
THE LIFE CYCLE AND DISABILITY: EXPERIENCES OF DISCONTINUITY IN CHILD AND FAMILY DEVELOPMENT

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Clinicians are often asked to work with parents who have one or more children with specific disabilities. Disability within the family can have a dramatic impact on family interactions and functioning across the course of the family life cycle. The authors review the potential role of disability within a family system and make specific suggestions for working with a family or the child with the disability.

As parents, we hold a vision of the future for our children. This vision is in constant revision as our children age and the world around us changes. But, in many respects, that vision stays the same—our children will grow up, move away, and develop lives of their own. (Hanley-Maxwell, Whitney-Thomas, & Mayfield Pogoloff, 1995, p. 7)

This quotation from Hanley-Maxwell et al. captures the essential vision of families. The emergence or recognition of a disability in a child, however, has the potential to violently threaten this vision. The number of children born with disabilities varies considerably depending on the definition assigned to *disability*. Children with obvious physical or congenital disabilities are most often recognized at birth, while children with more “invisible” disabilities, such as learning disabilities or attention deficit hyperactivity disorder, are often not recognized until they begin to have difficulty meeting the demands of schooling. This article focuses on children identified with disabilities in childhood (i.e., before 21 years

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of age). This is by no means a homogeneous group. Yet, the issues faced by their families, while varying by degree, do not necessarily vary in kind. It is important to acknowledge this fact, because while the need to support the family of a child born with cerebral palsy may be readily apparent, family members of a child with an obsessive/compulsive disorder will have similar needs and face similar issues in the process of reacting to and accommodating the child and the child's disability.

Families are resilient social units (Patterson, 1995; Wolin & Bennett, 1984; Wolin, Bennett, Noonan, & Teitelbaum, 1980). In the process of reacting to change, families normally develop nonstatic adaptational patterns. These patterns, however, can be adaptive or maladaptive depending on whether they result in either further enhancement or further restriction of individual and family development and resilience. The recognition of a child's disability can lead to a broad variety of possible reactions within the family system. These reactions, in turn, can lead a family to greater emotional growth and cohesion (Snowdon, Cameron, & Dunham, 1994; Thomas, Thomas, & Trachtenberg, 1993) as well as to periods of intense stress. Yet, even as the family attempts to gain a homeostatic state in reaction to the experience of disability, it continues to progress through family life cycle changes. In this article, we discuss variables that affect families as they move through the life cycle process with a child with a disability. We then provide a number of specific recommendations for clinicians working with families of children with disabilities in supportive counseling relationships.

Families

Hanson and Carta (1996) have described families as being defined by themselves and as including the following key elements: The members of the family view themselves as a family, the family members are affiliated with one another, and the family members are committed to caring and supporting one another. Change within families is inevitable and continuous and is thrust upon a family by time, life events (Stanton, 1992), and aging (Carter & McGoldrick, 1988; Patterson, 1995). Reactions to change are experienced uniquely within each family member and each family system. The rate of change in a family varies: A family may act within a stable set of interactions for years and then go through dramatic change over a short period of time. This may occur, for example,

at the time of the death of a family member or the birth of an infant (Patterson, 1995).

A family's ability to adjust to its environment is influenced by a number of factors, including the family's resources, interactional patterns, functioning, and transitions through the family life cycle (Bronicki & Turnbull, 1987; Carter & McGoldrick, 1988; Seaburn, Landau-Stanton, & Horwitz, 1995). Depending on these and other variables, families can develop, maintain, or change levels of isolation, chaos, rigidity, fluctuation, and growth over time (Bowen, 1978; Hoffman, 1988).

Family Reactions and Disability

Abilities, Disabilities, and Families

Distinctions between ability and disability are an intrinsic aspect of family, health, and educational organizations. Indeed, these distinctions have been codified in both state and federal laws such as the Americans with Disabilities Act and the Individuals with Disabilities Education Act. In the United States, a clear legal and medical division can be made between children in society with and without disabilities. The majority of all children are, after all, born without any disabilities and go on to live full and productive lives. Other children, however, are born with or acquire distinctive differences in their traits, abilities, or physical features. These differences, when severe, are often perceived as disabling. This perception affects the child but also affects the family and the members of the family system.

Loss and Confusion

Family members go through an identifiable grieving process when a family member dies (Kubler-Ross, 1969) or when the family experiences other severe losses. The death of a child is undoubtedly the most traumatic experience a parent can have (Rando, 1996). As individuals face a severe loss, a grieving process naturally occurs, the stages of which have been well documented (Kubler-Ross, 1969; Lavoie, 1995). These stages may include denial, blame, fear, envy, mourning, bargaining, anger, guilt, isolation, and flight (Lavoie, 1995).

