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Family and Professional Considerations for Adoptive Parents of Children with Special Needs

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Parenting a child with a disability can be a source of stress and strain on marital and family relationships. Early research focused on the pathology or maladjustment in families raising a child with a disability. More recent research identified positive adjustment in families and uncovers potential difference factors when comparing adoptive and birth families raising children with special needs. Identifying specific parent and family characteristics that contribute to the adjustment to parenting a child with a disability and distinguishing between parents and families who purposely chose to adopt a child with special needs and parents and families who rear a birth child with special needs are critical for educating professionals working with expectant parents, adoptive parents, and families. Identification of these characteristics can inform professionals regarding services or interventions that may help families experiencing difficulty adjusting to a child with special needs and can also support families during the prebirth and preadoptive placement decision-making process as well as throughout the child's life. This article reviews the existing literature on parenting a child with special needs, focusing on the characteristics, implications, and considerations of individuals who choose to adopt a child with a genetic or other physical or mental disability. The literature review includes information regarding which elements make the placements of children with disabilities successful, including adoptive parent expectations, experience with disabilities, preparedness and education needs, resources, and support systems. Finally, characteristics and challenges of expectant parents with high-risk or

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crisis pregnancies in which a fetal anomaly has been diagnosed are discussed with respect to appropriate training for health professionals who counsel patients seeking to determine an appropriate course of action during their decision-making process.

KEYWORDS adoption, adoptive parent adjustment, comparison of birth families and adoptive families, developmental disability, parenting a child with special needs, stress and coping, training for genetic counselors, training for health care professionals

INTRODUCTION

Parenting a child with a disability is often regarded as an extremely difficult and emotionally taxing responsibility. Parents must not only commit to becoming an advocate for their children's care, but they must do so while simultaneously managing the mental, emotional, and physical strain that a child with special needs may place on an individual and family. This strain may, at times, become too great for some families, who often experience a range of emotional reactions in response to the diagnosis of a developmental disability for their child.

Previously, studies have concentrated on the factors that contribute to the maladjustment of these families (e.g., Hastings, Daley, Burns, & Beck, 2006). More recently, however, research has begun to explore families who choose to parent a child with developmental disabilities (e.g., Lindh, Steele, Page-Steiner, & Donnenfeld, 2007). A large number of these parents make the choice to adopt a child with a disability. Understanding the characteristics and motivation behind such a decision (with consideration of the additional stress and effort required to parent a child with a disability) is critical to supporting families facing similar challenges. Glidden (Project Parenting, n.d.) of Project Parenting at St. Mary's College in Maryland, a 20-year federally funded project, has pioneered research exploring the characteristics of families who successfully adjust to parenting children with disabilities.

This article summarizes the literature regarding the characteristics and experiences of birth and adoptive families who parent children with disabilities, the implications and considerations of those who make this choice, and the elements necessary for a successful placement. Additionally, the considerations for health professionals who work with families parenting a child with special needs or expectant parents who may consider adoption as an option after a fetal diagnosis are discussed.

METHODS

The studies and articles for this literature review were obtained through the use of search engines and citations. PsychInfo®, PubMed®, and Google

Scholar® were the primary literature search resources used for this article. Additional studies were identified after reviewing citations in primary research articles. In excess of 100 articles and studies were considered for this literature review; consideration for their use was based on relevance, specificity, recent date of publication, and accessibility. Special needs adoption studies included in this literature review were limited to those that primarily focused on individuals with disabilities rather than those studies that used the broader definition of the term "special needs," which can include such things as child's age or membership in a sibling group.

SPECIAL NEEDS DEFINED

In the field of foster care and adoption, the term "special needs" has an all-encompassing definition. It can refer to any child who is difficult to place as a result of physical, mental, or behavioral disability, race, age, or membership in a sibling group. For the purpose of this article the term "special needs" focuses on physical and developmental disabilities distinctly organic in nature (e.g., genetic disorders) and of known etiology. The definition of a developmental disability typically describes a severe, chronic condition resulting in physical, sensory, and/or cognitive impairments which are expected to require extended services (Coleman, 1993; Glidden, 1991, 2000). Public Law 98–527 (Federal Developmental Disabilities Act of 1984) takes an additional step to identify the fundamental requirements of a disability. It specifies that a developmental disability must

- Be characteristic of a mental and/or physical impairment
- Manifest before age 22 years
- Continue for an undefined period
- Result in significant functional limitations
- Require long-term or life long services and/or treatment

Approximately 50% of children in the child welfare system who are legally free, or available, for adoption manifest disorders that are consistent with this definition (Child Welfare Information Gateway, 1999), and adoptive families are available for all ranges of disabilities (Glidden, 1991). These disorders can include Down syndrome and other forms of intellectual disability, cerebral palsy, and spina bifida, among numerous other disorders of known and unknown etiology.

Intellectual disability (ID) can range in functionality from mild to profound and is a result of incomplete mental development or impairment. Down syndrome, the most common form of ID, occurs in 1 in 800 births (National Institute of Child Health and Human Development, 2008). Children with Down syndrome possess an extra copy of chromosome 21 and often display such features as characteristic eye shape and size, weakened muscle tone, and short stature, in addition to some level of ID. Typically, the level of ID falls within the range of mild to moderate. Approximately half of all individuals with Down syndrome may also demonstrate congenital heart disease, among other possible health problems.

Cerebral palsy refers to a group of neurological conditions that affect body movement and muscle coordination (National Institute of Neurological Disorders and Stroke, 2008). Most children with cerebral palsy are born with the condition, a possible result of trauma shortly before or during birth; however, in some cases cerebral palsy can result from brain damage or injury later in childhood. Individuals with the condition present various abilities and inabilities in coordinating and controlling muscle movement.

Another common condition, spina bifida, results from the incomplete development of the brain or spinal cord or the protective coverings of these organs during the first month of pregnancy (National Institute of Neurological Disorders and Stroke, 2007). Functionality varies for individuals with spina bifida and may include various physical and mobility issues as well as some degree of learning disability.

