

Disability and Relationality: disrupting complacency, entering into vulnerability¹

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Abstract: *Contemporary Western societies have established processes to draw people living with disabilities into mainstream society. Specialist care services, government funding and legislated parameters for building codes, anti-discrimination have never been more secure across societies like Australia. At the same time, however, these same societies have entered into policies and priorities that seek to ensure a very limited number of disabled persons survive to birth and that they continue to be marginalised. A relational discourse founded on the recognition of mutual vulnerability and inter-subjectivity can confront our societal inconsistencies and offers the possibility of a way forward. Christian theology and practice have experience of entering into brokenness to hold a mirror to human existence, not to eliminate that brokenness but to celebrate it. A practical theology of personhood may enable the Church and society to more positively celebrate the diversity of the human condition rather than pay it lip service.*

Key Words: relationality; disability; practical theology; human personhood; Australia; Levinas; Vanier

INTRODUCTORY REMARKS

T This paper represents the first step in an investigation of the challenges posed by disability to conceptions and structures of normalcy. As an exercise in practical theology, this investigation will seek to critique current approaches to the discourse of disability and about disability, as well as to propose a more effective lens for reflection and action all in light of the gospel priority for the most vulnerable.

In an earlier piece of research I argued that theology, especially practical theology, can be a useful tool to understand health care at its most vulnerable point: in the meaning of personhood. This study aims to focus that perspective more deeply, to consider a particular group or class of persons who are especially vulnerable – those people living with disabilities. People who live with disabilities of one form or another are among those whose personhood is routinely questioned, in practise if not always in theory. They are those who subsist precariously due to their vulnerability in terms of living; and the regard in which they are held in modern Western societies is demonstrably subordinate to those of the majority of persons. This paper, proposes to simply highlight that our current thinking about disability is so deeply ingrained with conceptions of individuality,

¹ I need to acknowledge the assistance of Mrs Nyree Beer in preparing this paper for publication. Nyree provided much needed clarity around some of the ideas – drawing out aspects of my own theology into new avenues; she also provided a number of helpful editorial corrections.

rationality and autonomy as to be incapable of adequately including those with profound disability in the human community.

Contemporary Western societies, predominantly through a 'rights' discourse, have established processes to draw people living with disabilities into mainstream society. Moving away from a paternalist model to an empowerment paradigm has seen a dramatic increase in specialist care services; government funding and legislated parameters in a variety of categories for example, building codes and work practices; anti-discrimination legislation; and, programs to increase workforce participation have become common place. The place of human persons living with disabilities has never been more secure across societies like Australia. At the same time, these same societies, in privileging the rights of the able minded and the able bodied, have entered into practical policies, strategies and priorities that seek to ensure a very limited number of disabled persons survive to birth and that, following birth, disabled persons continue to be marginalised. These inconsistencies have become part of the patterns of social relations and call into question our commitment to the personhood of those living with disabilities.

At the heart of these contradictions is the strongly held position in Western philosophy and theology on the primacy of the individual which underpins and supports a conception of the human predicated on superiority, perfection and wholeness. From this perspective humanity is distinguished from other aspects of the world or universe by its superiority over the inanimate world and the animate world. Humanity is able to conquer without restraint – in fact, is required to do so by divine fiat (Gn 1: 28). Humanity is distinguished theologically through the link to God reflected in the concept of the *imago dei*. This theological construct takes on particular meaning when it is assumed that humanity images God in the same way as Jesus: individual, male, whole, celibate, no defects of mind or body and glorified. Over time these positions have given rise to the commonly held view that the human person is best described in terms of individuality characterised as self-reliance, rationality characterised as intelligence, freedom characterised as autonomy. In each of these dominant perspectives, those with disabilities, especially those with profound intellectual disabilities, are missing something. In this paper I want to demonstrate that a relational model, in contrast to the rationality/free will model, has the capacity to positively transform how we think about humanity in all its forms.

A relational discourse founded on the recognition of mutual vulnerability and inter-subjectivity has potential to confront our societal inconsistencies and offers the possibility of a way forward. Christian theology and practice have experience of entering into the brokenness which characterises human existence to hold a mirror to humanity, not to eliminate brokenness but to celebrate it. A practical theology of personhood may enable the Church and society to more positively celebrate the diversity of the human condition rather than pay it lip service as is so often the case.