While it is well recognized that parents experience grief reactions when a child dies, what is often less recognized is that families go through a similar grieving process when a child is diagnosed with a disability. This grieving process is individual to each family and may differ vastly in degree from family to family. It can occur regardless of the type or severity of the child's disability, as from the parents' perspective, there are no mild disabilities in their children. As Leung and Clark (1995) state, an individual parent or child may perceive a disability as being mild in another child and the same disability as being severe and potentially life altering in their own family member.

Parents' initial feelings of sorrow, grief, guilt, shame, despair, and/or self-pity may initially be overwhelming (Batshaw & Perret, 1986; Eden-Piercy, Blacher, & Eyman, 1986; Mary, 1990; Simmons, 1987). For many families, recognition of a disability means a sudden and irreversible "replacement" of present and anticipated images of the child with one of a child with a disability. When first informed that their child had a reading disability, parents may be faced with a vision of their child never completing high school successfully or never reading. Yet, this replacement most likely will not accurately reflect the "true child" but, instead, a vision built upon the family member's beliefs and past experiences of individuals with disabilities.

Changes With Development

The initial turmoil that parents feel can later give way to sadness, a feeling of desolation and isolation, and a longing for the lost, "normal baby" (Batshaw & Perret, 1986; Simmons, 1987). Yet, as parents get to know their child, these feelings can also foster love, acceptance, and close emotional bonding (Mary, 1990). People are not static. These disparate feelings revolve in a continuous process throughout the parents' and the child's ongoing life experiences. For many families, the child's development over time brings both joy and sorrow: joy when the child's strengths are revealed through development and sorrow when new facets or implications of the child's disability are revealed over time.

While there are similarities in the experience of the death of a child and the recognition of a disability in a child, there are several important differences: with the latter, there is still a child to be cared for; there are no established publicly recognized coping rituals for the recognition of a

disability; and the family and family members probably have never experienced this type of loss before. As a result of these factors, families are often left in unfamiliar and uncharted emotional territory with no guides to direct them toward ways to express their grief in a culturally acceptable format.

An additional burden for families is that they may not possess the language (Seaburn, 1995) to communicate their feelings and experiences. People experiencing a disability tend to believe that they are alone in this experience (Simmons, 1987). This belief can lead to an increased feeling of isolation and can be exacerbated if family members feel unable to communicate their experience to others. Language can also be problematic for families in that they suddenly must learn to communicate in the "foreign" world of medical settings, special education, and the disability service community.

Family Interaction Patterns

There are as many patterns and styles of family interaction as there are families. The presence of a child's disability does not necessarily cause deviant family functioning (Dyson, 1993). Many families of children with disabilities, like families of normally achieving children, have positive and cohesive family relationships (Dyson, 1996). Yet, by their nature, patterns of family interaction change between and within families over time.

Parental Stress

Regardless of the specific style of family interaction, research has shown that families of children with disabilities experience greater parental stress than families without children with disabilities (Dyson, 1993). Stress in families is also noted differently between mothers and fathers. Studies show that, in general, mothers of children with disabilities have higher levels of stress and depression than the children's fathers (Wyngaarden Krauss, 1993). Fathers, in turn, are reported to be more stressed than mothers by variables such as the child's gender, temperament, and communication abilities and by their own feelings of attachment to the child (Wyngaarden Krauss, 1993). Although it is not unusual for mothers and fathers to differ in the ways they react to their

child's disability, these differences may be the source of considerable conflict among family members (Conoley & Sheridan, 1996). Professionals can add to this conflict when they provide information to the mother alone and then expect her to translate this information to the spouse and other family members (Simmons, 1987).

Across the Life Span

Being part of a family involves a series of longitudinal interactions. As family members age, the family progresses through a number of life cycle stages (Batshaw & Perret, 1986; Bronicki & Turnbull, 1987; Carter & McGoldrick, 1988; Combrinck-Graham, 1985; Mallory, 1996). These stages are determined by the biology of human development, which follows a natural time line (i.e., it requires a certain amount of time for a baby to learn how to walk), as well as by social expectations and constructions (Batshaw & Perret, 1986; Gergin, 1991) that evolve in correspondence with human development.

Life Cycle Stages

In many ways, families are organized in terms of life cycle developments. Social rituals often serve to highlight, enhance, or enforce life cycle developments (Imber-Black, 1988). Social convention guides how weddings, funerals, and other rites of passage, as well as religious activities, medical care, and education, are performed. Life cycle stages such as the birth of a child, school entry, celebration of puberty, graduations, marriage, child rearing, and the birth of a grandchild represent developmental processes between the natural biological time line, psychological needs, and social convention.

