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PARENT LIFE MANAGEMENT AND TRANSFORMATIONAL OUTCOMES WHEN A CHILD HAS DOWN SYNDROME

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Our research examines three aspects of effective life management in parents of children with disabilities: strategies parents find helpful for effectively managing life, personal qualities that parents consider important to effective life management, and parent transformational outcomes on personal, relational and perspectival dimensions. This paper extends the data analysis to the results for two subgroups of families which have a child with Down syndrome, from two larger questionnaire studies (Scorgie, Wilgosh, & McDonald, 1997; Wilgosh, Scorgie, & Fleming, 2000). The purpose was to examine effective life management for these families, a sufficiently large and identifiable subgroup in each of the two surveys, to allow examination of consistency of findings for these families compared to the broader family data. The findings indicated similar dimensions of life management for such families, and important transformational outcomes, all of which have implications for parents of children with Down syndrome and the professionals with whom they interact.

Research is inconclusive as to the presence and effect of stress on families of children with Down syndrome. In a study of family stress and adjustment in three groups of

parents, Sander and Morgan (1997) reported that stress levels for parents of children with Down syndrome were greater than those of parents of developmentally normal children,

but less than for parents of children with autism. Roach, Orsmond, and Barratt (1999) also noted that parents of children with Down syndrome reported significantly higher stress and depression than parents of typically developing children, though not at a level considered clinically significant. Atkinson and Chisholm (1995) reported that those mothers of children with Down syndrome who tended to focus on stressors experienced greater affective distress than mothers who chose alternate coping strategies. This may suggest that outcome is not determined by the presence of stress but, rather, is influenced by how that stress is perceived and managed by the individual and family unit.

In fact, other research has shown that, even amid the stresses of raising a child with Down syndrome, many families manage life effectively (e.g., Cahill & Glidden, 1996; Roach et al., 1999). Cahill and Glidden (1996) compared parents of children with Down syndrome to parents whose children had other disabilities (e.g., autism, cerebral palsy, and seizure disorders) and found no significant differences between the families on measures of family functioning, also discovering that family functioning scores for the large majority of families of children with disabilities (including adoptive families [Glidden & Cahill, 1998]) fell within the norms for families in general. Likewise, in a study of family stress, comparing families of children with Down syndrome, hearing impairment, and developmental delay, with two control groups (nondisabled), Duis, Summers, and Summers (1997) found stress levels for parents of children with Down syndrome were similar to those of the two-parent control group. Furthermore, these scores were significantly lower than stress scores for parents of children with hearing impairment and developmental delays, and single parents of children without disabilities. The above studies suggest that many parents are able to effectively manage the stresses associated with parenting a child with Down syndrome. In fact, many families manage life very effectively when they have a child with Down syndrome or other disabilities.

In interviews with parents of children with Down syndrome and other disabilities, Stainton and Besser (1998) documented nine areas in which children with intellectual disabilities made a positive impact on their families. These included joy and happiness, an increased sense of purpose and priorities, expanded personal and social networks, increased spirituality, family unity, personal growth/strength, and increased understanding of and tolerance for individual differences. Skinner, Bailey, Correa, and Rodriguez (1999) documented transformations in Latino mothers of children with special needs, which included new ways of thinking about the world, a focus on the character-building aspects of suffering, and becoming more compassionate mothers and people.

Parents of children with Down syndrome have long asserted that, not only have they been

able to cope effectively with the stresses of their unique parenting situations, but also they have been changed positively and permanently as a result of their parenting experiences. Although professional literature has given little attention to parental transformation in

response to a child's disability, parents' own accounts of their lives and relationships with their children provide frequent reference to transformation. Transformations have been discussed by parents of children with a wide range of disabilities (e.g., Oe, 1996), but parents of children with Down syndrome have provided some of the most compelling and articulate accounts (e.g., Beck, 1999; Meyer, 1995; Rogers, 1953, 1981).