A CASE IN POINT

I have previously described the case of the Attard Twins – conjoined twins born to Maltese parents at St Mary's Hospital in Manchester in August 2000. It is worth recounting their story here to make the key points of this paper.²

Jodie and Mary (these pseudonyms were applied to protect the confidentiality of the parents and children at the time) were born in Britain following ultrasound in their home country of Malta revealed that the mother was pregnant with conjoined twins. Following the advice of their physician the parents relocated from Malta to Britain for the birth of their daughters in order to increase the chances of a successful birth, and to give the twins the best chance of survival. After diagnostic tests in Manchester the parents were offered a termination which they refused. The twins were born on August 8, 2000. Post-natal tests indicated that separation would certainly result in Mary's death: her brain was primitive; the heart enlarged and poorly functioning; and the lung tissue was non-functioning. With this in mind the parents refused consent for the recommended procedure and indicated that they would take their daughters home. This was challenged in the British courts which subsequently gave permission for the surgery. Separation took place on November 7, 2000 resulting in Mary's death. Her sister Jodie survived and subsequently underwent a number of reconstructive operations, and returned to Malta with her parents.³ It was later revealed that the twins were Gracie and Rosie Attard, the daughters of Rina and Michaelangelo Attard.⁴

Post-natal diagnostic tests revealed that Rosie's brain, heart and lungs were not normally developed. The brain was primitive; the heart enlarged and poorly functioning; and the lung tissue was non-functioning. Gracie's brain heart and lungs were anatomically normal, with adequate circulation and oxygenation. Rosie was completely dependent on Gracie's capacity to breathe and oxygenate blood for both of them. The twins were joined at the pelvis with a fused spine and spinal cord. Medical advice suggested that as the twins grew, Gracie would be unable to sustain them both. After this investigation of the extent of the "joining", it was determined that separation would probably result in Gracie's survival, but would end Rosie's life.⁵ The parents refused consent for the recommended procedure, citing their religiously grounded belief that they could not endorse a course of action that would bring about the death of one of their children and determined to take

² Patrick McArdle, *Relational Health Care: A Practical Theology of Personhood* (Saarbrücken, Germany: VDM Verlag Dr. Müller, 2008). See pages 23 – 24, 58 – 61.

³ Suzanne Rock and Nick London, "Amazing Gracie," (Leeds, Yorkshire: Granada Television, 2001).

⁴ I have found in the course of writing, re-writing, editing and thinking about this case that I have experienced a growing level of disquiet about the use of their pseudonyms. While it is clearly a standard legal tool to preserve the privacy of those involved, it reaches a point where the pseudonyms also permit the twins, their parents and the very case itself to be objectified. Such an approach encourages tacit acceptance of the view that if it is a case of both dying but it is possible to save one, then everything should be done to save one... and simply allowing the other to perish. Analogously, I wonder if this is similar to someone saving a single child from famine or warfare and focusing on the act of saving rather than the situation of the many left behind. It does not diminish the success or joy at the saving act... but it does permit us to feel more comfortable with what we can now describe as the inevitability of what happened to the other(s). I think the anonymity of Rosie made it much easier for those involved to simply discount her and the network of relationships in which she was an essential participant. Her death, then, is personally tragic but inevitable and, hence, of no wider significance.

⁵ J. J. Paris and A. C. Elias-Jones, "'Do We Murder Mary to Save Jodie?' An Ethical Analysis of the Separation of the Manchester Conjoined Twins," *Postgraduate Medical Journal* 77, no. 911 (2001): 593.

their children home to die. The physicians at St Mary's who challenged the parents' refusal in the courts, considered that, since both children faced certain death, every option should be explored to save the life of the child who had the possibility of surviving independently. Consequently, the hospital and the physicians commenced legal action to prevent the family from leaving the United Kingdom, to override the parents' decision about separation and to remove them from any role in the decision-making process about their daughters.

