A Study of the Meaning of Life of the Severely Disabled Child

Henk Kars and Joop Stolk

Much has been written about the emotional and educational challenges faced by severely disabled children; but little has been written about how the disabled child's parents experience the meaning of their child's life; and what it means to them to provide care on a daily basis for their disabled child.

We interviewed 22 parents (18 couples and 4 single parents) of children with severe handicaps like John. John's father talks about his son: "It sounds harsh to say so, but John is not able to do anything by himself. After his birth, John's development came to a sudden stop. The only thing he does spontaneously is to urinate; that he can do all by himself. He cannot walk, eat, or drink. He cannot talk, and he is almost blind. He is completely dependent on other people." The in-depth interviews—consisting of some 50 open-ended questions—were (Continued on page 2)

Excess Mental Talent: An Ethical Puzzle

Robert M. Veatch

No one, at least no one working in the field of intellectual disabilities, would be foolish enough to blame the intellectually disabled for their lack of mental skills. Except in the most exceptional cases, their condition comes from genetics, birth trauma, or other injury that by no stretch of the imagination could be considered their responsibility. Yet what parent among us can refrain from pride when our child returns papers or report cards with A's rather than lower grades? Who among us rejects the financial and other rewards of mental talent? How can it be that those who are deficient in mental talent are without blame while those possessing excess deserve the praise, glory, and financial rewards it produces?

It cannot be denied that possessing unusual amounts of mental ability generally brings its rewards. Sometimes that comes in the form of a large salary, sometimes as the praise for fine school (Continued on page 6)
focused on the following themes: (a) the parents’ experience of the meaning of life of their child with a severe mental handicap, (b) their experience of the meaning of their daily care for their child, and (c) how their care for their child has influenced their own lives. The two and a half hour long interviews were conducted at the families’ homes. The interviews were tape-recorded and transcribed on a later date; and the findings were analyzed using qualitative research-methods.

Most of the time, there were four people participating in the interviews: the parents and two investigators. Sometimes one or two of the other children participated during a part of the conversation. In this article, we will give a brief account of the results.

The “Outsider”

The interview started with the introduction of a hypothetical “outsider” who didn’t understand the meaning of the life a severely disabled child. We suggested that the outsider might pose the following question: “For the child to be this handicapped, so limited in what he can do, does the life of such a child really have any meaning? Always being ill, sometimes very ill, always needing to be cared for, always remaining dependent... His body might be growing, but he is barely developing. He will never attend school, will never be employed, will never be involved in a relationship... Does the life of such a child really have any meaning?”

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Nearly all parents tried to erase any of the outsiders’ doubts by explaining how they perceived the value of their child’s life. One parent is quoted here to illustrate the way the parents generally answered the outsider: “You don’t know our child. When we watch him laugh, we are always delighted. Someone who doubts the meaning of a disabled child’s life simply doesn’t understand that this child can be just as happy. When I see how much pleasure these children have, I look at myself in the mirror and think: ‘do I ever have that much fun?’

During the discussions the parents stressed that their disabled child had a meaningful life because (a) the child’s life had meaning for others and/or (b) the life of the child was meaningful because of the kind of person (s)he is and/or and (c) because God gave his or her life meaning.

We quote two parents:

“John knows how to get along with people. He helps one of his blind group-mates with his meals and goes to find a support worker when a resident has a seizure... He simply knows what to do... He would never hurt a soul.”

Bill’s mother stated, “I am glad I have him. You see, caring for him can be consuming, but think of the love, the thankfulness and all the things given in return from the child. You should see him sitting on his father’s lap on Sundays, like a two year old: it’s so wonderful for the child to hug his father and cuddle with him on his lap... What do I get from him? A lot! Such radiating warmth and love.”

All parents expressed the opinion that there is deep meaning in the life of their child, even though the child cannot grasp the meaning of many of the things that are usually considered to be important in life. Some parents,
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however, stated that there are limits to the meaning of life of their disabled child: if a child suffers from severe pain, and if there is no trace of joy in his or her life any more, then the meaning of such a life becomes incomprehensible.

