raising Children with Severe Disabilities”

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Abstract

This descriptive study sought to examine the resiliency factors families developed when faced with the challenges of raising a child manifesting a severe disability. The study compares and contrasts how families managed the additional responsibility and stress of raising a child with special needs. The

study seeks to identify, the key characteristics present in resilient families allowing them to not just survive but thrive.

The study found that there is relationship between resilience and Socio Economic Status (SES). The study also found that having the time and the ability to reflect was key to reconfiguration, which is seen as crucial in the development of resilience. Once afforded this type of time the families reconstructed their vision of family, of disability and their child. Lastly, the study found that the development of resiliency was enhanced by the development of rhythm in the family. Rhythm is defined in this study as the establishment of consistent rules, rituals and routines.

Key words- families, resiliency, disabilities, family systems, ecological, reconfiguration

Introduction

This study sought to examine the resiliency factors families developed when faced with the challenges of raising a child manifesting a severe disability. The study compares and contrasts how families managed the additional responsibility and stress of raising a special needs child and sought to identify, the key characteristics present in resilient families that allows them to withstand the stress of raising a child with special needs while also becoming strengthened and resourceful.

The study of resilient families, their characteristics and dimensions has been a rich area of research for the past twenty years. However, family resilience research in the area of raising children with severe disabilities has not been as thoroughly researched.

Initial efforts to uncover resiliency characteristics began with research into individual resilience (Werner, 1993, 1995). The focus of these studies was to isolate the characteristics that differentiated resilient from not resilient individuals. The results of these early studies formed a theoretical framework

for understanding individual resilience by creating lists of 'resiliency factors' evident in those identified as resilient in the Werner longitudinal studies.

While this research is related to the investigation of family resilience, the findings of individual resiliency studies are not always easily generalized. Family resilience has been described as the family's ability to withstand hardships and rebound from adversity while becoming more strengthened and resourceful (Walsh, 1998). Subsequent studies have identified resiliency as a set of characteristics possessed by families (McCubbin, 1988) or a flexible process (Walsh, 2003). McCubbin and McCubbin, (1988) created a theoretical framework for understanding the different and more dynamic qualities of family resilience by identifying three family types: Balanced, Midrange and Extreme, with the former being the most viable (McCubbin, & McCubbin, 1988). Within this family type there were two characteristics identified as important variables in the formation of the 'Balanced Family Type' in the McCubbin research. These were rhythm and regenerativity.

Characteristic 1 Rhythmic Family

Rhythmic families establish rules, rituals and routines in their home. Rules, rituals and routines are defined as a communicated sense of what is expected of children by the parents (Knestrict, 2007). Rituals are defined as family efforts to consistently establish and practice routines with the purpose of creating family togetherness, regularity and predictability (McCubbin, McCubbin, 1988). This research suggests that families able to establish these rules, rituals and routines were better able to develop feelings of closeness and such bonding creates predictability (Luster & Okagaki, 2005). These families are also seen as better able to demonstrate greater family satisfaction, closeness and flexibility.

Characteristic 2- Regenerative Families

Regenerative families are defined by their family's hardiness and coherence. This is the measure of how well a family develops coping strategies for dealing with family problems. Coherence is

manifested as the family's emphasis on loyalty, pride, faith, trust, respect, caring and shared values. This typology also includes a family's hardiness (McCubbin, McCubbin & Thompson, 1987). Hardiness is characterized by an internal sense of control of life events and hardships, a sense of meaningfulness in life and involvement in activities along with a commitment to learn and explore new and challenging experiences (McCubbin, McCubbin, 1988). The combination of these characteristics of Balanced Families is thought to describe resiliency in families

Taunt & Hastings (2002) describe the importance of the family's formation of positive perceptions of their child with the severe disability and a positive perception of the family circumstances. Such positive perceptions seem to aid the family in adapting well to the changes that arise within a family raising a child with severe disabilities. In their study they asked parents to report on the positive impact the child with a disability had on them, their family as well as extended family members. Secondly, they also asked parents to report on their feelings for the child's future. In response to the first question parents reported multiple positive effects on themselves and their families. Reporting changes in improved family dynamics, increased confidence, assertiveness and strengthened religious faith. In response to the second question the parents, although expressing some anxiety and fear about the future, generally expressed positive attitudes towards the future of their children with disabilities. Summers (1988), and Berr & Murphy (1993) both found that the parental perceptions were significantly correlated to parental reports of family satisfaction.

Walsh (2003) also provides a similar construct for understanding resiliency in families. This research puts forth three key factors which contribute to a family becoming resilient: The first factor Walsh cites is the family's ability to make meaning of adversity. The second is affirming strength and keeping a positive outlook. The final factor is having a spiritual belief system. In addition, the family must possess certain organizational qualities such as flexibility, connectedness, communications and the

ability to utilize resources to be able to rebound in the face of challenging stressful situations (Walsh, 2003).

Specific to families, disabilities and Socio Economic Level, (Park, Turnbull &Turnbull, 2002) found that 28% of children with disabilities, ages 3-21 are living in families whose total income is less than the income threshold set by the United States Census Bureau. They found that poverty impacted families along five dimensions including health, productivity, physical environment, emotional well being, and family interaction.