The British High Court supported separation on utilitarian grounds.⁶ This initial case was followed by an Appeals Court ruling which upheld the original decision and rejected the parents' decision to refuse their consent. The Appeals Court argued that the interests of each child should take precedence over parental wishes. While the intrinsic value of Rosie's life should be recognised, her right to life did not outweigh that of her sibling, for Rosie could not exercise her right to life in the same way as Gracie. Moreover, while this judgement came down in favour of separation, it could not remove the illegality of an action which, in and of itself, would result in the death of an innocent person. To overcome the potential of the doctors, hospital and National Health Service trust being charged with murder, the Court of Appeal ruled that the defence of "necessity" would be sufficient in this case to successfully defend such any such homicide charge.⁷ The Court of Appeal further noted that there was no moral basis for its ruling, nor any legal precedent.

Separation took place on November 7, 2000 resulting in Rosie's death. Gracie survived and subsequently underwent four reconstructive operations, and returned to Malta with her parents.⁸ Most recent reports, when Gracie was approaching her 3rd birthday, her development is normal or approaching normalcy.⁹

The case of Gracie and Rosie involves greater complexities than the usual issues around separation of conjoined twins because it raises the question of personhood on several levels. For instance, some physicians had argued that Mary¹⁰ was not a person, or, strictly speaking, a human being, but rather a teratoma—a parasitic collection of tissue or an abnormal growth.¹¹ These questions are also posed in different forms in relation to other forms of disability or variations from normalcy. One of the ironies of this case in relation to disability is that while Mary was considered to have no chance of viable life and hence could be completely discounted, Gracie is both offered the chance of life and sustained medical intervention to minimise any level of disability.

The decision made by the British Courts was self-confessedly utilitarian in orientation and application.¹² In terms of such a pragmatic calculus, the outcome of the

⁶ Richard Nicholson, "Should Doctors Separate the Siamese Twins? - No," *The Independent*, 10 September 2000.

⁷ Alexander McCall Smith, "The Separating of Conjoined Twins," *British Medical Journal* 321, no. 7264 (2000): 782.

⁸ Rock and London, "Amazing Gracie."

⁹ Martin Bashir, "Living with the Miracle of Gracie," *Times Online*, August 3 2003.

¹⁰ Given the point of this argument and my view expressed in n. 3 above, it is appropriate to use the pseudonym applied to Rosie in this and other similar instances.

¹¹ Riddell, "Pity Us, but Pity Jodie More," *The Observer*, 10 September 2000.

¹² Nicholson, "Should Doctors Separate the Siamese Twins? - No."

sanctioned medical procedure was successful. One child was enabled to live, even if the death of her sister resulted. As Swinton argues, this situation reflects the general Western social perspective on disability and impairment. It allows that such situations, however personally tragic, are not socially significant.¹³ If the choice facing the parents were as simple as saving one healthy child through the removal of a child who had no future, it still would have been a tragedy for any parent. The judge in the initial Court case recognised this in his judgement.¹⁴ Facing such a situation, what parent would not think, "I am killing one of my children."

The situation facing the Attards, however, was much more difficult than that acknowledged by the courts or the health professionals involved. The initial prognosis for the surviving twin indicated some significant degree of disability most likely in terms of highly circumscribed mobility, incontinence and infertility. Faced with this prognosis, the Attards were concerned that there were few disability services in their homeland, and that they did not possess the financial resources to provide adequate, ongoing medical treatment.¹⁵ Prior to the commencement of legal action, it was suggested that one option for the parents was to place the surviving twin for adoption in Britain in order to secure her medical care in the future, even if this would mean not seeing her again.¹⁶ It was recognised, too, that there was a possibility of Gracie herself not surviving.¹⁷

In this invidious position the parents opted not to choose *between* their children, but to accept the limits of the situation, and to act in accord with their Catholic principles. They considered any decision on their part to authorise an action which would kill one of their children would be morally wrong. While there was no explicit questioning of the personhood of either child by most people involved in the case, clearly very different ideas of personhood were in conflict. The parents accepted the essential equality of their daughters, while some of the physicians argued that Mary was simply a teratoma. The judges argued for the status of Mary as a person, but they limited any effective recognition of her personhood by enabling surgery designed to end her life to take place. That they recognised the personhood of Mary is evident, for included in the judgement to legitimise this surgical procedure was a recognition of the possibility of a murder charge. The Court of Appeal noted that such a charge could not be simply negated and, hence, this required that the Court of Appeal rule that the defence of necessity would be sufficient to defend such a charge.

