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# Humanum

Issues in Family, Culture & Science



HEALTH AND MEDICINE

## The Ability of Disability



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In many ways it is disability—its disfigurement, impairment, vulnerability and dependence—which raises the objection we have to life at its beginning and end. It is disability that we want to avoid. For this reason then we turn to disability directly, to ask to what extent the anomaly of disability casts a light onto one of the central features of the *humanum* as such.... to what extent, that is, it is an *ability*.

PAGE

#### EDITORIAL

MARGARET HARPER MCCARTHY: The Ability of Disability ..... 4

#### FEATURE ARTICLES

JEAN VANIER: What Have People with Learning Disabilities Taught Me? ..... 7

ELLEN RODERICK: Their Look Pierces Our Shadows ..... 11

#### WITNESS

DAN LAHOOD: Four Fathers ..... 19

KATHRYN FIALKOWSKI: Love: In Relation ..... 22

#### BOOK REVIEWS

MELANIE DANNER: Life Is A Blessing ..... 25

CARLA GALDO: Simply Present ..... 28

JOHN LARACY: Foucault's Disability: From Social Construct to Self-creation ..... 30

SARA HULSE: Vulnerability and the Cult of "Normalcy" ..... 33

RACHEL M. COLEMAN: What the Body Remembers and Our Culture Forgets ..... 37

KATHLEEN CURRAN SWEENEY: Being vs. Doing: Personhood and Vulnerability in John Paul II ..... 40

MICHEALA VAN VERSEDAAL: Meeting the Vulnerable: Encountering Christ ..... 44

BARBARA GAGLIOTTI: Lessons in the Backyard .....	46
FABRIZIO MERONI P.I.M.E.: The Terrible Mystery of Innocent Suffering .....	48
NICK BAGILEO: A Mother's Love .....	50



# Humanum

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EDITORIAL

## The Ability of Disability

MARGARET HARPER MCCARTHY

With “The Ability of Disability” we offer the third issue in our series on health and medicine. In many ways it is disability—its disfigurement, impairment, and vulnerability and dependence—which raises the objection we have to life at its beginning and end. (See our past two issues: “Beginning and End of Life” and “Re-Conceiving the Human Person”). It is disability that we want to avoid, be it the disability of the one about to be born or the one at death’s door, not to mention the “disability” that they will cause the mothers, fathers, and children who will be responsible for them. Just a couple of months ago the whole world watched as a young, attractive, recently married American woman explained why she had scheduled her own death for November 1st for the precise reason that she could see no value in the disabling effects of her recently diagnosed brain cancer. It is hard not to see that it is our attitude toward disability that determines how we will stand in the face of the more temporary kind brought on by disease—now that we have the “choice”—when we compare the action of Brittany Maynard and her family with that of our late editor Stratford Caldecott and his family. Describing his last months of life, “Strat’s” daughter Sophie writes:

When I think about the last six months or so of my father’s life, I remember the companionship we shared throughout my pregnancy and labor—my fatigue and impaired mobility mirroring his own. I remember the jokes we made about not having control over our bladders, and the consolation we gave each other over our fears of what lay ahead. But most of all, I remember the way his eyes widened as I placed his first grandchild in his arms, and the tenderness with which he watched her grow as he declined. I know with more certainty than I have ever known anything that if he were still here he would tell you it was worth living every last drop of life for those moments.....Was my father’s death lacking in dignity? If losing the ability to walk and eventually talk is undignified, then yes. If catheters and oxygen masks and sponge baths are undignified, maybe. These things are expressions of the body’s ultimate vulnerability, a total reliance on others. But to call vulnerability undignified is to allow ourselves to lose sight of the fact that there is beauty—and yes, dignity—even in extreme weakness, in the whole imperfect, messy, and glorious business of being alive.<sup>11</sup>

The striking feature of all of the texts we have gathered for this issue, from our “classic reprint” from the founder of L’Arche, to the witnesses of those whose lives have been transformed by people with disabilities, to the books in review, is that all of them in one way or another look at disability not so much as an anomaly, but rather, as a window to one of the central features of the humanum as such. It is in living with the “poorest of the poor” that we catch a glimpse of the “universal handicap” (Hauerwas) inscribed in the very fact of our being born, and, more fundamentally still, in the fact of our being created (Reynolds). We are vulnerability, we are dependence. Might it be that in the experience of “our poverties touching each other” (Nouwen) we are getting to the core of what it means that “the poor you will always have with you”?

The question, of course, is how to assess this distinctive “feature” of our humanity. If we identify the essentially human with self-determination, then the “disability” of our very coming to be in the messy process of conception and birth and our enfeebling and unpredictable approach toward death cannot but be a problem to take control of, as Maynard did when she decided to die “as she wanted.” And, turning this on its head, as does Foucault in his manifesto for “madness,” if disability is the exclusionary control word applied to those who desire liberation for pure self-creation, then, again, our very real (not socially constructed!) vulnerability still stands as an objection. What in the end, then, do we make of our essential disability?

Here, again, it is the disabled, in the narrow sense, who educate us. If they recall us to our “universal handicap” they recall us simultaneously to what that handicap instills in us—the desire to be loved (“do you love me?”)—and the humble readiness needed to receive and enjoy it. As St. John Paul II said: “You who are the abandoned and pushed to the edges of our consumer society; you who are sick, people with disabilities.... We need you to teach the whole world what love is” (*Familiaris Consortio*, 53). It is the coincidence in the disabled, then, of their poverty and richness, so evidently expressed in the “desire to celebrate life and have fun” (Vanier), that allows us to face disability, all disability, including our own, as an ability, the ability of love.

Lest we overlook the depth of the “ability of disability” in the experience of community—especially where it is lived as an expression of the Christian faith—let me add here another “text,” a prayer recently composed by Carlo Brown, a 12-year-old with Down Syndrome (my godson!). Carlo had gone to school without his uniform belt and was expecting the usual correction for this infraction, the “Roman Chair,” which involved sitting with his back to the wall for a period of time long enough to be, well.... a correction. Carlo was convinced (wrongly) that he would have to do the exercise for an entire hour and was in a state of fear about the coming trial. He thus went to the chapel and prayed with all his heart to be granted the strength to endure it. His aide, a non-believer, noticing that Carlo was speaking, began to write down the following words:

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Dear God, Can you send the Holy Spirit above me and help me to understand your mercy.

And, help me with Your Holy strength.

I know about you in your Son, Our Lord Jesus Christ. I Pray to God through your

heart

to help me to understand about Mary.

I love you with my whole heart.

Can you send the Holy Spirit to come to me

and help me to understand about Mary who

watched her son suffer under Pontius Pilate.

She was stabbed in her heart with a sword of pain.

I understand your powerful Kingdom. Jesus, please take a key from Heaven and give it to Peter

so he can open the Kingdom of Heaven.

Help me have strength to make it through Roman Chair.

I love you with my whole heart.

From Carlo Brown through the Body of Christ.

Amen

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It is in view of this ability—the ability to see the richness of our poverty, accompanied as it is by the One who is eternally “poor”—that we can face the most dramatic of disabilities, including our own.

[1] Article available at  
<http://verilymag.com/death-with-dignity-assisted-suicide-is-not-the-answer/>.



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# Humanum

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FEATURE ARTICLE

## What Have People with Learning Disabilities Taught Me?

JEAN VANIER

People with disabilities have taught me so much over these past forty-two years as we have lived and shared together in L'Arche as friends and companions, as brothers and sisters, as people brought together by God. In fact, they have not only taught me; they have *transformed* me and brought me into a new and deeper vision of humanity. They are helping me discover who I am, what my deepest needs are, and what it means to be human. They have led me into a new and meaningful way of life quite different from what society advocates. They have revealed to me the need for community in our societies and that those who are weak and vulnerable have something important to bring to our world today.

Before L'Arche, I was searching—not quite knowing what I was searching for. I had developed my capacities as a naval officer and had learned to be disciplined and efficient. I also studied and taught philosophy. Like everyone else, I wanted to do well and be appreciated by my superiors. My belief in Jesus and my desire to know and live the gospel message were important to me, but I had not yet found my “earth,” my anchor, my resting place. I am profoundly grateful to people with learning disabilities because with them I have found this “earth”: I have found a unity between my life and my faith, between what is interior and exterior, between what I think, feel, and understand and what I do.

This may give the impression that the founding of L'Arche was simply a process of self-searching and only for self-fulfillment. This is, of course, partly true. However, I fundamentally believe that L'Arche began as a response to a cry that I first heard when I visited an institution for thirty men with learning disabilities where Fr. Thomas Philippe, a friend, was chaplain. This cry, “Do you love me? Am I important? Will you be my friend?” was expressed or written on the faces of those men and of many others in different institutions and of those living in painful situations. I wanted to create a place where they could find inner freedom, develop their personhood and abilities, and be fulfilled, where they could let their deepest desires rise up and find a new meaning for their lives.

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*Each person, whatever his or her abilities or disabilities, needs to be nurtured in*

*love. ... When this need is not fulfilled, a deep wound is implanted in the heart.*

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Many of those who came to L'Arche were in deep need. They carried within their hearts the wounds of rejection. They suffered from a lack of self-esteem and from major physical and psychological difficulties. Some were prone to violence or had self-destructive attitudes and a fear of growth. It was clear to me that in order to be a place of growth, healing, and inner liberation, L'Arche needed the help of good professionals. Thanks to many psychiatrists and other professionals, I am learning an inner wisdom of bringing together the resources of human sciences (psychology), ethics, spirituality, and religion. I am learning the necessity of creating a milieu of life where people can find inner healing and which has clear structures integrated into the social, political, and health systems in a country. I am learning about the need for prayer and spirituality, not only for people with learning difficulties but for everybody. I am discovering more fully the place of church and of a religious affiliation. I am discovering a lot about the human person and the purpose of education: to bring people not just to greater autonomy and independence but also to greater maturity. Let me point out just a few things I have seen and experienced during these forty-two years.

1. Each person, whatever his or her abilities or disabilities, needs to be nurtured in love. The desire to be loved as a person, as someone unique, is at the source of the person's development and at the source of all self-esteem. When this need is not fulfilled, a deep wound is implanted in the heart. Many people with disabilities have been regarded by their parents as a disappointment and a source of shame. This profoundly wounds children. In order to grow to greater fulfillment, these children need a place of belonging where they feel loved and respected.

2. The fear in couples of giving birth to a child with a disability is imprinted in the culture of every society. They are often seen as "subhuman," and they are rejected—or put aside in some way. Many are aborted if the existence of an abnormality is detected in the mother's womb. Many are put away in large institutions. Throughout the world, hundreds and hundreds of institutions exist where people with learning disabilities live in inhuman conditions.

3. The values many modern societies hold are independence, individualism, and success for every citizen. More traditional societies are respectful of the old and the sick, but even they are often unable to see people with learning disabilities as important. In richer societies, the weak are seen as an economic and human liability. And so, people with learning disabilities are pushed to the margins of society.

4. Many people with learning disabilities need help from professionals in order to overcome physical and psychological difficulties, to grow to greater autonomy, and to develop their capacities in various fields. But, above all, they are yearning for meaningful, authentic, respectful, and committed relationships. Their cry for love flows also from their deep loneliness and their lack of self-esteem. They have called me to listen and to respond to their cry with competence, to welcome their vulnerability with tenderness, and then to be in communion with them. As we respond to this fundamental cry for friendship, they begin to transform and to heal us. We can either hide our vulnerability behind a strong, protective ego, or else we can discover that our vulnerability is a source of communion and unity. We do not need to control or have power over them. We can be in communion with one another, offering to each other our mutual need for one another. In this way they have awoken in me what is deepest and most precious: a desire to give life to others and to receive life from them through a communion of hearts.

In 1978 we welcomed Eric into one of our homes here in Trosly. He was sixteen and had spent twelve of those sixteen years in the children's ward of a psychiatric hospital. Eric had severe learning disabilities, but was also blind and deaf and unable to walk by himself. I don't think I have ever seen a young person filled with so much anguish. He just wanted to die. What meaning could life have for him? Our aim in L'Arche is to transform the broken self-image of someone like Eric into a positive self-image, the wish to die into a desire to live. When I left the leadership of the community, I spent a year in Eric's home for ten people with severe disabilities. His utter littleness and poverty, the moments of gentle trust, awoke in me a deep feeling of compassion. In the morning when we would bathe him in the warm water, his whole body would relax and manifest that he was happy. As the months went by, he became more and more peaceful. Eric taught me so much about being attentive to wounded, vulnerable persons: how to interpret their body language and live a communion of hearts with them.

People like Eric have led me into the need for community and for a simple lifestyle where the essential is to care for one another, to celebrate life, to be open, and to grow more loving and understanding toward neighbors and friends, a lifestyle where we are no longer each for ourselves alone, but together we are a sign of a new way of life, where the weak and the vulnerable and the marginalized have their place.

