

## **Being Disabled in the New World of Genetic Testing:**

### **A Snapshot of Shifting Landscapes**

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#### **Introduction**

This paper speaks biographically in order to introduce a real time snapshot of the forces genetic technologies bring to bear on the disabled and their families. We do so as an academic theologian and a neo-natal nurse experiencing the joys and frustrations of first-time parenthood. Our son, Adam, now two years old, has Down's syndrome, and it is the events of his first six months on which our account draws. This paper will outline the pressures we experienced as parents of a 'genetically handicapped' child, and then, in conclusion, offer a few theological reflections.

The biographical investigation of social phenomenon is related to phenomenology. The Canadian philosopher George Grant explains how such an approach attempts to circumvent the blind spots induced by the experimental methodologies of the social sciences. Grant suggests that some social forces are actually more accessible to a form of observant participation he calls 'enucleation', and his definition of this idea is worth quoting at length.

In another age, it would have been proper to say that I am attempting to partake in the soul of modernity. When we are intimate with another person we say that we know

him. We mean that we partake, however dimly, in some central source from which proceeds all that the other person does or thinks or feels. In that partaking even his casual gestures are recognized. That source was once described as the character of his soul. But knowing, in a strict sense, has excluded the concept of a soul as a superstition, inimical to scientific exactness. To know about human beings is to know about their behaviour and to be able to predict therefrom. But it is not about the multiform predictable behaviours of modern technical society that I wish to write. It is about the animating source from which those behaviours come forth.

What I am not doing is what is done by modern behavioural science, which is not interested in essences. A leading behavioural political scientist, Mr. David Easton, said recently: 'We could not have expected the Vietnam War.' This was said by a man whose profession was to think about political behaviour in North America, and whose methods were widely accepted by other scientists. But not to have expected the Vietnam War was not to have known that the chief political animation of the United States is that it is an empire. My use of the world enucleate indicates that I do not wish to use a method that cannot grasp such animations.<sup>1</sup>

Grant's claim is that the most important aspects of our technological age are grasped only through close participatory examination of the contours of experience in technological existence because, 'All descriptions or definitions of technique which place

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<sup>1</sup> George Grant, Time as History (Toronto: University of Toronto Press: Anansi, 1995),

it outside ourselves hide from us what it is.<sup>2</sup> To externalize technique in order to study it is to hide the reality that technique is ourselves, that technology is ourselves in action.

In myriad ways we sustain and perpetuate the social forces that meet in the interactions of medicine with the disabled, interactions which only occasionally emerge into view as something on which we critically reflect. This paper is one such exploration of what we experienced as the force and direction of our age's soul. Common opinion holds on one hand that the rise of genetic testing is particularly portentous for our relation to the beginning and future of human life, and on the other that genetic technology is an unstoppable expression of what modern society 'is.' Our inchoate perception that we are brushing up against what this age takes to be its fate initiated the processes of critical observation and reflection which follow.

The protest is immediately, and perhaps rightly, raised: 'But we can't simply step outside our age to observe it!' Our response is that observant participation becomes possible only from the vantage points provided by communities which transmit some counter-cultural logic or impulse and so provide resources for questioning what most take as commonplace. The firm hope in divine presence and the practices of creaturehood learned in Christian worship throw up alternative hopes and alternative ways of being human. This paper is an attempt publicly to articulate conflicting moments between forms of life in order to make them accessible for moral analysis and public discussion. Such articulation serves state and church by naming where differing views of reality produce conflicting forms of social behaviour.

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<sup>2</sup> George Grant, Technology and Empire (Concord, Ontario: Anansi, 1969), 137.

Stanley Hauerwas has famously worried that he ‘uses’ the handicapped for the purposes of just such ethical analysis and cultural critique, as ‘canaries in a mine.’<sup>3</sup> Unlike Hauerwas, we raise these questions as directly and permanently involved parties. In an important sense, everyone in society is an involved party, but our family has been involved in a more direct and visible way than most.

Our worry then is not the ‘use’ of Adam, but co-opting him in his family’s and church’s political engagement with society in ways that might impoverish him. Receiving this divine gift into our family has produced a wealth of new perceptions of how society (and marriage) works. His very being offers a theological diagnostic value in the social responses he elicits. This has proved especially obvious in our relations with modern medicine. Such inquiry is only part of the process of realizing that how we respond to these forces as parents depends on how we name and respond to the world we inhabit. It is with the hope of more sharply perceiving the soul of our age, and so introducing our son to the life of faith in a broken world, that we think out loud about our lives together. We do so emboldened by the observation that biographical, or first person experience, combined with sensitive cultural observation and personal conversation, were the only modes of sociological research available to our parents in the faith. In their writings we

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<sup>3</sup> This is a recurring concern, most fully expressed in ‘Timeful Friends: Living with the Handicapped,’ in Sanctify them in the Truth: Holiness Exemplified (Nashville: Abingdon Press, 1999), 143-156. Also John Swinton, ed., Critical Reflections on Stanley Hauerwas’ Theology of Disability: Disabling Society, Enabling Theology (Binghamton: Hayworth Pastoral Press, 2004), 11-25.

find many theologically and culturally sensitive conclusions about the spiritual dimensions of the forces their respective societies exerted on them.