Here we face the question: would not a more relational anthropology of human personhood have given greater prominence to other factors in the case? It would have led to a more sensitive recognition of the Attards' position, and demanded further discussion of the relationship between Gracie and Rosie. However, it has to be acknowledged that a different way of thinking may have led to different outcome—both children may have died and based on the medical advice available at the time, this is the likely outcome without

¹³ John Swinton, "Constructing Persons: John Macmurray and the Social Construction of Disability," in *John Macmurray: Critical Perspectives*, ed. David Fergusson and Nigel Dower (New York: Peter Lang, 2002), 239-48.

¹⁴ *Case of the Siamese Twins*, B1/2000/2969 Johnson J.(2000).

¹⁵ Paris and Elias-Jones, "'Do We Murder Mary to Save Jodie?' An Ethical Analysis of the Separation of the Manchester Conjoined Twins," 595.

¹⁶ Jeremy Laurance, "Parents of Siamese Twins to Fight Judge's Ruling," *The Independent*, 31 August 2000.

¹⁷ *Case of the Siamese Twins*.

surgical intervention. But such a negative outcome would not have meant that the decision was wrong on ethical and moral grounds. A relational anthropology does not automatically resolve ethical dilemmas, nor promise positive medical outcomes. But what a relational anthropology can allow for is a more complete analysis of ethical situations. In the case under consideration, the courts and physicians were in fact making a moral decision even if it was denied that morality entered into it. *Medical necessity* was the value dominating every other consideration, especially that of the moral decisions of the parents. Their personal dignity was, to all intents and purposes, publicly violated.

DISABILITY AND RELATIONALITY

The Attard Case is not an isolated or singular instance of moral dilemma – rather it is typological when considering the situation of disability. While all have benefitted from the move away from a deficit or defect model of conceptualising disability towards an empowerment or capabilities model this is an incomplete step in a process. The next step must be to recognise the universal brokenness of the human condition – our mutual and innate vulnerability, which is unmasked by illness and disability, not caused by, these dimensions of the spectrum of humanity.

One of the key limitations of capabilities models is that they continue to privilege individuality, autonomy and utility. Unless one can be attributed with qualities linked to self, choice, activity and usefulness – it is very difficult for most people in our culture to accord human status in any meaningful manner. As is clear from the Attard Case, the twin elements in the decision-making was that Rosie was deemed to have no individual life prospects at all, while Gracie could be seen as being able to hold a place of her own in the world. There was no recognition of their relationship or their meaning to each other. This perspective is not singular: Hans Reinders cites the case of Kelly, a child who has micro-encephaly. The Director of the group home where Kelly lives recalled the early days of her time in the home:

When Kelly was still a baby, the only thing she seemed capable of doing was to take a deep breath now and then. In her case we did not think of this as something she did, say, as something like “sighing,” as if she were lamenting her condition. Instead, we assumed her taking a deep breath was only a respiratory reflex. Until somebody noticed it seemed to depend on who spoke to her. When spoken to by particular voices the changing respiration pattern stopped. Once the voice stopped, she started again. Thank Heavens! At least she could do something, if it was only “sighing.” Our Kelly turned out to be human.¹⁸

It is a mark of how deeply ingrained is our expectation of ‘activity’ and ‘utility’ that what is noticed in this exchange and remarked upon, years later, is that “she could do something...Our Kelly turned out to be human.” It was Kelly’s act of sighing that was the focus of attention rather than that which caused the staff to notice it at all: the relational responsiveness which gave rise to the altered breathing patterns.

It is important to recognise that in this account of the interpersonal encounter two quite different notions of ‘human’ are being used almost interchangeably. The unstated

¹⁸ cited in Hans S Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology and Ethics* (Grand Rapids, Michigan: William B. Eerdmans Publishing Company, 2008). p. 20.

notion is that, of course, Kelly is human being the off-spring of human beings – this is implicit since the level of care offered to Kelly is exclusive to humans. The second notion, which is addressed though in language more appropriate to the first, refers to the issue of Kelly's personhood. This is, fundamentally, the same issues that were raised in relation to the Attard twins – clearly [namely?] both were human in the essentialist sense deriving from human beings. However, the personhood of Rosie was rejected in order to preserve her sister's claim to personhood, thus causing her status as a human being to be questioned.