Dale Evans/Rogers (Rogers, 1953), US actress and country singer, provided a brief but early insight into family transformation. In writing *this is the story of what a baby girl named Robin Elizabeth accomplished in transforming the lives of the Roy Rogers family* (p.7), she opened a discussion on transformation that has continued for the following half century. Robin Elizabeth, who had Down syndrome, only lived two years, but Rogers' book describes a family that was changed forever. In fact, through her mother's book, Robin Elizabeth's influence might be seen as having much broader impact. Prior to the 1950s, having a child with a developmental disability was generally considered to be an unspeakable topic. Rogers was one of three prominent women who changed that. Her open discussion of the subject in *Angel Unaware*, along with that of Pearl S. Buck and Rose Kennedy, broke a powerful social taboo that isolated families, and transformed society forever. Rogers' transformation was clearly religious in nature. Robin Elizabeth (an angel) tells God about her parents' transformation: *They're a lot stronger since they got our message. There's a new glory inside them and on everything all around them, and they've made up their minds to give it to everyone they meet* (Rogers, 1981, p. 94).

While the strong religious nature of *Angel Unaware* is shared by many parents' stories of transformation (e.g., Beck, 1999), others are more secular. Michael Bérubé's *Life as we know it* (1996) provides a secular, humanistic perspective and discusses *genetic destiny* (p. 3), describing his initiation into parenting a son with Down syndrome as a starting place for social criticism. Bérubé's opinions on social issues have not altered greatly as a result of his experience, yet certain indelible changes have been made. He suggests that physicians who only warn of the negative aspects of having a child with a disability perpetuate a dangerous bias. He feels strongly that the other side should be presented as well. *The message: if you choose to have this child, your life may become richer and more wonderful than you can imagine, and your child will grow to be a loving, self-aware, irreplaceable member of the human family* (p. 82). Barbara Gill's (1997) *Changed by a Child* also addresses transformations in general and her personal transformation after her son, Amar, was born with Down syndrome. The meditation, *Blessing*, concludes, *Let me be thankful for this doorway to meaning. Let me have the courage to walk through it. Let me choose it now* (p.229).

Gill's notion of choice seems to be shared by other parents of children with Down syndrome, in discussing their transformations. Fate thrust these children into most of the parents' lives without an opportunity for choice. Yet, many of these parents feel that they have made a choice, freely and fully, to accept the path on which fate placed them. They

chose to reconstruct their lives to fit their children rather than to struggle to make their children fit their old lives.

One parent who had the opportunity to choose was Martha Beck. Her book, *Expecting Adam* (1999), chronicles the choice that she and her husband faced when these young Harvard graduate students were informed that the baby she was expecting had Down syndrome. Her doctors and the professors who were grooming them for elite careers made it clear that there would be no place in that life for a child with a disability. Eventually, they followed their hearts and their child, and let go of the dreams that they had worked so hard and long to achieve. According to Martha Beck, it was the best thing that ever happened to them.

Clearly, then, stress and its management are not the primary variables in discussing life adaptation of families which have a child with Down syndrome. Rather, based on the research and general literature, these families appear to have positive coping skills and effective life management strategies. Individual parents have reported significant personal and family transformations, which they have attributed directly to the birth of their child with Down syndrome.

Our research has examined three aspects of effective life management in parents of children with a range of disabilities across a broad age range: strategies parents find helpful for managing life effectively, personal characteristics parents consider essential to life management, and transformational outcomes experienced by parents. The initial, parent-interview study (Scorgie, Wilgosh, & McDonald, 1996) identified nine themes, subsequently validated through two questionnaire surveys. The first survey (1996; see Scorgie, Wilgosh, & McDonald, 1997) involved parents of children with disabilities who were judged to be effective at life management. The second survey (1998; see Wilgosh, Scorgie, & Fleming, 2000) involved a somewhat broader sample of parents of children with disabilities, who were contacted through service agencies but not identified or pre-selected as effective life managers. The purpose of the two survey studies was to explore and validate the nine themes, beyond the findings of the initial, interview study.

The purpose of the data analysis reported here was to examine effective life management for families of children with Down syndrome, who formed a sizeable subgroup from our survey research, to examine consistency of their questionnaire results with the results across families of children with a range of disabilities. As indicated above, there is a fair

body of research and individual documentation on such families, supporting such a subgroup analysis.

Method

Participants. Parents of children with Down syndrome in the two studies totaled 53: 39 (74%) mothers, 11 (21%) fathers, two (4%) foster parents, and one (2%) guardian. Twenty-nine parents (23 mothers, five fathers, and one guardian) were part of the first study (good life management), and 24 parents (16 mothers and eight fathers), representing 18 families, took part in the second study (broader parent sample). All parents/guardians resided in Western Canada.