### **Life in Genetic Limbo**

Adam was conceived three months before a planned move from England to Germany. Stephanie wanted to wait until we reached Germany to register the pregnancy: she knew that it would be simpler to begin antenatal care in the country in which Adam would be born. This early disengagement from antenatal medicine left us knowing Adam only in the timeworn ways of experiencing and marveling at the baby's growth, its first kicks, and the changes in Stephanie's body. We believed that a moving and growing baby is a healthy baby, and felt no loss at the lack of medical corroboration of the point. Our conviction was that if the baby stopped moving or growing, then we would have it checked out. As the baby continued moving and growing we felt no pressure to discover if it was not doing so 'normally'. We were happy and all seemed well.

When we arrived in Germany, Stephanie was almost four months pregnant and began the inevitable process of organizing the details of having a child. Not knowing where to start, she first visited the Frauenklinik, a 'women's clinic' where she was examined and urged in the strongest terms to have a sonogram as quickly as practicable. The reason for the rush, we learned in time, was a scepticism about Stephanie's stated conception date and a nervousness about nearing the legal cut-off date for an abortion. In the course of discussion it also became clear that the only reason for the sonogram was to see if abortion was indicated. The whole set of considerations were ones with which we

disagreed, based on reasons which were not presented up front. Having only gone to the clinic to inquire about antenatal care and birth arrangements, this became our first experience of being offered medical treatment which we neither sought nor desired but were subjected to as a feature of the institutional, legal and social location of women's medicine.

What were the minimum presuppositions that made this conflict about appropriate medical care possible? From our side, our theological beliefs and hopes cashed out in a single criterion for diagnostic action which seemed to us commonsense, but turned out to be increasingly hard to maintain in the contemporary medical context. We asked simply and directly that all treatment of mother and child be correlated to the medical interests of both. We did not consider termination a 'treatment' for our child, nor diagnostic testing which was not directed at a proximate and remediable medical problem. In theory, we would have been open to a discussion of termination on grounds of the safety of the mother, but this consideration was never relevant. Thus, in this first case of conflict with the medical profession over the appropriate use of medical testing, the conflict of interests was sustained from the medical side by the perceived necessity of establishing an accurate date of conception. This places the question in the foreground of whether there are serious medical reasons for establishing gestational age, or whether this is inherently tied to the pressure of legal deadlines for abortion.

Not satisfied with her experience at the Frauenklinik, Stephanie contacted a midwife to discuss having a home birth. The midwife conducted her visits in the simple ways of a previous generation: measuring growth, asking how Stephanie was feeling, looking at her colour, asking about specifics like aches and pains in the teeth and bones.

The 20-week ultrasound scan also came up totally normal. Stephanie being in the pink of health both before and during her pregnancy, as well as still relatively young (29 years old), a home birth was allowed with little comment. To the day of birth, no countersigns indicated that anything but a normal baby was soon to arrive.

Adam was born one stormy August morning, three weeks early but apparently healthy. He nursed as expected despite his small size. Mother, father and midwife greeted the dawn with relief at the short night of labour and the arrival of a son sporting a complete compliment of fingers, toes, eyes and ears. We remained together at home for the next three days adjusting to the rhythmless biological cycles of our new family member, interrupted only by occasional midwife checkups.

On the fourth day Adam was scheduled for his first medical check-up, for which we were glad, as he seemed to have a somewhat infected navel and a bit of a rash. The doctor looked him over that midday and told us, 'New babies often have skin rashes. They can be completely normal and it will most likely go away.' An important transformation was soon to take place which should be noted here. Up to this point, despite his premature birth, Adam had been considered normal and so was only looked at with the cursory attention one pays to the normal ups and downs of infant life. He was, however, soon to become 'handicapped'; his every symptom a portent, and his 'future problems' not only mentioned, but dominating every examination and discussion of treatment. But on this fourth day at noon, he was still a normal child, with an apparently normal rash.