The morally and theologically significant aspect of the commentary on Kelly is that her respiratory patterns altered depending on who spoke to her. Kelly's relational engagement with others was noticed. Kelly responded to invitations to enter into relationship. This response did not require intention on the part of staff –they had no expectation that their communication would elicit a response- rather it is the engagement, the revelation of the self to another, which elicited a response. This example parallels the work of Jean Vanier with the profoundly disabled that is based on the centrality of a relational framework.¹⁹ Similarly, those who had already determined that Rosie's personhood was non-existent and that her life had no value then proceeded to attempt to undermine her humanity. Physicians from St Mary's Hospital variously argued that she was a teratoma, or that her face exhibited none of the usual characteristic engagement of humans, even severely disabled humans. In contrast, other physicians –not from St Mary's, called in to advise the courts, argued that Rosie was clearly alive and a person due to the high levels of animation in her face. In this regard I do not think either group were lying –they were only observing that which they had already come to believe.

Those scholars and theorists who propose a theory of social construction of disability (most practically evident in the view that there are no disabled persons but rather persons living with disability) argue that all persons living with disability are just as human as those who satisfy the definitions of normalcy. At one level the social constructivists oppose traditions metaphysical approaches to such questions as describing an idealised view of humanity to which no particular individual can actually conform. Yet they too eliminate genuine individuality in their quest for equality. In arguing that disability is incidental to who a particular person is, social constructivists may also be denying the significance of their personhood. Kelly is a person living with a disability but there is a sense in which, without the disability, the person at issue would not be Kelly.

The person is always indefinable.²⁰ The path to personhood is never finished. This is crucial when considering the situations of children, the infirm, the disabled and the unborn. If "personhood" is constructed as an ideal of some kind, say, a fully functioning rational adult, then all who fall short of the ideal must have diminished moral status. If, on the other hand, there is recognition that persons are beings in the process of becoming, then those who do not meet the usual ideal are not simply excluded or thought to have less moral status – they are at a different place on the same continuum. Just as all persons are at a different place on the continuum from all other persons.

¹⁹ Jean Vanier, *Becoming Human* (London: Darton, Longman and Todd, 1999). A feature of Vanier's work which is left implicit is that there is a transformation that occurs in those who take up his ministry and work with the disabled that is in no way less remarkable or less dramatic. Both depend on the relational encounter.

²⁰ L. Zagzebski, "The Uniqueness of Persons," *Journal of Religious Ethics* 29, no. 3 (2001): 421-22.

Theologically speaking, those who do not meet the social ideal have a special role in interpersonal relations, since they are among the most vulnerable. In them, we meet Christ, but also through them all are called forth into a deeper understanding of how we belong together in a personal world, subject to limitations, yet with the capacity for self-transcendence.²¹ In their very existence those who live with disability challenge our understanding of the full scope of humanity but also of who any individual is before the world and society. In the social constructivist parlance of “a person living with a...disability...disease...illness,” the condition with which the person is living confronts every other person they encounter. As Levinas contends, the person we meet or care for breaks into our lives as the essential *Other* who pleads not to be rejected and, ultimately, not to be killed.²² It is in the face of the Other (in the focus of this paper, the disabled Other) that we are confronted by our own vulnerabilities and frailties. In this confrontation we all too often choose rejection. The challenges posed to us by disability lead us, as a society and as practical theologians, to both argue for equality of access and treatment but also to attempt to ensure that congenital disability does not automatically mean diminished moral status and a resulting precarious hold on a place in the world.

Relational perspectives offer an alternative vision of humanity as well as illness and disability. In relational terms, the encounter with an-Other is fundamental to personhood. I have drawn on the work of the Scottish philosopher John Macmurray who conceives relationality as innate and optimistic nurturing. Such a perspective is essential for a positive engagement with persons living with disabilities. In the constraints of this paper, it is the more starkly confronting approach of Emmanuel Levinas that is more helpful. Levinas treats relationships as intrinsically asymmetrical which, in the situation of disability, is more effective [?] . It is the very asymmetry of human relationships that demands responsibility. While I do not have the space to develop it here, let it not be assumed that the asymmetry is all due to the person who has a disability – Levinas argues that all human relationships are asymmetrical due to the shifting balances of power, need and capacity to take responsibility over time.

