

**Thoughts Concerning Disability Within
A Family – A Foreword***

**by
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This book, written by my friend and colleague Dr. Wayne Nesbit, has the potential to enable parents and families with exceptional children and the professionals who work with them to act with greater knowledge and insight. It increases the likelihood that teachers, counsellors and other professionals who read and use it will provide their services in ways more likely to have positive benefits for these children and their parents and families. The concepts, perspectives, and guidelines for best practices found here are well grounded in a sophisticated understanding and an integration of knowledge gained from a review of the relevant literature from the study of families and particularly families with exceptional children, human exceptionality, and special education. The book reflects a significant shift in special education from a perspective focused almost exclusively on the child or the parent-child dyad to a broader view of the whole family system.

The theoretical or conceptual lens through which parents and families are viewed can have significance for insight into their needs, the nature of the interventions considered desirable, and the dynamics of professional relationships with parents. Another merit of this book is the author's ability to introduce a number of such perspectives and to see them all as having utility for informing our understanding of families with exceptional children. He appears to be at ease whether he is viewing matters from a loss and grief conceptualization, a family systems approach, or seeing the family embedded in a broad social matrix.

Nonfinite Loss: A Professional and Personal Perspective

For both professional and personal reasons, I am particularly pleased with Nesbit's detailed description of the usual stages of human grieving as they apply to parents of exceptional children. This stage theory perspective is very relevant if we view the experience of having an exceptional child as initially one of loss – the loss of the expected normal child. Although expectant parents may have some apprehension about whether their expected child will be normal, virtually all parents-to-be fantasize about their future with a normal child. All their dreams and imaginings about their future as parents and as a family appear to be founded on this expectation for normalcy.

Bruce and Schultz (2001) describe the type of loss and grief experienced by parents who have children with intellectual and other developmental disabilities as *nonfinite loss*. It refers to “losses that are contingent on development; the passage of time; and on lack of synchrony with hopes, wishes, ideals, and expectations” (p. 7). This insight as expressed by these authors emerged from their work with families of children with developmental disabilities and their contacts with the professionals who work with them. They capture the essence of the experiences which led to their use of this term as follows:

These mothers and fathers leave a doctor’s or neurologist’s office with a mass of foreign and frightening words, most of which threaten both their child’s and their own future. Often, these words are visually incongruent with the appearance of the child. Yet, over time, the disability or the disease slowly manifests itself. In fact, it is relentless, continuing to reveal its effects throughout the life span of the parent and child. *Nonfinite* became the most apt word we could find to describe the life-span grief of these families. (p. 8)

When the reality sets in for parents that their child has a disability, it usually elicits a grief response. After all, grieving is the normal human response to loss and therefore should not be seen as psychologically inappropriate or a sign of personal weakness. In fact, grief work can be very beneficial because it embraces the intellectual and psychological process of adaptation that takes place following a very significant change in one’s life. A convincing example of this challenging process is captured in the personal story of Rita Burke, a mother of four children, one of whom has cerebral palsy. She describes her reactions beginning at the point where she received her son’s diagnosis when he was nine months old:

What I didn’t know then was how this new knowledge would affect me, and what I would have to go through before I could adjust to my son’s cerebral palsy... . I remember saying to myself that these sorts of things happened to other people, and that I would soon wake up and life would seem normal again... . I imagined my son’s growing-up years spanning out before me, and visualized all the normal, everyday activities he would never be able to do... . I worried that my sadness would permeate our whole family and we would never feel happy or lighthearted again. ...I was angry at the condition itself, at the permanency of it. I felt a little resentment when I saw other children my son’s age who were ‘normal’ and starting to walk and I was still carrying Chris (Geralis, 1991, pp. 33-34).

This mother, over time and fortunately like most parents of exceptional children, adjusted to this new reality and successfully managed the passage from the shock of the diagnosis to a rewarding family life with this son and his three siblings, her husband

and her extended family. Ms. Burke does not disclose all the factors that may have influenced her path to adjustment and acceptance. However, many variables may mediate both the intensity and the unique manifestation of grief for a particular parent, including such factors as age of onset of the disability, severity and type of disability, birth order, size of family, parental prior experience with significant disappointment, strength of psychological resources, familial and social support, religious and cultural beliefs and values, and so forth.

From a personal perspective as a father of an adult son with a disability, I have found within the concept of loss and grieving meaningful and useful explanations for aspects of my personal journey. It has helped me to make sense of many of my emotional responses and so this psychodynamic explanation resonates as true for me. I believe that for many years now I have fully accepted the reality of my son's disability, a condition known as Sotos Syndrome. I am comfortable speaking openly and publicly about my experiences and I am eager to celebrate his abilities and achievements, including his success as a provincial and national Special Olympics swimmer.