At seven that night, Adam went from being a bit listless and blotchy to grey, limp and lifeless as Brian held him and talked on the phone. Though reviving within a minute,

he was, at Stephanie's insistence and against the midwife's intuition (for whom he was as yet a normal child who had probably just choked on some milk), soon taken to the local children's hospital emergency room for examination. It was Stephanie's insistence on medical testing which overcame the opinion of multiple medical personnel repeated at several stages of the process: 'If it will make you (i.e. the mother) feel better, we will check him over.' Having taken Adam in just for a check-up, it soon became apparent that this was no first-time-parent panic: Adam was in critical condition despite his relatively unworrying visible appearance. His blood oxygen was dangerously low and without attention he almost certainly would not have survived the night.

By midnight he was in intensive care with what turned out to be a serious blood infection, and the doctors told us that they could not with any certainty predict the outcome. Adam's odds of survival were simply unknown. Forty-eight hours later, and to our unimaginable relief, Adam had turned the critical corner. It was during the period of his ascent back from his drugged and betubed existence in his tiny box that Stephanie first noticed in his chart the words, 'verdacht Trisomy 21'—'suspected Down's syndrome.' After asking the doctors if this meant what we thought it did (and trying unsuccessfully to discern when they planned to tell us of their suspicion), we were left to absorb our dark discovery: Adam is not normal.

The emotional turmoil this discovery caused was immense, and not simply because of the unexpected nature of the news. In part we were simply reeling from the rapid swinging of our fortunes. One minute we were coming to grips with the possible death of a beautiful healthy boy, the next, the possible life of one disabled. The disorientation caused by an immediate shift from 'Where do you bury a child in a foreign



country?’ to ‘I’ll never do the things I love with my firstborn son’ should not be underestimated, and we were understandably disoriented. Thus, it should not have surprised us, either at the time or in hindsight, to have contemplated the horrible and yet predictably human question: ‘Maybe it would be better if he died.’<sup>4</sup>

On the tenth day of Adam’s hospitalization, we had our first discussion with the head physician about Adam’s suspected Down’s, a conversation which soon came around to the following statement: ‘We took blood on admission to establish whether Adam has Down’s or not, but the test failed. It will take about ten days to get the results of the new test back.’ We asked whether it was the law in Germany for genetic tests to be undertaken only with permission, and he admitted without explanation or apology that yes, parental permission is legally required.

We made our position clear. We were unhappy that they had taken blood and done a genetic test without our permission, and were now simply informing us that the test would be repeated: on those grounds alone we decided out of pure stubbornness that it was not in Adam’s or our best interests to simply sit back and let them proceed without

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<sup>4</sup> Soren Kierkegaard rightly suggests that this is indeed an all too human thought, and just so: sin. If Abraham had not loved his son Isaac, he would have been a murderer like Cain. Soren Kierkegaard, Fear and Trembling, Repetition, Howard Hong and Edna Hong trans. and eds. (Princeton: Princeton University Press, 1983), 74. Kierkegaard’s point is to draw out how easily subvertible supposedly disinterested parental love actually is, suffering as all love does under the ‘aesthetic illusion of magnanimity’ (Fear and Trembling, 93). See Amy Laura Hall, Kierkegaard and the Treachery of Love (Cambridge: Cambridge University Press, 2002), 71.

discussion with us. So we refused the test, a decision which, at least while we were in the hospital, we were very happy to have made.

We decided from that point on that we would insist on asking a relatively simple question when a diagnostic procedure was suggested: Will it aid Adam's treatment? This turned out to be a revealing question. The only reasons offered for having the genetic test fell under the category of 'for future planning'. This included testing for known problems suffered by children with Down's such as problems with sight and hearing, intestinal troubles and thyroid disturbance. However, we soon found that the real reason to test our son's chromosomes was to know what kind of Down's he has so that we would be informed about our chances of having healthy children in the future. Now the point of the discussion and the push for testing began to emerge from the murk of scattershot argumentation: you wouldn't want to have any more of 'these children'.

It is worth noting at this point that this is a position we often hear expressed. We have been forced to conclude that this is something like the standard western medical position, offered with some insistence and in good faith even by well-meaning Christian medical professionals in our families. Medical professionals have objected to the suggestion of this paper that simply having genetic testing has shifted medical behaviour toward the disabled. 'Testing is not a judgement on disability,' they chorus. Stephanie's second pregnancy again raised questions about this claim. One of Adam's primary medical carers, a specialist in Down's and with whom we are very happy, was outspokenly certain that we were making a mistake not to have detailed testing of Stephanie's second pregnancy, because 'it would put your mind at ease.' When Stephanie replied that she still was not interested, the response presumed that the screening would

occur in any case because we would agree to the routine regimen. This assumption set the physician at ease, because, in her words, ‘your risk is only one in 100 now, and they’ll do very detailed scans on you anyway.’ The scans being proposed might have been less invasive and dangerous to the foetus than amniocentesis, but the suggestion that we wouldn’t want another child like Adam, and the ‘treatment’ being offered the newest member of our family, certainly were not.