When a family has a child with disabilities more stress is added to the micro system of that family. Scorgie, Wilgosh and McDonald (1998) examined 25 studies of stress and coping in families of children with disabilities. They found that families with higher incomes have more choices available to help them cope. Yau & LiTsang (1999) found that higher income contributed to parental adaptability.

Family interaction is also impacted by lower socio economic levels. The supportive, nurturing and authoritative parenting style long associated with positive outcomes in parenting (Baumrind, 1973) are more difficult to implement when economic stressors are present (Lempers, Clark, Lempers, & Simons, 1989; Mcloed & Shanahan, 1993).

Method

Participants

Participants for this study were chosen according to three criteria:

1. **Two Parent Families**- this criterion was chosen because the current literature differentiates between single parent and two parent families. It is thought that single parenthood creates additional stress that would further compound the issue of family resiliency.
2. **Raising at Least One Child With a Severe Disability**- This was defined as a child with any physical, emotional or cognitive disability, diagnosed by a professional, and on an individualized education plan (past or present), was self reported by parent as being 'severely disabled'. The

investigators concluded that diagnosis, and school identification combined with parental self identification was an accurate way to identify a family's having at least one child with a severe disability.

3. **Willing to Participate in the Year Long Study-** The investigators concluded that willing participants were more likely to engage in open discussion and see the study to fruition. The attrition rate was as predicted only two families dropped out of the study.

The sample consisted of 20 parent pairs. (N= 20). Parents were selected from three Socio Economic levels. With this criterion the parenting pairs were distributed in the following fashion:

Upper Third in Income- 6 Parent Sets- \$ 85,000 - above

Middle Third in Income- 11 Parent Sets- \$ 41,000 - \$84,000

Lower Third in Income- 3 Parent Sets- \$ 40,000 – below

Miles and Huberman, (1994) suggest a sampling typology identified as 'criterion' to allow for specific identifiers. The subjects were chosen under these criteria because the existing literature has a preponderance of affluent participants. This study wanted to allow for the effect of Socio Economic Status (SES). To ensure this we needed a more representative sample in relation to SES.

Data Collection

Triangulated Data

The preliminary categories were identified by the investigators prior to the data collection. These 'expected themes' were based upon the investigators review of the current literature and the existing body of knowledge around family resiliency. In addition categories were formed to reflect an ecological perspective. Bronfenbrenner, (1979) proposed a model for understanding human development and interactions entitled 'ecological'. In this framework human development is seen as affected by not only within person characteristics (i.e. temperament, genetics, and health) but also by external factors such as support systems, political and cultural influences. See

Figure 1. While the existing research on individual resilience describes an almost entirely 'within' person framework, the ecological model allows one to see things through a larger context that includes systems outside of the direct contact of the family. Below is a list of initial code categories that reflect the existing systems affecting the development of these families in the study. These categories were derived by using the existing research on resiliency in families. Additional categories are added as we uncovered new material through the research process. The categories have also been aligned with the ecological system they represent. The use of the Bronfenbrenner model is an additional analysis tool.

1. Hardiness and regenerativity as defined by McCubbin and McCubbin (1988)- microsystem
2. Rhythmic characteristics (Rules, rituals routines) (McCubbin & McCubbin 1988)- micro and meso system
3. Access of public support services- exo and macro systems
4. Faith (Werner, 1992)- macro- all systems
5. Strong marriages- micro systems
6. Socio Economic Status- exo and macro systems
7. Positive affect (Taunt & Hastings, 2002)- micro system

The data collection plan was divided into three stages. Denzin (1978) states that triangulation means the use of two or more processes of data collection to surround the phenomenon. Chenail, (1997) also tells us that the method is used to "situate the phenomenon and locate it for the researcher and reader alike". Jick (1983) states that multiple methods can be used to 'examine the same dimension of a research problem'. In this study we used multiple stages to collect data and identify the participants 'reality' as stated by them in three separate data collection opportunities.

The first stage included a two-hour interview with each parent set. The identified themes were used to construct the interview questions as were derived from the literature. The questions developed were focused on established characteristics of resiliency in families including rhythm, hardiness (McCubbin &

McCubbin, 1988), and general attitude (Walsh, 2003), (Taunt & Hastings, 2002). To obtain the contextual information needed participants were asked specific questions about how they performed specific tasks at home. For example, in relation to the rhythm and hardiness they were asked questions like: "What type of rules, rituals and routines are present in your home?" and "How do you and your spouse deal with conflict within the home". In regards to the general attitudes present they were asked questions like "What is loveable about your child?" and "describe your child's strengths". The data was transcribed, coded and categorized using the initial themes identified above.

Stage two involved a two-hour focus group with all of the participants. The group was gathered and was presented with a reading entitled 'Welcome to Holland' by Emily Pearl Kingsley, a widely distributed metaphorical article written by a woman raising a child with a severe disability. She was often asked what it was like to raise a child with a disability and this article was her description of that experience. Kingsley described the experience of being pregnant and preparing to have a baby as similar to planning a wonderful trip to Italy. It was similar to the process of learning the language, learning the culture and anticipating all of the wonderful experiences that would be part of this 'trip'. However, as the traveler is flying to Italy the pilot announces that they are no longer going to Italy they are now going to Holland where they must stay. Kingsley then relates the disappointment in the change of plans, and of the eventual acceptance of 'Holland' and the realization that Holland is not Italy yet it too can be a very nice place to reside. (Text of 'Welcome to Holland' in Figure 2.)