John Paul II said something to this effect in a document he wrote in 2004 for a symposium on the "Dignity and Rights of Disabled People":

It is said, justifiably so, that disabled people are humanity's privileged witnesses. They can teach everyone about the love that saves us; they can become heralds of a new world, no longer dominated by force, violence and aggression, but by love, solidarity and acceptance, a new world transfigured by the light of Christ, the Son of God who became incarnate, who was crucified and rose for us.

Since people with learning disabilities are limited in their capacity to rationalize and form ideas, and their verbal language is limited, they tend to communicate more through their bodily gestures and simple words of love, or of anger. Through them I have discovered the importance of work and interesting activities for their personal development, but their desire to celebrate life and have fun are even more important because they are a sign of mutual belonging. In this way they call us all to celebrations that bring people together with all that is beautiful: food, wine, song, dance, laughter, dress, decoration. It is a time when all can rejoice—with their abilities and disabilities—and give thanks to God for having moved us all from loneliness to togetherness. The child within my own self has learned to laugh and celebrate and give thanks for all that bonds us together. People with disabilities have called forth the child in me. They have taught us all in L'Arche how to rest in love and mutual caring, how to celebrate life and also celebrate death, to speak about death, to accompany people who are dying. Death is a part of life: it is not something to be terrified about, but rather is the final passage into a new life.

As those who are weak and vulnerable have called forth in me the wisdom of love, they have also made me more vulnerable. I have been brought closer not only to what is most beautiful in me, but also to the world of darkness, fear, and anguish within my own heart, to all my own difficulties in relationships, and to my need to prove myself. Faced with their anguish, I have seen violence rise up in me. But since I live in community and have the support of my brothers and sisters in the community, this violence is contained. It is only when we touch the powers

of destruction within us and begin to accept that they are there, but do not let ourselves be controlled or governed by them, that we can truly understand and accept others in their anguish—and then help them to grow.

Martin Luther King said that people cannot stop despising others—as well as other groups of people—unless they begin to accept what is despicable in themselves. What is it that we all despise in ourselves? Isn't it our radical poverty, our utter helplessness in many situations, our need of others, our mortality, and our capacity to hurt others? We did not ask to be born. We do not know when or how we will die. We do not possess life. We receive it. I have discovered that this helplessness makes me turn more to God and to my brothers and sisters in community. I cannot say that I have accepted all that is despicable in me, but I am more aware of my need for transformation.

I can also say that living with those who have known rejection and have been despised has opened up my heart to the pain of all those throughout the world who are “different,” who have experienced rejection and hatred because of a disability or not. They, too, need love so that they no longer live closed up in fear but open up in trust. I have come to the realization that peace cannot come to our societies and our world unless those who are rich and powerful accept loss and a certain helplessness in order to enter into authentic relationships with those who are weak, vulnerable, and powerless, and unless the latter rise up from their depression, aggression, and anger and find trust in themselves and in others. This can only come about if we rediscover new ways for the weak and the strong, the rich and the poor, to meet each other and to discover their common humanity.

In this way, the cry of the weak and the vulnerable can bring together people of different religious traditions. They can become a source of unity. After participating in an interreligious pilgrimage with people with learning disabilities in Bangladesh, the Taizé Brothers wrote the following:

We discover more and more that those who are rejected by society because of their weakness and their apparent uselessness are in fact a presence of God. If we welcome them, they lead us progressively out of a world of competition and the need to do great things, towards a world of communion of hearts, a life that is simple and joyful, where we do small things with love. The challenge today in our country urges us on to show that the service of our weak and vulnerable brothers and sisters means opening a way of peace and unity: welcoming each other in the rich diversity of religions and cultures, serving the poor together, preparing a future of peace.

People with learning disabilities are leading me more fully into an understanding of the gospel message and of the life of Jesus. Jesus' life and message are for all, but in a special way for those who have been cast aside. To enter into the kingdom of God we need to become like little children. Saint Paul tells us that God has chosen the weak and foolish in the eyes of the world and that they are necessary—indeed, indispensable—for the church, which is the body of Christ. So many of us intellectualize this message of Jesus and remain inside our own heads. People with disabilities have helped me to realize that it is a message of the heart, a message of love and of humility adapted to those who cry out, “Do you love me?” and who are open to a personal relationship with God. This cry for relationship from people who are weak and vulnerable has helped me to live closer to Jesus, the Word who became flesh, vulnerable and little, the one who begs each one of us to receive him into our hearts so that we may receive others into our hearts.



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FEATURE ARTICLE

## Their Look Pierces Our Shadows

ELLEN RODERICK

Attitudes towards disability have undergone significant developments in our time. Jean Vanier's account of the isolation and anguish of the disabled men and women hidden away in desolate psychiatric institutions in northern France in the 1960's seems like a relic of a bygone age. The dominant stigma at that time was that a disabled child was a punishment by God. While not every child shared the fate of being placed in a state asylum, where the conditions of life in no way enabled their human flourishing, it was the cultural norm that these children would lead hidden lives, away from the schools, main streets and churches that formed the social fabric of the local community.

Since the 1970's, however, there has been a significant shift in our attitudes towards people with disabilities in Western countries. In the United States, for example, a sharp contrast can be seen between Justice Holmes' infamous dictum in *Buck v. Bell* (1927) and the more recent Preface to the Americans with Disabilities Act (1999). Arguing for the mandatory sterilization of the "feeble minded" so that they would not produce "socially inadequate offspring," the majority decision in *Buck v. Bell* stated:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles are enough.

The tone of public opinion has since changed dramatically. Fifteen years ago, the U.S. Congress proclaimed the following in the Americans with Disabilities Act: The Congress finds that (1) "physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination; (2) historically, society has tended to isolate and segregate individuals with disabilities, and... such forms of discrimination against individuals

with disabilities continue to be a serious and pervasive social problem ; [and] (3) the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous.” Many other Western countries have witnessed this progressive movement towards the integration of people with disabilities as equal citizens into their schools and communities. For example, the Council of Canadians with Disabilities (1976) and France’s *Etats Généraux du Handicap* (2005) reflect this movement.

However, beneath what appears to be a new attitude of acceptance and respect for persons with disabilities, one befitting the modern, liberal citizen, there lurks at the same time the latent attitude that the lives of people with disabilities are actually *not* acceptable. Beneath the fragile façade of “inclusion” and “integration,” the buzz words driving the change in public opinion and government policy for the last 30 years, there lies a deep seated contrary belief that it would have been better for them if they had never been born. The growing moral pressure for parents to undergo pre-natal screening and the tremendous increase in disability discrimination abortions reflects the attitude that their existence should certainly be avoided at all cost.

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**While logical arguments about the nature of personhood and the rights of the unborn are helpful and essential, it is often in the encounter with a person with a disability that a new level of certainty is gained about the value of their life no matter what their level of disability. It is such an encounter that is able to cut through the dominant but deceiving narrative of what constitutes a respectable “quality of life.”**

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Burdened with the knowledge of their child’s future physical or mental disability, parents today often find themselves shouldering the almost inconceivable “responsibility” of deciding what constitutes a worthwhile “quality of life” for their child and for their families. And as many studies show, more often than not these parents are deciding to end the life of their disabled children rather than carry them to term. “Burden of Knowledge: Tracking Prenatal Health; In New Tests for Fetal Defects, Agonizing Choices for Parents” (*New York Times*, June 20, 2004) and “Dreaded Diseases Dwindle with Gene Testing” (NBC News, February 17, 2010) report the staggering number of such decisions and the stories of the families who make them. The most common reason reported for terminating such a pregnancy is the future “quality of life”: Will our child suffer too much because of his or her disability? Will he or she be too much of a burden on our marriage and family life?

While in some ways we seem to have come very far in our attitudes towards disability, in light of the above we must ask ourselves: Has much changed? The widespread acceptance of a vision of “quality of life” that idolizes ease and success or at least one that excludes suffering, seems to land us back where we began. One thing that has changed is that with the availability of genetic screening and growing acceptance of abortion for genetic reasons, disability is no longer perceived as the fault of God, but the fault of the parents who didn’t intervene to prevent the birth of such a child. We should ask ourselves if this systematic attempt to eradicate disability will result in more shame, rejection and stigma surrounding people who are born with disabilities.

Yet, as many of us know, these attitudes are not the full story. Many of us have witnessed the joy and humanity of a family member or friend with a disability and the richness that an encounter with them has brought to our lives. Many of us know from our experience that the suffering of a child, spouse or friend due to a disability, while it is not willed for its own sake, nonetheless has the capacity to evoke in us a depth of relationship and compassion that we would not have experienced otherwise. The vulnerable and innocent suffering of a child with a disability does put a strain on one's marriage and family life, but as many families attest, this can be a unique path to enter more deeply into the meaning of marriage and family life, rather than being only an obstacle.

This more profound understanding of disability, however, is something that one seems to discover primarily in an encounter with a person with disabilities or a family who has welcomed him or her. While logical arguments about the nature of personhood and the rights of the unborn are helpful and essential, it is often in the encounter with a person with a disability that a new level of certainty is gained about the value of their life no matter what their level of disability. It is such an encounter that is able to cut through the dominant but deceiving narrative of what constitutes a respectable "quality of life."

Such was my experience when I met a young man whose family ran a home for people with disabilities while on a mission trip to Latin America at the end of my sophomore year of college. The contrast between what I perceived as "quality of life" as a hyper-achieving college sophomore (the classic case of success, awards, great grades, popularity, etc.) and the quality of life of the poor yet joyous Mexicans who welcomed me, made the witness of my friend's human encounter with people with disabilities all the more convincing and attractive. He introduced me to the thought of Jean Vanier, the founder of the L'Arche community, who through his own encounter with people with disabilities discovered, he says, what it means to be human.

With a sincere thirst for meaning, and aware that my previous ideals had been called into question, I returned to my college campus that fall and introduced myself to the local L'Arche community. They happened to have their day program for adults with disabilities on my very campus. I began to drop in to volunteer between my classes, and slowly I was befriended by Margie, then Dorothy and Sam. Through these visits spent playing cards, knitting, enjoying a cup of tea, or sometimes just sitting together, they introduced me to a different "quality of life," exemplified in spending time together, listening, friendship and celebration. Thus began a long friendship with the L'Arche community. During a yearlong visit to L'Arche in France, I was invited to live in Le Surgeon, a home for 6 adults with severe disabilities, most of whom were unable to speak or conduct their daily lives with any degree of autonomy. Sitting around the dinner table that first night, I remember feeling completely out of my league, uncertain if I would ever learn to communicate with and get to know these people that seemed so completely different from me, physically, mentally and culturally. But little by little, the slow but intense daily rhythm of community life enabled a real encounter.

It is the joyous proclamation of the possibility of such an encounter with persons with disabilities and their unique capacity to reveal the depths of our common humanity that characterizes Jean Vanier's message and the community of L'Arche which he founded. In 1964, Vanier, who at the time was teaching philosophy at the University of Toronto and searching for his vocation, was invited by Père Thomas Phillippe, his spiritual father, to visit an institution for men with disabilities in a village in northern France where he was serving as a chaplain. Vanier tells the story of his first encounter with this small institution of 30 disabled men, ages 16-40, who, living under lock and key, displayed violence and anger the likes of which he had never seen in his privileged upbringing. Rejected by their families and protected

from the local villagers, Vanier intuited that the source of their anguish was a cry for human relationship, for an encounter with someone who showed them love and concern. Through their cries for friendship, Vanier felt the prompting of the Spirit to do something for men in their situation. In dialogue with Père Thomas, he bought a small rundown home in the village and he welcomed two men from the local psychiatric asylum at Clermont to live with him and share a common life based on the spirit of the Beatitudes. And thus began the community of L'Arche which has since grown to be an International Federation of 146 communities in 35 countries.

Through the establishment of small houses for these men where they could feel "at home" and places of work, recreation, and worship, Vanier began to witness a slow transformation in them from anguish to joy, from violence to peace. After twenty-five years of life in the community, Vanier wrote *Man and Woman He Made Them*, in which he shares what he has discovered about the human person through his daily life at L'Arche. Written partly in dialogue with John Paul II's Wednesday Audiences on the nuptial meaning of the body which were appearing at the same time, the book is "about the importance of relationship and community as the place where people with learning disabilities can grow and develop both humanly and spiritually, where they can grow in faithful love (2)."

In this book, Vanier articulates a Christian anthropology that, while inspired by the experiences of people with disabilities, is universal in its scope. In contrast to the value of a person's life being based on their predicted "quality of life," Vanier argues that in the light of Jesus, the disabled person is a herald of a new set of values.