In the end, we were unpersuaded that the tenuous links between the genetic test and any possible benefit to Adam’s health warranted us giving permission for a re-test. From our perspective, and given the weakness or even counter-productivity of the reasons offered for having the test, it looked to us as if the insistence on the test was grounded in it being part of a routine battery applied to children suspected as disabled. Given this, and the fact that the initial test had been taken without our permission, we refused consent to the repeat genetic test. Adam’s suspected Down’s remained just that—suspected.

Again we can uncover the logical presuppositions sustaining this conflict about genetic testing. From our side we were again acting on the criterion of refusing testing that does not directly further Adam’s current treatment. From the medical side it appears that two main considerations played the most significant roles. The first was that such testing is routine, yields interesting and potentially useful information, and might be of some use in thinking through possible medical issues. There might be no direct benefits to Adam, but it is dimly possible that there might be some in the future and we (the medical profession) like to have the information. Second, you (the parents) might want to think about the future, and at the root of what you will want to avoid in the future is a

second child with Down's. Both presuppositions transparently aim at the augmentation of medical power, not necessarily at the expense of the present patient but certainly not to his benefit.

Now began a psychologically fascinating period in which we experienced something like the tortures of those who do undergo much more rigorous fetal testing. Like those receiving a first diagnosis of possible Down's *in utero*, we could not be 100 percent sure yet whether he had it or not. For us this yielded a constant debate about symptoms. Maddeningly, Down's is a syndrome exhibiting a phenomenally wide range of symptoms which many people without Down's may also have: creases in the hands, premature birth, low tonus, small size. For six months we only intermittently enjoyed Adam as we alternately scrutinized his symptoms and then tried to push them out of our consciousness. Behind that unstoppable mental oscillation lay an insidious crossroads. In one direction lay the question 'Do I betray my normal child by suspecting him of defect?', and the other, 'Do I betray my disabled child by withholding some treatment which he might need at this early stage?' It was a question which determined many details of parental life, and one we could not yet resolve.

These and similar questions are surely also present in the mind of those told that their child *in utero* is suspected to have Down's—with the one extremely significant distinction that has become *the* moral boundary characterizing the age of legalized abortion: our child was outside the womb. Having passed the birth canal he was indisputably a citizen, a right holder, and a person in the fullest sense. We find it hard to imagine standing at this crossroads if his face had not been visible, and if we were surrounded by reasonable authorities, families and friends telling us, 'Don't risk it. Start

over with a clean slate.’ Under such circumstances one imagines how easily any moral scruples about abortion fade into insignificance with the path so helpfully smoothed by everyone involved.<sup>5</sup>

So too did the ambiguity of the ‘suspected’ have a clear effect on us. In previous ages the only way to diagnose a borderline case of the syndrome would have been to ‘wait and see,’ while monitoring a child’s eating, sleeping and development. Their fears were tied to the high child mortality of the age, but this was a very different sort of fear from that of modern parents. Today the landscape of parenthood is radically different in that simply feeding and caring for an infant who is apparently growing and developing is cast as dangling on the edge of a dangerous precipice. The advent of testing brings the future to bear in a new and forceful way. This all-too-present future unsettled us, a fear learned from Adam’s doctors. In an ironic and very revealing way, Adam’s being ‘suspected’ played a heuristic role helping us to see the aims, skills and interests of the doctors examining Adam and so to question whether their fears coincided with our proper parental concerns. We embarked on a round of doctor visits to find someone to look after

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<sup>5</sup> Barbara Katz Rothman’s book, The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood, rev. ed. (London: Pandora, 1994), is an important contemporary study of these forces, and a stinging indictment of the claim that prenatal testing facilitates parental bonding with their unborn children. Rather, ‘Increased knowledge, without increased responsibility on the part of the society, translates to increased knowledge with inevitable responsibility on the part of mothers. We are asking mothers to become the gatekeepers of life. We are individualizing social problems of disease and disability, medicalizing life itself, and doing it on the bellies of pregnant women,’ xiv.

him, and found that he unnerved doctors increasingly unfamiliar with Down's infants and who instinctively reached for genetic testing as a diagnostic panacea.

The combination could and did become explosive on occasion. When Adam was five months old Stephanie took him to the doctor for a cold, fully aware that Down's children tend to respiratory tract infections. The doctor looked at his medical records, and then looked at Adam. Then came a question, uttered in tones of moral outrage: 'Why haven't you had the genetic test done?' The result: a heated and deadlocked exchange of views, in which the doctor made bold to win Stephanie to her position, at one point even saying, 'You know, don't you, that Adam will never go to normal school.' The delivery of this verdict was the only result of the appointment: there was no further examination, no suggestion of treatment. Somehow, even from quarters where you might not expect it (this time a female homeopathic physician) the demands of the ideology of genetic testing managed to crowd out attention to the symptoms of infection, with the result that Adam was denied medical attention to his actual sickness. Turned out to be a cold, which Stephanie was left to deal with, alone, shaken, and denied medical advice.