The focus group was led in a discussion by the investigators about their perceptions of the article and if it accurately spoke for them. Finally, the group was asked to verbalize how their personal 'trip' has gone and whether or not they felt hijacked to Holland? The investigators found collecting data through the use of a third person story to be a very useful tool. Many of the parents seemed guarded during the interview but felt free to speak freely during the focus group because the discussion focused on a story

rather than first person stories. The data from the focus group was recorded, transcribed and coded according to the initial themes identified.

Stage three consisted of time spent in the homes of each of these families observing them, their families, and how they lived their life. Time of stay averaged two hours in each home witnessing a specific part of their day when the entire family was present. For some that was the evening and others it was the morning. In this stage it was not the verbal statements we documented but the behaviors witnessed. Since all of our participants had children in school or in sheltered work situations no observations took place in the afternoon. The field notes were compiled and coded onto a data collection sheet for each family and were organized by the initial themes.

Multiple and independent measures can provide a more certain portrayal of the phenomenon (Jick, 1983). Collecting data in three different contexts allowed for multiple comparisons of the data. If a family stated in the interview stage that they had established very well defined rules, rituals and routines which allowed the family to function in a predictable fashion then expressed the importance of rules, rituals and routines in the metaphorical conversation and also displayed these same values in the observation: the data was triangulated.

Analysis

By analyzing systems the family exists in and the systems they are interacting with, one can gain a perspective of family resilience that is not only from 'within family' but also from 'without. Figure (1) is a representation of the Ecological model. The analysis aided in the identification of the system each of the study's findings occurred within. This was an important part of the analysis because it allowed the investigator to identify those pressures on a family that were in and out of their control. If it were out of the family's control then it existed in one of the outer systems. If it were in the family's control it was in their micro system making it controllable. Characteristics of families such as regenerativity and rhythm are described in the research as controllable and existing within the micro system of any given family.

However, this study was very interested in uncovering the pressures originating in the outer systems but determining outcomes in the micro systems of the families in the study. This theoretical model allowed the investigators to view the data in this way.

While the initial transcripts were generated through computer-supported methods the bulk of the interpreting and coding proceeded manually. The process proceeded by looking only at the triangulated data. If the families consistently (across all three stages of data collection) identified or displayed evidence that aligned with a particular code we transferred that evidence onto an additional coding sheet. At the same time we noted the system that the code existed in. The initial themes were maintained throughout the study and only two new or emergent theme categories were added. It became evident at the beginning of the data analysis that there were two emerging patterns coming to the surface in the families displaying resiliency and not with the families who were less resilient.

The first was identified as **'reconstruction'** and referred to the family's ability to 'reconstruct' their conception and understanding of their child with a disability. This new code category was added to the existing ones and represented a process that was occurring in the family's micro system thus representing a 'within' family occurrence. We then went back through the data and sorted all transcripts that contained evidence referring to the 'reconstruction' concept. Reconstruction can be defined as a process the family experiences that is identifiable by the following characteristics:

1. A consistent pattern of reflection and discussion about the child with a disability and a generally positive regard for that child and his/her strengths and loveable qualities (Taunt & Hastings, 2002).
2. The adoption of a 'criterion referenced' frame of mind. In other words the parents began to 'measure' their child not by comparing them to 'typical' children or what they anticipated he/she would be before they were born (norm referenced), but by comparing the progress the child makes to their abilities.

3. A new construction of their understanding of 'disability'. The more resilient families tended to view the term 'disability' in a negative sense and saw the differentiation as offensive.

One parent stated:

"I just realized that this child was a gift and a blessing. From that point on I saw my child as 'my child' first and his disability just became another part of him, like his hair or his eye color. Something to deal with. But.... That's Jake! That's who he is! "

The second new category was an affirmation of the importance of SES. This is a condition that represents an exo and macro systems occurrence. These systems represent processes that occur on a cultural and political level. SES status is not a process that the family is in direct control of. Neither are the outcomes of a lower SES. This is significant because occurrences outside of the direct influence of the family are problematic precisely because they are out of the control of the family and they profoundly affect the family and their access to services for their children. All of the families identified as 'less resilient' were also struggling financially to meet the needs of not only their child with a disability but the entire family. All of the 'more resilient' families were not. All three families in the study identified as 'less resilient' were struggling financially and had more difficulty accessing support services. The transcripts were again coded and a substantial amount of data was found to support these new codes in the 'less resilient' family category. Financial stress is reported to have a negative impact of the emotional well being of families of children with disabilities. This stress translates into negative developmental outcomes for both the children and the parents in the family (McLeod & Shanahan, 1993).

This research was written up as a realist tale (Van Maanen, 1988). The research questions were to be reported by the 'native' in two of the three stages and confirmed by the fieldworker in the third stage. The 'natives' point of view is most important and the fieldworker is merely reporting observed behaviors in a descriptive act, as an unobtrusive observer. Further, Schwandt & Halpern (1998) suggest a

balanced approach in reporting findings using the participant's perspectives and world view to structure the report.

Reliability and Validity

The data used to make conclusions in this study was triangulated; the investigators only used data that was confirmed in all three stages of the data collection. This method has been widely used and seen to enhance a study's generalizability and reliability (Rossman & Wilson, 1991). In addition, (Lincoln & Guba, 1985) stress the importance of confirmability. Since only triangulated data was used in the results section we are confident of the level of confirmability for this study.