After his early work centred on phenomenology, Levinas developed his own ethics-oriented philosophy. In this he rejects traditional metaphysics and epistemology to focus on one-to-one human relationships as archetypal for all relations—the face-to-face encounters between persons. Commenting on the face of the Other, he writes:

The first thing which is evident in the face of the other is this rectitude of exposure and defencelessness. In his face, the human being is most naked, destitution itself. And at the same time, he faces. It is a manner in which he is completely alone in his facing us that we measure the violence perpetrated in death. Third moment of the epiphany of the face: it makes a demand on me. The face looks at me and calls me. It lays claim to me.²³

²¹ H. Tristram Engelhardt, “Whose Religion? Which Moral Theology? Reconsidering the Possibility of a Christian Bioethics in Order to Gauge the Place of Religious Studies in Bioethics,” in *Notes from a Narrow Ridge: Religion and Bioethics*, ed. D. S. Davis and L. Zoloth (Hagerstown, Maryland: University Publishing Group, 1999), 126.

²² Emmanuel Levinas, “The Face of a Stranger,” *The Unesco Courier*, no. 7-8 (1992): 67.

²³ ———, *Is It Righteous to Be? Interviews with Emmanuel Levinas*, ed. Jill Robbins (Stanford, California: Stanford University Press, 2001), 127.

In the face, the Other is stripped bare in a vulnerability that cannot be hidden. It calls forth immediately an ethical response, as "the face looks at me and calls me". Ultimately, this claim is, "do not kill me".²⁴ An essential asymmetry is involved in this kind of relationship. There is a kind of primordial fear present as the self faces the possibility of being negated by the Other. But this apprehension in the presence of the Other must not turn back on itself, for it becomes the basis for responsibility to and for the Other.

So it is, the self is known and knowable only in relationship with the Other. Levinas presents the encounter with the Other with a self-transcending emphasis. This relationship is, therefore, asymmetrical and experientially disruptive, calling to responsibility. The objective Other always has priority over the subjective self.²⁵ It is not a matter of an untroubled affective exchange between an I and a Thou in a common field of experience, but more a question of coming up against a disruptive difference—between the suffering Other and the ego-self it confronts.²⁶ For Levinas, the Other is met in its vulnerability—biblically describable as "the stranger, the widow, the orphan to whom I am obliged".²⁷ As with the scriptural priority for the neighbour, relationships as Levinas portrays them imply a radical challenge to one's personal identity.²⁸ The authentic personal self can be constituted only when confronted with the suffering Other facing "me" with a summons to moral responsibility, as if to ask the question, "Where are you?" The ego is challenged to become a responsible self when faced by the Other who pleads, in effect, not be abandoned or killed.²⁹ This responsibility to, and for, the Other reaches the most extreme point:

... in responsibility for the Other, one is, in the final analysis, responsible for the death of the other. Is not the rectitude of the other's look an exposure par excellence, an exposure unto death? . . . This is probably the foundation of sociality. . . the fear for the death of the other is certainly at the basis of the responsibility for him.³⁰

From this it is easy to see how Levinas' work is helpful for an analysis of disability, but it is most useful as a mirror. It is not just the person we are looking at who is Other, vulnerable and precarious...I am also Other to the one I am observing. Disability is a confronting and precarious state because it confronts me with the limitations of my own identity. When I value rationality, individuality and autonomy in myself, I find it challenged by those whose very existence questions the value I place on these capabilities. Such an interpretation is supported by Jean Vanier:

Many young and less young people come to L'Arche without any experience with people who are weak; they come 'to help' but they soon discover that in fact they are

²⁴ Silvia Benso, "Of Things Face-to-Face with Levinas Face-to-Face with Heidegger: Prolegomena to a Metaphysical Ethics of Things," *Philosophy Today* 40, no. 1 (1996): 134-35.

²⁵ Glen Morrison makes the point that the designation Other refers to the personal other, as distinct from a general other. It corresponds to the translation of the French term *Autrui* as distinct from *autre*. See Glen J. Morrison, "Emmanuel Levinas and Christian Theology," *Irish Theological Quarterly* 68 (2003): note 4.

²⁶ Damien Casey, "Levinas and Buber: Transcendence and Society," *Sophia* 38, no. 2 (1999): 70.