Many parents have said that with acceptance comes the capacity to see the whole person no longer defined primarily by their disability. Acceptance may also free them from any previous psychological constraints and with it comes the emotional freedom to become an advocate for their exceptional child. Acceptance can also underpin the courage to speak more openly about a child's disability, to describe it and label it, to be assertively engaged with the professionals who provide services to them or to their child, to celebrate their child's strengths and achievements and so forth. It may be a necessary prerequisite for full participation in school-based procedures for determining the appropriate programming for their child. Some parents at this stage may decide to be advocates for improved school and community services for individuals with disabilities and some may become active in associations with this objective.

I believe that the grieving process, of which acceptance is normally the triumphant outcome, may be to some degree a circular one. It is the case for many of the parents of exceptional children with whom I have worked, and for me as well, that a period of transition can re-ignite feelings of sadness typical of the 'chronic sorrow' to which Nesbit refers. A time of transition such as the beginning of public school, the move from junior high to high school, the end of the high school years, the period when young people typically acquire their driver's license, the period of adolescence, the movement of peers to post-secondary education, the marriage and parenthood of peers can bring the disabled individual's limitations into sharp relief. The reality, in the case of some disabilities, that a son or daughter will never drive a car, never be a parent, never function totally independently can evoke a recurring sadness or sense of loss.

On a personal note, I can vividly recall this feeling when attending with my family the wedding of a neighbour's son. My disabled son was present and fully enjoying this celebratory event. At one point I recall myself silently and privately weeping as I watched him dancing. I believe I was sad because I was reminding myself that he was unlikely to be married and unlikely to be a parent himself. Or maybe this feeling was

evoked, at least in part, because I knew that I would be denied the opportunity to celebrate his marriage and his parenthood and, by implication, my grandparenthood. Maybe it was because I would never experience the sweet, sad poignancy of seeing him leave home for his independent life adventure. So, it is sometimes not easy to know for whom the tears flow!

Not only does the loss and grief perspective provide validation of my own personal experience, it has been most valuable as a way of affirming and giving meaning to the experiences of the many parents of exceptional children with whom I have worked. I continue to be amazed at the frequency with which these parents readily accept and use the language of loss and grief to describe and to make sense out of their experiences.

In an undergraduate course entitled **Working with Families with an Exceptional Child** which I developed and often teach, my students have conducted more than 100 interviews with parents of exceptional children. In fulfilling this course requirement, they too are surprised by the extent to which these parents are comfortable with this use of the vocabulary of loss and grief. Often these parents are sharing their personal stories retrospectively because their disabled child is older. They can reflect with thoughtful candour about their parental experiences with the confidence that comes from having successfully confronted and adapted to challenges. After all, as the philosopher Kierkegaard is alleged to have said, "Life is lived going forward but is understood looking backwards."

I can clearly remember an occasion when a father of a five year old autistic son said to me through his tears, "You know, I went to a funeral this summer. It was for the child who never came and finally I think I can accept Peter." Then, as his sobs increased, he said, "You know, Susan has not done that yet and it's very hard." I knew intuitively what he meant. This incident provides one of the most dramatic examples from my experience of the expression of 'symbolic death' and the process of letting go of the potential child and embracing the actual one. It also captures the reality that two parents can very often be at different stages in coming to terms with the fact that their child has a disability. This situation can, of course, add to parental stress, cause communication difficulties, and delay parental readiness to advocate as a team.

In my experience, it is not uncommon, particularly in the case of mild disabilities or less visible conditions such as a specific learning disability, for mothers to notice and acknowledge or label their child's difficulties before fathers are ready to do so. Of course, this is more likely in families in which the mother is the primary care giver during the child's early years. The process towards acceptance can be even further delayed for grandparents, aunts and uncles, and other members of the extended family.

Complicity and the Search for a Cure

Sometimes other family members, because of their lack of readiness to entertain the possibility of a disabling condition for their grandchild/niece/nephew, can unwittingly

become accomplices to parental denial. This can be expressed in various ways such as, “Go away, there is nothing wrong with Joan that a few more months of development won’t take care of” or “Don’t be so silly; sure, he is just a little slow in getting started” or “Stop worrying, my dear. Sure, Martha’s youngest son was a little slow at first but look at him now with an engineering degree.” These statements may be motivated by a need to reassure but often they are a reflection of the reassurer’s inability or lack of readiness to engage with an emerging and perhaps painful reality.