Distorted Life Cycles

Families of children with disabilities go through life cycle stages, yet some stages may be elongated, shortened, or never experienced. A child's disability may cause a family to become stuck in a life cycle stage. Families may also experience suspended expectations of normal life cycle change. This may occur when families are told, for example, not to expect that their child will ever learn to read, reach sexual maturity, or be capable of raising a family of his or her own (Brotherson,

Oakland, Secrist-Mertz, Litchfield, & Larson, 1995). In addition, as the family moves along the life cycle continuum, additional stresses can occur as the family confronts greater problems in child management (Dyson, 1993).

Continuity and Discontinuity

Every family, as it progresses through the life cycle, constructs its own developmental line. A disability in a family can force the family onto a different developmental line from other families (Thomas et al., 1993). This developmental line will include some of the same features (births, deaths) as that of other families but may not include others (a child being toilet trained, high school or college graduation). It is extremely difficult for families of a child with a disability to hold onto their unique developmental line because the rest of the world is, most of the time, on a very different time line. An analogy to this is that of a night worker whose daily experience of the world is the same but ultimately different from his neighbor who works days. This daily experience of discontinuity can leave some families with a deep sense of continuously grieving their loss. This, in turn, can present great difficulties for these families in coming to terms with and valuing their own developmental line.

This experience of discontinuity may necessitate changes throughout the family system. A grandparent may have to be more available for child care than she anticipated for her life stage, an older sibling may be elevated into a co-parenting role, and/or friends may have to make special arrangements to accommodate the family during gatherings. Although similar developments may occur in all families, the family of a child with a disability may be more conscious of the struggle of developing and maintaining an identity and of staying within the constraints of its own biological and social developmental line. Professionals can help families develop a specific developmental line (Stanton, 1992) to improve their own sense of continuity and individuality (Bowen, 1978). Achieving and recognizing milestones can help them develop and reinforce their sense of family continuity.

Resilience and Coping

There are a number of resources that may assist parents and families in dealing with the potential stresses associated with having a child with a

disability. These resources include maintaining health and energy, applying a problem-solving approach to family situations, changing perceptions of stressful situations, and maintaining family relationships and social supports (Snowden et al., 1994).

Supportive and cohesive family relationships are a predictor of lower parenting stress. Particularly, relationships that allow for the free expression of feelings with little personal conflict are associated with lower parenting stress (Dyson, 1993). Supportive relationships outside of the family system also lead to better family adjustments, particularly for mothers (Wyngaarden Krauss, 1993).

The perception of the impact of the disability on family functioning also affects family stress and functioning. Families with more positive appraisals of coping skills show less parental stress, better family adjustment, and less psychological distress among both mothers and fathers. Similarly, families that change the way they think about their situation by changing their perception often show greater resilience. Helping families emphasize what they have learned and how they have grown as a family can help them adapt to continuing and persistent family stresses (Patterson, 1995).

Suggestions for Practitioners

Information

Families of children with disabilities need a great deal of information, and over time they need information in changing areas related to the child's growth, development, and the continued impact of the disability (D'Amato & Yoshida, 1991). As the family's experience and need for information changes the clinician must be prepared to reanswer old questions and to provide new information.

How information is relayed to the family can have a dramatic impact on the family's ability to adapt to and interact with the child. Information provided to families must be clear and concise and, when necessary, repeated several times (Conoley & Sheridan, 1996). Often, parents report leaving the doctor's office and not being able to recall the name of the syndrome they were just told their child had. Repeating the information several times during the conversation and providing written information can help families process the information as well as give them something to refer to afterward. Information, when necessary,

should be provided in terms that make sense to nonmedical personnel and in a manner that is sensitive to the family's vulnerability.

When providing emotionally laden or particularly important information, clinicians should put forth every effort to notify both parents together. If there are other family members who need to hear the information, try to have these individuals there at the time of the conversation (Patterson, 1995). If this is not possible, the session can be tape-recorded for the family, or additional follow-up sessions can be scheduled for the other family members to provide them with the information. At these times, it also helps to allow the family private time together following the conference to talk and digest the information just provided.

Clinicians should provide written information as often as possible. Family members may find having information to refer back to at a later stage useful. Medical information is often difficult to digest in the midst of an interview. Written information can have therapeutic effects, providing clarity and reducing confusion at a stage when families need to rethink the information they have received. Written information can also serve as stimulation for family conversations.

Finally, clinicians should be careful not to overwhelm the family with too many facts and details early on. Families may not be ready for or capable of processing, at the moment, the whole range of information about a particular disability or issue. Small steps are important. Talking to a parent of a 5-year-old about later adolescent sexual issues may be counterproductive. Certainly, at some point the parents will need to have this information, but with consideration of pacing and timing, it can be provided as they need it. In addition, family members may not be at the same level of development at the same time. Sporadic brief family meetings help family members review their understanding of the information and roles they have.