The Word, becoming flesh, came to reveal the great dignity of *each* person, above all the poorest and the weakest, and to call them to live in communion which is united like a body. The last are first. The values of the Christian vision are neither power, nor social influence, nor riches, nor human glory, not even individual liberty as an end in itself. Its values are those of love exercised in the 'body' of community, which is the Church. (53)

Vanier believes, with St. Paul, that God has chosen the weak and foolish to confound the strong. Thus, persons with disabilities become privileged witnesses to this anthropology because "they live closer to the heart, so they are open to the message of Jesus which is essentially a message of the heart." (3)

Commenting on the contemporary approach to disability within modern liberal societies, which is predominantly to secure their "rights" to jobs, housing, education and health care, Vanier argues that even if all of these rights are guaranteed, they are not enough to secure the happiness of the men and women he lives with. What he has learned through all his years at L'Arche is that "the deepest longing of each one is to create bonds and to live with others in the spirit of family." (57) It is this desire to be loved and welcomed gratuitously, and to discover one's own capacity for such relationships that Vanier sees as the fundamental human need, disabled or not. Vanier's emphasis on the centrality of discovering one's capacity to give and receive love, in a word, to be fruitful, and seeing disability not primarily in the negative terms of limitation but in the positive terms of a capacity for relation is one of Vanier's unique contributions to our understanding of disability. "When human beings discover they are truly loved by God and that they can live a relationship with God, a change takes place in them. They are no longer disheartened by their limits and disabilities. By this union with Jesus, they can communicate life." Vanier continues: "Once they find meaning in their lives, they are not just 'disabled' but they become fruitful. They can share their unique gifts with others. Each one

finds their place.” (157)

The outline of this anthropology in *Man and Woman He Made Them* follows the movement from “brokenness” to “healing” which occurs within the belonging typical of the experience of “home” and “community” and that expresses itself ultimately in “celebration.” The human heart and the experience of childhood are central concepts in Vanier’s theological anthropology. Created in love by God and for God, the human heart is the core of the person. It is the heart that desires to love and to be loved gratuitously. Through original sin and the sufferings incurred in early childhood, when one is most vulnerable and in need of love, this heart has been gravely wounded. Instead of accepting one’s vulnerability within a communion of love, one tends to close himself off from others. “The great suffering and original sin of human beings,” writes Vanier, “is to no longer believe in the innocence of communion and mutual trust which opens us up to others, to the whole world and to God. It is to let ourselves be seduced by efficiency, power, freedom, pleasure and material possessions rather than building one’s life on love and welcome, with all the risks of suffering that entails. It is to close oneself up on oneself” (36). The path from this “fragmentation” of the heart to its healing begins in the encounter with a faithful love through which the person re-discovers his own interior beauty and the gift-character of his existence. Knowing oneself to be loved, one can risk entering into relationship with others.

Vanier and his experience of L’Arche has attracted the attention of many over the years, both within and outside the Christian community. Believers of every stripe and atheists alike are drawn to this community by a common attraction to what they see as a profound humanity and affection for reality that neither ignores the real suffering of the disabled nor idealizes the non-disabled people who choose to stay with them. Two recent books testify to the power of what is being lived at L’Arche.

In the spring of 2009, Julia Kristeva made her first visit to Trosly-Breuil, a little village nestled away in the Compiègne forest in northern France, to meet Vanier and spend the day with the members of the L’Arche community. This visit gave birth to a friendship between Vanier and Kristeva and sparked a yearlong exchange of engaging letters. Published as *Leurs regards perce nos ombres (Their Look Pierces our Shadows)*, Vanier and Kristeva reflect on the nature of disability from the contrasting perspectives of Vanier’s deeply Christian faith and Kristeva’s humanist-atheist philosophy. This vivid, smart and honest exchange of ideas and experiences was published in the original French by Fayard Press in 2011 with Italian and Polish translations soon following.

The friendship between them that we are made privy to in this collection of letters is an unlikely encounter in our own time. On the one hand, Vanier is a devoutly Catholic layman, a former naval officer and philosopher by formation, who has lived for 45 years alongside men and women with disabilities in the spirit of the Gospel Beatitudes. On the other, Kristeva is a French-Bulgarian atheist and a well-known philosopher, literary critic, feminist and psychoanalyst. While Kristeva may be less familiar to audiences outside of France and the academic circles where she is esteemed, her espoused humanist philosophy reached a global audience when she was invited by Pope Benedict XVI to address the Interfaith Meeting for Peace in Assisi in 2011 as a non-believer. Kristeva is also the mother to David, her son who was born with a neurological disability, who she says introduced her to the world of people with disabilities and who deeply transformed all of her thought. A critic of the radical individualism typical of contemporary Western culture, Kristeva argues that a renewal of society will only come about through the promotion of a type of humanism that makes the vulnerability of the human person thematic for the first time in history. In addition to her many academic accolades, Kristeva has been a driving force in the French political arena for the recognition of

the rights of people with disabilities and their integration within society.

While their different worldviews characterize and animate their letters, what unites Vanier and Kristeva is their certainty that people with disabilities have something essential to teach us about what it means to be human. In an age that more or less seeks to eradicate any form of disability through early genetic screening or mercy killing at the later stages of life, and where people are caught up in the ideology of “normality” (power, money, success, perfection), they hold that contemporary Western civilization urgently needs an “indispensable mutation” in its understanding of humanity. How are people with disabilities at the forefront of this transformation? They agree that in the encounter with people with disabilities we are confronted head on with the stark fact of human mortality – that is to say with death – and thus, the vulnerability inherent in being human. Since persons with disabilities cannot play the game of “normality,” they call into question the foundations of this ideology and reveal dimensions of ourselves that we would rather not address, such as our mutual dependence, our suffering, and our eventual death. Their lives challenge our own.

The title of the exchange of letters, *Their Look Pierces our Shadows*, is particularly apt to express their shared understanding of disability. The title is a reference to the play *Little Eyolf* (1894) by the Swedish dramatist Henrik Ibsen, in which tragedy befalls a family when their disabled son drowns. Grieving the loss of her son, the mother in Ibsen’s play remarks that it is the memory of the look in Eyolf’s eyes that has the capacity to penetrate the depth of her humanity. Kristeva asks Vanier if their mutual understanding of disability could be encapsulated by the mother’s insight into the unique encounter she has had with her son and the capacity of this encounter to reveal her humanity. “These words bring us back to our ambition,” writes Kristeva, “yours and mine, to change the gaze of the non-disabled on persons with disability. Ibsen helps us to do this by reversing the perspective: it is Eyolf who looks at us, it is the look of the little boy with a disability that counts, for it is him who will pierce our shadows.” (67)

While Vanier and Kristeva agree that these shadows represent a fear or rejection of vulnerability, which is the basic human condition, the difference in their understanding of vulnerability emerges in their dialogue as well.

How are vulnerability and disability understood outside of the Christian revelation of a God who entered our human condition and made it a path to the encounter with Christ? As a humanist, Kristeva rejects the notion of a transcendent God. The horizon of her thought therefore is the social-political pact among equal citizens. Identifying the origins of her own thought with the French Enlightenment, she argues that in their historical attempt to place man above God, the original humanists failed to properly integrate man’s vulnerability into their philosophy. Thus for hundreds of years humanism has systematically rejected many weak people from the social pact. This is the mistake that Kristeva is striving to rectify through her re-founding of humanism. Why has there been this systematic oversight regarding man’s vulnerability? As a psychoanalyst, Kristeva argues that man has latent fears of death and of weakness. She writes that in front of these fears, we can either attempt to ignore them (as in the history of humanism) or manage them through science (through modern eugenics), or we can learn to accept and live with them (her position). People with disabilities have a privileged place in her attempt to re-found humanism. Their presence evokes our fear of mortality and invites us to confront and incorporate our own death. Only in this way, by accepting our own death, can we enter into a true solidarity with the disabled person, allowing him to be himself and flourish as an equal political subject.

One of the themes running through this exchange of letters is the meaning of Christian charity.

Kristeva wonders if the Gospel admonition to love the poor perpetuates the isolation of people with disabilities rather than encourages the recognition of their equal humanity. Kristeva argues that the Beatitudes of Matthew 25 seem to suggest a “philosophy of generosity” which isolates the disabled person as a mere recipient of someone’s good work. Christian charity, argues Kristeva, lacks any real “inter-action” with the disabled, which would recognize their equality with the giver. Thus, instead of integrating disabled people within the social pact, we end up “isolating them with love.” (71) Kristeva sees her new modern humanist approach to disability as the positive counterweight to this reading of Christian charity.

Interestingly, what Kristeva sees in Vanier’s experience of L’Arche challenges her negative understanding of Christian charity. In this respect, she thinks that Vanier has brought about something of a revolution in our understanding of disability and possibly also in the Christian tradition of charity and works of mercy. She sees something in Vanier and his community that she desires within her own humanism but is unable to bring about. Kristeva herself seems to be aware of the limits of her assertion of the political rights and social equality of the disabled. She admits that her real concern is to find people who are able to accompany the disabled, such as her son, David, in such a way that they grow in freedom. Struck by the humanity, respect and joy she perceived in the interactions between the handicapped members of the community and those who have freely chosen to share their lives with them, she writes in her first letter to Vanier: “It is not easy to be in an intimate proximity to irreparable physical and mental wounds...Yet the humanity of your L’Arche neither denies nor exalts these irreparable failures and wounds. You are happy to welcome, if I dare say, because this corresponds to the wounds of each one of us.” “How do you do it?” she asks Vanier.

One of the novelties of Vanier’s experience of L’Arche is his understanding that “encounter” must be at the heart of an adequate understanding of Christian charity. Vanier stresses that in the encounter with the disabled, the young volunteers who come to L’Arche begin to discover and respect their own humanity and its vulnerabilities and desires, and with this new awareness of what unites them, are able to “share” life together. His deeply trinitarian understanding of charity brings to the fore such elements as the radical dignity of the person and his call to love, the tension between belonging and freedom, and each one’s desire for fruitfulness that perhaps in the past have been neglected under the guise of doing “good works.” Vanier says that L’Arche does not exist to do good things for people but to participate in the mission of Jesus who says to each person: “I love you as you are, I have confidence in you, I want to help you to discover how beautiful you are, that you are capable of giving your life for others.” (203) Animated by the spirit of charity, L’Arche exists “to help each one to welcome people just as they are, to appreciate them, to see their beauty and to respond to their needs for growth and liberation.” (34)

Another example of the provocation of the experience of L’Arche was a weekend symposium sponsored by the John Templeton Foundation in 2007 titled “Learning from the Disabled.” The purpose of the symposium was “to explore the value of sharing one’s life with mentally or psychically handicapped people as a way to fulfill the vocation of a human being.” Thirteen investigators – scientists, social scientists, theologians, and ethicists – gathered in Trosly-Breuil “to examine how the experience of caregivers may overturn the classical notion of *opera supererogatoria* to the extent that, far from being a form of ‘good Samaritanism’ or action beyond the pale of duty, their work with the disabled can sometimes result in their own moral transformation.”[i]

The fruit of this symposium was gathered together and published as *The Paradox of Disability: Responses to Jean Vanier and L’Arche Communities from Theology and Science*. One of the most interesting contributions to this discussion is from Dr. Xavier Le Pichon, one of the founders of

modern plate tectonics and chair of geodynamics at the Collège de France in Aix-en-Provence. Based on evidence from the geological and anthropological records, Le Pichon asks the question if perhaps vulnerability has been part of our human self-understanding since the origin of the species, contra the Darwinian mantra of the survival of the fittest. He brings to our attention the historical evidence of compassion and care for the vulnerable among the Shanidar group of Neanderthals to argue that vulnerability may be more central to our human experience than we sometimes think. He develops this provocative thesis elsewhere in *Aux racines de l'homme: de la mort à l'amour* (Presses de la Renaissance, 1997) and “Fragility and the Evolution of our Humanity” (Interview with Krista Tippet, August 16, 2012) and the essay “Ecce Homo” (both available online).

For Vanier, the themes of encounter and vulnerability upon which these two books reflect have their foundation in his own encounter with Jesus Christ and the vulnerable face of God that his life, death and resurrection have revealed (Vanier, *Jesus, The Gift of Love* [New York: Crossroads, 1994]). Without this horizon, we cannot adequately answer Kristeva’s question: “How do you do it?” This horizon is the Kingdom of God where the weak and poor are the privileged teachers of communion and love. In this Kingdom, suffering and pain are not to be shunned *tout court* but have been transformed within the community of believers into a place where Jesus is present, into sacraments where Jesus abides. Ultimately, this Kingdom is the “ecstasy of love that Jesus is living with the Father before all time” that he offers to us “through communion with and in his flesh.” The understanding of disability that has sustained Vanier’s fifty years at L’Arche is that a person with a disability is above all a person with a vocation to love and a brother or sister called to the Wedding Feast (Rev 19:6-9).

[i] The Templeton Foundation, available at <http://humbleapproach.templeto...>



# Humanum

Issues in Family, Culture & Science

WITNESS

## Four Fathers

DAN LAHOOD

*As he went along, he saw a man who had been blind from birth. His disciples asked him, "Rabbi, who sinned, this man or his parents, that he should have been born blind?" "Neither he nor his parents sinned," Jesus answered, "he was born blind so that the works of God might be revealed in him." John 9:1–3*

By way of introduction I should say that my wife and I have operated St. Joseph's House for the last 32 years. SJH is a Day Care and Respite Care home for children with multiple disabilities. In addition to this work we, along with other like-minded people, founded a Ministry called Isaiah's Promise. Isaiah's Promise supports families who have decided to carry their child to term after receiving a poor pre-natal diagnosis. If the defense of life at every stage is a seamless garment, we like to think we have added a few stitches to its making. The bulk of the stitching, though, is the work of the families who demonstrate the love and courage to welcome the life they have been sent.