All participants in the first survey, including the Down subgroup, were nominated by personnel from one of four service agencies for such families in Western Canada, as having effective life-management strategies (see Trute & Hauch, 1988, for similar subject selection). Participants in the second survey (not pre-selected as effective life-managers) were contacted through four different service agencies, eliminating possible overlap of families contacted for the first survey. After university ethical approval of the research, the cooperating agencies mailed questionnaires to prospective participants, along with a cover letter assuring confidentiality, return envelope and postage. For survey studies one and two, the overall response rates were 80 of 198 mailed surveys (42.3%) and 116 of 381 (22.3%), respectively. Because t-tests revealed few significant differences (on only two of 59 LMS items), the data were pooled for all families of children with Down syndrome, for all subsequent data examination and discussion.

Forty-five respondents (84.9%) represented dual-parent homes and 38 (71.7%) lived in urban settings. Thirty-two (62.7%) of the children with Down syndrome were males, 19 (37.3%) were females. Of the 51 children with Down syndrome contained in the 47 represented families, five children (9.8%) was between 0-5 years of age, 22 children (43.1%) were between 6-12 years, 13 children (25.5%) were between 13-21 years of age, and 11 (21.6%) were over 21 years of age ($M = 15.0$ yrs).

The Life Management Survey (LMS). The LMS (Scorgie et al., 1997) is a 59-item instrument designed to explore three aspects of life management in parents of children with disabilities: effective management strategies (Questions 1-31), effective parent characteristics (Questions 32-43), and positive transformational outcomes (Questions 44-59). (The original survey instrument was expanded in 1998 to include two additional items about vocational transformations; these were not strongly endorsed by parents and will not be discussed further.) Opportunities for open response comments were provided at the end of each survey item and at the conclusion of each of the three survey sections.

Results

For each of the three aspects of effective life management, i.e., strategies employed,

personal qualities, and transformational outcomes, three themes had been identified in earlier, qualitative research (Scorgie, Wilgosh, & McDonald, 1996). Only those survey items ranked *very important* or *essential* by the majority of parents of children with

Down syndrome (i.e., with mean scores of 4.0 or above) will be reported, with examples from parent written comments..

Important Parent Strategies

Participants were requested to indicate how important each of the 31 strategies has been to them as a parent of a child with special needs. Strategies dealt with reframing, balancing roles and responsibilities, and gathering resources.

Theme 1: Reframing. Several strategies emerged as strongly important or essential to effective life management. Parents felt that learning to accept their children *as they are* was vital to managing life ($\underline{M} = 4.4$, $SD = .99$). Parents generally agreed that acceptance was a prerequisite to a positive outlook on life (e.g., *Acceptance brings out the best and invites growth*). Parents also viewed such strategies as valuing what their children contribute to their families ($\underline{M} = 4.4$, $SD = .77$), and taking into account the child's goals and dreams ($\underline{M} = 4.3$, $SD = .71$) as very important or essential to effective life management. Parents noted that their children bring such traits as joy, care, love of life, and sensitivity toward others to their families and larger communities (e.g., *Amy has an incredible gift of welcome; she prays often for people who are hurting and loves them*). A second group of strategies pertained to how parents view themselves. These parents asserted that developing skills to advocate self-confidently on behalf of their children ($\underline{M} = 4.3$, $SD = .84$) and trusting their own instincts ($\underline{M} = 4.3$, $SD = .86$) were essential to effective life management. While parents strongly asserted that they really do know what is best for their children and have had to learn to value their own judgments accordingly, they also affirmed that they needed the expertise and support of child-focused professionals to provide optimal programming options for their children (e.g., *I need the facts more trained/experienced personnel can give*).

Theme 2: Balancing roles and responsibilities. Two strategies were strongly endorsed by parents related to balancing their various roles and responsibilities: safeguarding their marriages and nurturing themselves. Safeguarding marriages by spending time together, learning to communicate openly, and creating mutual ownership of family problems and solutions was ranked high ($\underline{M} = 4.3$, $SD = .73$). While parents admitted that a healthy marriage was foundational to family well-being, several respondents stated that it tended to be difficult to carry out in practice (e.g., *Very easy for husbands and wives to forget about their own relationship, which is foundational to everything else*). Parents also agreed that safeguarding their own physical and emotional health ($\underline{M} = 4.0$, $SD = .92$) was a very important strategy for effective life management (e.g., *Although I have*

between all children in the family ($\underline{M} = 4.0$, $SD = 1.0$)(e.g., *Giving each child quality time was/is key*), were very important to effective life management.

