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Children with developmental disabilities : considering positive impact on the family system

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Abstract

Families who have at least one child with a developmental disability face challenges unique to their situation. With reported incidents of developmental disabilities on the rise, research parameters are being expanded to give more complete consideration of growing family needs. While the historical treatment of these families has often been negative, current research trends have begun to consider positive impact on families.

Positive impact includes areas such as quality of life, the child as a source of happiness, and an overall increase in personal family strength. The trend towards positivism is beginning to be reflected in theoretical understanding and in the delivery of interventions to families. As practitioners continue to incorporate positive, ideology into their theoretical framework, families with a child with a disability will reap the benefits.

CHILDREN WITH DEVELOPMENTAL DISABILITIES: CONSIDERING POSITIVE

IMPACT ON THE FAMILY SYSTEM

A Research Paper

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Abstract

Families who have at least one child with a developmental disability face challenges unique to their situation. With reported incidents of developmental disabilities on the rise, research parameters are being expanded to give more complete consideration of growing family needs. While the historical treatment of these families has often been negative, current research trends have begun to consider positive impact on families. Positive impact includes areas such as quality of life, the child as a source of happiness, and an overall increase in personal family strength. The trend towards positivism is beginning to be reflected in theoretical understanding and in the delivery of interventions to families. As practitioners continue to incorporate positive ideology into their theoretical framework, families with a child with a disability will reap the benefits.

In today's research arena, increasing amounts of attention are bestowed on families who have one or more children with a developmental disability. Until approximately 20 years ago, these studies have traditionally focused on a single negative variable: an identified causal relationship between having a child with a developmental disability and increased levels of familial stress. However, recent trends in literature have shifted focus to the ability of families to adapt when faced with the unique challenges of raising a child with developmental disability.

This literature review will define developmental disabilities, as well as give statistical information regarding families who contain one or more children with a developmental disability. Additionally, this review will focus on the transition in research from negative relationships, to positive mental health attributes of families with a developmentally disabled child. Specific emotional response patterns among families with children with disabilities will be reviewed. Theoretical considerations and interventions for this particular family system will be detailed. Finally, areas for future study will be outlined.

<p style="text-align:center">Current Landscape of Developmental Disabilities</p>

Families Who Are Affected

Many researchers believe the incidence of children born in the United States with some form of disability seems to be on the rise, particularly developmental disabilities such as autism. The American Academy of Pediatrics [AAP] estimates 12% – 16% of families in the United States are comprised of at least one child with a developmental or behavioral disorder (2001). Approximately 2,800,000 children in the United States have

been diagnosed with some type of learning disorder (Bryan, Burstein, & Ergul, 2004). Of children with Learning Disorders, the likelihood of co-occurring social problems is also a factor. It is estimated 38-75% of all children diagnosed with a Learning Disability also have social difficulties (Bryan, Burstein, & Ergul, 2004).

Definitions

Complicating the understanding of developmental disabilities is the lack of agreement among practitioners. The definition of developmental disability varies across disciplines, practitioners, and researchers. According to the AAP, the term developmental disability has a range of types and severity. Developmental disabilities have been broadly defined to refer "to any chronic or severe mental and/or physical impairment that is manifested before age 22 years, is likely to continue indefinitely, and results in substantial limitation of function" (Gabor & Farnham, 1996). It should be noted the AAP has stated severe disabilities are much easier to identify, yet has cautioned there is no consensus among practitioners or families about one specific point at which diagnosis and treatment become necessary (AAP, 2001).

Historical Context

Our Negative Past

Research literature has been replete with studies which assess the negative impacts associated with having a child with a disability. While the primary negative variable studied has been family stress (Hastings & Taunt, 2002), other considered consequences include marital and partner dissatisfaction, caregiver isolation, and loss of income. A deficit based focus has been the basis for

theoretical underpinnings in mental health and educational literature, fueling the types of intervention and treatment strategies prescribed for families and children. Risdal and Singer stated that during an approximately 20 year period, between 1948-1967, over 50 research articles delineating the negative aspects of raising a child with a disability appeared in literature (2004). He further clarified the studies during this period frequently suggested families should consider placing their child in a residential or medical setting permanently, in part due to the severe suffering families were believed to experience (2004). Outcomes for families were considered bleak, leading many families to feel hopeless about their options and potential outcome.