The Meaning of Care for the Disabled Child

The parents were asked if they found meaning in all of their efforts to provide care for their severely disabled child. All of the parents answered the question in the affirmative; to them, caring for their child was worthwhile for the sake of the child. They responded, “It is meaningful because the child is so dependent on us that he wouldn’t survive without our care”; and “the child needs an advocate, someone who stands up for him.”

For the parents, the value of all their efforts was found in making their child’s life as enjoyable as possible. Other answers from the parents of severely disabled children indicated that providing their child’s care had meaning for them also because it gave them deep satisfaction and made it possible for them to realize fundamental human values. Steven’s father considers the special care given to disabled children as “a test of how humane we are... that we treat even the least of human lives with care and respect.”

An important interview topic was how the daily care for their disabled child influenced these parents’ lives. Several parents indicated that providing the care for their child shaped their characters. They explained how they gained more insight into their own lives, and how they had become more competent to cope with the problems of daily life. They learned how to put things into better perspective and learned to see the relativity of the things they used to take for granted. One parent told us, “I see with admiration how my sister’s child begins to walk and talk.” These parents told us, too, that the disabled child had affected their relationship with their partner and with their other children. Five couples stated that the disabled child brought them closer and strengthened the family ties. Greg’s father stated that he and his wife grew closer: “You always hear about how parents of disabled children separate. Well, we have had a difficult life together; our personalities are quite different... We did grow closer... because you need each other and you don’t want to lose your child.”

Final words

Our study gives some insight into what the experience of raising a severely disabled child can mean to the child’s parents. However, it is only a beginning. We plead for further studies of the significance of parental care given to disabled children, (particularly with parents of different religious and philosophical backgrounds), in order to direct more attention to this important aspect of the bond between parents and their disabled child.

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Transformational Outcomes Associated with Parenting Children with Disabilities

K. Scorgie

For the majority of parents, the discovery that their child has a disability is traumatic. However, despite the difficulties they face, most parents manage to deal adequately with the new challenges and adjustments that parenting a child with a disability brings. Furthermore, many parents have asserted that though the stresses in their lives have often been great, they and their families have experienced beneficial outcomes which might not have otherwise occurred. While parent literature has documented these positive outcomes extensively, much of the professional literature has ignored or, worse, denied them. What bewilders these parents even more, however, is the implicit assumption held by many professionals (even those who are trained to work with individuals with disabilities and their families) that parenting a child with a disability is, at best, a stressful and bleak undertaking (one professional has likened it to that of the mythical Sisyphus). This negative view of parenting is especially surprising in light of recent research which suggests that stressful events that occur unexpectedly, impact life in several domains, and are highly significant to the person (such as the diagnosis of disability in a child) often result in transformational outcomes. Aldwin (1994) argues that the stressful event does not itself produce the transformation; rather it serves as a catalyst, or sets in motion the process, for the transformation to occur. And because stress, by its very definition, is something that overloads an individual's current coping system, the experience of a traumatic event may ultimately force a person to develop different ways of understanding and organizing life, thus changing, or transforming, the individual.

One of the reasons for the lack of documentation of transformational outcomes in research on stress and coping might well be the emphasis placed on stress "management." If successful coping is evaluated in terms of reducing the negative effects of a stressor alone, transformations may well be overlooked. Furthermore, transformations may not be detected in research that examines only short-term responses to stressful events. Longitudinal or life-range reflections may be required to detect these changes.

The Present Study

In order to document transformational outcomes in parents of children with a variety of disability characteristics, a recent study was conducted in Western Canada which included in-depth interviews with 15 parents and a survey of an additional 80 parents/caregivers (see Scorgie, 1996). Parents were asked questions such as: "What have you learned through parenting [child's name]?") or "How have you changed as a result of parenting [child's name]?") Transformational outcomes were documented in three areas: personal, relational...
and perspectival.