Findings

Identifying Resilient Families

Rules, Rituals and Routines- Rhythmic Families- Micro system process

Rather than identifying families as resilient or not resilient the investigators found it useful to view families along a continuum ranging from 'less resilient' to 'more resilient'. In this way we can see that family resiliency is not an 'either or' proposition but rather a dynamic process.

Seventeen (17) of the twenty (20) families in the study were found to be more resilient using the criteria of the McCubbin & McCubbin (1988), Taunt and Hastings (2002) and (Walsh 2002) research. These families showed a preponderance of characteristics described in the review of the literature such as established rules, rituals and routines that structured the family's homes, daily schedules and thought processes. This predictability and structure allowed families to function smoothly even though they were taking care of a child with a severe disability.

Rules

In all of the 17 'more resilient' families rules were established and followed that included the child with a disability. This fact was important in establishing order and predictability in the home but

also for establishing one set of rules for the entire family including the child with a disability. One mother stated the following:

***"I used to go to the MRDD on the weekends for trainings and workshops
And they used to tell me that I was doing it the right way. That I shouldn't
make our family adapt to Karen but we should make Karen become part of the
family just like the rest of the kids"***

In all of the 17 'more resilient' families a firm set of values based rules were in place and all of the children were expected to meet these demands regardless of disability. This inclusive expectation helps families to become a more unified group with clear expectations enforced by the parents.

Routines

Routines were seen as crucial in the family's pursuit of resilience. Clear, well practiced and consistent routines were observed to create structure and predictability in the homes. This organization created an environment where more energy could now be directed towards finding resources and taking care of people rather than managing behaviors.

Family 3 was raising 6 children. Their youngest child was born with a severe cognitive disability. The mother described the brilliant and highly structured way of doing the laundry while at the same time taking care of all the other things in the house, including a young 2 year old developmentally disabled child. The laundry room was furnished with a set of shelves. On each shelf was a laundry basket. Each child had their own basket. As she completed a child's laundry for the day they were instructed to come and exchange their 'dirty basket' with the clean one. This structured task was strictly adhered to and allowed an orderly system for completing laundry. The mother states that:

'My mother-in-law showed me this trick. She raised 10 kids. This allows me to free up some time to spend with April' (not her real name). I'm doing laundry almost everyday but with the kids helping I don't spend quite as much time as I might"

Family 7 also offers evidence to the importance of rules, rituals and routines in families. This family has an eight year old son diagnosed with a severe emotional disturbance. This child would often lay down on the floor and tantrum. He would curse and hit both the mom and the dad. He has also been caught stealing money and has hurt the family dog in anger. This family has worked hard at establishing a very high level of structure and predictability in their home because this seemed to help their child cope. As long as the structure was maintained and the rigid routines were enforced the family appeared to function fairly normally with no incidents of tantrums or assaultive behavior. When the father asked about this, he replied:

“As long as we keep up with the structure Bobby copes relatively well. When he is coping well life is pretty good. Step out of that routine and all hell breaks loose. It’s during those times (when we structure things) I can enjoy Bobby and hug and snuggle all of those normal things”.

This ‘normalcy’ was observed by the investigator. The simple process of preparing a young child to attend church with the family was even more challenging in Family 7 given the child’s tendency towards aggressive behavior. However, a rigid routine followed consistently goes a long way towards providing this child with the support he needs. The father stated:

“We have a very rigid schedule and a firm set of rules. Bobby knows that he must get up at 7:30, get dressed before he comes downstairs, eat breakfast and brush his teeth before 8:30 and be ready to go by 8:45. If he can’t do these things at these times he gets a consequence. No discussion. If we let up on him at all he tends to fall to pieces. So we are very rigid with his schedule and I believe he thrives because of it.”

The rhythm that is established using these methods seems to offer a high level of predictability that is important for the entire family. This rhythm also seems to provide a level of consistency of care for the family as well. The care of a child with a severe disability can be all consuming. Structuring the family life in these ways seems to benefit all of the family members.

Rituals

Rituals are routines with meaning (Knestrict, 2005). The more resilient families tended to be more conscious of establishing and maintain family rituals. One family had a weekly pasta night. During this night family members would meet at each others homes for a mid week family dinner. These parents talked about the pasta night and its importance:

“Every week we meet at one of our houses for pasta night. Whoever can make it comes and helps cook, the kids play and we eat. We have been doing this for years and the kids just love it. They can play with their uncles and aunts and with grandma and grandpa. It also gives everybody a chance to interact with Emily and see that she is a lot like any of our other kids. It helps them see her as normal”

Another family in the study talked about how they have developed a family ritual, which allows family members to take their child with a disability for a weekend. This became a very important moment in this family’s life because the parents are both in their 70’s and concerned about the future of Karen, their 39 year old daughter:

“My son and his family take care of Karen on the weekend sometimes. He has made up a bedroom for her and everything. His wife grew up with a brother who was disabled so she is also quite comfortable having Karen in the house and taking care of her. The kids are great about it too. They have two other children. In fact, after a couple of times going over there my son and daughter –in law came to us and said that they wanted to take care of Karen when..in the future...we couldn’t. I told them way in the future (laughs). But that is very comforting.