PARENTING A CHILD WITH A DISABILITY: ELEMENTS OF STRESS AND COPING

Although parenting in general involves a great deal of stress and adaptation, this responsibility may be more difficult for parents of children with disabilities. A review of literature by Glidden, Billings, and Jobe (2006) revealed that, in addition to the daily tasks of providing for and nurturing their children, these parents must also navigate the challenges of accepting the child's diagnosis and limitations, locating and accessing services and resources for care, and planning for future care of their child upon entering adulthood. Elevated levels of stress can result from grief over the loss of the "expected" child and life goals, relationship concerns, financial anxiety resulting from an increase in bills and necessary time off from work, the desire for acceptance by others, increased time demands and decreased personal time, loss of daily routines, and the process of navigating challenges in obtaining required services (Bailey et al., 2005; Center for Children with Special Needs, 2007). Glidden, Flaherty, and McGlone (2000) argue that even the most prepared and committed caregivers may feel overwhelmed with responsibilities, leading to an increase in strain and maladjustment.

Whereas several factors may contribute to the variation that is seen in family and individual responses to the demands of parenting a child with a disability, the amount of stress experienced by a family may account for much of this variation. Navigation of this stress is imperative for families to achieve adaptation and adjustment. According to Crnic, Freidrich, and

Greenberg (1983), family adaptation is directly related to availability of coping resources, as these resources act to buffer the stress that families typically experience. For instance, families with higher income levels may find it easier to provide relief from daily caretaking demands by allowing the primary caretaker to arrange for child care (Farran, Metzger, & Sparling, 1986). There is also evidence that cultural beliefs and backgrounds may influence family perspective and parenting approaches in caring for a child with a disability (e.g., Blacher & McIntyre, 2006). As discussed below in greater detail, parent well-being, gender, coping style, personality and perspective, disability severity, social and professional support and other resources, and experience with the medical community also play major roles in family stress and adaptation.

Existential and Reality Crises

The birth of a child with a disability or the diagnosis of a disorder in an infant or child is a stressful event during which parents must recognize their child may not meet the life goals and plans that parents had expected and intended for the child (Makri-Botsari, Polychroni, & Megari, 2001). This stress can lead to inadequate coping, social isolation, and relationship issues (Brooks-Gun & Lewis, 1982). Immediately after the birth of a child with a disability or after the diagnosis of a child's disability, parents often experience a sense of despair and meaninglessness and begin to question their own identity and personal values, the meaning of life, and their religious beliefs (Glidden, 1986, 1990). Because of this response these events are generally referred to as existential crises (Glidden, 1986) and must be resolved before moving forward with adjustment. Subsequently, daily parenting yields to additional issues and demands that a child with special needs places on a family. These reality crises, as they are commonly termed, must be resolved to successfully adjust to the child (Glidden, 1990). The greatest emotional strain on time and energy occurs at the time of birth or diagnosis, when parents must face and resolve both existential and reality crises. There is also an extreme demand for lifestyle change at this time (Glidden, 1990).

Commitment to the child, family strength, preparation, child's characteristics in relation to parental preference, parents' attributes, and social support are among the factors that influence the relationship between existential and reality crises (Glidden, 1990). If there exists a strong commitment to the child, adaptation will not be significantly influenced by existential issues; however, a lack of preparation may generate existential crises resulting from a lack of self-confidence and coping ability. Glidden (1990) has posited that this awareness explains why adjustment is generally easier, at least initially, for adoptive families than for birth families and why some adoptive families and birth families adjust better than others.

Parental Well-Being and the Role of Gender

Parental well-being has been linked to maintenance of general family psychological health (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006); however, its importance is highlighted by research indicating that parental well-being may play a role in child behavior issues (Hastings et al., 2006). Thus it is important to examine contributing factors of parental depression, anxiety, and stress when discussing family adaptation.

Research (Glidden, 2000; Kersh et al., 2006; Makri-Botsari et al., 2001) has suggested that mothers of children with disabilities tend to exhibit depressive symptoms, stemming from family economic issues, marital and family concerns (Kersh et al., 2006), and social isolation. The American Academy of Pediatrics reports that social isolation often results from excessive parenting demands placed on parents, in addition to frequent changes in residence, leading to separation from extended family and other supports (Johnson & Kastner, 2005). Mothers experience anxiety and stress resulting from the loss of these support systems, new time constraints, and the inability to obtain employment due to time and energy requirements of parenting children with disabilities, leading to a negative self-image (Makri-Botsari et al., 2001). A study of mothers in Greece with children who exhibit special needs demonstrated that maternal self-esteem is often lower without the support of an organized group and when child care is not shared with others (Makri-Botsari et al., 2001). It is also important to note that mothers who experienced some degree of depression initially continued to report increasing levels of depression over time as well as an increase in personal burden and a decrease in family pride (Glidden, 2000).

In general, research has focused primarily on the well-being of mothers of children with disabilities, because mothers frequently assume the responsibility of daily caregiving and child-related activities. In Roach, Orsmond, and Barratt's (1999) research, fathers were more likely to assume the responsibility for paid employment than for child care. Research that has focused on paternal well-being, however, has suggested that fathers and mothers are similar when it is considered that both experience an initial reaction to a diagnosis, adaptation to the disability, negative reactions to professionals, stress of parenting a child with disabilities, and concerns about accessing resources and services (Hornby, 1992). Nevertheless, the various responses and concerns experienced by fathers of children with disabilities may differ from those experienced by mothers. Whereas both fathers and mothers report uncertainty about such issues as meeting the child's needs, development and limitations, and where to access support services, fathers have reported further stress resulting from their concern about social acceptance for their children (Saloviita, Italinna, & Leinonen, 2003). Additionally, financial demands resulting from child care, specialized transportation, loss of second income, and medical equipment are also a significant concern for fathers (Goble, 2004; Pelchat, Lefebvre, & Perreault, 2003).

Depression and decreased parental competence that is sometimes found in fathers have been attributed to the fact that few men enter fatherhood with strong parenting skills and child care knowledge. Those who are prepared often find that the actual experience is more difficult than they had expected. When coupled with the realization that they are unable to protect their child from disability or solve all the issues their child will encounter, as the socialized role of the father does, parenting a child with disabilities may seem especially daunting (Quinn, 1999). Thus it is not unexpected that fathers of children with disabilities may feel a loss of control and lack of confidence as a parent. Accordingly, it has been found that father involvement in families with children with disabilities is less than in families with typically developing children (Roach et al., 1999). Nevertheless, the importance of father involvement in child care is evident, as involvement acts to reduce the caregiving burden on mothers and increase parental competence as well as father–child attachment (Roach et al., 1999).