Personal Transformations

Personal transformations clustered into two categories: acquired roles and acquired traits. Parents reported experiencing personal enrichment through assuming a variety of new roles such as parent group leaders, conference speakers, advocates for persons with disabilities, teachers, writers, and members of advisory councils for schools, hospitals, or agencies. In addition, several mentioned developing talents or skills which enabled them to engage in new hobbies, volunteer work or vocations. Parents also spoke of acquiring new personal traits such as becoming more compassionate, learning that they could achieve, developing inner strength and self-confidence, nurturing themselves, and cultivating stronger personal and spiritual convictions. Interestingly, parents reported that the impetus for many of their personal transformations arose from the need to resolve some difficulty in their lives.

Relational Transformations

The most common relational transformations were expanded friendship networks, the ability to see life from another person's perspective, making a difference in the life of another person, and creating a stronger marriage. Other relational outcomes included a new appreciation for the dignity and uniqueness of each human being, the ability to be comfortable around people who are "different," a better understanding of the interdependence of life, changes in parenting of other (non-disabled) children, and the ability to accept others without judgement or discrimination.

Many parents have experienced positive transformations through parenting a child with a disability

Changing Perspectives

Perspectival transformations most commonly reported were valuing each day, celebrating life, revising views of success, and discovering what is truly worthwhile in life. Respondents also mentioned learning to restructure priorities, living one day at a time, developing wisdom and discernment, and acquiring a more holistic approach to and acceptance of life. While, these positive transformations did not preclude the concurrent existence of negative life outcomes, such as increased life and family stress, vocational restrictions, frustration with bureaucracies (e.g., government, agencies, medical personnel, and educators), and loss of valued social and recreational activities, the presence of negative outcomes in no way diminished the authenticity or value of the positive transformations.

The results of this study support the claim of many parents that they have experienced positive transformations through parenting a child with a disability. While additional research is needed to explore the nature and extent of these transformations, the documentation of transformational outcomes should influence our understanding of disability. While parents may experience distress over the diagnosis of disability in a child, professionals must avoid catastrophising the results of this diagnosis in a way that emphasizes grief, stress and hopelessness. Rather, professionals must present the full range of possible outcomes for parents and their families, and assist them in charting a course that will increase the probability of beneficial outcomes. Facilitating contact with parents who have experienced positive transformations may be one of the most effective strategies.

Furthermore, the need to consider and present information regarding transformational aspects of parenting is important when deliberating such controversial issues as withholding beneficial treatments (e.g., surgeries) from persons with disabilities or terminating a pregnancy when a diagnosis of disability is made. Catastrophising negative outcomes may cause parents and caregivers to make decisions that, at a later date, they question or deeply regret. At the very least, professionals must examine the implicit or explicit communicative impact of their statements and prognoses to parents and family members.
This does not imply holding out false hope, but rather conscientiously representing the full range of potential personal and family outcomes.

Many parents resent the assumption that parenting a child with a disability is, at best, a distressing and negative ordeal. While they freely acknowledge the difficulties involved, many parents ardently attest to ways in which they have been beneficially transformed personally, relationally and perspectively. If it is true that transformations are involved in the successful resolution of crisis events (and this study would indicate that they, at least, accompany them), then the professional literature in the field of disabilities should begin to address both the impact of this knowledge for decision-making processes and ways in which these positive transformational outcomes might be facilitated.

References:


The Excess Talent Puzzle

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work, sometimes as the glory of winning the contest of intellectual skill. Maybe the time has come to ask whether, and to what extent, those rewards make sense.

Unusual mental talent is undoubtedly a complex phenomenon. Most believe that, to some unknown degree, it has something to do with the genes we inherit. To be sure, exactly what the relationships is between genes and mental ability is a mystery. Conservatives who attempt to link intellectual ability to genes and genes to race surely are crudely simplistic. Surely, much intellectual skill has to do with environment, nurturing, and other factors beyond the chromosome, but the genes must have something to do with it. Without some basic minimum of genetic equipment, intellect is impossible. We cannot plausibly claim credit for those genes. This at least must raise a question about whether we deserve credit for what those genes make possible. It is more a matter of luck in the natural lottery of life. Likewise, it seems strange that we would claim credit for the nurturing and environment that is also necessary for intellectual ability. Just as with genes, these are more good fortune in the lottery, in this case, the social lottery of deciding which schools, which enrichment, and which support systems we luck into. Claiming credit here does not make much sense either.