This capacity to be an accomplice to denial can apply as well to the behaviour of professionals such as physicians, special educators, psychologists, counsellors and others. It too may reflect their discomfort with confirming or entertaining the bad news prospect of a child’s disability. It is also my view that some ideological stances that, for example, advocate an absolute prohibition against the use of labels or promote the view that the use of terms such as ‘children with special needs’ or ‘exceptional children’ is inappropriate since ‘all children are special’ can reinforce an individual and societal impulse to deny unpleasant realities.

Once again, on a personal note, this capacity was a feature of our early experience as we sought answers to our son’s developmental challenges as a young child. We went to visit a well-respected and experienced pediatrician. My wife, Marion, a registered nurse, who first drew full attention to our son’s difficulties and advocated that we should investigate matters further, may have taken the lead in describing her insightful concerns to this physician. At the end of the consultation he declared that there was really nothing wrong with our son and that our concerns were a reflection of our parental, and particularly, his mother’s anxiety. This anxiety, he suggested, was typical of new and inexperienced parents such as we were. He was wrong and we felt that his response was dismissive, intentionally so or not. In fact, we still see his reaction as a failure to provide an appropriate and helpful professional response to our genuine concerns.

Whether the parents’ road to full acceptance of their child’s disability is short or extended, as Nesbit acknowledges it can be, there may be diversions along the way. One such distraction is what some call ‘a search for a cure’. Of course, it is expected and appropriate that parents be fully informed by the most up-to-date knowledge about the condition that disables their child. Their parenting, advocacy, and the professional services provided to them and their children, should be greatly influenced by this knowledge. Sometimes, however, the pursuit of a cure can be less a search for relevant knowledge than an expression of a lack of readiness to accept the cold truth that there is no cure, not now and not in the foreseeable future.

Pearl Buck, a well known writer and the mother of a child who was severely disabled, describes her futile search more than 50 years ago in her book **The Child Who Never Grew**. She expresses her understanding of this search as follows:

...driven by the conviction that there must be someone who can cure, we take our children over the surface of the whole earth,

seeking the one who can heal. We spend all the money we have and we borrow until there is no one else to lend. We go to doctors good and bad, to anyone, for only a wisp of hope. We are gouged by unscrupulous men who make money from our terror, but now and again we meet those saints who, seeing the terror and guessing the empty purse, will take nothing for their advice, since they cannot heal (p. 17).

Fortunately, not all parents with a disabled child engage in this type of searching. Some who do, never meet those saints to whom Pearl Buck refers. The Bratt family, for example, received no such saintly advice as they pursued the outcomes they expected for their brain-damaged son, Jamie. The story of their family's experiences and disillusionment with the controversial 'patterning' program presented by the Institute for Achievement in Human Potential in Philadelphia is poignantly chronicled in their book **No Time for Jello: One Family's Experience with the Doman-Delacato Patterning Program** (Bratt, 1986).

In it, Berneen Bratt describes the experience of driving home from the hospital after receiving the diagnosis that their nine month old son was brain damaged with a likelihood of seizures and an array of other physical, behavioural and learning disabilities:

As we began our drive home, Jamie finally got to take a long overdue nap in his car seat, and I sat gloomily in the front seat. It had taken more than nine months of worry and chasing around to find out the truth. Now that we knew what had happened in the past and what we could expect for the present, we still didn't know what the future would hold for Jamie.

Alden reached over to hold my hand. He said, "We know he won't be a watchmaker or a right-handed pitcher for the Red Sox, but I think he'll do all right. We'll help him overcome his difficulties as they arise."

I thought about what Jamie's difficulties might be. How would he ever be able to tie his shoes, cut his meat, zip his jacket, climb a tree, ride a bike, drive a car, play baseball, swim, ski, or golf? The list was endless and the answers unbearable. It was a two-handed world. I closed my eyes in despair and napped along with Jamie. (p. 10)

Is it any wonder that parents enveloped by such anxiety and overwhelmed by thoughts of the challenges to come are vulnerable to whatever promises of relief, cure, or miracle that come their way? It is not surprising, then, that the now discredited and highly publicized statements from some professionals that autism can result from childhood vaccinations have caused untold anguish. Many children today have significant

preventable disabilities because their parents declined to have them vaccinated out of fear. Parents of disabled children will continue to be vulnerable to pursuing whatever hope-filled actions or programs are presented to them, whether fully tested or not. Therefore, the responsibility of the professionals who help them is to enable parents to be as fully informed as possible before investing in any such promissory pursuit.