Rituals might start as routines but over time they change into rituals. These rituals tend to allow family members to attach to each other. Nightly meals together may start out as a pragmatic way to feed everybody but over time, as families’ share this time they grow closer to each other because of the

ritual. These family rituals were also described in the McCubbin & McCubbin, (1988) research on resilient families.

The investigators observed that in the 17 'more resilient' families there was typically a higher level of rules, rituals and routines present. The practice of using these methods to structure family life was seen as a facilitating factor that allowed families the time to be reflective. This reflection led them to a reconstructive process that led the 'more resilient' families towards a new understanding of their child and of the term 'disability'.

Criterion Referenced Reframing and Reconstruction of Reality and Meaning- Micro System Process

Part of developing a positive outlook on disability (Taunt & Hastings. 2003) appears to be the ability of parents to reconstruct their understanding of disability. This is not a simple process. Bogden (1994) wrote of this process when he talked about moving beyond the terms and definitions provided by a perspective of pathology, towards a contextual meaning of the individual. In the eyes of these resilient parents they no longer saw the 'disabled child' they saw their child first. This was evident in the comments made by a mother whose child has a condition called Idiodycentric 15, a rare genetic disorder causing severe developmental delays, global apraxia, and very odd 'autistic like' behaviors.

“Christine is a beautiful child with lots and lots of strengths. She loves to climb and she loves to color. She can sing and play and dance. She is also quite the artist. She has significant issues physically and cognitively but she is a beautiful child.”

These comments from Family 7, whose child was diagnosed with bipolar disorder and severe emotional disturbance, reflect the acceptance of the child. This child often has to be restrained because he can become a threat to himself and the other children in the family.

"You know we have to deal with a whole lot with Johnny. But in the end, he is our son. We see him as a gift from God. A gift! We are honored to be given this gift and we love him more than life itself"

These families are able to see the child first and the disability second. This 'criterion referenced view' differs from the 'norm referenced view of less resilient families. These more resilient families tend not to compare their family or child to others or 'typical' families. This manifested itself in the study as positive feelings expressed about the child and family derived from not a comparison but an appreciation of the child and his or her abilities. An entirely different construction of reality was documented with less resilient families. These families were less able to see their child in this 'criterion referenced way and still were seeking comparisons to typical children. For example, Family 12 is raising a child with comparatively mild developmental disorders, accompanied by some issues with sensory integration and speech problems. This mother stated:

"Sometimes I just feel like all I do is take care of Quentine. I don't have any time for myself. I get so angry at him for not being able to use a toilet I could scream. Sometimes I do scream and yell at him. I think and think and think about what to do for Quentine next, what about school? When will he talk more clearly? Will he play baseball like our neighbors kids? Will he have friends?"

Resilient families are free to form positive attitudes around their child and the disability. Family 5 has a child with a severe genetic disorder called 22q3 Deletion Syndrome. This condition is manifested by absence of speech, muscle tone and the ability to walk, sit up or talk. He must be fed and bathed and diapered. The level of commitment to care is quite high. However the parents of this child are filled with joy when they talk about him. When asked what was loveable about their son the father said:

"He's the happiest kid you would ever want to meet. Our house is always full of laughter. He is just very sweet"

These statements were corroborated by my observations in the home. The positive attitudes about the child and the disability were also evident when I watched as these parents took care of their children. I observed positive affect and positive interaction 90% of the time. (162 minutes average before a negative interaction was observed).

In the family described above, there was evidence of their positive attitude witnessed in the caretaking of their child. In the morning the father was up very early to prepare himself for work and to prepare their son for his day at school. It began with changing his 10 year old son's dirty diaper, cleaning him and dressing him. Then he must carry him downstairs, place him in his wheel chair and strap him in so he doesn't fall out. The mother then gets up and prepares their second child for school and cooks breakfast for the entire family. Both parents work full time. The parents must get both children on the bus, get themselves ready for work and arrive at work on time. The morning routine in this house lasts about two hours, beginning at about 6:30. During these observations there was considerable stress however, there was much joy expressed as well.

The affect observed during these morning routines included laughter and affection as well as lots of hugs and expressions of affection. "I love you very much" and 'Nice job buddy' as they were dressing their son. This family obviously enjoyed each others company in spite of the rigid routines and stressful circumstances. One resilient father stated:

" Look, we get into a routine and it goes pretty smoothly. But like any family you get irritated. That happens sometimes. Not a lot."

Our findings indicated that this reconstructive process was not accessible for all families. There were specific markers observed in families that were able to reconstruct this 'criterion referenced' perspective. It was also observed as a process that occurred at different rates and in different ways for

families. This reconstruction of a 'criterion reference' hinged upon having time to reflect on the global meaning of 'the family' as well as a different understanding of disability. Establishing a global meaning of family refers to the way in which a resilient family places their family and their family's challenges in an ecological framework. They begin to think of their family not as a 'family with a child with a disability' but as just a 'family'. The father in family #5 stated-

Look, our daughter has needs as well. We may have some different circumstances but I am sure there are other families dealing with much more than this"

Families who experienced this process had the time to talk with each other about family issues, the realities of their specific family life. They had time to organize their life, their days and schedules. They had time to search for services and resources. They had time to spend with all of their children not just the child with special needs. These circumstances allowed the families to configure a new understanding of their circumstances and create a new framework for understanding the child's abilities and future.