At the beginning of our ministry we had no idea where any of this would lead. It was and is chaotic, joyful, inspirational, wearying, sad, edifying, instructive. It is a life we could not have imagined but one we now cannot imagine having not lived. Mother Teresa was reported to have described a child with a disability as the "treasure of mankind." That may be apocryphal, but we have found it to be absolutely true. Many of the kids who came to our home over the years have died, but every year at Christmas their parents return. And they tell us how they miss their son, their daughter. They tell us, not in so many words, that the love they had for their child was the life they could not have imagined before their child arrived; but one they could not have imagined not living once the child was here. This is true for the Isaiah's Promise parents as well as the Saint Joseph's House parents. Not one carries any regret, whether their child lived for minutes or decades, that that person was part of their lives. Their life to them was a Gift, a Pearl of Great Price, if you will.

Let me try to convey the depth of this love by sharing a few of the stories of parents and children we've had the privilege to know. Bobby was deaf, worked two jobs—at Walter Reed Hospital and at a nursing home—as an orderly and had a beautiful wife, Mary, who was also deaf. She likewise worked at the same places. They had two children, Bobby and Carlos. Both

were severely disabled, unable to speak or walk. They communicated minimally using sign language. Bobby and Carlos came to Saint Joseph's House for respite for 15 years or so. As the boys grew, we noticed that Bobby was growing too. "Hey, Bobby," we tried to finger-spell, "you been working out?" "Yes, I have to be strong to lift the boys." He looked like Superman. His boys weighed over a hundred pounds and he lifted them effortlessly. He would swing the heavy wheelchairs into the cart behind his van which he used to transport them. A few weeks before his death, he knocked on our door. I did not recognize him. I could see he was turning yellow beneath his brown skin. He weighed a hundred pounds. He wrote on his pad, "I bought steroids at the gym. I wanted to be strong. I have liver cancer. I am dying." At his memorial service, his best friend quoted Bobby: "I will not let the world throw away my boys like trash."

George and his wife had a daughter with severe Cerebral Palsy, and George was largely responsible for her physical care; he was devoted to that work. He did not have a wheelchair van when he would pick her up at Saint Joseph's House. He would lift his daughter out of her chair and put her in the back seat. I could see the strain on his face and would always say, "George, let me give you a hand." "No, this is my job." After his death, we learned that George had a heart defect that killed his father in his late thirties. He knew he had the same condition. It killed him at fifty. But day in and day out, he lifted her, changed her diaper, bathed her and loved her to the end.

Jay is a musician, a very fine musician, good enough to have auditioned to be Tony Bennett's accompanist. Jay had a daughter named Katie who was compromised, having an unknown twin that died some time before she was born. Jay is full of life and he showed the most life when he was with his daughter, told her dumb jokes, bad puns and would sing "If I Only Had a Brain" to her at the drop of a hat. He practiced his piano with Katie in a wheelchair by his side and Katie would smile, roll her eyes in wonder and would get grumpy when he stopped. After Katie died at 21, I was returning some dishes to their house after the funeral reception. Walking up the driveway I heard nice piano music. The closer I got, I heard not just the notes but the emotion that poured from Jay's fingers. I heard him play a lot, but not like this. This kind of beauty, this art, could only be a product of a depthless love. As quietly as I could I left the dishes on the porch and stole away.

It was Easter Sunday and Pope Francis was greeting people in the Square. He saw Dominic in the crowd and walked over to him. Dominic has Cerebral Palsy and was being held by his father, a professor at Providence College. Francis took the boy from his arms, brought him close and kissed him. Bobby, George and Jay would have repeated this gesture a thousand times, more than that. A 77-year-old man did this. Then we saw the Pope's embrace of the man covered with tumors. I don't know the scientific name... I thought he was kissing the Elephant Man. Afterwards, the man was quoted as saying, "I felt like I was in Heaven." The joyrides Francis takes with young adults with Down Syndrome around St. Peter's testifies to this same spontaneous love and acceptance. (It helps apparently to wear a Lionel Messi jersey if you want him to stop!) The last I'll mention was a stunner for us. The Pope had encountered a young family with an Anencephalic baby the week he was in Rio for World Youth Day. According to reports, the parents had approached Francis, told him their story and asked for his Blessing. They told him that doctors, family and friends had urged that they abort their child. They resisted and sought out the Pope to tell him their story and receive a Blessing. Anencephaly, a fatal condition, is the most common we encounter in our work with Isaiah's Promise. At the Mass to close World Youth Day, during the Eucharistic Procession as the Gifts were brought forward, the announcer said, "A young family was asked by the Pope to bring their child who is disabled to the altar." Twenty-seven years ago our child was diagnosed *in utero* with a fatal condition called Polycystic Kidney Disease. Like the young family in Rio we were urged by doctors, certain family members and acquaintances to get an abortion. We

resisted and it changed our lives forever. We, like Bobby and George and Jay and Francis, with the Grace of God, came to see our children's lives as a Gift.

The miracle that led to Paul VI's beatification was the healing, *in utero*, of an unborn child. Doctors found that the fetus had various conditions "incompatible with life" and urged the parents to abort their child. This is a common experience for the families we encounter at Isaiah's Promise. This intervention from Heaven is a clear indication to the Church and the world that the "poorest of the poor," the child diagnosed with a disability in the womb, is not outside the ambit of God's Love and Mercy whether they are healed or not. He seems to say, "You care for them now and I'll care for all of you later"—a perfect riposte from Blessed Paul VI, an Apostle for Life, to the all-too-common attitude that rejects out of hand those found to be "defective." Paul VI's miracle amplifies Pope Francis' admonition made at Assisi. In meeting with a group of kids with disabilities and their caregivers, he said, "Their wounds need to be heard."

When fathers live their vocation heroically, when they support their family in every situation, when they love oblivious to society's judgments and when men and women of goodwill come to recognize and support them in their witness, the culture of exclusion will become the culture of embrace.



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# Humanum

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WITNESS

## Love: In Relation

KATHRYN FIALKOWSKI

When one speaks of the person, one refers both to the irreducible identity and interiority that constitutes the particular individual being, and to the fundamental relationship to other persons that is the basis for human community.

—International Theological Commission, *Communion and Stewardship: Human Persons Created in the Image of God*

Our family of eleven children grew up in a one-bathroom, three-bedroom row house in Philadelphia. In very large families, there are subgroups and I, the youngest, was within a group called "the babies." I shared this group with two of my brothers: Walter and David. Walter, ten years my senior, became ill as a toddler and, after being placed in a malfunctioning oxygen tent, developed significant intellectual and physical disabilities. My brother David, only two years my senior, was born with significant intellectual and physical disabilities. While "babies" signified a phase—staying at home while the big kids went to school—our relation to each other in that phase was cemented in the years to come.

On the first day of school, our mother transported my brothers Walter and David in a little red wagon while I skipped alongside holding her shirt tail. At the school our mother carried Walter up two flights of stairs, descended, carried David up, descended, and finally as she carried the wagon up, I marched up the steps with her. No longer "babies" by name, we were finally in school! I was four, David was six, and Walter was fourteen. Though it had no meaning to me at the time, our school was a ground-breaking summer pilot program established by our mother for children of various ages with "multiple disabilities." Despite great variance in age and abilities, through each other we all learned more than anyone expected. According to the experts (at the time) children with significant disabilities were uneducable. The pilot program was hailed as a radical success and when asked, "To what do you attribute such success?" my mother would simply say, "A little child would lead them."

The mothers of these disabled children learned to ignore the experts and trust their instincts. Despite predictions that David would never walk, every day our mother stood David up and walked with him, saying as she did so, "Stand and walk, David." At first she knelt on the floor

and held him up, allowing him to get used to having his feet under him. He walked on her feet and she strode with him. He held her outstretched hands and she lead him. Little by little my mother moved herself further away to the point that she used a string held taut and he would walk by inches. There were years upon years of “Stand up and walk, David” and the subsequent process of holding on yet letting go. There was one specific moment when I became conscious of the futility of this ritual and I thought, “Are. You. Kidding. Me?” In that precise instant, David stood up and walked across the room to our mother. He was ten. I was eight. I became witness to the interior mystery of David (and Walter).

Successively we continued attending the same schools together until it was time for each of us to graduate. Walter graduated at 21, David at 25, and I at 17.

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**So too, in death, it was asked: “What, after all, was the value of his life?” I have no words to describe our anguish having to assert the inherent and unlimited value and dignity of a human life, all human lives, this human life, this one so deeply loved, Walter. Walter’s life was a gift of inestimable value.**

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After graduating, Walter left home for “placement” in a “modern” institution. At twenty-nine, in another ground-breaking event, Walter became the first individual with significant disabilities to move into a “home” in the community. Tragically, there in his “home,” Walter asphyxiated on a peanut butter and jelly sandwich. He was only thirty-three when he died. While he lived, many tried to measure his life in anticipated limitations, “He’ll never...walk, go to school, live in his own home...” So too, in death, it was asked: “What, after all, was the value of his life?” I have no words to describe our anguish having to assert the inherent and unlimited value and dignity of a human life, all human lives, this human life, this one so deeply loved, Walter. Walter’s life was a gift of inestimable value.

Despite the tragedy, and in some way because of it, our parents had hope for David. David moved to the community at twenty-nine and our parents developed employment opportunities for him. They worked through numerous transition details including, ultimately, the transition of the role of advocacy. At thirty, I was established as David’s primary advocate. As hard as it was for them to relinquish their advocacy, their love, like that taut little string, was a measured letting go, preparing for the time when they would no longer be with us.

It has been twenty years since I inherited the advocacy role. Year after year I continue to learn from David. He possesses wisdom that I am slow to learn.

For example, I made a perfect plan so that David could enjoy some local gardens and holiday decorations. With coats and hats, we left the house and started walking to the car. David decided to walk at one inch per minute. Halfway to the car David stopped and stood immobile for ten minutes more. After arriving at the gardens, I shut off the radio and David responded with yells of discontent. We progressed by inches. I pushed. David stopped. After an hour and a half, exhausted, frustrated and near tears, I dropped on a bench next to a big holiday display. David sat next to me and started laughing.

David’s laughter made me reconsider the evening: David went outside and the cool winter air carried the smell of wood-burning fireplaces. It was good. It got cold and we got in the warm car where we turned on the radio and listened to oldies music. It was good. At the garden

hundreds of well-wishers said, “Hello” and “Have a great evening!” to David. It was good. My planning and pushing was devoid of pleasure. When we finally sat together, David laughed heartily—a display of pure joy. There we remained with heads together and rosy cheeks, enjoying the night, enjoying the community. We sat on that one bench until David got up to go. It was so very good—once I learned to experience the evening from David’s point of view.

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From the moment of my birth my identity was developed in relation to my family and within the group of “babies.” Though separate and distinct we were also one. Though my brothers were labeled with disabilities, I know that I am the one who is impoverished, who lacks.

My brother David understands things that I can only hope to grasp. He has an inherent sense of time, an inborn joy, and more than anything he possesses the same superabundant love as my mother. To sit with my brother David is to be moved by the power of his love. Despite my impatience and arrogance, my sins and shortcomings, he loves me. David’s love is purely generous. And, through my relation to him, I’m the one who continues to grow.

“It is most often to others that we owe our survival, let alone our flourishing ... the virtues that we need ...[are] ... the distinctive virtues of dependent rational animals.”

—Alasdair Macintyre, *Dependent Rational Animals*



# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## Life Is A Blessing

MELANIE DANNER

**Clara Lejeune-Gaymard**, *Life Is a Blessing: A Biography of Jerome Lejeune* (The National Catholic Bioethics Center, 2010, 139 pages).

*This article was featured previously in our issue on Fatherhood (Winter 2012/13).*

*Life Is a Blessing* recounts, largely in vignettes, the life of Dr. Jerome Lejeune as seen through the eyes of his daughter Clara. A great depth underlies her seemingly simple narrative of his life in three arenas: geneticist, doctor, and father. She asks with some sorrow, “Why should we call to be our witnesses strangers who will never know with what love he loved us? Why confess to them that we will never really know it ourselves, since love is so mysterious, obscure, and painful, even in its own domain?” (p. 112). Her labor in undertaking the task nonetheless is a real blessing for readers who have the grace to encounter a man whose extraordinary fruitfulness flowed from a certainty of being loved.

Jerome and his wife Birthe created a home characterized by “hospitality without limits,” experienced by his children and the constant stream of guests. For the former, it was the foundation of a positive sense of self: “The child who sees that his parents love each other understands everything.... He is there because his parents loved each other one day, one night, thus bringing about the miracle of life. He is happy because his parents still love each other. He is happy because his parents are happy that he is there, a witness to their love” (pp. 1-2).