Here again our parental priority was that Adam be treated for the presenting sickness, on this occasion his cold. From the medical side the conflict could only have been sustained on the basis of a belief, or a fear, that treatment was not advisable without a proper, scientific (read genetic) conformation of diagnosis. This, in turn, yielded a medical perception that a child's parents were resisting a proper social understanding of the child, and so irrationally avoiding the genetic test that would both dispel the parents' illusions of health and concretely document that the child belonged in the social and medical role assigned to children with this syndrome. The actual conflict ended with the

stymieing of both objectives: Stephanie did not accept her social role, and Adam was not treated for his cold. Here the presence of the genetic test was the *condition* for the conflict between medicine as diagnosing a genome and medicine as treating a patient.

Through the recommendation of a friend in our church, we finally made a connection with someone who was both a neo-natologist and the father of a child with Down's. He looked at Adam and said that, for several reasons he patiently explained to us, he felt there to be something like an 85% chance that Adam had Down's. For the first time we felt like someone with medical training had actually *looked* at *Adam*. Here was one of a dwindling number of medical practitioners with first-hand experience of the increasingly rare condition called Down's Syndrome, and who could therefore assess Adam with the eyes of experience. In addition, both he and his wife could give us the kind of parental advice we sought about how to deal with Adam's particular health difficulties. For the first time our cross-road dilemma seemed to be resolving. It was looking more likely that he did have Down's than that he did not, and more importantly, that we could handle it whatever the answer. We passed the news on to our families across the Atlantic who also, never having met Adam, would have tentatively to begin their own journeys of acceptance.

Adam seemed to be developing well, if slowly, and whether he did have Down's syndrome or not he showed only mild versions of the classic symptoms. We had been told during his first hospital stay that he had a characteristic hole in his heart, but from our limited viewpoint, and from what observers, including medical professionals, cared to express to us of any worries they might have had, the leakage caused by the hole seemed not to be particularly threatening. Having therefore put the possibility of surgery out of

our minds, and having waited to have the cardiac ultrasound in order to see if the hole closed on its own, we were unpleasantly surprised when the scan results arrived: the holes between Adam's atria and ventricles were developing into a lethal combination, and he would have to immediately undergo open-heart surgery. The doctors were unanimous in urging surgery as quickly as possible to avoid irreparable damage to other organs due to massive imbalances in his inter-systemic blood pressures.

By this time we had decided that if Adam would already be having routine blood work as part of his surgery, we would also allow the chromosome test. It turned out that the main factor in our decision was not a new conviction that Adam would receive better treatment as a result. At this stage the doctors, with our express permission, were simply treating him as having Down's, and had quit asking us to do the genetic test. When Adam went in to have his heart operation we reversed our position, not on medical grounds, but as a concession to two social pressures.

The first resulted from an aspect endemic to the maternal tribe, the desire to belong and to be able to hand on 'trade secrets' about child rearing. Not knowing the exact state of Adam's condition meant that from the beginning Stephanie struggled with answering the basic questions that are inevitably presented to new mothers: 'How old is he?', 'What is he doing now?' etc. As Adam's growth and development were slower than that of 'normal children', Stephanie felt she was constantly having to answer such questions without herself really knowing what to answer. The crucial point, however, came shortly before Adam's operation when another mother, after looking at Adam, said to Stephanie, 'my son has Down's Syndrome too.' This question crystallized Stephanie's



growing need to leave this limbo and know to which community Adam, and herself as his mother, would ultimately belong.

The ‘hard fact’ of a genetic diagnosis would constitute a socially acceptable permission to begin to seek out other parents of children with Down’s and begin to throw ourselves into learning about the condition. It would resolve our crisis of belonging. We felt caught between a medical establishment unwilling to say Adam had Down’s without a genetic test, and the puzzled silence he continually evoked from most people, both inside and outside the church. After the test, we soon learned, Adam would come to be admired for the opposite reason, as a fine example of that unfortunate race called Down’s children.