Families who did not experience this process' were distracted from this type of reflection. There was a constant search for services, follow up phone calls and seeking of resources. Several of the families in the study found it impossible for both parents to continue working outside of the home. In all of these cases the mother quit her job to care for the child/children. But with less income coming into the house economic stressors increased making the act of reflection difficult. The presence of a child with disability becomes the center of the family's life. All other events became secondary. This is confirmed in other studies referring to the siblings of children with disabilities (Grossman, 1972; Wilson, Blacher & Baker, 1989; Stoneman, Brody, Davis and Crapps, 1988).

Tenacity- Regenerativity and Family Hardiness

Finally, all of the seventeen families found to be more resilient each shared a tenacity that manifested itself in the manner in which they advocated for their child and their family as a whole. The

same mother who fashioned the laundry room routine with her children also spoke of the difficulty in securing services for her child with a disability. At one point in time the family lost their insurance coverage. As soon as this occurs they lose their slot for occupational therapy, physical therapy and other support services. To reinstate services it took many phone calls and letters and contact emails to get back into the slot they had occupied previously. The mother stated to me that ' I was not going to let them take this away from my daughter. I was going to do what I had to do to get the services she deserved.' McCubbin & McCubbin, (1988) called this characteristic 'regenerative' when seen in families. This was evident in the example provided by Family 4. Their youngest child was diagnosed with autism at two years old. The mother shared a story about the day a neighbor told her to start looking at the diagnosis differently. She states:

" I remember calling a friend the day after he was diagnosed. She was in play group and we have known each other for years and I was crying and I was very, very upset. She said "Are you going to let that word change your relationship with your son." Snap out of it! Knock it off! Do what you have to do for your kid because (autism) is just a word" I needed to hear that. It was the best advice I had gotten. Feeling sad and depressed was a waste of my time. I'm done with that. Now I have things to do!"

Another mother in the study was 76 years old. She and her husband had raised and cared for their 39 year old daughter since birth. She explained that what she was told by a doctor on the day her child was born changed her mind set for the rest of her life. She states:

The doctor sat down by my bed to talk with me. He told me that Karen (not her real name) was mongoloid...that's what they called Downs Syndrome in those days. He told me that it would be better for Karen and the family if we put Karen away in a home for the rest of her life. Well, I thought...this was my child I'm not gonna do that. In fact, when my husband went home to tell our sons about their sister and about what the doctor had said. The boys told Pat 'that's our

sister. You bring her home'. Karen was a gift from God. We were going to love her just like anybody else. It's always been that way"

Socio Economic Status (SES) and Access to Services: The Strongest Finding in the Study- Exo and Macro System Process

Of all of the findings in this study, the strongest was the finding of the importance of the Socio Economic Status and Access to Services. These themes represent processes outside of the day to day family existence and are determined by powers outside of the family's control. These are considered Macro and Exosystem functions within the ecological model and impact the family through cultural and political trends. Yet they have enormous impact on the day to day micro system events within a family. The more resilient families in our study had the following characteristics present in their family ecologic system. All of these are dependent or influenced by family income and resources:

1. Upper to Upper Middle Class SES with standard insurance provided by employer for entire family.
2. Living in a school district that adequately services their special needs child. This is almost always determined by SES. The school districts with elite services typically are the districts serving a higher SES (Districts families in the study attended).
3. These families are provided a higher quality of insurance that remains uninterrupted and provides additional services not provided by the schools.
4. This high level of insurance allows a high level of pre and post natal care. This usually results in quicker identification and service integration.
5. Without the distraction of wondering where the care for the disabled child is coming from families are able to form the rules, rituals and routines necessary. They are also able to be more regenerative.

6. Transportation is essential in accessing services, getting to and from doctors appointments and transporting family places.

The less resilient families in this study do not represent the poorest of the poor but the working poor. They are working in jobs that provide minimum insurance or none at all. Below is a Table I. It illustrates the difference that income made in the lives of two of the families in our study. On the left is a list of events for Family 13. This family was seen to be less resilient for a variety of reasons pertaining to rhythm and regenerativity. There were few rules, rituals and routines observed in this family, they were unable to speak very positively about their family and their life. In the focus group the father expressed how the birth of their child had caused stress in the family and on their marriage. They had six children with their youngest being born with severe Down syndrome.

On the right is Family 8. This was the most affluent of the families. The father was a doctor and they family lived in an upper class neighborhood. They also had a large family of seven children, the youngest born with severe Down syndrome. The difference is that they had every economic advantage available to them. As a result they had a much easier time adjusting, more time to develop rhythm and regenerative skills and were seen as more resilient. It is the investigators conclusion that SES plays a very strong role in determining a family's ability to develop the resiliency factors describe.

Table I

Family 13 had a more difficult time providing the necessary support for their child. The reasons preventing this transmission were almost entirely due to SES or a related variable. Family #8 had significantly higher SES and was able to provide a consistent resource flow, transportation, top quality schooling and auxiliary therapy beyond that which is covered by insurance.

These findings held true throughout the data set. Of the 17 families found to be resilient in this study, all seventeen of them were in the upper two categories of family income. The three less resilient families were in the lower income category. More money allowed these families to live in nicer places that provided a higher level of care for all children. The greater income allowed these families to locate and access information about services, the ability to establish and maintain the same consistent level of services and to provide additional services for the special needs child.