Effectiveness of Coping Styles and Positive Perspective

Consideration of the various challenges and stresses inherent in families parenting a child with a disability requires an understanding of which parental characteristics and elements affect success. In fact, parental coping skills and abilities are significant indicators of future success in such families. Parents who use problem-focused coping and social support demonstrate greater adjustment than those who depend on emotion-focused coping, such as denial, escape, and avoidance (Glidden et al., 2006; Stoneman & Gavidia-Payne, 2006; Won, Greenberg, Seltzer, & Krauss, 2003). In other words, individuals who directly confront a situation and focus on a resolution rather than indulging in guilt and wishing for alternative outcomes are better able to regulate negative emotions, engage in positive thinking, and display positive attitudes in general (Makri-Botsari et al., 2001). In fact, individual and family functioning may be best predicted by the use of problem-focused coping strategies (Stoneman & Gavidia-Payne, 2006).

Although many mothers use problem-focused coping strategies by becoming their child's primary advocate (Poehlmann, Clements, Abbeduto, & Farsad, 2005), others may engage in maladaptive coping styles as a direct result of depressive symptoms; however, lower levels of these depressive symptoms have been found in mothers who receive caregiving help for the child and who participate in organized support groups (Makri-Botsari et al., 2001). The importance of social and community support are addressed later in this article, but suffice it to say that under these circumstances mothers have been found to take a more positive coping approach and to report higher levels of self-esteem than when support is not present. It is important to note that mothers have reported changes in coping processes over time (Poehlmann et al., 2005), suggesting that those who begin the coping process by using emotional coping strategies may ultimately learn to engage in more problem-focused coping.

Personality and level of optimism also contribute to adaptation and coping with child care challenges of parenting a child with a disability. Recognition of the positive contribution that a child with a disability makes to a family may result in less familial stress (Hastings & Taunt, 2002). Baker, Blacher, and Olsson (2005) found that mothers with higher dispositional optimism demonstrated better adjustment and coping than mothers with pessimistic tendencies when managing their child's behavioral issues. Optimistic fathers also reported reduced levels of parenting stress (Baker et al., 2005); however, marital adjustment and depression were not affected by paternal optimism level as they were in mothers.

Importance of Social Support

The presence of social networks and support is an essential factor for coping and adaptation. Evidence suggests that family stress increases over time when caring for a child with a disability (Johnson & Kastner, 2005), and without sufficient support challenges that are intrinsic in such family situations may lead to hopelessness and despair (Bailey et al., 2005). Informal social supports have been positively correlated with a family's stress level (Berkson, 1993) and ability to adapt to stressful events (Parke, 1986). Mothers of infants with special needs who experienced greater levels of stress but who had weekly visits with friends typically demonstrated more active involvement with their infants than mothers who engaged less frequently in contact with peers (Unger, 1979, as cited in Parke, 1986). Parke concludes that informal social networks may indirectly affect child development by impacting the nature of parent–child relations and suggests that both informal and formal familial support systems may aid in adjustment and adaptation by providing accurate developmental timeframes, observing and advising to improve child care techniques, and providing reprieve from caregiving demands. Johnson and Kastner (2005) recognize and endorse the importance of respite care for families parenting a child with a disability.

Community support demands are based not only on the child's characteristics and needs but also on characteristics of the family. These characteristics can include household composition, coping abilities, income, and work schedules (Johnson & Blasco, 1997; Johnson & Kastner, 2005). Nevertheless, despite the undeniable need for support systems, particularly informal supports, research has demonstrated that parents of children with ID receive far less informal support than parents of typically developing children (Parke, 1986). Reasons for this observation may correspond with the avoidance of social contact or social exclusion as a direct result of an assumed stigmatization of the family. Additionally, close relatives may experience grief, as parents do, over the loss of the "expected" child. This grief may make social interaction difficult within the family. Families may also be too exhausted by daily caregiving demands to maintain ties to extended family and friends (Parke, 1986). Finally, physical inabilities may also account for the lack of informal support in these families. Relatives and friends may be unable to provide assistance and support merely due to the need for specialized caregiving arrangements or equipment required for a child with special needs (Parke, 1986).

Perhaps the most important form of social support is that of spousal support (Belsky, 1984). A supportive marital bond can play a key role in softening the negative initial impact of a child's diagnosis (Poehlmann et al., 2005) or the birth of a child with a disability (Parke, 1986). Lack of spousal support has been shown to increase the difficulty of these situations (Poehlmann et al., 2005). In addition, Dickie and Matheson (1984, as cited in Parke, 1986) have linked spousal support to parental competence, determining that emotional support (e.g., affection, respect, marital satisfaction) and cognitive support (e.g., child care agreement within the marital dyad) positively influence parental competence.

Nevertheless, it is the quality of the marital relationship and reported marital satisfaction that directly impacts parental well-being (Kersh et al., 2006). Marital adjustment and satisfaction can be impacted by child behavior (Simmerman, Blacher, & Baker, 2001), spousal coping skills (Lev-Wiesel, 1998), individual coping style (Bouchard, Sabourin, Lussier, Wright, & Richer, 1998), and the number of "daily hassles" (Stoneman & Gavidia-Payne, 2006). Mothers who testify to higher marital satisfaction generally experience fewer depressive symptoms, lower stress levels, and more effective parenting. Adjustment, coping ability, and adaptation depend on the strength of both the family and the marriage (Glidden, 1990). Thus a positive marital bond may act as a resource for family adaptation (Glidden, 2000), which may explain why single mothers have reported greater adjustment difficulties when compared with mothers who are part of a marital dyad (Glidden, 2000).

Conversely, a poor marital relationship is not only an inferior resource but may even act as an additional stressor that consumes other resources (Glidden, 2000). Parke (1986) contends that marital relationships can be disrupted by stressful events, such as the birth or diagnosis of a child with a disability, leading to reduced spousal support. However, although it is commonly assumed that families with children who have disabilities may be more likely to experience divorce, Urbano and Hodapp (2007) found that parents of children with Down syndrome are actually less likely to divorce than other parents. Those divorces that do occur in these families tend to happen during the first two years of the child's life. Urbano and Hodapp (2007) speculate that this finding could be the result of parental depression over unrealized expectations, the severity of early medical issues, or inaccessible resources and services. Regardless of the reason, it appears even more necessary to locate services and establish support systems for these families, particularly during the initial period of the child's life.