The second reason for having Adam genetically tested was more pragmatic. In Germany social benefits are offered to parents of children medically certified as handicapped, and we were told that a genetic test would be required to secure Adam’s diagnosis. An irony of this aspect of our experience is that now that we are in Scotland, we are discovering that certain forms of tax benefit are not readily extended to families with Down’s children because they are not considered ‘severely’ handicapped.<sup>6</sup>

It was not, in the end, medical pressure which led us to permit a test which we felt was not a direct benefit to Adam’s health. It was a sense of social isolation paired with a context in which the only person who dared to state the obvious based her knowledge on her own child and not a test. So our decision to test rested on the much messier and less defensible sense that the test would provide social benefits primarily to Adam’s harried

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<sup>6</sup> Department for Work and Pensions, Disability and Carers Service, Disability Living Allowance.

parents. We justified the decision on the grounds that within the context of another hospitalization, it would not cause Adam any new suffering, and would resolve social conflicts for *us*. Those conflicts were financial, emotional and interpersonal in that we wanted to be full participants in the social support system. What is clear is that neither for us nor for those around us did Adam straightforwardly belong: he certainly belonged as a child in all groups, but he was in limbo without the test in the sub-groupings which provide the concrete support and education of parents.

Even we were surprised at the relief we felt at receiving the genetic diagnosis. The pressures of six months of either/or, of the crossroads of two looming alternate futures had weighed on us more than we could have articulated at the time. During this period we found that the social pressures for a ‘definitive’ diagnosis were stronger and more varied than we would ever have imagined. In the end, acceptance of Adam as he is was made easier for us by the fact that the major milestones in our learning of his condition coincided with his life or death moments. As Michael Berube puts it in his book *Life as We Know It*, in the wake of a life and death crisis, hearing that a living child has Down’s ‘seemed like a reprieve.’<sup>7</sup> Whatever challenges Adam’s life would present in the future paled into insignificance beside the altogether more threatening possibility of his not existing at all. All life takes on a remarkable luminance against the backdrop of death.

### **A concluding unscientific postscript.**

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<sup>7</sup> Michael Berube, *Life as We Know It: A Father, a Family, and an Exceptional Child* (New York: Pantheon Books, 1996), 5.

Having told our story, we would not presume to extract a moral for general application. The following observations are a loose collection of realizations which have been pressed on us by these experiences. The most overwhelming sense of continuity we found in these experiences of the impact of genetic testing, what might for us be called the ‘soul’ of the age, is best characterized as a pervasive and very particular form of fearfulness. Perhaps our most vivid impression is of the mismatch between the great anxiety about testing Adam when compared with the meagerness of the medical problems that it could be expected to resolve. Noting this disproportion allowed us to see the way our refusal to test was perceived as a threat to medical authority which assumed that the anxiety of medical practitioners would and should constitute a reason for us to be anxious and thus to comply with the recommended course of action.

The anxiety in question seems to have been generated by a range of possibilities: that we could not be trusted to do the ‘best’ for our child, that physicians were being denied the information they felt they needed to do their job, and the fear that medical authority was being displaced or threatened by our asking for medical interventions to be justified by criterion other than their own. In short, our behaviour constituted a challenge to the techniques which reassure medical personnel by providing a sense of mastery or control. The various medical professionals with whom we had contact must not be singled out as bad eggs on this account. On the contrary, it is their very best and conscientious humaneness which fueled the conflicts we have narrated. They were expressing inherited versions of responsible parenthood which differed from ours. Their

belief in the neutrality of genetic information masked a sharply normative claim that no good parent would resist genetic testing.

Some have protested that framing the story in this way betrays an unwarranted suspicion of medicine. This objection tends to overlook that we kept returning to medical practitioners for advice about our son, and that we thought this to be an important part of our parental responsibility. We are grateful and consider medicine a form of God's grace in having saved Adam's life not once, but twice, and through the most intensive and invasive techniques medicine has developed. Yet, despite the pervasive dogma that medicine is non-coercive, in our experience, any questioning or refusal of proposed courses of treatment were cause to place us under suspicion as recalcitrant, unreasonable, deniers of facts, etc. Irrationality seems most readily applied when the only medical reason for a test is that it is routine. Take the example of HIV testing during pregnancy. The transmission factors for the disease are well known. If faced with a pregnant medical professional (Stephanie being an example), one would expect their word to suffice that an HIV test is unnecessary. Yet the test is routine because medicine systematically distrusts people's statements about their health status. There may be good reasons for this distrust. But there are also good reasons to note how this corrodes the patient's belief that their words are being taken seriously. The impression is left that routine has displaced attention to individuals, and become the rationality against which only the irrational could raise questions, and only the suspicious would think to.

In the face of this atmosphere of anxiety, we have found Luther's meditations on Psalm 127 provocative and comforting. 'Unless the LORD builds the house, those who build it labour in vain. Unless the LORD guards the city, the guard keeps watch in vain. It

is in vain that you rise up early and go late to rest, eating the bread of anxious toil; for he gives sleep to his beloved. Sons are indeed a heritage from the LORD, the fruit of the womb a reward.’ Luther sees in these verses a contrast between human activity which takes place in trust, faith and appreciation of the variability and fecundity of God’s love through creation, with human activity framed by anxiety about our efforts to create goodness. ‘Because God gives him nothing unless he works, it may seem as if it is his labour which sustains him; just as the little birds neither sow nor reap, but they would certainly die of hunger if they did not fly about to seek their food.’<sup>8</sup> The same, Luther says, is true of human procreation.