As researchers continued to focus on negative outcomes, the idea of a family tragedy was introduced. It was believed a family tragedy occurred because the family experienced the loss of the "ideal child" and would need to grieve this loss as they came to grips with the disabled child (Risdal & Singer, 2004). The idea of a family tragedy became the basis for theoretical models, interventions, and subsequent research. The family tragedy theory has continued to impact research, influencing the direction of current studies.

Negative Family Impact

The view practitioners had of families with a child with a developmental disability has evolved dramatically over the past 60 years. Prior to legal considerations, many families were denied services particularly as the severity of disability increased. Frequently these families had to choose between state institutions or isolation (AAP,

2001). Further, families have been blamed for the difficulties their children face, ostracized for being different, and subjected to inappropriate treatment within the historical context of disabilities (McCracken & Baglin, 2001).

A Shifting Paradigm

While it is undeniable that parents who have a child with a developmental disability will deal with challenging situations not faced by parents who are raising a typically developing child (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004), assumptions made in deficit skewed literature have limited the way families are evaluated and assisted. Because these studies have been frequently performed from the point of view that potential negative factors occur in the exclusion of positive or mediating factors, the result of these assumptions has been to potentially limit the interventions available to families. While families undoubtedly face influence from a child with a developmental disability (McCracken & Baglin, 2004), research has not be able to definitively assess whether the family will experience this impact as a constructive or destructive variable in the family system.

Historically, as researchers focused on deficits, families began to question why their experiences, frequently positive, weren't being reflected in the services provided and research studies in which they were asked to participate (Hastings & Taunt, 2002). It wasn't until positive psychology, coupled with a push from parents who advocated for a different view of their children, that researchers began to conceptualize a new view of families.

A New Approach

During the 1980's, studies started to appear which considered families within the context of a strengths approach (Hastings & Taunt, 2002). This trend was mirrored in disability literature as studies were conducted to examine families within a family systems context, considering the interconnectedness of one member to another, and taking into consideration available coping mechanisms and overall family well-being. Investigative trends involving these families began to explore potentially positive impact, such as overall satisfaction, the joy associated with raising a child with a disability, increased social contact, and personal awareness.

Across group comparisons. As researchers began to consider positive impact among families, across group comparisons which studied families of children with and without disabilities began to appear. Families with a child with a developmental disability have been juxtaposed against families with typically developing children, and research has determined little to no difference in satisfaction reported among families in both subsets (Hastings & Taunt, 2002). In fact, some researchers have indicated the opposite may be true. Families with a child with a developmental disability may experience greater amounts of personal satisfaction and higher levels of marital satisfaction. Research has not indicated a significant difference in positive perceptions between families who have a child with a disability, and families who have typically developing children (Hastings & Taunt, 2002). While research has frequently identified more stress in families of children with disabilities, researchers have also shown that

these families have the same or higher reports of positive impact when considered with

families of typically developing children (Hastings & Taunt, 2002)

  Developmental stages. Other researchers have identified specific stages of

change which occur in families with a child with a disability, from denial to acceptance

concluding with overall patterns, of long-term resilience (Risdal & Singer, 2004).

Researchers are continuing to explore and define the potential for positive impact in

families with a child with a developmental disability.

Positive Themes Identified in Research

  Several specific areas of positive outcomes have been identified in literature.

Hastings and Taunt identified these areas after a meta-analysis of available literature.

These areas involve the following key themes identified by Hastings and Taunt:

1. Pleasure/satisfaction in providing care for the child.
2. Child is a source of joy/happiness
3. Sense of accomplishment in having done one's best for the child
4. Sharing love with the child.
5. Child provides a challenge or opportunity to learn and develop.
6. Strengthened family and/or marriage
7. Gives a new or increased sense of purpose in life
8. Has led to the development of new skills, abilities or new career opportunities
9. Become a better person (more compassionate, less selfish, more tolerant)
10. Increased personal strength or confidence
11. Expanded social and community networks.
12. Increased spirituality.
13. Changed one's perspective on life (e.g., clarified what is important in life, more aware of the future).
14. Making the most of each day, living life at a slower pace. (Hastings & Taunt, 2002, pg. 118)

The Impact of Positive Thinking

Hastings and Taunt noted "The radical alternative to starting with the assumption that families will face challenges associated with raising a child with a disability would be to start with the assumption that the child will have a positive impact upon families" (2002). The idea of families experiencing positive impact is radical in several regards. First, it is considered counterintuitive to traditional literature, assumptions, and current intervention styles. Secondly, positive outcome variables have the potential to have several mitigating factors, including the possibility of stress reduction, and the ability of families to deal with the challenges they face in appropriate and constructive ways. In short, positive assumptions repudiate several decades of long standing literature which has assumed the worst of families who have a child with a disability.