Equal commitment by both individuals within the relationship, flexibility, and effective communication are necessary to avoid conflict within the relationship and to ensure positive family adaptation. Patterns of stress management may develop with time, practice, and commitment between parents, leading to sustained families in which both parents are able to provide support and emotional strength (Westhues & Cohen, 1990).

Impact of Disability Severity

Diagnosis type can impact parental concern over the child's health and emotional well-being, as well as the degree to which family activities are limited or interrupted (Eddy & Engel, 2008). Furthermore, stress level and parental well-being may depend, at least in part, on the type and severity of the child's disability. Research (e.g., Fidler, Hodapp, & Dykens, 2000; Hodapp, Ly, Fidler, & Ricci, 2001; Roach et al., 1999) has attempted to identify a hierarchy of parental well-being based on disability type, although numerous studies (e.g., Blacher & McIntyre, 2006; Hastings et al., 2006) have found that the link between parental well-being (including depression and marital satisfaction) and diagnostic type is primarily related to the level of child behavior problems. Families appear to experience greater levels of stress and pessimism when a child exhibits more overall behavior issues as well as more externalizing and internalizing problems (Hodapp, Dykens, & Masino, 1997). Thus, although parents of children with Down syndrome experience greater caregiving challenges than parents of typically developing children (Roach et al., 1999), higher levels of parent-related stress, negative impact, and pessimism are reported by mothers of children with autism, cerebral palsy (Eisenhower, Baker, & Blacher, 2005), Smith-Magenis syndrome (Fidler et al., 2000), Williams syndrome (Fidler et al., 2000), and Prader-Willi syndrome (Hodapp et al., 1997). In fact, parents of children with Down syndrome have even been found to experience a greater number of child-related rewards than other families of children with special needs (Hodapp et al., 1999). Nevertheless, additional studies have suggested that other aspects of a child's disability may impact experiences of parent-related stress (Eisenhower et al., 2005). Still, the child's disability alone may be enough to impact maternal stress, regardless of behavioral issues and cognitive abilities (Eisenhower et al., 2005).

Success in Parenting a Child With Disabilities

In addition to coping strategies and support networks, success in parenting a child with a disability depends on numerous factors. Initial reactions and adjustment to the birth and diagnosis of the child's disability have been associated with long-term adjustment. Early issues must be regarded as potential areas for difficulty later (Glidden, 1991; Glidden & Pursley, 1989). Preexisting characteristics of the family are also important factors in predicting a family's ability to adapt to a child with a disability as well as previous experiences and long-term support (Gath, 1977; Glidden, 1986; Glidden & Pursley, 1989). Commitment, beliefs, and personal experience with disabilities have been cited as key indicators of parenting success (Glidden, 1991), as are flexibility and acceptance of the child's condition and abilities (Reid, 1983).

Another factor in predicting success is availability of early intervention services. Most families (82%) reported that they were more successful as a result of early intervention (Bailey et al., 2005). These services aid in providing parents with skills to advocate for the care of their children, leading to an overall sense of optimism for the future and empowerment. Parents who used early intervention services reported feeling more competent to function in a parenting role and to advocate with professionals for the child.

According to Glidden (1991), the most ideal situations are those in which mothers demonstrate little initial reluctance and no depressive symptoms, a positive spousal relationship exists in which both parents actively participate in caregiving roles and provide mutual support and nurturing, parents exhibit greater experience with disabling conditions, and stronger religious beliefs are present. Regardless of the situation, theorists suggest that adaptation may result from a process of three predictable steps. Recognition of the disability is the first step, followed by an emotional response (e.g., grief, anger, anxiety), and finally acceptance and adjustment (Blacher, 1984). Although individuals may not move through these stages so predictably, there is evidence that many do reach the final step in this process. Regardless of the situation, parental expectations adjust over time as families become more familiar with their child's characteristics and abilities (Clare, Garnier, & Gallimore, 1998), and most are successful in adapting to and coping with the demands of parenting a child with disabilities (e.g., Flaherty & Glidden, 2000; Glidden & Johnson, 1999; Glidden & Pursley, 1989). This coping process, however, is dynamic and ongoing (Blacher, 1984; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). New milestones as the child matures may cause a change in demands, leading to necessary changes in adaptation and coping strategies (Farran et al., 1986).

A COMPARISON OF BIRTH FAMILIES AND ADOPTIVE FAMILIES OF CHILDREN WITH DISABILITIES

The research reviewed previously focuses on the experiences of birth and adoptive parents and families of children with disabilities. To identify considerations and implications for adoption practice, we must first examine how adoptive families of children with disabilities differ from birth families of children with disabilities. One of the most apparent differences between birth and adoptive families involves premeditated commitment and preparation. Most adoptive families who have a child with special needs made a conscious choice to adopt a child with a disability. Thus they may exhibit a higher initial commitment to the child and his or her specialized needs. Alternately, birth parents may not possess the initial commitment that adoptive parents feel, as the decision to parent a child with a disability is not usually a choice for them (Glidden, 1990). Because of this level of initial commitment, in conjunction with the advanced knowledge of the child's condition, adoptive parents have the opportunity to evaluate their preparedness for the placement and can opt not to proceed with the placement if they feel unsuited for the issues the child may present. Preparation may include acquiring knowledge regarding the child's level of functioning, financial preparation, and preparation of siblings and extended family for the child's entry into the family. Birth parents may also have the opportunity to prepare for the birth of a child with a disability as a result of prenatal screening and testing advancements; however, some may not have access to this medical care, or a diagnosis may not be possible with current prenatal screening/testing practices. As a result, these parents may not have prior knowledge of the child's condition. Consequently, some birth parents could be mentally, physically, and financially unprepared for the impending medical costs and caregiving demands inherent with children who have disabilities. As stated previously, familial economic issues are often a source of maternal depression in such cases, placing an even greater strain on birth families. Preparation is discussed in greater detail below as a contributing factor to success in adoptions of children with disabilities.