The process that the investigation uncovered seems to work from the macro system in towards the family. The higher the SES of the family the more likely it was that they had the necessary resources available to them to take care of their family including their child with a disability. These resources were made available because of their higher SES. These might include home that could often times be remodeled to meet the special needs of the child or the funds to pay for additional physical or occupational therapy. One family in the study even paid for their son's aquatic and equine therapy. Higher SES often also meant more money available for respite care which in the case of several of the families in the study, translated into more leisure time for the parents.

In all 17 of the 'more resilient' families this higher SES translated into more time available in the day. It is our hypothesis that higher income provides a higher level of resources available to parents they require less time, effort and energy to access these services. This allows them to have more time to devote to other things in the family life. This would also include more time for the parenting couple to discuss, process and come to some kind of reconfiguration that allows them to think of their child differently and the concept of 'disability' differently.

A Caveat to SES

We also found that a potential equalizer in the attainment of resources is the local county, state and federal programs established to provide support for all families in need. The local Mental Retardation and Developmental Disabilities Boards (MRDD) in local counties does an outstanding job of contacting new parents, establishing relationships and developing services for children and adults needing support. Unfortunately these services continue to lose funding. The level of support across the nation for all of the programs has dipped to record lows. Without appropriate funding for these programs services are cut and families are left without support. This was illustrated in the study by talking with the mother of Karen. She had been involved with the local MRDD and public schools for the past 39 years and she has noticed a tremendous drop in services for her daughter. School districts are also providing less in the way of services.

Another organization that was found to provide a high level of quality service was the Special Olympics. During the study we witnessed a full year of fitness related activities provided by this organization. Activities ranging from softball complete with uniforms and gear to bowling, swimming and track events.

Implications

There are three major implications of the findings in this study.

Implication #1- Socio Economic Class Matters- The level of income and access to resources is the controlling factor in the pursuit of family resilience. It affects the family's ability to access resources, where they choose to live, what schools they choose to send their children to, what type of medical care they have access to. These are fundamental macro system variables that directly impact the outcomes in the micro system of each of the families.

This fact has major implications on policy at the local, state and federal level. If these services are SES determined then the county, state, and local service providers need to be better able to serve all people regardless of SES. This is especially true when 28 % of the people raising children with disabilities fall below the poverty line (Fujiura & Yamiki, 2000).

Implication #2- Rhythm- as manifested in rules, rituals and routines, provide structure and predictability in homes. This predictability is essential in all homes but is critical in families with children with disabilities. Rules and routines provide the structure and predictability that has been shown to provide stability to families in times of stress (Wolin & Bennet, 1984). Rituals are shown to create closeness within families and can have the effect of bringing family members together physically and emotionally (Fiese, 2002). These rules, rituals and routines allow the parents more time to access resources and to reconstruct a different understanding about their child. This new understanding is described as 'criterion referenced'.

These are teachable skills. The structuring of homes and families and the implementation of rituals are skill sets that can be taught to families. These skills could be the focus of parent training at schools of centers and could be easily imbedded in trainings already available in county MRDD programs as well as special education parent organizations.

Implication #3- Reconfiguration -Beyond the fact that the reconstruction process was observed, little is known about how it occurs in this context. Other disciplines have written about the process. Jarvis (1987) suggests that reflective thinking is different for different people and seems to be individually constructed. Russell (2005) states that this practice can be taught and should be taught. Regardless, given the observed link to SES. the investigators are not hopeful about the possibilities of teaching this process directly.

The observed disruption that the lack of resources creates is ubiquitous. It affects all of the choices the family makes at every level of family life. Many of these families were exhausted at the end of each day and were merely surviving. There was no time or energy left to spend on reflection.

Limitations of Study

There are some limitations to this study. The selection of families, while dependent upon SES was still not as differentiated as the investigators would have liked. When locating families in the lower socio economic grouping we had to compromise. We were unable to locate families below the poverty level for this study. This may be due to the inherent difficulty in contacting people who are struggling to survive but a subsequent study should make the effort to include a more complete range of income levels. Because of this difficulty in sampling we were limited to three broad ranges of income. It is reasonable to assume that the more refined the economic categories the more precise the findings would be. For example, would having three lower SES categories allow the investigators to more accurately target the point at which resiliency is unattainable in relation to SES?

Future Research

This study looked at families falling into three separate socio economic groups. Future research should attempt to uncover the stories of families raising children with disabilities in working poor and poverty stricken homes. The voices of these families are often silenced. A descriptive study of their situations is required to bring light to their issues and difficulties. Also, a deeper study of exactly what is occurring with the reflective family during the 'reconstruction' stage would allow us to analyze the process, identify parts and possibly obtain a greater understanding of how to support even the lower SES families in facilitating the reconfiguring and reflective process that was shown to be crucial in the resiliency process.

Conclusion

All of these factors contribute to a family's inability to develop the rhythmic and regenerative qualities of balanced and resilient families. If one is struggling to meet the basic needs of family there is little time to be reflective about your child's disability or to establish meaningful rules, rituals and routines. The findings of the McCubbin & McCubbin, Taunt & Hastings and Walsh research on resiliency informs us of only half of the resiliency equation. Money and resources is the other half. It is in the Macro and exosystems that resiliency must first be valued and thought about. Adequate funding of support services, school districts, mental health services, and prenatal clinics will allow all people, regardless of income, to relax enough to be reflective, to establish rules, rituals and routines and to develop a more enlightened construction and understanding of their child's disability and their family's new configuration. Further research investigating the ecology of families in poverty and working poor families raising children with a severe disability is needed to provide policy makers with the evidence to show the importance of increased support services for families raising children with special needs.