<div align="center">Theory</div>

Theoretical models which have specifically focused on positive impact have not been well defined. Taunt and Hastings have stated there is no one explicit theory that considers positive effect (2002). However, there are several theories which consider positive perceptions. These include the Family Adjustment and Adaptation Response Model, the Resiliency Model of Family Stress and Adjustment, Family Schema, Bandura's Self-Efficacy model, and Family Systems Theory.

Family Adjustment and Adaptation Response Model (FAAR)

The FAAR model assists practitioners by predicting the possibility of positive impact among family experiences with children with disabilities. The model identifies ways families can neutralize stress by achieving balance between coping mechanisms and

the pressure they are under (Taunt & Hastings, 2002). Families may achieve this balance

by emphasizing the positive aspects of their life, such as personal growth or pleasure

derived from their family and downplaying difficulties posed by raising a child with a

disability.

Family Schema

A family schema involves the development of meanings which inform values

and socialization (Taunt & Hastings, 2002). The family's perceptions inform their ideas

and values, thus influencing the way the world is viewed in their schema. Families then

utilize this input in consideration of stress or influencing factors, and achieve balance by

considering input based on their personal schema.

Self Efficacy

First described in the writings of Bandura, self-efficacy deals with the individual's

belief in his or her skill in a particular area (Hastings & Taunt, 2002). In other words,

self efficacy allows the individual to conceive his or her ability to adapt to a particular set

of circumstances on the basis of personal ability to positively cope with issues in the

environment. Coleman and Karraker describes self-efficacy as the perceptual

understanding of one's skills when considered in the context of the presenting

circumstance, and the belief the individual will be able to effectively manage the

presenting situation (1997). They continue to say the understanding of an affirming

social system will impact the individual's understanding of self-efficacy. In essence,

individuals who believe they have some measure of personal control over his or her life

event, through innate ability or coping resources, will be able to access more positive

perceptions in relationship to the presenting concern.

Family Systems Theory

Family systems theory identifies as its foundation the principle that each

member of the family impacts and influences the other, and individuals cannot be

considered outside the context of the family constellation. McCracken and Baglin

observed that while research exists suggesting families should be the focus of services,

this has been done in the absence of family systems theory (2001). Ignoring the

interconnectedness of family members may result in unintended consequences among

family members not integrated into the treatment and intervention process (Stoneman &

Gavidia-Payne, 2006).

Despite indications of the importance of the role of the family in the life of a child

with a disability, services continue to be geared towards the individual child.

Practitioners have generally adopted a neutral role towards the family (McCracken &

Baglin, 2001). Families are seen as potential supporters of a child and the gatekeeper to

services.

Concluding Comments on Theory

Hastings and Taunt has suggested that while no one theory accounts for the

positive perceptions among family members of children with a disability, there are

considerations for the future development of theories. These two options are to do one of

the following: 1) research may continue to consider families through the lens of the

stress which has been identified as a part of the family system or 2) develop an entirely new model which accounts for positive family perceptions. (Hastings & Taunt, 2002).

Emotional Response

As researchers have continued to highlight a more positive outcome for families with a child with a disability, new study contributions have focused on ways the family responds in this environment. Response variables include wide range of emotions, both positive and negative.

Emotional response of the family does not involve one emotion that is consistent over time. It is fluid, and fluctuates with the stages of the family and child's development. For example, families at the earliest stage of this process may need to know very detailed information regarding their child's diagnosis and prognostic information to in order to decrease feelings of anxiety and gain some sense of control. Families with an older child, or ones who have already gone through the initial diagnostic process, will not necessarily want the same etiologic information (Wong & Wong, 2003).

As noted earlier, one of the biggest criticisms of early literature is that it frequently considers only one variable, most often negative, to the exclusion of other possible responses. The following discussion will consider the multivariate response of families, both positive and negative.

Emotional Response Cycle

Researchers have identified several stages families may go through specifically at the time of the diagnostic process of learning their child may have a disability (Gabor &

Farnham, 1996). These stages are based in part on the grief stages first identified in the

work of Kubler-Ross.

Denial. The first identified stage of the emotional response cycle is denial. One

or more family members experience denial, defined as a defense mechanism which may

help alleviate some of the early shock and overwhelming feelings associated with

obtaining a diagnosis (Gabor & Farnham, 1996). This may be a necessary defense that

will help families work through the feelings associated with obtaining a diagnosis,

particularly if families find the news difficult or surprising. A potential concern with this

stage is that it may impede the family moving towards feelings of acceptance regarding

the diagnosis.