Additionally, adoptive parents are able to examine marital issues, family income, level of child functioning, level of comfort with the child's disability, coping styles, familial characteristics, and beliefs before making the decision to adopt (Project Parenting, n.d.) and can be guided by social service professionals early on in the process regarding resource options. Essentially, adoptive parents are typically able to make the choice to raise a child with a disability and may select a child that is the best fit for their abilities and circumstances. The birth of a child with special needs, however, is random in regard to parental personality traits, and the child may not be a good fit with the parents' qualities and traits.

Another potential difference between birth and adoptive families is the availability of support. Adoptive families typically have a network of pre- and postadoptive services available to them that are arranged through adoption agencies (Glidden, 1990; Glidden & Pursley, 1989). Many birth families, on the other hand, are not always aware of the services for which they qualify. Research has suggested that birth families receive less formal support and participate in fewer community activities than adoptive families (Bailey et al., 2005). Moreover, participation in religious and community activities is a common characteristic of successful adoptive families, implying that a lack of this type of support may impact the adjustment and functioning of birth families (Deiner, Wilson, & Unger, 1988; Glidden, 1986, 1991; Marx, 1990). Additionally, adoptive families often receive greater informal support than birth families. Although birth families may face scrutiny and avoidance from friends and extended family who view the birth of a child with a disability as a tragedy and who may be uncomfortable or embarrassed around the birth parents, adoptive families are often regarded positively, even as "saint-like" (Glidden, 1990, p. 202). Family and peers are often eager to offer support and help caring for the child. Finally, in some cases guilt may be assigned to one birth parent for a genetic disability, undermining family strength and resulting in spousal and relationship issues. Adoptive parents typically make a joint decision to adopt a child with a disability, further increasing spousal bonds and allowing for joint responsibility (Glidden, 1990).

Above all other differences, however, is simply that because adoptive parents *choose* adoption, they do not typically experience initial reactions of shock, denial, despair, and depression (Glidden, 1990) as severely as birth parents may experience these emotions. In other words, adoptive parents do not experience existential crises. As Glidden (1986) contends, most adoptive parents experience reality crises as a "'pure' consequence of the reality of caring for a difficult child" (p. 133) rather than as an extension of existential struggles. Facing reality crises without the burden of guilt, bitterness, grief, and anger intrinsic to existential crises permits adoptive parents to immediately work toward finding solutions for these reality issues (Glidden, 1986). This also leads many adoptive parents to use more problem-focused coping strategies than birth parents, who may initially cope with existential crises indirectly through denial and avoidance (Glidden et al., 2006).

Although adoptive parents and birth parents both encounter challenges and difficulties in parenting children with disabilities, it has been suggested that the psychological impact of these challenges is much greater for birth parents and that the attitudes and psychological states of birth and adoptive parents differ as a direct result of different circumstances surrounding the child's entry into the family (Glidden, 1986). Additionally, a greater availability of resources and the further "development of even more positive perceptions of the adoption experience" (Glidden, 2000, p. 22) may compensate for stressors experienced by adoptive parents. Nevertheless, it is important to emphasize the fact that differences between birth and adoptive families' abilities to adjust and adapt fade with time, yielding equally successful adjustment outcomes in longitudinal studies (Flaherty & Glidden, 2000; Glidden & Jobe, 2004). In addition to the differences discussed, adoptive parents may experience further issues and emotions that are separate from those of birth families; however, these issues are not within the scope of this literature review.

CHARACTERISTICS OF FAMILIES WHO ADOPT CHILDREN WITH DISABILITIES

Research has demonstrated that adoptive families of children with developmental disabilities frequently function more like birth families of children without disabilities (Glidden, 1986; Glidden & Pursley, 1989). Examining familial characteristics allows insight into factors that may contribute to placement and functioning success.

A Delaware study that investigated 56 families who had adopted a child with special needs found that most of these families were adaptable, religiously active, and cohesive; these characteristics have been supported in subsequent research (Cowling, 2003; Deiner et al., 1988). Numerous additional studies, such as those conducted by Marx (1990) and Glidden (1986, 1991), reaffirm the importance of religiosity and strong spiritual beliefs in familial adjustment. Other research has indicated that families who make the choice to adopt are inclined to be older, more flexible and patient, tolerant, more energetic and child oriented, more highly educated, and married for a longer period of time than those who choose to adopt children without a disability (Glidden, 1990; Reid, 1983). However, other studies have not found that families who adopt children with disabilities are as highly educated as other adoptive parents (Glidden, 1986).

Many parents already have previous birth or adopted children, which is often regarded favorably by agencies (Reid, 1983). Glidden's (1986) research with adoptive families found that 82% of the adoptions were deemed successful and concluded that these families were generally involved in a marriage of good quality; had some degree of religious affiliation; owned their home, often in suburban or rural areas; were self-employed or engaged in a professional or high-level management career; and were highly educated (Westhues & Cohen, 1990), although additional studies have contradicted these characteristic findings, claiming middle to lower class status, blue-collar employment, and lower education (Glidden, 1986). Above all, however, a large majority of these families had specifically requested to adopt a child with a disability and had previous personal or work experience and familiarity with the disability in question (Glidden, 1986). This previous experience encourages adoptive parents to set realistic and logical goals for the child, resulting in pleasure and contentment with the child's progress (Glidden, 1991; Westhues & Cohen, 1990).

In addition to those qualities and characteristics previously described, adoptive families of children with disabilities usually exhibit strong personalities, engage in stable relationships, and possess determination and an optimistic attitude (Gath, 1983). They may also consider themselves successful in parenting and capable of caring for a child with specific special needs. As a result of caring for previous children with disabilities, many adoptive families have experience advocating for a child within health and educational systems (Child Welfare Information Gateway, 1999). Families may engage in positive reappraisal, a coping strategy that focuses on the positive interpretation of events. Although this strategy of viewing situations as less problematic may delay a solution, it can be effective in adjusting to permanent conditions (Glidden et al., 2006).