For Jerome, hospitality was born of his own experience of being deeply loved, so the awareness that life is a blessing blossomed from his earliest days. From his diary, we learn that his father rejoiced on his deathbed that he and Jerome “had lived together without ever a [harsh] word between us,” and Jerome describes the happiness he enjoyed with his father as “one of the most beautiful gifts Providence has given me” (pp. 130, 136). In short, the paternity he lived toward his children and his patients can be outlined thus: father, because first son. With such a powerful example of paternity, it is not surprising that Jerome joyfully embraced the Fatherhood of God and passed on to his five children “what he considered the most precious gift that a father can give his children: the gift of knowing that they are loved, infinitely loved, by the God of the living” (p. 108).

Their parents introduced Jerome and his two brothers to beauty, immersing them in literature, music (his mother was a musician), and art (his brothers became artists). “As adults, they considered that what their parents had given them was beautiful and good. They cultivated it without contesting it” (p. 84). Jerome, though a doctor, because of his upbringing, looked at the world with an artist’s eye and filled his lectures and writings with metaphors to make them more easily grasped, often using images drawn from his Sunday walks in the countryside.

Between this emphasis on beauty and the perception of life as gift, Jerome’s life and work was infused with a sense of wonder. Man alone among the creatures has the capacity for wonder, as he told his children: “admiring a sunset, contemplating beauty, being aware of the Infinite, and hence being able to reason about the human condition – only man has that grace” (p. 16). Wonder and curiosity constantly reinforced each other and led to knowledge: “Understanding the human body, its subtle mechanisms, the origin of life – for him it was an object of study, but also of unending wonder. What a marvelously ingenious and complex machine is this body that makes us live!” (p. 24). One of Dr. Lejeune’s early discoveries (in 1959) was the presence in persons with Downs syndrome of a third chromosome on the 21st pair, a genetic anomaly he called trisomy 21. In a cultural context in which children with this disorder were often believed to be the consequence of moral depravity in the mother, his finding gave dignity to people he called “the disinherited.” Thirty-five years later, at Dr. Lejeune’s funeral, a man who was one of the seven whose karyotype led to the discovery of trisomy 21 stepped unbidden to the microphone to make the following tribute: “Merci, mon professeur, for what you did for my father and my mother. Because of you, I am proud of myself” (p. 123). Later, Dr. Lejeune went on to find the genetic causes of cri-du-chat, monosomy 9, trisomy 13, and other rare diseases. He also made a breakthrough regarding the prenatal use of folic acid to prevent spina bifida. He accompanied countless parents in embracing their genetically handicapped children: “[After the appointment,] we left with our baby, all of us much calmer. He helped us to discover our love as parents” (p. 27).

In his passionate desire to improve the lives of the “disinherited,” Dr. Lejeune spent the remainder of his life searching for a cure for trisomy 21; he believed a cure for this most prevalent of genetic intellectual disorders (1 in 750 births) would pave the way for the cure of the less common ones. He gave unstintingly of his time to his patients, their parents, his research, the training of a whole generation of French geneticists, participating in international conferences, and serving as a scientific advisor to numerous governments. Much recognition and many prestigious prizes came his way, but he continued to live a completely unpretentious lifestyle, e.g. wearing the same suits for decades and riding his bicycle to and from work daily. He renounced the opportunity to have “power lunches,” coming home from the university to eat with his family each afternoon. During the summers, Birthe returned to her native Denmark with the children. Jerome accompanied them on the long drive, but only stayed a few days before returning to Paris to continue his research. He missed his family tremendously, but he did not complain about the painful separation. Each evening, he wrote a letter to Birthe. In fact, for the length of their marriage, they wrote to each other every day they were apart.

It was essential to Dr. Lejeune’s work that he knew himself to be so loved (by God, his parents, wife, children, and patients) because it gave him the strength and courage to continue his work when the praise and approval of the media, colleagues, and the international scientific community turned to scorn and persecution. In San Francisco in 1969 when he went to receive the William Allan Memorial Award from the American Society of Human Genetics, Dr. Lejeune committed career suicide. Understanding that his discovery that allowed persons with trisomy 21 to be identified in utero was going to be used to destroy rather than treat them, he testified *as a geneticist* about the uniqueness of each child. His speech was received in utter silence.

That evening his letter to Birthe anticipated the certain result of his testimony: “This afternoon, I lost my Nobel Prize” (p. 39).

For Clara and her sister, their childhood came to an abrupt end the day they cycled to school past a wall spray-painted “Lejeune and his little monsters must die!” (p. 47). Suddenly, the university deprived Dr. Lejeune of his office space, lab, and funding for research. For the last 15 years of his professional life, funding came from abroad. “He experienced the betrayal of friends, administrative harassment, the condemnation that the modern press can wield.... If he suffered, he never let us see it. In the face of insults, he used to smile, saying, ‘It is not for myself that I’m fighting, so these attacks don’t matter’” (p. 97).

In 1994, John Paul II appointed his friend Dr. Lejeune, then terminally ill, as the first president of the Pontifical Academy of Life. He held the post just over a month until his death on Easter Sunday. For the funeral, the Pope sent a message: “We are faced today with the death of a great Christian of the 20th century, of a man for whom the defense of life became an apostolate.... Prof. Lejeune was always able to employ his profound knowledge of life and of its secrets for the true good of man and of humanity, and only for that purpose” (p. 138). When John Paul II visited Paris in 1997, he prayed at the tomb of his friend, despite the vociferous protests of the French government.

Love, hospitality, wonder, courage, and strength – these all indicate a truly human itinerary. For this reason, in April 2012, a solemn Mass in Notre Dame Cathedral marked the close of the diocesan phase of the cause for canonization of Dr. Jerome Lejeune, and all the pertinent documents were forwarded to the Vatican. So Clara Lejeune-Gaymard’s biography witnesses to a paternity that was not reserved for his family alone but radiated out to the whole world. Perhaps before long, he will be a patron saint for many fathers, doctors, scientists, and above all for the “disinherited.”



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# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## Simply Present

CARLA GALDO

**Henri J.M. Nouwen**, *Adam: God's Beloved* (Maryknoll, NY: Orbis Books, 1997, 2012.).

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*From the moment I saw Adam's body lying in his casket, I was struck by the mystery of this man's life and death. In a flash I knew in my heart that this very disabled human being was loved by God from all eternity and sent into the world with a unique mission of healing, which was now fulfilled. (15)*

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Much of Fr. Henri Nouwen's writing is characterized by simple language that plumbs deep spiritual depths. This book is no different; however, unique to this work are the autobiographical elements that also reveal some elements of Nouwen's personal journey in his final years of life. A Dutch-born Catholic priest, Nouwen was also a prolific writer and well-known academic for decades before he became both member of and pastor for the L'Arche Daybreak Community in Toronto, Canada. Stepping away from academia and into a community home where he lived with and served intellectually disabled individuals, Nouwen encountered Adam Arnett, the book's namesake.

Adam was unable to speak, was afflicted by seizures throughout his life, and in need of help for most of his basic daily life tasks. He was the person in the community most in need of care and assistance, and he was "assigned" to Fr. Nouwen when he first arrived. He helped Adam get ready for the day, which involved bathing and dressing him as well as supporting him while he ate and drank. Although he approached his task with trepidation at first, eventually he gained confidence and a great love for his disabled friend and community member.

Adam's death punctuated a sabbatical which Fr. Nouwen took after ten years as Daybreak Community's pastor, during which time he intended to write a book pinpointing the answer to

the basic human question “What do I believe?” At first he began work on a theological analysis of the Apostles’ Creed. When Adam died, the project was nudged in another direction. Adam, in his brokenness and vulnerability, became the lens through which Nouwen could see more clearly the way each person is called to relationship with and revelation of Christ. The pattern of Christ’s life, from his hidden life as a child and young adult to his public life, passion, death, and resurrection, was the same pattern Nouwen saw in Adam’s life and death.

Nouwen’s short work, which was still being written at the time of his sudden death at age 64, fleshes out in detailed and accessible terms the immense gift that disabled persons are to the Church and to humanity. Catholics are accustomed to hearing about and, hopefully, exercising “the preferential option” for poor and vulnerable persons, but the value of such persons can often be described in trite terms. Given the culture’s tendency to exalt only those who are beautiful and/or useful, it is good to be armed with more than surface-level platitudes when trying to explain and defend the place of the disabled and weak among us. Nouwen emphasizes that Adam was not an unusually gifted or angelic individual; he was just one person among many at the community. It was Nouwen’s close relationship with him that enabled Adam to become the mute yet eloquent revelation of the mystery of God’s incarnation among us.

Adam’s ability to bring healing and peace was not limited to his long-term caregivers. Nouwen shares several striking anecdotes about friends or strangers who came to share the community’s life at L’Arche for short visits, and who, through their care time with Adam, came to a better place in their spiritual journeys. Adam’s “ministry” to these individuals was clearly unique, given that he “didn’t know about care, ministry, healing or service. He seemed to be without concepts, plans, intentions, or aspirations. He was simply present, offering himself in peace and completely self-emptied” (64). Confronted with Adam, visitors often came to know and accept their own, less visible disabilities. Nouwen doesn’t miss the nuances, however— he takes care to point out that this was not always the case for those who met Adam: “For some it was an experience of peace, and for others a self-confrontation; for some it was a rediscovery of their hearts, and for others it meant nothing” (64). Nouwen himself had a significant moment of healing thanks to Adam, a time in which he struggled with doubts and demons and uncertainty of his worth and of God’s love for him. Through the experience of what he calls “our poverties touching each other” (80), Nouwen saw his own brokenness, need, and dependency reflected back to him. Adam’s existence, his very way of being loved and loving, reassured him that even in the midst of his fragility, he is still lovable, and beloved, by God.



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# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## Foucault's Disability: From Social Construct to Self-creation

JOHN LARACY

**Michel Foucault**, *History of Madness* (Routledge, 2009).

Michel Foucault's first major study, *History of Madness*, documents the unjust social exclusion of the disabled in the modern era but fails to offer a coherent and credible way to transcend it. Initially a teacher of psychology and a psychiatric researcher, then the famous philosopher and radical social critic, Foucault (1926–1984) followed an intellectual path astonishingly similar to that of Friedrich Nietzsche, his chief influence, from a questioning sense of the tragic condition of modern man in the 1961 edition of *History of Madness* (cf. Nietzsche's *Gay Science*, books 1-4), to a firmer confidence in the potential for uninhibited self-creation in the additions to the 1972 reissue (cf. *Gay Science*, book 5). Thus, by contrast to the more certain and total rejection of moral objectivity exhibited in his later work, this early work portrays the author's own difficulty in deciding how to respond to social oppression.

David Macey, Foucault's biographer, noted the difficulty of *History of Madness* and how it "defies attempts to summarize its contents" because its expansive investigation into various social strata weaves together complex analyses of diverse historical sources, including famous works of visual art, literature, philosophy, and theology, as well as obscure legal and medical documents. But it does display a philosophically-tinged historical logic, including a definite method as well as key terms and claims, which are susceptible to concise description and critical engagement. With regard to methodology, Foucault explicitly states his purpose to avoid the common presumption of "narratives of progress" that read history as if scientific reason and institutions were its inevitable *telos*. Thus, rather than portray the history of madness as a movement toward the triumph of modern psychiatry, he shows how the genesis of social structures from the Middle Ages to today founded the unique concepts and experiences of madness in these distinct eras.

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**Foucault's assessment of Christianity here fails to sufficiently consider its claim that divine wisdom is the foolishness of love, which gladly suffers on the cross for**

## the beloved (see 1 Cor 1-2).

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This method is matched by a set of key terms, including “madness,” “reason,” and “unreason.” In contrast to mental illness, which is a physical illness that affects reason, madness for Foucault is strictly socially-constructed. He defines it most concisely as the “absence of an *oeuvre*,” which is to say, the lack of any effective role in the culture. To be clear, he is not claiming that madmen lack the capacity for creativity but rather that those deemed mad in any era are preemptively deprived of creative influence in being excluded by the dominant culture. Madness, then, is an exclusory name for what he calls unreason: those dark, subterranean forces of nature that exceed the grasp of reason, including animal passions, especially sexual passion, disease, and death. His basic thesis is that Western reason, particularly since the 17<sup>th</sup> century, has unknowingly constituted itself as the mastery of unreason through an act of exclusion by which it assigns to unreason the name of madness, rather than entering into dialogue with it. Although his method claims to avoid morality and teleology, this thesis implies a moral imperative: the oppression of the “mad” *should* give way to the celebration of unreason; that is, the power of reason *should* join forces with the irrational powers of nature in the act of free self-creation. Accordingly, dispositions of mental illness, disease, and disability, should not be considered abnormal, but should be seen as apt material for the creativity of reason.

