

Welcome to Holland

Resiliency in Families Raising Children with Special Needs



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Summary

In 2007- 2008 Thomas Knestrict and Deborah Kuchey, assistant professors of education at Xavier University in Cincinnati, Ohio completed a study on family resiliency. They wondered: What are the skills and characteristics of parents and families who adjust to the challenges of raising a child with special needs? Why do some families struggle? Why do some thrive? Do the thriving families have skills that can be taught to others who struggle?

The study looked at 20 families and included interviews, focus groups, and observations in the home. The study found that resilient families were rhythmic, creating highly structured and predictable homes with rules, rituals and routines. This structure created time for reflection. Resilient parents constructed a hopeful understanding of their child's future, of their child's abilities and of the concept of disability in general. These resilient families also were fierce advocates for their children and worked very hard to obtain the services their children needed to flourish.

The most powerful and troubling finding was that these resilient skills were often tied to socioeconomic status. The study found that the more money and resources families had predicted their level of resiliency. The findings were exciting and led the researchers to explore new ways of helping families faced with the realities of raising a child with special needs. This video is about three of these resilient families.

Key points:

- Resiliency is defined as the family's ability to withstand hardships and rebound from adversity while becoming more strengthened and resourceful (Walsh, 1998).
- Resiliency is demonstrated in this video by three families who participated in the study and have flourished in spite of major adversity.
- Resilience is developed over time.
- Resilience is comprised of two areas. These are rhythm and regenerativity.
- Resiliency begins with a decision to move forward and establish rhythm in the home. Rhythm is really the establishment of rules, rituals and routines. These establish structure and predictability.
- This predictability creates order and time for parents to reflect on their family, their child and the meaning of the disability.
- Regenerativity is defined by the family's hardiness and coherence. Coherence is a measure of how well a family develops coping strategies. Hardiness is a measure of the family's internal sense of control over life events.
- Resilient families develop a 'criterion referenced' frame of mind. This means they no longer measure their child or their family against other families. They take their child where he/she is and celebrate the growth from that point on.
- Historically, families had few options when caring for their child. Often the child was placed in a state institution. Choosing to raise a child with severe disabilities is a very brave thing to do.
- Parents raising children with special needs need to advocate for their child and to remember they are the captains of the ship. They have final say as far as academic placement.
- Family resilience in this context is most accurately viewed in an ecological perspective (Bronfenbrenner, 1979).

What is Resilience?

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 the Werner 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 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. 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, which served to undergird the present investigation.

How do these families demonstrate these qualities?

What are Rhythm and Regenerativity?

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 are better able to develop feelings of closeness and that such bonding creates predictability (Luster & Okagaki, 2005). These families are also seen as better able to demonstrate greater family satisfaction, closeness and flexibility.

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 familie.

What are some examples from the film that show rhythm and regenerativity?

Developing a Criterion Reference? What does this mean?

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 and Taylor (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.

The following 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 the investigators observed these parents taking care of their children. Positive affect and positive interaction was observed in 90% of the observed interactions.

In this family 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 2 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 other's 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 reconstructive 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 become secondary. This is confirmed in other studies referring to the siblings of children with disabilities (Grossman, 1972; Wilson, Blacher & Baker, 1989; Stoneman, Brody, Davis & Crapps, 1988).

Where in the video did these families talk about constructing a new understanding about their children and their families. What did they say to make you think they had gone through this process?

Review

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Questions for Discussion

1. Does the 'Holland' story seem to speak to you? Why? Why not? Try to write your own version of this story. Also, try and imagine what it must feel like to be taken to 'Holland', metaphorically speaking.
2. Why do you think these families (or extended family) felt the initial pang of disappointment? What must be going through their minds at this moment?
3. What does the greater culture tell us about children with disabilities? What does the fact that we gave birth to a child with a disability say about us? Where do these constructs come from? What are the outcomes of these beliefs?
4. What is the level of predictability in your home? Is it rhythmic? If it is high what external variables support you in establishing rules, rituals and routines?
5. What is your family's level of regenerativity? Does your family tend to view life through a 'criterion reference' frame of mind? What does that mean?
6. The second family talked about their child 'being a great joy'. How does this reflect a criterion reference frame of mind?
7. The third family dealt with the birth of their child in the early 1970's. How are things different now?
8. After viewing the video what is your estimate of the socioeconomic levels of these families? Should that matter? Does that matter?
9. After viewing the film what is your estimate of the amount of time these families spend, each day, meeting the needs of their child with special needs? What about the rest of the family?
10. As a culture and as a nation, how well do you think we support these families? Is there room for improvement? If so what can be done? If you feel things are pretty good support your beliefs.

Suggested Activities

1. Take an inventory at your home. Evaluate the level of rhythm you have created. Have you established rules, rituals and routines? (See Rules, Rituals and Routines video by Dr. Thomas Knestrict, distributed by Learning Seed)
2. How have you constructed your understanding of disability? Have you adopted a criterion reference perspective? Reflect on your family, your children and your understanding of disability. Are you prone to compare the child with a disability to 'normal' children or do you take them where they are. Support your belief with observable behaviors.
3. Teach someone you are close to about rhythm, regenerativity and especially the idea of criterion reference.
4. Tell two people about this film and describe the families to them. In your description try to use your family as a comparison. This will force you to take a look at the resilience factors in your family.

Research Project

1. Show the 'Welcome to Holland' piece shown at the beginning of the film to a several friends. Ask them if this reflects their experience. Record their answers. Ask them also how they might change the story.
2. Read the writings of Froma Walsh and Emmy Werner. Werner wrote about individual resiliency. Walsh about family resiliency. How are the concepts similar? How are they different?

Additional Resources

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