Adjustment. Adjustment deals with anger, feelings of sadness, and guilt (Gabor &

Farnham, 1996). Families may experience a wide range of emotions during this phase.

While sorrow is typically experienced during this stage, Gabor and Farnham have

identified "Chronic Sorrow" as another possibility. Chronic sorrow is typically more

intense, and frequently identified as maladjustment by health practitioners (Gabor &

Farnham, 1996). However, Gabor and Farnham note during this stage, it may in fact be a

common response associated with parents of children with disabilities, and should not be

misinterpreted.

Acceptance. In this stage, families are able to adjust to their situation and develop

realistic ideas about the process. Gabor and Farnham note acceptance is not the final

stage (1996). Instead, families may continue to go back through the various stages as

new information is integrated or as they continue to find ways to cope.

The "all right" stage. Researchers have suggested there may be another stage beyond acceptance known as the "all right" stage. This stage is characterized by families helping families, specifically families who have passed successfully through the other stages assisting families who are in the denial or adjustment phases. This stage has been shown to be very effective in helping families form positive perceptions and develop coping resources (Hastings & Taunt, 2002).

Stress

Stress has been the most frequently identified emotion experienced by families with a child with a disability. Some research has implied families with a child with a disability may experience a more extreme form of stress, otherwise known as chronic stress (Gabor & Farnham, 1996). Chronic stress occurs because of the extreme demands placed on caregivers, coupled with isolation and an inability to take care of themselves. In addition, chronic stress may leave caregivers more susceptible to illness (Gabor & Farnham, 1996).

While stress does occur in families of children with disabilities, coping mechanisms have been shown to effectively reduce stress. No differences have been shown between families of children with disabilities and those of typically developing children when it comes to the utilization of coping resources and the effective reduction of levels of stress (Stoneman & Gavidia-Payne, 2006). Stress management has several known benefits; including improved quality of life for families, as well as lower levels of placement in residential facilities for children with disabilities (Chan & Sigafoos, 2001).

Isolation

Families of children with a disability may feel they cannot share their concerns with others because of fear of rejection. Additionally, because families may experience their own feelings of ambivalence, they may be uncomfortable sharing those feeling with others because of the reactions they may receive (Gabor & Farnham, 1996). The responsibility of caring for a child with a disability may make it more difficult to socialize with peers, and further increase feelings of isolation among families.

Guilt

Another experience among families has been feelings of guilt. Families expressed self-blame about their child's situation, wondering if they had somehow caused the disability. There were expressions of guilt, as parents wondered if they had "done something wrong during pregnancy" (Wong & Wong, 2003). Families are frequently left to wonder about their responsibility in their child's disability if practitioners do not consider their emotional well-being.

Positive Emotional Impact

While the bulk of research has focused on negative emotional response, the focus of research has recently shifted to give further consideration to the positive contributions associated with having a child with a disability. Baker, Blacher, Crnic, and Edelbrock have noted disability may have positive impact on families, and have specific contributions not typically considered in the family, such as the development of more effective and appropriate coping resources (2002).

What once was considered a family tragedy to be endured, has now been reframed to look at the potential opportunities for personal growth and joy from family members who are connected to a child with a disability. Consistently in research, these positive emotions are associated with coping strategies and resources which have aided families in stress reduction and increased personal satisfaction among family members. As families experience positive impact, they may also have the added benefit of having greater resilience against symptoms of depression. (Hastings & Taunt, 2002)

Strength. One of the positive emotions identified by researchers is strength. Families have exhibited perseverance and the ability to continue to grow and share in the face of changing and sometimes difficult situations (Gabor & Farnham, 1996).

Assertiveness. Families have identified developing skills of assertiveness as another positive area of growth gleaned from their experience with having a child with a disability. As families have become advocates for the needs of their child, they have recognized assertiveness as a reward of both their efforts, and their child's growth (Gabor & Farnham, 1996).

Installation of hope. Establishing feelings of hope in families with a child with a disability has been closely associated with positive outcome. Families frequently express a desire for hope in their situation (Gabor & Farnham, 1996). Gabor and Farnham further outline establishing a relationship of trust between families and practitioners as a prerequisite for the fostering and development of hope.

Interventions

Currently, there are several possible interventions being explored for use with families of a child with a disability. A few of these, derived primarily from individual theories, are highlighted below.