Foucault’s historical investigation begins in late medieval and renaissance Europe where the mad were sometimes exiled and reduced to wandering but remained part of the social fabric. On the one hand, they were an occasion for charity, as shown by the way that hospitals began to reserve a special place of care for them. On the other hand, they were a sign for the imagination of hidden worlds and cosmic forces, as shown by the paintings of Dürer and Bosch. But as Christian thought advances, the dark powers represented by madness were integrated into an order of divine reason that unilaterally determined their ultimate meaning. Foucault’s assessment of Christianity here fails to sufficiently consider its claim that divine wisdom is the foolishness of love, which gladly suffers on the cross for the beloved (see 1 Cor 1-2). Accordingly, “madmen” like St. Francis who love too much, far from being absorbed or excluded, are exemplars of Christian wisdom, and the mentally ill and disabled with their capacity for empathy have a unique potential to become sacraments of divine love. The claim that reason and infinite passion are one in Love would challenge Foucault’s basic division between reason and unreason and point to a positive sense of madness.

Foucault’s more illuminating account of the shift from the Renaissance to classical modernity focuses on a major symbolic event: the founding of the Hôpital Général in France in 1657 where madmen, the poor, sexual deviants, and thieves, among others, were confined together *en masse* in harsh conditions without distinction. Initiated throughout Europe in order to overcome the unrest and moral decay associated with idleness—the chief sin of the emerging bourgeois order—this mass confinement created a “uniform world of Unreason” apart from society. Thus the mad, now associated with the limitless frenzy of animal passion, were indiscriminately grouped together with homosexuals, adulterers, and victims of venereal disease, all of whom were considered moral threats to the bourgeois family.

Foucault then focuses on another symbolic event: Philippe Pinel’s mythologized liberation of the mad from their chains at Bicêtre Hospital in 1794 and the founding of a new kind of mental asylum at Salpêtrière (the analogy in America is Dorothy Dix and William Tuke in England). While familial conflicts became more and more a private affair, a problem of guilt over the failure to achieve bourgeois ideals, the severely deranged continued to be confined in these

new asylums modeled on the patriarchal family. In this space, unchained madmen were preemptively silenced by the authoritarian gaze and moral monologue of the doctor who stands as reason over against unreason. Although Freudian psychoanalysis restored speech to the mad, Foucault sees this too as a form of “the absolute Gaze,” a kind of mirror for madness that controls it by showing it to be such. Despite the development of authentic physical cures for mental illness, psychiatry today continues to blindly constitute itself as dual control of bourgeois immorality or “madness,” on the one hand, and physical disease, on the other.

But the book’s conclusion expresses hope for an unspecified change in light of the enduring artwork of excluded “madmen” like Van Gogh and Nietzsche who entered into dialogue with unreason, called into question the domination of reason, and thus make the world “aware of its guilt.” With this surprising ending, Foucault seems to call into question his a-moralism and relativism, for he suggests here that the beauty of the persecuted and their persistent creativity make a claim on the human community and reveal its failure to secure its own common good. In other words, this uncertain but subtly hopeful conclusion points to the idea that the beauty and goodness of others, especially of marginalized “madmen,” make a claim on “the world,” calling for shared repentance and social transformation. Foucault implies, then, that there is common good and objective beauty transcending not only bourgeois morality but also individualistic self-creation.

However, in the added preface and appendices to the 1972 edition, a more optimistic tone accompanies a more radical acceptance of his original presuppositions: human reason is unrestrained self-creation through the control and appropriation of unreason, disorder, and destruction. Foucault, an avid political activist for freedom from social norms, hoped that mankind could share in this pursuit together, despite the fact that nothing good, true, or beautiful could possibly endure. But his own life and work, like Nietzsche’s, casts doubt on this celebration of pure self-creation in the face of ultimate destruction. For while they both succumbed to disease before old age (Foucault of AIDS, Nietzsche supposedly of syphilis), their thought-provoking critiques of the modern epoch and their pathos for those oppressed by it continue to raise the question of whether there is more for which to be hoped. While Foucault, moreover, should be commended for helping us to separate the ideas of moral culpability and mental disability, his total denial of norms for personal health or wholeness undercut the possibility for the integral healing of mind and body. Even more importantly, his false ideal of individualistic power undermines the true power of the mentally ill and disabled: the power to receive, give, and elicit mutual love.



# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## Vulnerability and the Cult of “Normalcy”

SARA HULSE

**Thomas Reynolds**, *Vulnerable Communion: A Theology of Disability and Hospitality* (Brazos Press, 2008).

What is health? What does it mean to ‘be’ disabled? What is the relationship between “disability” and perfection; disability and church; disability and the new life found in Christ?

These are the questions that drive Thomas Reynolds’s text, *Vulnerable Communion: A Theology of Disability and Hospitality*.

Written from the heart of a father of a disabled son, the text remains theologically rigorous yet personal and concrete. Before launching into a social, philosophical, or theological reflection, most chapters begin and end with a story about Reynolds’s son, Chris. Chris has been diagnosed with several neurological disorders, including Asperger’s syndrome, bipolar disorder, Tourette’s syndrome, and obsessive-compulsive disorder. It is from personal encounters with his son that Reynolds’s reflections take shape.

In the introduction, Reynolds recounts the story of his son’s removal from Sunday school on account of “inappropriate behavior.” Though not meant in malice, the episode, which occurred in the early stages of Chris’s diagnoses, was enough to turn the Reynolds family from the church. Reynolds concludes that this lack of welcome is rooted in an inadequate, modern, exclusionary anthropology, upheld by societal mores and what he calls the “cult of normalcy” (a phrase admittedly inspired by Stanley Hauerwas’s expression, “tyranny of the normal”). It thus becomes Reynolds’s mission in the text to dismantle this modern anthropology (with its accompanying visions of “health” and “normalcy”) and re-cast disability in light of an adequate anthropology, rooted in the redemption of Christ. Further, he calls into question Christian charity vis-à-vis the disabled, noting that persons with disabilities are not simply a one-way occasion for Christian charity, but are themselves icons of the limitations and vulnerability common to us all.

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**I am a finite creature; thus, I am limited, held in being, and constitutively related to God and others. This vulnerability and dependence is more essential to me than what I can do or produce.**

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The first chapter focuses on currents of social and theological thought regarding disabilities. Reynolds identifies the “medical model” of disability, which “tends to reduce disability to a problem requiring diagnosis and treatment, a broken object to be fixed, made better or overcome. In doing so...the person becomes reduced to a function of disabilities rather than vice versa” (25). In other words, the medical model reverses the order of things: it reduces a person to his disabilities, making disability the defining element of the person, and thus undermines the dignity and identity of the person (consequently, we speak of “the disabled” versus “persons with disabilities”). Further, according to this model, disability is an anomaly: something abnormal, common to “the disabled” alone, that must be fixed. Without this “fix,” a person experiences limited quality of life.

This medical model is rooted in the “cult of normalcy” explored in chapters two and three. By “cult of normalcy,” Reynolds indicates the tacit, unquestioned set of beliefs held by modern liberal society regarding what constitutes “normal” human life and flourishing, “values such as freedom, equality, independence, rationality, productivity, efficiency, and prosperity” (70). So long as a person subscribes to these values, society is “tolerant” of him or her. Persons with disabilities, however, transgress these modern ideals, and thus threaten group identity. As a result of their inability to assimilate to modernity’s definition of normal (self-sufficiency, rational autonomy, productivity and so on), they are construed as un-healthy (health being the ability to realize liberal ideals in mind and body) and, further, are un-welcome (fail to be received in a mode other than pity).

Though this anthropology developed out of the 19<sup>th</sup> century secular liberal tradition, Reynolds observes it is widely accepted and unquestioned by Christians today. Persons with disabilities are thus construed as “the disabled”: human beings to be pitied on account of their inability to engender liberal ideals in mind and body (and who must, therefore, experience lesser quality of life). They may also be construed as potential “opportunities” to exercise “our” Christian charity. In either case, the person is reduced to his disability, and his disability is cast as something broken that must be fixed. The Christian model of disability, in other words, accepts as its basic framework the anthropology undergirding the medical model.

Regardless of where it is manifested, Reynolds identifies the most dangerous implication of this model as the lack of welcome toward the person with disabilities. Though liberal ideology touts “tolerance” as one of its cardinal values, Reynolds observes that we are tolerant only insofar as persons fit group identity. When one is unable to conform, the person is unwelcome. The effects of this are grave and offend against the deepest desires of the human heart. Reynolds insists that “[t]he basic question of human existence...is whether there is a welcome at the heart of things. Will I be received and embraced?” (51). This welcome is also essential in terms of our self-realization, for the human being subsists as one who is constitutively related to God and others, and receives knowledge of their “I” in and through these relations. In light of this, the walls built by the cult of normalcy gravely violate the dignity and identity of the person with disabilities. The *oikos* (home) we long for is traded in for an *oikonomia* (economy) of *exchange*, that “designates conventions and qualities that comprise what it takes to belong” (57). Being different, the disabled body is treated as a stranger, thus unable to experience

welcome and self-realization.

In chapter four, Reynolds begins to “paint a more adequate portrait of being human, a vision grounded in themes of embodied relation, vulnerability, and love” (18). He asserts that “being human and whole means more than self-creative autonomy and productive efficiency” (18). Indeed, we are persons in and through our relations, and, further, as creatures, we all share a common vulnerability and finitude (limitation). The notion of autonomous self-creation is an “illusion” (105). I am a finite creature; thus, I am limited, held in being, and constitutively related to God and others. This vulnerability and dependence is more essential to me than what I can do or produce. Thus, Reynolds concludes, the sharp division between “the disabled” and the “non-disabled” is also an illusion. As he explains, “[d]isabled and non-disabled people do not count as two mutually exclusive categories of human beings. All people are linked indissolubly, sharing a fundamental condition: vulnerable personhood” (105).

In chapter five, Reynolds explores this anthropology of vulnerability and dependence vis-à-vis creation, meditating on being as gift and the notion that all creatures have been loved and willed into existence. He re-casts welcome in light of *esse* and *creatio ex nihilo*: because I exist, I am welcome, I belong. I have been invited into being. “Welcome is at the heart of reality” (140). Therefore, the most appropriate posture of my being is one of gratitude and hope.

Chapters six and seven enter the specificity of the Christian faith, exploring themes of “image and likeness,” redemption, and church. Very much in line with St. John Paul II, Reynolds explores the idea of God-as-Trinity and the implications thereof. God is not simply autonomous and self-sufficient, but a communion of persons. Therefore, in the creaturely realm, human relationality does not “cross out” this image, but is indeed a very icon of it—a reflection of and participation in the inner-life of God Himself. Further, Reynolds turns to Christ, whose divinity was affirmed and made manifest precisely in his vulnerability. In Him, vulnerability is not rejected or hidden, but taken up and exalted as divine; disability and perfection are wed. “Far from something to be cured and gotten rid of...disability is a locus of divine relational power” (232).

This vision of Christ has radical implications for church life and ministry. Churches should live hospitality, not as a one-way, moralistic act, but as a participation in and act of gratitude for the welcome at the heart of reality. Further, the charity of Christians should be informed by our common vulnerability and the curious type of perfection revealed in Christ. Reynolds quotes Jean Vanier, who states: “This is my vision for our churches, that they become places of belonging, places of sharing...[among] broken men and women, like you and like me” (249). The “fuel” for this mutuality and inclusion is our creaturely status and reception by Christ, who loved us first (1 John 4:19).

In the end, it is clear that Reynolds accomplishes what he set out to do. In light of Christ, health is re-cast as dependence, gratitude, and relationality. The cult of normalcy is overturned, and disability is re-cognized as a property rooted in the creaturely status of the human being, and further embraced by Christ. The implication for Christian churches, then, is a movement from a model of pity, informed by liberal ideals, to one of empathetic welcome, rooted in a living awareness of our own vulnerability qua creatures of God.

While I am on the whole sympathetic with Reynolds’s argument, his position does raise certain questions. In Reynolds’s attempt to avoid the stigmatization of persons with disabilities, he comes dangerously close to implying that there are no natural norms for human health. He appears to collapse the distinction between the conventional and the natural. This raises a red flag insofar as it throws into question the end of medicine. While we certainly don’t want to

subscribe to a cult of normalcy, neither do we want to deny medicine's goal of restoring the body to good working order (which requires a notion of "good working order" as such).

Reynolds's reflections clearly have positive implications for the question of health beyond persons with disabilities, such as the unborn child, elderly persons, and the suffering body. Following the vision laid out in the text, we find the "golden thread" for interpreting these other states of being: namely, that every human being has been loved and willed into existence and is therefore worthy of love and belonging. Further, far from inhibiting true communion, these states of being draw us into it, as they call us to remember the vulnerability and dependence common to us all.



# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## What the Body Remembers and Our Culture Forgets

RACHEL M. COLEMAN

**Stanley Hauerwas**, *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (University of Notre Dame Press, 1986).

Our culture has no memory, and indeed at times it seems to actively prevent one from forming in its people. By memory, I do not mean here each individual's remembrance of past events, which may coincide with others'. Rather, I mean something along the lines of a deep intuition of where we as a culture have come from, what we as a society value, and who we as a people are. The Canadian philosopher George Grant has written at length about this in his essay, "In Defense of North America." [1] We North Americans, Grant observes, have a difficult time saying who we are because our cultural memory is lacking. We know not what the *humanum* is, as this knowledge has not been passed down through our generations.