Reid (1983) emphasizes the flexibility, patience, and motivation to adopt found in parents who choose children with special needs. Alternately, she reports that adoptive parents of healthy, White infants place an emphasis on marital relationships, a love of children, and the desire to parent. Research indicates that adoptive parents describe a variety of motivations for adopting children with special needs (Glidden, 1986; Glidden & Pursley, 1989; Westhues & Cohen, 1990). Lindh, Steele, Page-Steiner, and Donnenfeld (2007) found that access to resources and previous positive experience with a person with Down syndrome are the two most frequently noted reasons for families who adopt children with Down syndrome. Franklin and Massarik (1969), however, identified two distinct types of adoptive families who choose to care for children with special needs. The first type is described as being less well-educated and less focused on achievement. These individuals view the child "as just a child" (Glidden, 1986). The second type of adoptive family is prosperous and highly educated, focused on accomplishments, and citing the desire to help a child as a motivation. These classifications may help explain the variation in research findings regarding education and employment characteristics of families who adopt children with disabilities.

SUCCESS IN ADOPTION OF CHILDREN WITH DISABILITIES

Investigations into adjustment and adaptation in families who adopt children with disabilities have all drawn a similar conclusion: The level of satisfaction and number of positive outcomes for these families are relatively high (Flaherty & Glidden, 2000; Glidden, 2000; Glidden & Johnson, 1999). Disruptions are uncommon, and, in general, adoptive family members describe a positive experience and good adjustment. One study indicates that although 88% of participating mothers reported some negative impact with respect to adopting a child with a disability (e.g., behavior and personality changes in siblings, financial strain, negative reactions from extended family, spousal disagreements), in excess of 87% of mothers surveyed reported that their adoption experience met or exceeded previous expectations (Glidden & Pursley, 1989).

Moreover, continued success in adaptation and adjustment has been documented over periods up to 12 years postadoption (Glidden & Johnson, 1999). In fact, many families express satisfaction in terms of the benefits and rewards derived over time (Glidden, 2000). Communicated benefits have included a general increase in happiness, giving and receiving love, pride and pleasure in the child's accomplishments, strengthening of family and spousal bonds, and personal and familial growth in becoming more tolerant and patient, more sympathetic and compassionate, less selfish, and more flexible (Glidden, 1986, 1990; Glidden & Pursley, 1989; Haugaard, Moed, & West, 2000; Johnson & Kastner, 2005).

Contributing Factors of Success

Brodzinsky, Smith, and Brodzinsky (1998) outlined five critical areas that influence an adoption of a child with special needs:

1. Integration into the family
2. Attachment formation and grief support
3. Reasonable expectations of child behavior and family functioning
4. Management of difficult child behavior
5. Availability of supports and social services

Although these five areas may apply to the broad definition of the term "special needs," it is not difficult to see how they apply specifically to a child with a disability.

In addition to these five points, the success of the adoption also depends on reestablishing some sense of familiarity and comfort within the family (Mullin & Johnson, 1999). Inevitably, the family unit experiences a level of disturbance when a child with a disability is adopted. Parents may use external and internal parental resources to establish stability and security for other children in the family, allowing for birth children and previously adopted children to feel relaxed and comfortable with how they feel regarding the experience. To help ensure a successful outcome, adoptive parents should address and affirm children's feelings, concerns, and behaviors while demonstrating confidence. Support groups can also assist birth and adopted children through the transition of placement. Mullin and Johnson (1999) maintain that the possibility of success increases when the needs of birth and previously adopted children are understood and the family system is supported throughout the transition.

Brown's (1996) research on experiences of adoptive parents of children with special needs specifies that the following post-placement services are significant in predicting successful adoptions:

- Crisis intervention
- Outpatient drug and alcohol treatment, if necessary
- Maintenance subsidy
- Physical therapy
- Special medical equipment
- Family counseling

Again, these services may apply to all definitions of special needs adoptions; however, the study implies that availability of the appropriate services for an adoption may increase the likelihood of success. Additional services and resources that may promote a successful adoption include respite care, baby-sitting, familial support groups, and "life planning" (Marcenko & Smith, 1991). Parent groups promote communication regarding challenges and difficulties surrounding parenting a child with a disability. These groups can offer social, educational, and support services, including respite care. Financial assistance is also available to adoptive parents and can include monthly stipends and medical costs.

Research has also indicated that adoptive parents of large families function and adjust as well or better than families that are more conventional in size (Glidden et al., 2000). Erich and Leung (1998) found that the strongest factor in predicting success of family functioning was the number of children in the home. Rosenthal, Schmidt, and Connor (1988) agree that there is less disruption when more children are present. Whether these results accurately reflect the impact of large families on adjustment and functioning or that families who experience success in coping and adjustment typically choose to adopt subsequent children is unclear. However, it is an important predictive factor to consider when evaluating the likelihood of adjustment success.

Finally, Lazarus, Evans, Glidden, and Flaherty (2002) discuss implications and considerations for transracial adoptions of children with special needs. Inracial and transracial placements of children with disabilities do not appear to affect the probability of success. Rather, satisfaction and adjustment remain consistent throughout, and arguments against transracial adoption do not support the child's best interest in these cases. Lazarus et al. (2002) assert that race is less likely to be a significant factor when a disability prevents the comprehension of racial awareness and identity.

Preparation and Adoption Success

Not surprisingly, a direct relationship has been described linking preparedness, familial adjustment, and success. Preparation is essential in informing adoptive parents about a child's past, diagnoses, abilities, resources, adoption issues, and parenting and coping strategies (Molinari & Freeborn, 2006). It has also been shown to increase familial cohesiveness (Sar, 2000). Families who have been exposed to information regarding their child's health issues report a higher level of satisfaction and seek less support than those families with little to no previous knowledge (Molinari & Freeborn, 2006). Brown (1996) affirms that presenting more adequate information regarding the child to adoptive parents decreases the likelihood of unrealistic expectations and goals and increases the family's preparedness for issues that may develop. Additionally, informal support, rather than professional care providers, coupled with other resources have been found to benefit families by increasing self-confidence and a sense of competence (Molinari & Freeborn, 2006). Thus it is imperative to identify and strengthen family supports before placement, particularly for single adoptive parents of children with disabilities (Glidden, 2000; Molinari & Freeborn, 2006), to ease the inherent demands.

Preadoptive parents and service workers can engage in numerous tasks to prepare for the adoption of a child with disabilities. Although education and training in caring for children with special needs has been regarded as the most helpful preparatory task, instruction concerning familial impact of adoptions, disruption prevention, resources available, and strategies for coping and dealing with difficult situations can greatly contribute to adjustment and successful adaptation (Glidden et al., 2006; Sar, 2000). Home studies can also be a source of information and support. During this time families may explore changes within the family unit that may occur after placement and useful strategies for coping with such changes (Mullin & Johnson, 1999).