Making Sense of It

As human beings we are persistent and creative makers of meaning. The capacity to generate theories about the nature of all things human and the rest of the universe and our place in it is a wonderful manifestation of the human drive to understand all phenomena – to make meaning. Philosophers, theologians, scientists and others devote their entire lives to the search for answers about the nature of life and the cosmos.

When critical and profound events occur in our lives we often become personal philosophers as we try to explain such events to ourselves. So it is not surprising that parents of exceptional children often devote some consideration to the question ‘Why?’ as they try to make sense of the changes to their lives and the life of their disabled child. This question ‘Why?’ is expressed in the words of this mother as she struggles with the early realization that her son has cerebral palsy:

“Why and how could this happen to such a precious child, and how could this happen to me? Why should I have to answer everyone else’s curiosity when no one is satisfying mine!” (p. vii, Geralis, 1991).

This question, cloaked in exasperation and some anger, will very likely be replaced some time later with a more reflective one.

Ian Brown (2009) in his highly acclaimed book **The Boy in the Moon** presents a very personal and eloquently candid account about the life of his extremely disabled son, Walker, and his own search for meaning. He writes, “What is the value of a life like this – a life lived in the twilight, and often in pain? What is the cost of his life to those around him?” (p. 3). His search for answers took him to the French village of Trosly-Breuil to visit the L’Arche community created by the well known Canadian Jean Vanier for adults with cognitive disabilities.

Vanier’s deeply held view was expressed to Brown as follows:

“We see the face of God within the disabled. Their presence is a sign of God, who has chosen ‘the foolish in order to confound the strong, the proud and the so-called wise of our world.’ And so those we see as weak or marginalized are, in fact, the most worthy and powerful among us: they bring us closer to God” (Brown, 2005).

Brown is unable to share in Vanier's belief that God's presence and intentions are evident in his son's life and, by implication, in his own life as his father. However, he does share with us the following personal insight as he reflects on the impact that Walker has had on him:

The more I struggle to face my limitations as a father, the less I want to trade him. Not just because we have a physical bond, a big simple thing; not just because he's taught me the difference between a real problem and a mere complaint; not just because he makes me more serious, makes me appreciate time and Hayley and my wife and friends, and all the sweetness that one day ebbs away. I have begun simply to love him as he is, because I've discovered I can; because we can be who we are, weary dad and broken boy, without alteration or apology, in the here and now. The relief that comes with such a relationship still surprises me (p. 285).

Of course, not all parents of exceptional children will reflect on the question 'Why?' and search for meaning to the same extent and with the same drive as Brown. Many have said in interviews with my students or with me that after the initial shock of the disability they picked themselves up and simply found the personal resources to just get on with the parenting tasks and challenges that lay ahead of them without dwelling on the 'Why is this happening to me?' question. In fact, I believe that this was our parental response to the reality that our son had a developmental disability. However, if we wish to understand those parental efforts to find some answer to the 'Why?' question, we need to listen for their explanations as shaped by the family's own legacy and the beliefs and myths from their religious and cultural background.

For many families, their religious community is an important source of support. It can offer both practical assistance as well as a source of meaning for the presence in their lives of an exceptional child. However, for some parents, the arrival of a child with a disability may challenge their religious beliefs. Given their belief in an ordered moral universe, it can lead them to question "God's judgement and fairness." Yet others frequently express beliefs such as "God only gives me the responsibility for that which I have strength to handle" or "I know that God will see me and my family through whatever challenges lie ahead." and so forth.

Whether positive beliefs are drawn from one's religious background or come from a non-religious personal source, they can sometimes support resiliency and the ability to adapt. The families who are most successful in adapting to an exceptional child, it seems, are those who create meaning that reinforces their sense of competency and mastery. Many parents volunteer observations about a particular positive effect that their exceptional child has had on them or their family. Some of these include such statements as, "I have become a better person because of Joanne"; "I have learned a deeper meaning about life"; "Philip has taught us to be more forgiving of each other and

to be more generous.” One parent expressed the following more complex self-awareness:

My son’s handicap has opened my eyes to different things in the world. I’m more accepting of differences, especially if it’s something that can’t be helped. It’s also made me irate at times with “normal” people. They take so much for granted and I can’t stand to see them do something that hurts people with handicaps. It could be a stare, a comment, or even just taking a handicapped parking place wrongfully.