We might ask what this has to do with the mentally handicapped, or society's treatment of those who are mentally handicapped. Enter Stanley Hauerwas's *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church*. Published originally in 1986, some of what it takes up seems rather naïve, given the bioethical issues we now face as a culture (the chapters on brain death, physician-assisted suicide and IVF, for example, all treat these issues as if they are remote possibilities), but the underlying point of all these essays remains clear: when what it means to be human is premised upon only what we as autonomous individuals can do or produce, rather than upon a much broader and deeper understanding of the *humanum* that takes into account our communal nature and even our natural neediness, the most vulnerable in our society will at best be pushed off to one side and neglected, and at worst be persecuted for their very vulnerability.

The book is a collection of reprinted essays, originally published from the years 1975–1981. The topics range from medicine and medical ethics in general, to caring for the mentally handicapped in particular. Though Hauerwas never uses the term memory thematically, I think it a good way to tie together the at times disparate points of these essays—no matter to which deficiency Hauerwas alerts us, all have this deep cultural memory problem (or amnesia, as it were) in common.

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**...to be and to do the good is never a quest for a single individual's superiority or freedom, but rather a community's memory of itself and what it exists to do.**

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The first part of the book addresses medicine broadly, and here Hauerwas returns us to the memory of our own body, that is, the intuitive knowledge we have of both the natural powers and the natural constraints of our body. The body, then, is a natural sign of what is true about the whole of the human condition—we are limited and vulnerable, and we rely on each other all the time. The practice of medicine is a particular way in which we address this natural vulnerability (though not the only one). Medicine, Hauerwas reminds us, is not—or at least was not, for a long time—an all-out technological pursuit of life, but rather an art that is always dealing with and working within the constraints of nature. Patients and doctors alike remind each other of the memory of the body—for this is what doctors deal with, a body that lives and breathes and thinks in a necessarily limited way, and whose bounds cannot always be overcome—even with the most sophisticated technological innovation.

We come up hard against these limits when we encounter suffering, either our own or others'. This is the point at which our body—which is normally so enabling or active—becomes a burden and we know not how to face it. Hauerwas suggests that this is why we so often turn to technology in these moments; “too often we seek to do something, rather than simply learn to be with” (175), he writes. The memory of our body—what it is, its beauty, its significance—also necessarily entails the acknowledgment of our dependence, especially during these times of suffering, when we are at a loss.

It is this memory of our dependence that leads us to reject those that are mentally handicapped, Hauerwas avers. The great strength of these essays is that Hauerwas realizes, and helps his reader to realize, that the situation of those people who are mentally handicapped is not alien to our own. They, too, are human; therefore, we all have more in common than not. But this last part is no longer a given, and that has a lot to do with how we understand ourselves and what it is to be human in this culture.

Our dependency, our insufficiency, is not an evil. Nor is it an annoyance to be taken care of in some way or another. It is, rather, in some sense our very form, that out of which we grow and learn what it is to be human. Think of an infant in all its helplessness. But it is this substantial part of our nature with which we, Hauerwas points out, are entirely uncomfortable as a culture. We do not like to be reminded of it in any way, and therefore people who are mentally handicapped, who are dependent in perhaps more outward ways, are ostracized in a society like ours.

This does not mean that those who are mentally handicapped are reducible to their dependency, devoid of any agency of their own. “Are handicapped people not born like the rest of us with limits and possibilities?” (182) asks Hauerwas. This is the point: that we are always dealing with the *humanum* in all its dependency, though that dependency shows forth in every body in different ways all the time. But our society is based on an ethos of pure freedom, says Hauerwas—to be able to do what we want, when we want is, it seems, the ultimate good.

Nor can one individual or many individuals together simply overcome this ethos if they accept its given premise about what it means to be human. Hauerwas spends some time on the concept of rights and how we can see through the experience of the mentally handicapped and

those around them that fighting for rights over against society is not a solution to the poor treatment or ostracization of those with mental handicaps. Rights come precisely out of an ethos of pure freedom, and thus “fighting for them” will never be an answer to changing our society as a whole. Hauerwas emphasizes again and again throughout these essays that to be and to do the good is never a quest for a single individual’s superiority or freedom, but rather a community’s memory of itself and what it exists to do. Thus, the “issue is not whether retarded[2] children can serve a human good, but whether we should be the kind of people, the kind of parents and community, that can receive, even welcome, them into our midst in a manner that allows them to flourish” (167).

Too often the question about the mentally handicapped revolves around doing something about—trying to fix—the handicap or the person with the handicap. Hauerwas turns the question on its head, asking us instead to remember first of all what it means to be human, and whether, in this remembering, we might finally recognize the handicaps in our broader cultural understanding.

[1] This essay can be found in *Communio: International Catholic Review* Volume 38.2 (Summer 2011).

[2] This is obviously a culturally loaded term, but Hauerwas does give a reason for using it despite its grossly negative connotation. He thinks “mentally handicapped” ambiguous: “Many suppose that ‘mentally handicapped’ suggests mental illness. Of course someone mentally retarded could also be mentally ill, but it would be a terrible mistake to underwrite the idea that mental retardation and mental illness are necessarily related” (16). Hauerwas’s broader underlying point, however, seems the strongest reason to keep the word as it appears in his texts: that the stigmatization of the word “retarded” relies already on a society formed by an ethos of pure freedom, and he would rather not play into that ethos.



# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## Being vs. Doing: Personhood and Vulnerability in John Paul II

KATHLEEN CURRAN SWEENEY

**Jeffrey Tranzillo**, *John Paul II on the Vulnerable* (Washington, DC: The Catholic University of America Press, 2013).

In this substantial work, Jeffrey Tranzillo confronts the underlying cultural assumption that the seriously disabled, elderly and dying do not have lives that are worth supporting. This stance is based on a defective understanding of the human person, Tranzillo emphasizes, suggesting that a more appropriate anthropology of vulnerable human beings is needed. To that end, Tranzillo draws on the philosophy and theology of the human person as developed by Karol Wojtyła/Pope St. John Paul II in works such as *Person and Act*, *Person and Community*, *Theology of the Body*, *Evangelium Vitae*, and the late pope's social encyclicals.

Tranzillo explains that Karol Wojtyła sought to integrate the phenomenological analysis of subjectivity with Aristotelian anthropology and so developed an extensive examination of human consciousness in relation to human actions. Challenging Max Scheler's reduction of personhood to consciousness, Wojtyła considered it erroneous to separate the person's self-conscious activity from his natural bodily psychosomatic activity. Such a reductionist view that diminishes the human person to just a center of consciousness (and autonomy), he thought, did not reflect the actual reality of our experience, and provides grounds for dangerous attitudes toward human development and disability. It is an error that puts more importance on what one does than on what one is. The consciousness of oneself as a personal subject is but one aspect of human experience, not the whole of it. Therefore, consciousness alone could not exhaust the definition of a person. If a human being has potential for rational acts, it is because he is already constituted as a concrete human person, a metaphysical subject who is an integral unity of body and soul from the first moment of existence. Rational conscious acts proceed from the essence of what the human being is. Action reveals the person but only because of what the human being is (*operari sequitur esse*). Relative to the disabled, Tranzillo cites Wojtyła who wrote:

The fact that the human suppositum, or metaphysical subjectivity, does not

display the traits of personal subjectivity in certain cases (i.e. in cases of psychosomatic or purely psychological immaturity, in which either the normal human self has not developed or the self has developed in a distorted way) does not allow us to question the very foundations of this subjectivity, for they reside within the essentially human suppositum. (Wojtyła, *Person and Community*, 225)

In other words, consciousness is not the essence of personhood because this essence is comprised of the composite of body and soul (the human suppositum) present from the moment of conception. At the same time, it is important to recognize that the spiritual soul is the source of unity for the composite human person. This may be expressed in the immaterial realities of self-consciousness, personal freedom and human acts that transcend the body. But regardless of physical or spiritual conditions that come and go, we are always, from the first moment of our existence, persons whose ontological structure is constituted by the union of the human body and soul. This spiritual soul as a source of personal unity explains why we cannot lose our fundamental dignity and transcendence even when there may be an immaturity of development or a disintegration of physical or mental capabilities.

In his 1976 article “Person, Subject and Community,” Wojtyła pointed out that the life of each of us begins and develops in interpersonal and social relationships, and these continue to define our existence even before our experience reaches the level of conscious reflection. My “I” is also constituted by the communal relationships of which I am a part...I need a “Thou”—another “I” to help bring out the “I” in me. We need relationships to fulfill ourselves as persons, to discover who we are, to grow in full possession of ourselves, which is accomplished by giving ourselves to others and receiving the gift of others to oneself. Revealing ourselves to others is a self-transcending act which can be affirmed by the welcoming reception from a “Thou,” which establishes a trusting relationship.

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**Only God can bring out good from human suffering; only Christianity can transform dependence, vulnerability, weakness, and poverty into vehicles of grace from God.**

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Uniquely personal forms of activity, Tranzillo points out, remain open to the most vulnerable of the vulnerable, even while they are incapable of performing actions requiring a fully mature psycho-moral personality. In the case of a severely mentally disabled person, there is still an active expression of himself precisely as a passive subject who is vulnerable and dependent because of his inability to subject his natural dynamisms to his own personal governance. In passively offering himself to another or others, this vulnerable person invites and may oblige others to discover themselves anew in the actions they take to affirm the humanity of this vulnerable “Thou.” In this interaction, the mentally disabled person may develop a measure of capacity and independence he would not otherwise have achieved. In any event, both persons in this relationship grow in self-fulfillment. Caregivers often say they have received much more than they have given in caring for such vulnerable persons. The non-functional person can give a functional person, who may often be scurrying about “doing,” pause to consider what is truly important in life. After all, says Tranzillo, sheer functionality is not a value in and of itself. It is only as the radiation of one’s being to others since “being with and for others” is an ontological disposition before being realized in “doing

with and for others” (122).

“But sadly there are communities and whole societies that erect or fail to dismantle barriers that keep the person with severe physical or mental disabilities from participating in interpersonal and social life to the extent he can” (123). Those who choose to alienate vulnerable persons because they seem inconvenient, embarrassing, burdensome, useless or even threatening, develop an egoism that alienates them from the deepest truth of their being as persons, says Tranzillo.

The physically disabled may not be impaired at the level of their rationality or self-consciousness, but they may not be able to communicate externally through acts of self-expression. They are, however, capable of performing interior acts of the highest order. Since interior acts may not give signs that are discernible from the outside, those who are most radically disabled may not be able to convey to anyone that they are being deprived of some care or respect that is fundamentally their right as a human person. This would be particularly true of those who are in an unconscious state. Tranzillo states that studies of unconscious experience seem to confirm that “persons can retain their consciousness while in a state of unconsciousness,” i.e. they are aware of their inner self and external environment, able to hear, understand, and to feel, while unable to respond. (Cf. p. 101 of Tranzillo; “The Unconscious Experience,” *American Journal of Critical Care* [1995]: 227–32.)

Tranzillo also discusses the biblical anthropology of man as the image of God, which is deepened in the New Testament revelation of the Trinity of Divine Persons in a communion of personal love. Being vulnerable, Tranzillo points out, is not primarily a plea for help but an expression of the inherent drive to fulfill the image of God in oneself through personal and social communion with others. The dignity of dependent vulnerable persons also lies in the promise of resurrected life as the final destiny to which each is called—a reality in which the psychosomatic nature of the human being will be wholly spiritualized in a perfect reintegration of spirit and body. Thus, the human body is in itself a sacrament, a sign of the divine love that is both its origin and its destiny.

Tranzillo highlights St. John Paul II’s reflection that union with Christ is not only in his glory but is also in sharing in his suffering and self-emptying—the sacramental aspect of human suffering. Only God can bring out good from human suffering; only Christianity can transform dependence, vulnerability, weakness, and poverty into vehicles of grace from God. Vulnerable persons who accept this become a new creation through participation in the grace of Christ and in his redemptive suffering.

Tranzillo particularly emphasizes the moral vulnerability of those who willfully violate the whole truth about the personal dignity of the undeveloped, disabled, or dying, and thereby make themselves vulnerable to spiritual disaster in their soul. Every human person has a vocation to love in truth. It can happen that those who can be considered “strong” have inordinate trust in a “pride of life” manifest in material possessions, social status, achievements, style of life, etc. They can give in to fear of the vulnerable as obstacles to their own personal goals, a drain on their wealth, or an embarrassment to their style of life. When the hidden life of an unborn child or a person with long-term serious illness or disability seems inconvenient, a threat to their goals or way of life, the strong can decide to take power over that life in abortion or euthanasia. We gravely endanger the gift of our own life if we adopt such perverse attitudes and support the structures of sin that conspire against the vulnerable. The moral conscience of society can be degraded and can, in turn, condition people’s consciences against life, confusing good and evil. This deep moral confusion is now widespread, affecting leading institutions—legal, political, economic, scientific and

medical—which have campaigned for abortion or euthanasia as “rights.”