Theme 3: Utilizing resources. Although parents indicated that learning how to collaborate with professionals was important ($\underline{M} = 4.0$, $SD = .81$), several mentioned that it required a great deal of energy and patience to deal with the highly structured bureaucracies many professionals represent. Parents stated that, while they value and need the expertise of professionals (e.g., *You need excellent [professionals], caring and communicating with you*), they resent professionals who assume parents are uninformed or unable to make appropriate decisions for their children (e.g., *Some professionals think they know more than parents. . . not so*).

Important Parent Characteristics

The LMS was designed to examine three categories of personal characteristics: personal traits, decision-making and problem-solving ability, and philosophy of life/belief system. Parents were instructed to indicate how important each of the twelve personal characteristics has been to them as a parent of a child with special needs (1 = *not important*; 5 = *essential*).

Theme 4: Personal traits. Four parent traits were considered very important or essential by over 70% of respondents. Maintaining a positive outlook ($\underline{M} = 4.3$, $SD = .66$) was foundational to achieving optimal child outcomes for many parents. Some parents found that viewing their child as capable served as a self-fulfilling prophecy (e.g., *Our positive outlook about expectations paid off, as our son has great language ability*). A second highly valued parent trait was patience ($\underline{M} = 4.2$, $SD = 1.0$) (e.g., *What appears to be impossible has often happened when patience and expectation are teamed up appropriately*). Willingness to grow and learn also ranked as very important or essential for the large majority of parent participants ($\underline{M} = 4.2$, $SD = .74$). Several parents remarked that the need to keep abreast of current best practices has necessitated that they continue growing and learning (e.g., *Our son's development has depended on our knowledge*). A fourth foundational parent trait was determination ($\underline{M} = 4.1$, $SD = .79$). Parents equated determination with refusing to give up, or persisting until an acceptable outcome is achieved (e.g., *Determination is the difference between reaching a goal and falling short; it finds answers when others say there are none--and so progress comes about*).

Theme 5: Decision-making and problem-solving ability. None of the survey items in

focused on our son's progress to a fanatical degree, my other hobbies and interaction have provided the balance). Parents affirmed that strategies, such as setting limits on external expectations ($\underline{M} = 4.0$; $SD = 1.0$), and balancing time, attention and energy

this category received a mean score of 4.0 or greater. While most parents accepted that they will remain major decision-makers for their children throughout their children's lives (e.g., *I accept that my daughter may always need some kind of support throughout her life*), several reported feeling overwhelmed by this reality (e.g., *This is not something I*

relish). Many hoped that, over time, their children would become more active in decision-making processes.

Theme 6: Personal belief system/philosophy of life. Approximately 90% of the respondents considered the belief, *life is what you make it; you have a choice about how you will live life*, as very important or essential for effective life management ($\underline{M} = 4.7$, $SD = .62$). Respondents indicated that, to avoid frustration, they have also had to learn to accept the many variables in their lives over which they have little or no control. However, for many parents the more important strategy was finding solutions (e.g., *Instead of asking 'Why me?' I ask, 'How am I going to handle this?'*). These parents also valued having strong personal convictions ($\underline{M} = 4.0$, $SD = .86$). For some parents, reliance on strong inner faith/religious convictions was valuable; for others, belief in one's child or one's own inner strength was important (e.g., *There will always be issues where you question yourself. Therefore, staying focused and going with gut feelings are important*).

Transformational Outcomes

Parents ranked degree of personal agreement/disagreement for 16 transformational outcomes (1 = strongly disagree; 5 = strongly agree).

Theme 7: Personal transformations. Four personal transformations were rated highly by parents. Parents felt that they had learned to speak out for their children, rather than remain passive ($\underline{M} = 4.4$, $SD = .77$) (e.g., *I didn't have the confidence to ask questions in a group or meeting; needing to advocate changed that*). Parents also described themselves as more compassionate toward others, especially those in need ($\underline{M} = 4.2$, $SD = .74$). Another personal transformation that occurred was the discovery that they could achieve, rather than remain powerless ($\underline{M} = 4.3$, $SD = .71$). One father commented, *Watching [my child] achieve things never thought possible to her challenges me to get with it!* Parents also felt that their parenting experience had made them stronger, rather than weaker ($\underline{M} = 4.0$, $SD = .75$).