A Family Systems Perspective

I am pleased that Nesbit decided to view the experiences of siblings with an exceptional brother or sister from a family systems conceptual framework. This perspective has a great deal of utility for deepening our understanding of the dynamics and the needs and strengths of the whole family. It also invites us to focus attention on the family subsystems of: couple, parents, extended family and, of course, the sibling subsystem to which the author turns his informed and insightful attention.

Entry into parenthood typically results in structural and functional changes within the family unit. The presence of an exceptional child can result in even more profound changes and potentially both negative and positive consequences for siblings. These consequences are well detailed in this book.

Two important attributes of the family system are: firstly, it is a self regulating social system with tacit roles and rules which govern behaviour as it pursues its important social functions; secondly, members of the system are interdependent, with change in one part affecting the whole. This latter aspect is humorously captured by Lavoie (1995) when he says, “A family is like a group of people lying on a waterbed because, as in families, whenever one person makes a move all the others feel the ripple.” (p. 4)

It appears that those families that can handle change and particularly the change required when there is an exceptional child are those with a reasonable degree of cohesion and adaptability. Some families adapt well to the additional demands and associated stress and this can sometimes intensify and strengthen already well-functioning roles and structures. Such challenges can evoke and help develop qualities and abilities that may have been latent prior to the arrival of a child with a disability. One mother and wife reflects on the positive impact on her marital relationship:

The doctor told me he had Downs Syndrome...I had to tell Frank. I was dreading it. I thought he would blame me and not want anything to do with the baby. Well, for the first few days after I told him, he didn’t say anything about the baby. I was still in hospital. He came in with some flowers and said ‘Sorry’, that’s all

– just ‘Sorry’. After a minute he looked at me and said, ‘I haven’t been much help, but it’s over. He’s our baby and I think we will cope. We’ll have a damn good try.’ You know, we had been married for five years and I didn’t think he had it in him...but we never looked back from that day. This little one really brought us together...he’s brought a lot of love into this family. (Cunningham, 1987, p. 56)

There is certainly a need to know more about the factors that contribute to the resiliency and adaptability of families when challenged by the critical demands that come with having an exceptional child.

A Cultural Perspective

There is also a need for educators and other professionals to understand families from a cultural perspective. As Lamorry (2002) reminds us, “Each culture has its own explanations for why some babies are born with disabilities, how these children are to be treated, and what responsibilities and roles are expected of family members” (p. 67). It is essential that these explanations and the expectations of families with whom we work be understood. Cartledge and her colleagues (2000) provide the following useful inventory of the cultural attributes of minority families with whom educators are likely to have professional relationships:

- The **extended family** consists of blood relatives that are multigenerational. The primary role of this kinship system is to ensure that the family provides for the welfare of all members of the kin network at all times (e.g., child care, supervision, parenting, material and monetary resources, and emotional support to children and family members).
- **Mutual aid** is a common element in the extended family life of culturally diverse families. Family members often pool resources for survival and growth.
- **Fictive kinship** among nonblood-related people exists in diverse communities because of common ancestry, social plight, and history. Fictive kin also provide mutual aid, caregiving, and family support.
- **Racial identity** is an awareness of the history of one’s own cultural group. Individuals exhibit pride and dignity through the maintenance of customs and traditions.
- **Religious consciousness** is the active participation in the cultural group’s religious beliefs and practices. Reliance on faith and the church to support family life is an attribute (p. 33).

As Schulz and his associates (2006) see it:

In order to establish culturally sensitive relationships and to offer interventions with any family of a child with special needs, it will be appropriate for the professional to reflect on the following questions:

- a. What are the core cultural values of this family and how might they be different from mine?
- b. How are various roles and responsibilities likely to be distributed in this family?
- c. What beliefs might this family hold regarding human exceptionality? How might these influence their relationships with the affected child, in terms of expectations, parenting, disciplining, and so forth?
- d. What role does religion and other cultural institutions play in the life of this family?
- e. What might the family's educational values be and how might they view the role and intervention of a mental health professional? (p. 30)

A Final Comment

I am privileged to write this lengthy Foreword for this most recent book by my colleague, Dr Wayne Nesbit. His ability to view the family through a number of conceptual lenses serves to broaden and deepen our understanding of families with exceptional children. It also provides a meaningful framework to advance our understanding of those primary interpersonal attachments within sibling relationships.

There is considerable insight into the dynamics of those sibling attachments and the potentially positive and negative consequences when there is a disabled brother or sister. On this important matter the book is chock full of timely advice and recommended best practices for families with an exceptional child and all of those who work with them.

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