This suggests that one way to begin to think about the dynamics of our experience of genetic testing is as a symptom of modernity’s near-complete loss of the sense that human action is only discovering our sustenance and continuation as a species, nation or family, not a grasping or creating it. To think of ourselves in this way is to think of medicine as an activity of carers for what we have received. If we think we create, or are absolutely indispensable in the preservation of human life, then we become anxious with the anxiousness that marks those without faith.<sup>9</sup> To put things this way is to throw

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<sup>8</sup> Martin Luther, ‘Exposition of Psalm 127, For the Christians at Riga in Livonia,’ Luther’s Works, American Edition, Vol. 45: Christian In Society II, Walther Brand ed. (Philadelphia: Fortress, 1962), 326. The insight is based on many biblical texts. Augustine makes the point by quoting 1 Corinthians 3:7 in The City of God, XXII.24.

<sup>9</sup> Luther makes the point elsewhere in a comment on the prayer of thankfulness for healing (through medical treatment) of Hezekiah in Isaiah 38:10-20: ‘...for you heard in the song above that all things are kept and cared for by the Word. Then the ungodly cry:

Christian views of genetic testing into a very different light, suggesting very different aims, and a very different attitude.

Luther rightly observes, long before Hannah Arendt,<sup>10</sup> that children are the wellspring of all society, and so we should expect the bearing of children to be a region of human activity which is especially prone to the anxieties of fear, and the lust for power of human promethean urges. Procreation is either humanity's most important resource to be technologically 'managed' at all cost, a site of ultimate power struggle and angst, or it is a particularly rich seam of God's gift to humanity, the 'jewels in the mines': 'Like arrows in the hand of a warrior; so are the children of youth.'<sup>11</sup> Hauerwas is thus right to remind us that talk about the social forces which come to bear on the disabled and those

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'If the word does everything and provides nourishment for everything, we do not want to eat or take medicine.' For them he takes up this example. As for you, make use of means. Do not rely on them but use them, since God has created them. If they do not help, commit the matter to God. Do not say: 'Doctor, if this will not help this time, I refuse to take it anymore.' Yes, you want to have your own way! So we all go beyond the proper use of means by clinging to them... Others despise works altogether, so does this song ascribe the power to the Word and not to the medicine. Yet it does not forbid that we use them, but the prophet's example supports their use, since he poultices the wound with a cake of figs.' Martin Luther, Luther's Works, American Edition, Vol. 16, Lectures on Isaiah, Chapters 1-39, Jaroslav Pelikan, ed. (St. Louis: Concordia, 1969), 344.

<sup>10</sup> Hannah Arendt, The Human Condition (Chicago: University of Chicago Press, 1958), chap. VI.

<sup>11</sup> Job 28:1-6; Psalm 127:4.

who care for them is a way to address questions of social justice that circumvents the liberal, democratic definitions of justice within which it is hard to conceive of the handicapped as one of us.<sup>12</sup>

If Luther suggests that the beginning of a proper relation to the handicapped is a sense of the gift nature of all human life, Augustine provides a bit more detail about how to understand the ‘otherness’ of the handicapped as a divine gift to humanity. In the midst of a discussion about the limits of the human race, Augustine stresses that being human is not defined by criterion of physical or mental perfection which ‘deformity’ vitiates, but is grounded in descent from Adam.<sup>13</sup> He therefore concludes that, far from approaching the ‘different’ as defective members of the race, and to be shunned, we should instead see them as God’s special works, because God ‘knows how to weave the beauty of the whole out of the similarity and diversity of its parts. The man who cannot view the whole is offended by what he takes to be the deformity of a part; but this is because he does not know how it is adapted or related to the whole.’<sup>14</sup> Later he suggests that this creaturely otherness is a sign of God’s otherness, and a proof that we should expect the unexpected from Him, supremely, resurrection from the dead.<sup>15</sup> This eschatological openness to the disabled is well encapsulated in Karl Barth’s comment that ‘the value of this kind of life

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<sup>12</sup> Stanley Hauerwas, Performing the Faith: Bonhoeffer and the Practice of Nonviolence (Grand Rapids: Brazos Press, 2004), 230.

<sup>13</sup> Here anticipating Robert Spaemann’s similar point. See Bernd Wannewetsch’s contribution to this volume.

<sup>14</sup> Augustine, City of God, XVI.8.