Theme 8: Relational transformations. Two relational transformations were rated highly by parents, who agreed that they have learned to see life from a different perspective, learned what it is like to live in someone else's shoes ($\underline{M} = 4.1$, $SD = .81$). One respondent remarked, *One thing it has [taught me] very strongly is that comparisons can be set aside and everyone can be enjoyed for who they are!* The second relational

transformation rated highly was knowing that they had made a difference in the life of another person through advocacy ($\underline{M} = 4.0$, $SD = .79$). Parents spoke of writing letters and pamphlets, leading parent groups, and advocating changes to school, church and community programs. One mother shared her hope that, because she had made a difference in the life of her child, her child would someday be able to make a difference in

the life of another. She wanted to give her child the *gift* of knowing that she, too, had made a difference.

Theme 9: Perspectival transformations. Parents agreed that parenting a child with Down syndrome has given them a more authentic view of what it means to be successful in life ($\underline{M} = 4.0$, $SD = .87$). One parent summed up the perceptions of several others with the comment: *Success had been measured by accomplishment and material wealth. I now view success as having quality of life, of being accepted for who I am and of well-being and friendship.* Parents also agreed that they have learned what is really important and valuable in life ($\underline{M} = 4.1$, $SD = .83$). Parents cited such values as to love, to be loved, to accept others nonjudgmentally, to be needed, to respect and cherish life, and to help others.

All of the above findings are consistent with the overall results for the two surveys, as previously reported (Scorgie et al., 1997; Wilgosh et al., 2000). This is, perhaps, not surprising given that the parents of children with Down syndrome represent a subset of the total sample. However, it does affirm that these parents, and many other parents of children with disabilities, demonstrate effective life management strategies which are not unique to parents identified by service agencies as effective life-managers, consistent with the research cited above (e.g., Cahill & Glidden, 1996; Glidden & Cahill, 1998). Further research is needed to examine life management when parents are not connected to a service network.

Discussion and Implications

The fact that there was agreement among parents from both surveys on the effectiveness of a large majority of life management strategies might suggest that there are a set of strategies that are important to parents of children with Down syndrome across the board. These parents felt that accepting and validating their children, and valuing what they contribute to their families and to the community, were very important to effective life management. Parents also supported the need to trust their own instincts, to advocate self-confidently, to work collaboratively with professionals, to safeguard their marriages, and to nurture their physical and emotional health. These strategies suggest implications for effective intervention with parents of children newly diagnosed.

Parents indicated that they needed support for and recognition of the importance of their

parenting role from the professionals with whom they interact. They especially valued professionals who value their children, view them as unique individuals, and collaborate with families as members of a team, rather than those who see them as a *case* to manage. Unfortunately, many parents expressed negative perceptions of professionals, especially those who were arrogant, critical, insensitive, or entrenched in one-way thinking. Clearly professionals as a group need to be aware of the possible negative image of professionals

that parents may bring to parent-professional interactions. Perhaps some professionals should be challenged as well to examine their perceptions of parents.

Given the literature on the demands and stresses of parenting a child with a disability, the encouraging finding is that parents acknowledge positive benefit. The large majority of parents in both subgroups indicated that they have changed permanently and positively through their parenting experiences; many were adamant that the changes they have experienced were directly linked to their experiences of parenting a child with Down syndrome.

Research contends that life events that come suddenly, affect many life domains, and challenge one's basic assumptions about life, often result in transformations (Aldwin, 1994; Janoff-Bulman, 1992; Palus, 1993). Some researchers even profess that these permanent changes in self-perception, behavior, or outlook on life, may be necessary to resolve a crisis positively. Though references to positive parent transformations are found in the writings of parents of children with disabilities, the professional literature is just beginning to document and validate them.

The results of this research indicate that transformational outcomes do, indeed, take place in the lives of parents of children with Down syndrome. This was true for two subgroups of parents, those selected as having effective life management strategies, and those more broadly identified from having had some contact, however brief, with a service agency. Surely this has implications about the way disability is presented and represented to parents of children newly diagnosed. A limitation of both LMS studies lies in the fact that a broad base of families, including those falling outside of the scope and range of service providers, has not been represented in the findings. From difficulties such families may be experiencing further information could be gleaned on needs of families and issues related to life management strategies.

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Footnote

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