Family Systems Approach

In this approach, the family is at the core of all treatment options. Instead of focusing on the child only as the identified client, the interventions are structured in such a way as to meet the needs of the entire family, based on family responses, in a team approach by practitioners (Gabor & Farnham, 1996)

Family system aid. This is one specific type of intervention used in the Family Systems approach. It involves considering the response of each member of the family, and looking at means of interaction in the family (Gabor & Farnham, 1996). The individual family members are then targeted based on response patterns for treatment interventions.

Self-efficacy

As noted earlier, self-efficacy has several positive aspects. Generally, it is associated with overall mental health wellness. Additionally, parental self-efficacy has been shown to have a positive relationship with parental attitudes, behaviors, and a decrease in stress (Hastings & Taunt, 2002). For parents to establish self-efficacy, it is important for them to gain knowledge about child-rearing, develop confidence in their parental abilities, and develop appropriate social support with family and friends who will encourage their efforts (Coleman & Karraker, 1997)

Treatment interventions involving self-efficacy may therefore involve finding

ways to allow parents to experience success in their interactions with their child

(Coleman & Karraker, 1997). Parents may also benefit from appropriate instruction on

developmentally appropriate skills and techniques to utilize with their child. Helping

families to find appropriate means of support would also be an important area of

intervention for families who are learning skills surrounding self-efficacy.

Wrap-Around Services

The purpose of wrap-around services are to bring together families and support at

both the professional and informal level to collaborate for the purpose of the families

overall well-being. Wrap-around services allows the family to be provided with a

support team, who will assist in making sure the needs of the family are met, services are

coordinated, and eliminate the experience of duplication of unnecessary services (Kramer

& Houston, 1999).

Support Groups

Support groups are frequently made available to parents. Support groups may

provide support through a few different ways. Groups may reduce stress levels by

allowing parents to normalize feelings, develop stress management skills, and working

towards goals of positive parenting (Risdal & Singer, 2004). Groups may also provide a

safe atmosphere for parents to discuss their pain and difficulty, allowing them to receive

emotional support from their peers. Through psychoeducation, parents may receive tips

on new ways to manage their personal situation.

Need For Further Study

As studies continue to focus on positive ideation among families, interventions will be adapted to suit this new trend (Taunt & Hastings, 2002). Several areas are targeted in research literature for further study include broadening the definition of the family, exploring sibling impact, looking at early identification of coping resources, increasing understanding of the role of self-efficacy among families, and broadening the research parameters to allow for greater generalizability to the families with disability populace.

Gabor and Farnham identify areas of deficiency in literature including a need for studies based on aspects of interpersonal relationships with single parents and longitudinal studies exploring the needs of siblings of children with disabilities (1996). Considering parental self-efficacy in the context of other situation specific circumstances, such as the child's peer or academic difficulties has been an area for further study suggested by Coleman and Karraker (1997).

Taunt and Hastings have identified most of the current research literature on families with children with a disability as containing unrepresentative samples (2002). Further, the types of research performed have not given enough consideration to other demographic variables, such as the parent's age and health, the child's age, or the severity of disability (Taunt & Hastings, 2002).

Additional possibilities for further research would expand the idea of family. Many research areas to date have focused on parents, excluding extended family which may play an integral role the in the child's development and the family system.

Additionally, little consideration has been given to blended families, or LGBT families who are raising a child with a disability.

While there are theories being applied to families, particularly when considering positive impact, a specific theoretical basis has not been established. Hastings and Taunt have suggested designing a more clear definition of positive perceptions, and looking at outcome data for their impact on families (2002). Continued research efforts in this area that could refine understanding of positive impact would be a welcome addition to research literature.

Conclusion

Research data has only begun to explore the impact on families who have a child with a disability, particularly when variables including positive perceptions are considered. As research continues to shift in order to accommodate the newer trends towards positive psychology, as well as family identified benefits, it will be important to consider how this will impact the work with families. The way services are provided to families, including interventions may need to be altered in order to accommodate this new understanding (Hastings & Taunt, 2002). Theoretical understanding will need to continue to be redefined in order to accommodate the growing body of research which supports positive impact in families of children with disabilities. Additional consideration will need to be carefully weighed when providing services to families, given the emotional impact of family members on one another.

Most importantly, there is a solid foundation of research which supports the idea of positive attributes within families of children with disabilities. This literature has

given a voice to families which mirror their experiences. While family response will

continue to be fluid across time and experiences, researchers have clearly indicated that

no one response is typical of families. The use of positive associations will be crucial in

service delivery to the family system.

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