<sup>15</sup> Augustine, City of God, XXI.8.

is God's secret. Those around and society as a whole may not find anything in it, but this does not mean that they as a society have a right to reject and liquidate it.'<sup>16</sup>

For Augustine then, human otherness and difference in all its variety is part of God's way of keeping us from falling into the wonderless idolatry of homogeneity. Like Luther, Augustine sees the fault line running between those who see diversity as a gift, and those for whom it evokes anxiety. Perhaps the polarity gives us a way to understand Bonhoeffer's comment, written amidst the anxieties and violence engendered by the quest for a perfect race, that the strong are not made stronger by euthanizing the weak. The strong have been made stronger by understanding the value of those consigned to the outside by our merely human visions of perfection and human community.<sup>17</sup>

Though not putting it in these terms, perhaps what Bonhoeffer was looking for was a way to say that living with the handicapped is beyond our means. Those who live with them know this. Statistics tell us that most parents abort handicapped infants because they feel they don't have the resources to raise them.<sup>18</sup> But those who embrace their children (any children) as having been given defy their urges to protect themselves against them and so open themselves to the Spirit's work. This is not to coerce the Spirit's help by asking for it and acting as if we will receive it. The Spirit's most surprising and essential work is to comfort us by transforming our ideas about who we

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<sup>16</sup> Karl Barth, Church Dogmatics III.1, 423-424.

<sup>17</sup> Dietrich Bonhoeffer, Ethics, Dietrich Bonhoeffer Works, vol. 6, Ilse Tödt, Heinz Eduard Tödt, Ernst Feil, and Clifford Green eds., Reinhard Krauss, Charles West, and Douglas Scott trans. (Minneapolis: Fortress Press, 2005), 194.

<sup>18</sup> See Amy Laura Hall's contribution to this volume.



are and what we can do. We learn that the abilities we need to flourish are abilities we don't have but must be given, and therefore must ask for. Theology needs to abandon its false modesty about the resources promised in the Spirit. When it does not, it cannot avoid the trap of wishing for perfection from humanity. Either we say that the Father gives through the Son and helps us to receive in the Spirit, or we end up hoping with the world for the least complicated experience of parenthood, marriage, work, and so on. The problem of not being able to receive the handicapped with open arms turns out not to be an insufficiently inclusive anthropology, but an atrophied pneumatology.

Perhaps if Christians inhabited this understanding of disability they might, for instance, buck current ways of narrating life with handicapped children. Bookstores are filled with stories in which parents-to-be conceive with the aim of producing a perfect child, and so narrate their story with their handicapped child in terms of how difficult it was to adjust to the letdown of disability.<sup>19</sup> How different the story could be if told within a culture that took children, all children, and especially the different, as gifts. Then we might hear stories such as that suggested by Luther, Augustine and Bonhoeffer, in which the perception of someone as deformed gives way to a new realization that deformity is

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<sup>19</sup> Danny Mardell, Danny's Challenge: The True Story of a Father Learning to Love His Son, Sally Weal, ed. (London: Short Books, 2005), and Mitchell Zuckoff, Choosing Naia: A Family's Journey (Boston: Beacon Press, 2002) are sobering examples of such a parental narrative which, at different levels of intellectualization, both portray the struggle to justify and respond to parenting a 'different' child conceived in many ways as a burden.

in the eyes of the beholder.<sup>20</sup> Such an approach does not minimize the importance of medical devotion to ameliorating all peoples' physical problems. But it is to urge doing so by seeing clearly that either our faith and gratitude or our fears will shape the political strategies we pursue. In relation to the genetic test, our experience suggests that, for a range of possible reasons, contemporary medicine finds itself in a framework of fear rather than gratitude, and so finds it difficult to separate medicine as a project responsible for creating 'normal' children from medicine as a human technique for caring for each person's physical problems.

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<sup>20</sup> In this, Barbara Kingsolver's fictional commentary is right on the mark: 'Mama Mwanza almost got burnt plumb to death when it happened but then she got better. Mama says that was the poor woman's bad luck, because now she has got to go right on tending after her husband and her seven or eight children. They don't care one bit about her not having any legs to speak of. To them she's just their mama and where's dinner? To all the other Congo people, too. Why, they just don't let on, like she was a regular person. Nobody bats their eye when she scoots by on her hands and goes on down to her field or the river to wash clothes with the other ladies that work down there everyday.' Later, she articulates the reflections of a disabled westerner who craves such acceptance. 'The arrogance of the able-bodied is staggering. Yes, maybe we'd like to be able to get places quickly, and carry things in both hands, but only because we have to keep up with the rest of you, or get the [punishment]. We would rather be just like us and have that be all right.' Barbara Kingsolver, The Poisonwood Bible (London: Faber and Faber, 1999), 60; 559.