Adoption Disruptions and Negative Experiences

Although adoptions of children with disabilities typically demonstrate a high level of success, some studies have focused on the factors contributing to disruption and negative experiences in adoptions of children with special needs. Knowledge of such factors can lead to better recommendations for practice in these adoptions. Barth and Berry (1988) found a higher likelihood of disruption for adoptions in which the child displays some level of ID. However, it is important to note that 20% of the families involved in this study were unaware of the child's condition before placement, further supporting the importance of preparation and parent access to health information before adoption. Subsequent research has suggested that the rate of disruption for children with developmental disabilities is equal to that of children without disabilities (Haugaard et al., 2000).

Disruptions can occur as a result of a variety of situations. A great deal of research cites better educated, higher-income families as being more susceptible to disruptions in cases of special needs adoptions (Glidden, 1991, 2000; Haugaard et al., 2000). However, contradictory results have been demonstrated through additional studies. Zwimpfer (1983) proposes that high-income families may be more willing, and financially able, to seek professional help in caring for a child with special needs. According to another study, single fathers are unlikely to experience success when adopting a child with a disability (Festinger, 1986). Disruptions are also more likely when adoptive parents do not have previous experience with disabling conditions or with children in general. These parents may not accept the child's condition as permanent and often express unrealistic expectations, leading to adjustment difficulties (Glidden, 1990, 1991; Rosenthal, 1993). Additionally, infertile couples who choose to adopt a child with a disability generally exhibit high expectations, low tolerance for difference, and may not have adequately mourned their inability to have a child by birth (Westhues & Cohen, 1990). This situation is also more likely to lead to an unsuccessful adoption outcome. Finally, adoptive parents who experience feelings of insecurity and ambivalence regarding their choice to adopt a child with special needs may feel as if they are discounting the welfare of their birth and previously adopted children. Strong reactions from their children may increase the likelihood of potential disruption (Mullin & Johnson, 1999).

Although adoptive parents of children with developmental disabilities have identified problems involving negative child characteristics; sources of worry, anxiety, and guilt; and a lack of emotional bonding (Glidden, 1990), it is important to note that no link has been found between adoption outcome and child's level of functioning. Thus even children with the most severe disabilities and conditions can be successfully placed for adoption (Glidden, 1991).

ROLE OF HEALTH PROFESSIONALS AND THE NEED FOR PROFESSIONAL EDUCATION

Health Care Professionals Caring for Children With Disabilities

Health professionals play a vital role in caring for birth and adopted children with disabilities. Parents rely on these professionals to explain their child's condition and to offer counsel regarding options and care requirements. Failure to explain and resolve a medical issue, such as in cases of misdiagnosis, often leads to frustration and a sense of hopelessness for parents (Molinari & Freeborn, 2006). In fact, adoptive parents have expressed disappointment in health care professionals, citing a need for communication among providers as well as a lack of knowledge pertaining to community resources for adoption issues (Molinari & Freeborn, 2006).

The Center for Children with Special Needs (2007) identified essential details for health care professionals to remember when communicating with parents of children with disabilities:

- Remember that parents are the experts regarding their children.
- Maintain a positive attitude.
- Provide an appropriate environment away from the child in which to talk with parents.
- Show care and enjoyment of the child.
- Consider that effective communication takes time and effort.
- Maintain a trusting and open relationship with parents.

Counseling in Cases of Fetal Anomaly

Each year in the United States approximately 3% of pregnancies result in the birth of a child with significant birth defects (Centers for Disease Control and

Prevention, 2006). As a result of current societal practices, it can be assumed that a rising trend in these numbers may soon be noted. As the average maternal age at conception rises (resulting from a newfound emphasis on education and career establishment), the risk of conceiving a child with a chromosomal disorder also rises (Centers for Disease Control and Prevention, 2006). In addition, research has found that assisted reproductive technologies may be responsible for the occurrence of some congenital abnormalities (Hansen, Bower, Milne, de Klerk, & Kurinczuk, 2005). The scientific advancement and increasing social acceptance of reproductive technology as a means to conceive may lead to increasing numbers of identified fetal abnormalities. Therefore it can be argued that increasing numbers of women and men may be faced with a pregnancy in which a fetal anomaly is diagnosed or suspected, escalating the number of cases in which health professionals may be consulted for potential pregnancy options. Because of these changes in public practice, in addition to technological advancements in fetal diagnosis allowing for earlier and better detection of fetal anomalies, it is necessary for health professionals to be prepared to discuss adoption as an appropriate option for the birth of a child with a disability or for pregnancies with a suspected or identified congenital disorder. As a result of limited knowledge, resources, and referrals accessible to health professionals regarding adoption (Henry, Pollack, & Lazare, 2007), this option is unlikely to be discussed with patients with specific and accurate detail and depth. Eighty-eight percent of individuals and families waiting to adopt a child with Down syndrome contend that awareness must increase among the medical community regarding families who wish to adopt children with disabilities (Lindh et al., 2007). Moreover, health care providers may assume that women who undergo prenatal screening and testing would wish to terminate the pregnancy if a diagnosis were made (Skotko, 2005). Mothers have reported feeling rushed by health professionals into making a decision about a pregnancy (Skotko, 2005), most likely because health professionals are aware of the legal time constraints placed on pregnancy terminations. Skotko's (2005) research indicates the inaccuracy of this assumption.

Receiving a diagnosis of an identified or suspected fetal anomaly in a pregnancy or at the time of birth is often an emotionally taxing experience for expectant parents (Finnegan, 1993). The diagnosis or possibility of a fetal anomaly or condition may prompt feelings of confusion or loss of control, among other conflicting emotions. Individuals typically react differently depending on past experiences and preconceptions. In addition, individual reactions can be influenced by the response of health professionals. Negative experiences with the medical community may decrease parental ability to cope and adapt to a child's diagnosis (Poehlmann et al., 2005). In addition, Poehlmann et al. (2005) demonstrated that maternal emotional responses to a child's initial diagnosis can be greatly impacted by insensitivity or lack of empathy from health professionals. Therefore health professionals must react by providing timely and sensitive information regarding all pregnancy options, support, and referrals to families who receive a prenatal or postnatal diagnosis (Poehlmann et al., 2005). Knowledge about options has been shown to aid in diminishing feelings of helplessness (Kaunitz, Grimes, & Kaunitz, 1987). Lindh et al. (2007) stress the need for health professionals to present balanced and accurate information on all pregnancy options, while also discussing the positive contributions and attributes of children with disabilities (Poehlmann et al., 2005). In addition, it is critical for health professionals faced with these situations to be familiar with appropriate adoption-sensitive language and information on state laws and policies, referrals, and resources, in addition to knowledge regarding nondirective counseling in specific circumstances (Perry, 2003).