Why, then, should intellectual talent command reward?

Reward for Effort

Moral and pragmatic arguments have been offered in defense of such rewards. The moral arguments are more appealing, especially to those who have been successful in intellectual pursuits. The most common is probably the claim that it is the individual's hard work that produces intellectual accomplishments and that this hard work deserves reward. The student who studies very hard and thereby does better than fellow students who are equally equipped intellectually is seen as deserving the better grade as well as the praise, glory, a future rewards that accompany it.

The problem with this appeal that could called the "effort deserves reward" defense, however, is its simplicity. The truth of the matter is that effort explains at best only a small part of the variance in school or other intellectual performance. We all recall the fellow student so smart that he or she could get the highest score of the test without any significant studying and the less well equipped classmate who couldn't do better than mediocre work regardless of the effort. Moreover, we also remember the advice about what "all work and no play" makes us. The one who expends extraordinary energy in one kind of intellectual pursuit will
simply be unusually lacking in other important areas. That is at least what the common wisdom tells us. It seems hard to deny that what really is getting rewarded is some combination of genes, nurturing, and luck perhaps modestly supplemented with effort. While effort must account for some portion of the variance, it is undoubtedly less than the winners in the natural and social lotteries would have us believe.

**Reward as Incentive to Social Contribution**

There is a second argument in defense of rewarding intellectual talent. Regardless of whether those who possess it are deserving, bestowing money, praise, glory, and status, it is argued, is necessary to stimulate important contributions to society. If, and only if, we pay the talented large salaries and bestow high status, can others in society receive the inventions, literary product, creativity, and the other useful product of great intellect. It is rational, according to this view, to give the talented enough reward to provide an incentive to produce this product.

This argument is suggested by the work of John Rawls, probably the twentieth century's most important political philosopher. Beginning with *A Theory of Justice*, published in 1971, the idea has prevailed that those who are better off deserve social goods (like money and status) when necessary to stimulate them to serve the welfare of those who are among the worst off in the society. According to Rawls it is not merely pragmatic to provide such rewards to the more talented, it is actually the *just* and *right* thing to do. This argument is terribly useful, indeed dearly loved, by those in the business of serving the needy. It provides the definitive rationale for fine salaries for those working with people with mental disability.

**Problems with Rewarding Talent**

There are real problems with the Rawlsian defense of reward for talent, however. At most it works for rewards for those who really use their talent for the benefit of those who are among the worst off. It makes some sense to pay the fireman well based on special physical skills that can be life-saving for others. Yet, more often than not talent, even intellectual talent, is rewarded independent of its incentive to produce needed help for the miserable or needy of the society.

Why is it that those with the greatest intellectual talent...also deserve large salaries and other rewards?

The inventor of the technologies of television, the computer chip, and even the hula hoop command reward without concern for the benefit they might bring to the neediest. It is, to say the least, inefficient, to attempt to improve the lot of the worst off by indiscriminately rewarding intellectual and other talent. Those who command that extravagant rewards of a society—the movie stars, athletes, and entrepreneurs—are in general hardly the most devoted servants of persons with retardation or other needs. Surely the devoted teacher of the disabled deserves at least as much reward.

Here then is the ethical puzzle: why is it that those with the greatest intellectual talent—those who have had life easy from the earliest days of school, who reap the praise and status of their talent—also deserve large salaries and other rewards?

Perhaps the only honest answer is that they don’t. One of the underdeveloped parts of the study of ethics and intellectual disabilities is the examination of rewards linked to exceptional amounts of intellectual ability. One possibility: much as those who possess such talent would like to believe, they simply don’t deserve the rewards they reap. If intellectual and other talents are gifts, then it is not that their rewards are deserved; it is not even that they are supported pragmatically by as Rawlsian stimulants of service. Rather as gifts they command gratitude; they demand not claims of just reward, but grateful burden for the service of others. Just maybe intellectual talent is not only its own reward, but the mark of great obligation. The greater the talent, the greater the need for gratitude and the greater the obligation.

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Bibliography

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