Collaboration

Collaboration (Seaburn, Lorenz, Gunn, & Gawinski, 1996) is an integral part of successful care. Families must help make decisions regarding their children's care (Snowdon et al., 1994) and will feel more valued and more in control of their and their child's lives when they participate, in appropriate ways, in their child's care. Parents often need guidance, however, in understanding the realistic roles they can play in

helping their children grow and develop. Clarifying roles can reduce the anxiety of uncertainty and the sense of loss that family members may experience.

Support

Most clinicians help families deal with the emotional repercussions of understanding disability-related information. Often, clinicians can have a profound impact simply by helping families recognize that the strains and hassles in their lives are real and that they can create tensions or stress for most families. This recognition can be a major step in helping families feel empowered and more hopeful that they can take charge and better manage their lives (Patterson, 1995).

In working with families, the clinician must also ensure that her or his support staff understands and respects the families of special needs children. The ability of the clinician to advise families is compromised if parents are not given the message of support and value by the clerical and clinical staff. The clinician's office must be a safe place free of accusations, condescending remarks, or put-out facial expressions (Taylor, 1995).

The family's need for support will vary over time as they move through different phases of development. Over time, a family may shift among relying primarily on interpersonal support within the family, support from the extended family, support from the medical and educational communities, and support from the larger community and other people who share similar experiences. Reassessing family needs at different times during development and continuing to guide family members toward specific support systems and relevant information helps provide the ongoing support families need. Often, a specific case manager can help families identify and access community and educational services for their children and themselves (Conoley & Sheridan, 1996). This person can also serve as a resource in helping families form alliances with local or national organizations (Conoley & Sheridan, 1996).

Keeping a Future Perspective

Anticipation serves a function similar to that of relevant information; it is a cornerstone of effective supportive counseling. Anticipation provides a "working map" for families and also helps them deal more effectively

with unpredictable events and developments. Families can prepare for the future by developing their own expectations of what may happen in the near or long-term future (Gellerstedt & le Roux, 1995). These discussions can also include anticipated developments for all family members (e.g., siblings, grandparents, or parents), as well as issues related to loss, grief, sexuality, identity and self-esteem, and relationships with peers. Discussing their child's progress as well as their own can help families maintain an optimistic but realistic view of their child (Snowdon et al., 1994).

Identity

One of the problems parents experience when they lose a child through death is that there is no name that identifies or symbolizes their grief as they move through time (Rando, 1996). Words such as "widow" help maintain some forms of identity when one has lost a spouse. Disabilities, in contrast, are often named. Although this can provide some direction for more effective care, it also starts the process of adopting new or changed identities for children, parents, and their families. Identifying with a name, however, is complex and confusing. One child with Tourette's syndrome could not get herself to say the word. She continued to refer to "this thing I have," while her family was relieved that they finally had a name by which to identify her behavior. Having "what's in a name" discussions with families may result in better distinctions between the self and disability. Reflecting on the specific meaning families attach to names can help them develop the necessary distance from the formal descriptions of disability and its role and usefulness in their lives.

Strengths

Identifying strengths (Seaburn et al., 1995) is an ongoing process in counseling. It may take some time for parents to become accustomed to a positive approach, but if they are continually asked to identify their child's strengths, they will learn to relate more to the child and less to the disability. Identifying strengths does not imply minimizing problems or experiences. "Strengths" refer to the actual skills that children and their families use to deal with daily expectations. They also refer to accomplishments, such as getting into a wheelchair independently, taking a bath, getting to school on time, or entertaining friends.

Conclusion

The recognition of a child's disability, regardless of the actual disability, can be compared with the experience of an intense loss. Some families experience this as the death of a "normal" child and his or her replacement with a child with a disability. The family can hardly ever be adequately prepared to deal with the immediate and long-term implications of the disability for the child's and family's lives. Parents and other family members will be more directly touched by the child and the disability and will have a greater reaction to this disability than other family members.

In working with families, it is important to realize that the emergence or recognition of a disability is a life-altering event that may dramatically affect interfamily and intrafamily functioning for extended periods of times. As families continue to move through the life cycle, they will develop skills and knowledge regarding the child and the child's disability. During the initial stages of coping with a disability, family members often react to the disability and not to the child. During these times, clinicians should help families see the child and not just the disability.

As families move through the life cycle, the experience of a disability can lead them into a different developmental line from other families. This can result in a sense of discontinuity from others and a further sense of loss. Helping families develop and celebrate their own developmental line, given their specific circumstances, will empower them to deal with ongoing fluctuations and discontinuity. An individualized developmental line for a family can help them reclaim a celebration of milestones, anniversaries, and beginnings and endings of life cycle events. By developing a better sense of their own and their family's unique life cycle, parents will learn to deal more effectively with any potential or actual sense of loss and grief and to celebrate their and their child's own unique gifts and abilities.

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