Thus the role of the health care professional is extended to encompass the following responsibilities (Kaunitz et al., 1987; Perry, 2003):

- Provide accurate and current information regarding all pregnancy options.
- Educate the expectant mother and father regarding fetal condition and probable outcomes.
- Offer emotional support and help establish a support system for expectant parents.
- Provide resources regarding pregnancy options and fetal diagnosis.
- Provide need-based referrals for expectant parents.
- Possess skills in grief and guilt counseling.
- Possess level of comfort in crisis management techniques.
- Be familiar with possible marriage considerations, sibling and extended family considerations, ethical matters of twin and multiple pregnancy separations, and factors of reproductive medical techniques.
- Use adoption-sensitive language and nondirective counseling techniques.
- Be acquainted with cultural implications surrounding nondirective counseling.

Training for Medical Professionals

In standard medical practice adoption may be overlooked as an option in pregnancies, particularly in cases in which a fetus has suspected or identified special needs; this may be related to the lack of formal education in medical schools regarding adoption (Henry et al., 2007). Pregnancy counselors routinely present a wealth of information regarding parenting a child with special needs in addition to significant information regarding pregnancy termination. Adoption, if mentioned at all, is often added as an alternative to parenting and termination rather than an equal option, and scant information is made available to expecting parents. When questioned regarding this option, many health professionals have admitted that they are unprepared to answer questions beyond basic knowledge and are unsure of where to locate additional information (Perry, 2003). This response is not surprising. Although training in pregnancy counseling is included in the education provided to health professionals, limited information regarding adoption, particularly special needs adoption, is presented as part of customary medical training (Henry et al., 2007).

Genetic counselors, in particular, have expressed a desire for education and resources containing essential information about the process of adoption for patients facing a crisis or high-risk pregnancy. Upon previously questioning genetic counselors regarding the possible usefulness of such a resource, 95% of respondents replied in favor of an Internet resource for both expectant parents and health professionals. Many also admitted that if questioned they do not believe they could provide appropriate referrals for patients in such situations (Perry, 2003).

Medical education and training is vital to increasing the general knowledge of adoption for use in practice with expectant parents, adoptive parents, and families. By identifying factors that might contribute to the adjustment of parenting a child with disabilities, professionals can be informed as to services or interventions that may help families experiencing difficulties adjusting to a child with special needs. Moreover, families can benefit from this information during the prebirth and preadoptive placement decision-making process as well as throughout the child's life span. As previously established, evidence has shown that children of all functional levels can be successfully placed (e.g., Glidden, 1991).

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Research has demonstrated that parenting a child with special needs requires certain characteristics, preparation, and support and can be a source of stress and additional strain to marital and family relationships. Families who choose to adopt children with special needs have highlighted the particular elements for successfully parenting children with disabilities. A significant difference between families who parent children with a disability by birth and those who adopt children with disabilities is the factor of choice. Adoptive families of children with special needs have the opportunity to decide whether parenting such a child is within their means and abilities. Unfortunately, families who are presented at birth with a child diagnosed with a developmental disability do not have the benefit of choice or significant preparation. The role of the health care professional during a pregnancy and birth, and thereafter, can be significant in supporting parents' decisions and ability to plan for a child's needs. Therefore health care professionals who counsel parents during pregnancy and postnatally require appropriate education and skill development to adequately prepare parents to make a decision that is most suitable for their families.

In the event that a family chooses to parent a child with a developmental disability, there are several factors that can contribute to successful adjustment and adaptation. Adequate and accurate information about the child's disability and about possible financial, medical, and familial issues can help families prepare for the demands of caregiving. This information can also promote realistic expectations for the child's development and future. Additionally, providers should ensure that families have established access to permanent support systems of their own so that they may no longer need to rely solely upon health care professionals (Farran et al., 1986). These should include increased support for parents of children with ID (Blacher & McIntyre, 2006). Furthermore, because fathers may not have access to the number of parenting support services that new mothers do, paternal support systems should be identified and established to encourage success among fathers of children with disabilities. These systems should take men's schedules into account and provide time with other fathers who are in similar situations (Quinn, 1999). In doing so, fathers will have the opportunity to establish realistic expectations, discuss concerns, and become more involved with their children's care. Finally, for couples adopting a child with disabilities, access to services that can provide marital support may be helpful, particularly for those families of children who demonstrate greater behavioral issues and who may experience marital dissatisfaction as a result. As previously discussed, the support of a spouse or partner can be the most beneficial type of social support.

Glidden (1986), whose work has focused mainly on identifying characteristics of parents who raise children with disabilities and who has compared adoptive with birth families, poses this question: "Do adoptive families have an easier time because they do not suffer existential crises, or are they, to begin with, special families, high on family integration, commitment, and responsibility?" (p. 141). This question has yet to be answered with empirical evidence; an exhaustive review of literature and research regarding birth and adoptive families of children with disabilities does disclose that adoptive families consistently demonstrate better initial adjustment and adaptation. Ultimately, however, it appears that there is no way to accurately measure whether this is strictly a result of a difference in the child's entry into the family or whether it is due to a characteristic difference inherent in the design of adoptive families. It does indicate, however, that what has been learned from these families can help professionals prepare and support birth families who are faced with raising a child with special needs.

An extensive amount of literature has been published on the topics of adoption, special needs adoption, parenting a child with a disability, and parental coping and adaptation. For this review a selection was compiled and used to draw general conclusions. However, the final topic has not been extensively reviewed. Training of health professionals regarding adoption, particularly in offering this option to patients facing a prenatal or postnatal diagnosis, has only just begun to be explored. Future research should explore the training and preparation of medical professionals to offer and provide balanced adoption information and referrals to patients and determine the impact that knowledgeable support from health care professionals can have on parents' informed decision-making.

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