²⁷ Emmanuel Levinas, *Totality and Infinity: An Essay on Exteriority*, trans. Alphonso Lingis (Pittsburgh: Duquesne University Press, 1981), 215.

²⁸ Graham Ward, *Theology and Contemporary Critical Theory*, ed. David Jasper, 2nd ed., Studies in Literature and Religion (Basingstoke, Hampshire: MacMillan Press, 2000), 99.

²⁹ Levinas, "The Face of a Stranger," 67.

³⁰ Emmanuel Levinas, *Ethics and Infinity, Conversations with Philippe Nemo*, trans. Richard A. Cohen (Pittsburgh: Duquesne University Press, 1999), 119.

being helped! Their hearts and minds are being opened. They discover how prejudiced they were. They realise that they do not have to become money-makers or success seekers. There is another way of being and of living, another meaning to life different to what they hear in the media and even in school or at university.³¹

Relational encounters between persons always contain the risk of rejection and even the possibility of ultimate rejection, where the Other is dismissed or even killed. The Holocaust remains an archetypal experience of people forced into a "condition inferior to that of things, an experience of total passivity".³² In looking to the face of the suffering Other—calling for an ethical resistance – the previously indifferent ego is offered the possibility of expiating the evil that the Other has suffered.³³ Only by embracing this responsibility for the suffering Other can the self begin to bear the image of the God responsible for the universe. At this point, Levinas' thought resonates with a Christian understanding of the role of Jesus taking on himself the sins of the world and giving himself for its salvation.³⁴

The Other is never, a projection of the self. For the Other confronts the self with a disruptive and pleading alterity that eludes all previous horizons and projections.³⁵ In the presence of the Other, the self is not reinforced in its selfish indifference, nor is the Other possessed or bounded by the ego's subjectivity. It calls forth a self-denial that is the genuine mark of an ethical response which is without limit, "to give to the other taking the bread out of my own mouth, and making a gift of my own skin".³⁶ The presence of persons living with disability challenges us to recognise the presence of the Other who calls us to responsibility.

In the context of disability, it easily happens that the person living with disability becomes faceless, and simply categorised by their disability. But Levinas would have us appreciate the person as irreducibly Other, whose vulnerability calls forth a far more personal and relational response.³⁷ He argues in *Totality and Infinity* that all sense of meaning emerges in our relational encounters with the Other. Seeing the face of the Other stripped bare, leads to recognition that existence can be understood only in relational terms, as the Other summons the true self into being:

To begin with the face as a source from which all meaning appears, the face in its absolute nudity, in its destitution as a head that does not find a place to lay itself, is to affirm that being is enacted in the relation between men...³⁸

³¹ Jean Vanier, "The Need of Strangers," in *Critical Reflections on Stanley Hauerwas' Theology of Disability*, ed. John Swinton (New York: The Haworth Pastoral Press, 2004).

³² Emmanuel Levinas, *Difficult Freedom: Essays on Judaism*, trans. Séan Hand (Baltimore: The Johns Hopkins Press, 1997). Cited in, Morrison, "Emmanuel Levinas and Christian...": 12.

³³ Morrison, "Emmanuel Levinas and Christian...": 13.

³⁴ Emmanuel Levinas, *Entre Nous, Thinking-of-the-Other*, trans. M. B. Smith and B. Harshav (New York: Columbia University Press, 1998), 75.

³⁵ Levinas, *Totality and Infinity*... 43.

³⁶ Emmanuel Levinas, "Ethics as First Philosophy," in *The Levinas Reader*, ed. Séan Hand (Oxford: Blackwell Publishers, 1989), 138.

³⁷ Rahel Naef, "Bearing Witness: A Moral Way of Engaging in the Nurse-Person Relationship," *Nursing Philosophy* 7 (2006). Naef uses Levinas' ethic as the basis for her claim that bearing witness is "an ethical way of practising nursing..." 147.

³⁸ Levinas, *Totality and Infinity*... 299.

The links between the confronting ethical philosophy of Levinas and the prospect of a relational analysis of life with disability is clear. The full development of that analysis and its practical applications are the work of the future. However, the stories of Kelly, Gracie and Rosie, as well as countless others, indicate the need for such an analysis and for a move away from the metaphysics of rationality and autonomy.

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