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Figure 1

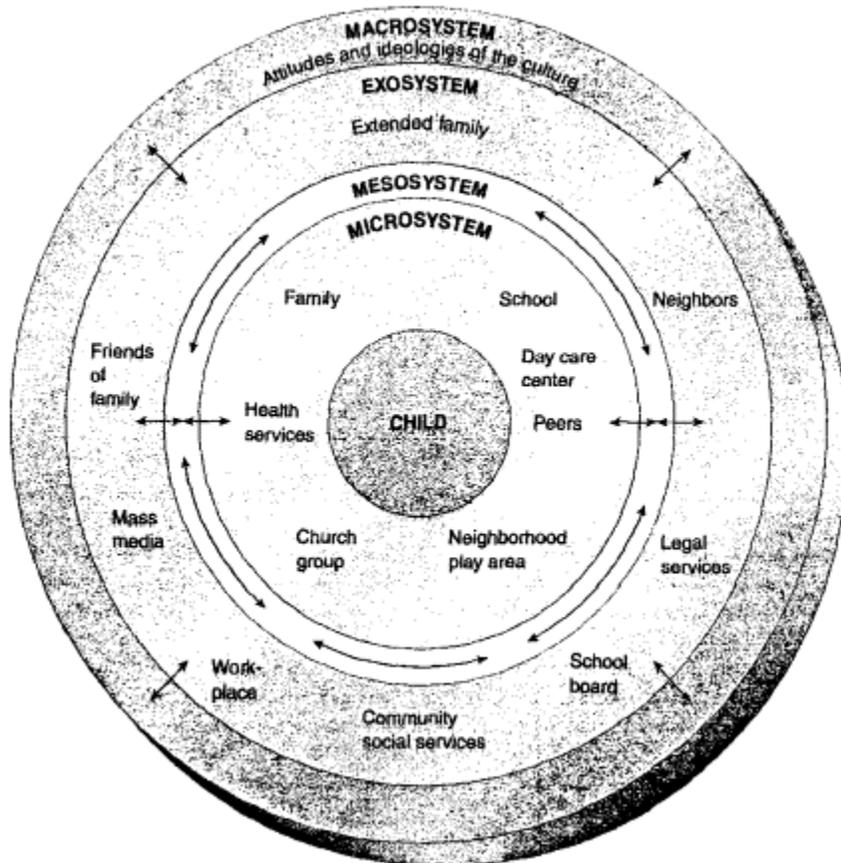


Figure 1- source: Kopp, C.B. & Krakow, J.B. Child Development in a Social Context. Addison Wesley Publishing.

Figure 2

Welcome To Holland

by

Emily Perl Kingsley

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has

windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, *ever* go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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* * *

Table I

Comparison of Two Families Using Socio Economic as an Indicator

<p>Family 13- Six Children Youngest with Down Syndrome</p>	<p>Family 8- Seven Children Youngest with Down Syndrome</p>
<p>Became pregnant with sixth child</p>	<p>- Became pregnant with seventh child.</p>
<p>- at the time of first trimester family without insurance/ No prenatal care during first 4 weeks of pregnancy</p>	<p>- Very good insurance. Consistent throughout pregnancy and after</p>

<p>- Insurance reinstated at seventh month prenatal care resumes until birth.</p>	<p>- Amniocentesis done. They learned that they had a good chance of having a baby with Down Syndrome.</p>
<p>- Normal pregnancy no problems foreseen.</p>	<p>- They began learning about condition months prior to birth.</p>
<p>- As soon as child was born they knew something was wrong. Born with Down syndrome.</p>	<p>- Lining up resources. Family beginning to prepare.</p>
<p>- Child is found to have severe cognitive delays and a ventricular septal defect (hole in the heart.</p>	<p>- Baby is born with severe cognitive delays and respiratory problems.</p>
<p>- Moved to western state for work. There for a year and a half. No care was established out there.</p>	<p>- Dad is a doctor made contacts for care, OT, PT, medical care.</p>
<p>- Moved back to Cincinnati. Located in local district known for special education.</p>	<p>- Mother called school district about options in surrounding districts - Moved to a new district, bigger home, and better schools.</p>
<p>- Care schedule established. OT and doctors routines established.</p>	<p>- School district contacts mother about services.</p>
<p>- Husband loses job/ insurance. In the time that it took to get on sponsored insurance family lost spots</p>	<p>- Family pays for extra OT and PT and speech in addition to that provided by school.</p>

<p>in OT and PT and with doctors. No therapy.</p>	
<p>- Mom tries to provide in home. Childcare issues A balance accumulating because of out of pocket cost of care when they did not have insurance.</p>	<p>- Provides child with extra enrichment activities after school and during summer</p>
<p>- Can't find baby sitters.</p>	<p>- Mom does not work has a sitter part time.</p>
<p>- Inconsistent Rules, rituals and routines in home.</p>	<p>- High level of structure and predictability provided by mother and father.</p>
<p>- No support network beyond immediate family.</p>	<p>- Developed a strong support network in the neighborhood, church and school.</p>
<p>- Double the amount of negative comments in interview/focus group pertaining to family and child.</p>	<p>- Extremely positive in interview and in focus group</p>