Tranzillo grounds his anthropology of the vulnerable further with insights from W. Norris Clarke’s metaphysics of the person, which locates relation in the very ontological structure of being. But here too, there is a need to distinguish between self-communication as an ontologically operative attribute of the personal being on the one hand, and the fully self-conscious appropriation of this attribute on the other. One’s conscious disposition is subject to change and therefore accidental, whereas the ontological dynamism of the person is essential and unchangeable. Even if the most vulnerable persons have not reached, or are no longer at a point of conscious self-communication, their personal being is nevertheless “radiant with the resplendent beauty of the spiritual dynamism of their human form which presses outward to meet the Source and goal of that dynamism, the inexhaustible Beauty of Trinitarian Love”(334).

This review only points to some of the salient concepts at work in this valuable treatise which offers a much-needed, comprehensive examination of the philosophy and theology important to an anthropology of the vulnerable. Perhaps the most important point Dr. Tranzillo makes is that the moral vulnerability of those who cooperate with the evils of abortion, euthanasia and abuse or neglect of the disabled or dependent is the greatest deprivation of all (cf. 184).



# Humanum

Issues in Family, Culture & Science

## BOOK REVIEW

### Meeting the Vulnerable: Encountering Christ

MICHEALA VAN VERSEDAAL

**Jean Vanier**, *Drawn into the Mystery of Jesus through the Gospel of John* (Paulist Press, 2004).

This book, written by Jean Vanier, the well-known founder of L'Arche and Faith and Light, eloquently meditates on each chapter in John's Gospel. Published in 2004, *Drawn into the Mystery of Jesus through the Gospel of John* is based on a 25-part television series on the Gospel of John, which was completed in September 2011. The series, *Knowing Eternity*, was produced for a Canadian multi-faith channel, Vision TV. The form of the book is as follows: the beginning of each chapter starts with a Scripture citation (usually corresponding to one chapter in John), a short, accompanying meditation by Vanier, and a black and white image drawn from a series of mosaics created by Fr. Marko Rupnik, S.J. for the Redemptoris Mater chapel of Pope Saint John Paul II. The profundity and simplicity of the featured mosaics beautifully harmonize with Vanier's words to illuminate the particular selections of John's Gospel. In addition to the mosaic and Scripture citations, each chapter of Vanier's book includes frequent scriptural excerpts from other books of the Bible, as he expounds on the stories in each chapter of John.

Vanier writes conversationally about his own spiritual journey and experiences in L'Arche and Faith and Light communities. This work does not consist mainly in specific reflections on the spirituality of L'Arche, however; nor is it primarily autobiographical. Rather, it is a profound scriptural meditation, which is informed throughout by Vanier's lifelong experience of service to the intellectually disabled; and the wisdom he has acquired from this work lends him a distinctive perspective on the Gospel of John. With this rich background, Vanier is able to inspire the reader's own prayerful reflection on the Gospel of John. Vanier sensitively incorporates stories of people living in L'Arche communities to reflect the encounters with Christ portrayed in John's Gospel. These examples disclose the vulnerability, trials, and weaknesses that all of humanity shares, regardless of physical or mental ability. Their weaknesses mirror our own and help us to recognize our own desire for love and community, and our own need for God's mercy.

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*This new way to God is not through a separation from our bodies, a struggle to become a pure spirit; it is in and through our bodies and in all that is weak and broken in us that we meet God...All Jesus asks is that we come to him with humble and trusting hearts. (256–57)*

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The stories of physical or mental brokenness and vulnerability Vanier encountered in L'Arche shed light in a privileged way on the characters of the Gospel. Each person portrayed in the Gospel is a real symbol of the Christian and his relationship with Christ. Vanier's meditation continually shows the importance of identifying ourselves with the people whom Christ encounters in the Gospel, and the importance of being with and seeing ourselves in the vulnerable: "As we get close to the poor and weak, we begin to accept our own poverty and weakness; we learn how to become vulnerable to others..." ( 239). He frequently begins sentences and phrases with the pronoun "we," which underscores his frequent invitation to the reader to identify with the people Christ calls, touches, heals, and forgives in the Gospel.

Vanier's persistent theme is the gift of a humble heart trusting in Christ. In each pericope he therefore returns to the centrality of encountering Christ, heeding his call, trusting in his goodness, entering into the mystery of his life, relinquishing one's sovereignty over one's own life, and receiving his forgiveness. In the introduction, Vanier writes: "I propose that we do not read this Gospel simply as someone wanting more theological, historical and biblical knowledge, but rather as someone who desires to be drawn into a mystery" (14). The mystery of Christ's humanity and suffering with and for us is a fundamental theme to which Vanier returns as he guides the reader through the Gospel of John. Vanier endeavors to show us that the human experience of suffering and mercy, as shown in John's portrayal of Christ's earthly life and ministry, give us the paradigm by which we can understand and evaluate our own lives.

Vanier's work is a beautiful and gentle guide leading us through John's Gospel. Vanier seeks to show that John wrote his Gospel to lead the Christian into a relationship with Jesus so that "each one of us can identify with him [the beloved disciple] and become a 'beloved of Jesus'" (12). At every turn, Vanier shows how the Evangelist draws the reader into the biblical scene, involving him in the drama of its characters. The reader thus becomes one of those who is spoken to, touched, healed, and loved by Jesus. Having been gently led by Vanier into this human encounter with Jesus, he is now drawn into deeper intimacy with him.



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# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## Lessons in the Backyard

BARBARA GAGLIOTTI

**Timothy Shriver**, *Fully Alive: Discovering What Matters Most* (New York: Sarah Crichton Books/ Farrar, Straus and Giroux, 2014).

Special Olympics Chair Timothy Shriver's new book *Fully Alive: Discovering What Matters Most* is part memoir, part history and part wisdom literature. Tim is the son of Sargent Shriver and Eunice Kennedy, the sister of JFK and the originating charismatic figure behind the Special Olympics movement. He is an educator, social activist, film producer, and entrepreneur and is a leader in the field of social and emotional learning. The book is a reflection on his life-long experience of people with disabilities and what we all stand to learn from these special people.

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**Shriver says he learned very early on that power and celebrity were not enough to satisfy, and his own “hunger to find out how to fit into the world” would eventually lead him home, to his own “backyard.”**

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From the outset, he makes the surprising claim that the person with the most influence in his high power, high profile family was his aunt Rosemary Kennedy who, according to the medical vernacular of the day, was "mentally retarded." Indeed, the first part of the book is a painful reminder of the degrading way people with disabilities were treated throughout history. It chronicles the ghastly policies of the 20<sup>th</sup> century, including the eugenics craze in America that informed the Nazi sterilization program and led families to be ashamed of their “in-valid” offspring. The Kennedys, like most families, were distraught at the news that “nothing could be done” for their daughter save institutionalization. Joseph and Rose Kennedy, Tim’s grandparents, sought to resist that advice, and urged their children: “remember, Rosemary is your sister and you always look out for your sister. Never leave her out!” And, like many families, they did everything in their power to find a cure, eventually attempting a lobotomy which left Rosemary’s cognitive capability seriously compromised. Joseph Kennedy Sr. was so

devastated by the ordeal that he sent his daughter away to a Catholic institution in Wisconsin where he reportedly never saw her again. “The code of secrecy kicked in and Rosemary disappeared without a word from anyone,” not even her siblings knew where she was until much later. These events had a profound effect on Rosemary’s sister (and Tim’s mother), Eunice, who devoted her life’s work to bettering the understanding and treatment of people with intellectual disabilities. With the election of President Kennedy, he and his siblings saw their chance to let Rosemary’s influence finally break through on the world stage. Today, the Special Olympics movement includes upwards of four million athletes in 170 countries, changing the hearts and minds of countless millions more throughout the world.

The book takes us on a very personal and fascinating journey to the discovery of what matters most in life. Shriver says he learned very early on that power and celebrity were not enough to satisfy, and his own “hunger to find out how to fit into the world” would eventually lead him home, to his own “backyard.” Tim’s own involvement with special needs children began while he himself was just a child at Camp Shriver, a summer camp his mother started in their country home in Maryland to find out “what they *could* do, not what they could *not* do.” In Tim’s quest for meaning, his teachers, he says, were St. Bernard, St. Francis, Jesuit Bernard Lonergan, Dorothy Day, leading Hindu, Buddhist and Muslim teachers, Jean Vanier, founder of the L’Arche communities, Loretta, Marty, Rosario and scores of other Special Olympics athletes who embody “grit” and “joy” enough to move spectators and perhaps, most importantly Rosemary, from whom he first “learned that everyone has a gift.”

This is a moving and beautifully written book in which Tim Shriver shares a lifetime of experiential learning. In anecdote after anecdote, he sits us down at the “school of the heart” and shows us the value of vulnerability and the power of listening. In the end, it is the giftedness of each one of us that Timothy Shriver discovers, and his story is very compelling on account of its authenticity and unabashed enthusiasm. The reader will not be disappointed should he stop and listen, too.



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# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## The Terrible Mystery of Innocent Suffering

FABRIZIO MERONI P.I.M.E.

**Carlo Gnocchi**, *Pedagogia del Dolore Innocente* (1956; currently not available in English translation).

Familiar with human suffering, injustice and war, Fr. Carlo Gnocchi (b. 1902), a diocesan priest from Milan, Italy, served as a military chaplain during the Second World War. After that he felt a specific priestly call to serve the spiritual and human needs of those who escaped death during the war, but remained seriously wounded and spiritually affected by the inhuman atrocities of the conflict. Thanks to the daily Eucharist, the mystery of the Cross was so present in his life and ministry that Gnocchi's profound Christian sensibility and heroic service to the suffering and dying seemed to come naturally to him. Ever mindful of man's supernatural destiny, his professional work of curing the sick and tending the wounded was undertaken with an eye to his patients' eternal fulfillment in Christ. The Ambrosian priest always intended care-giving to make concrete and real the distinctly Christian approach to broken lives, that is, by addressing amputated bodies and wounded psyches with hope and love. Fr. Gnocchi grasped that human suffering, physical pain, and spiritual distress can be mysteriously welcomed as our true participation in Christ's suffering on the Cross for the sake of our redemption from sin and evil—the real cause and root of all human sickness, suffering, hatred and conflict.

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**Fr. Gnocchi's Christian judgment on innocent suffering springs from his Eucharistic experience of Christ's innocent suffering on the Cross, his spiritual and physical healing during his earthly life, and his filial free offering of himself in the Eucharist for the restoration of humanity.**

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*The Pedagogy of Innocent Suffering* (Pedagogia del dolore innocente) is a short but intense spiritual reflection written by Saint Carlo Gnocchi and published just a few days before his

death (February 28, 1956). It unfolds his deep dedication and life-giving service to his beloved amputee children (“I suoi amati mutilatini”). He felt the need to accompany and, indeed, become one with the children injured during the war after being indelibly marked by the experience of his chaplaincy to Italian soldiers on the battlefields of Greece, Albania, Montenegro, Croatia, and Russia. He established houses, schools, and a social organization for the sake of the most vulnerable and innocent among the wounded, namely, children. Having witnessed lives irremediably destroyed by the war, his writing probes the problem of evil as it arises out of the suffering of children—innocent of the malicious desires that lead to war. Why do children need to suffer for an evil they could not even conceive of, let alone perpetrate? They are not even capable of hating their enemies, those who injured them. Gnocchi finds his answer in the cry of Christ on the Cross, the suffering of the Innocent Man, the Son of God himself, which makes itself present in these innocent children so grievously injured, both psychologically and physically. Throughout the pages of this meditation, we can perceive the mystical experience of a saint—transparent to the purity of divine light—whose humanity has been placed in between human innocence and the monstrous force of evil. The incomprehensibility and injustice of children’s suffering at a human level prompts Fr. Gnocchi to go directly to its root: human sin. Fortified by his faith in the saving Cross of Christ, he can examine the problem clearly and unflinchingly, and his conclusion is profound. Fr. Gnocchi’s Christian judgment on innocent suffering springs from his Eucharistic experience of Christ’s innocent suffering on the Cross, his spiritual and physical healing during his earthly life, and his filial free offering of himself in the Eucharist for the restoration of humanity. Fr. Gnocchi’s questioning as a priest does not spring from, let alone nurture, any anger against God or hatred and revenge against those guilty of war atrocities. Rather, he comes to recognize that the suffering of these children can be united to Christ’s sacrifice for the sake of human salvation precisely because their suffering is innocent, blameless, and totally transparent to the fullness of the true and spotless humanity of Jesus Christ. Their offering becomes efficacious and reconciling even for their enemies and murderers, like the Holy Innocents in the Gospel, *because* they suffer without reason, without any justifiable cause, without any actual sin. For them and through them innocent suffering manifests its mysterious pedagogy. By being offered as the sacrificial act of those who, as children, simply love, their suffering can be a profound act of mercy toward their persecutors and killers. The innocent suffering of children, though terribly mysterious for us, can—thanks to its blamelessness—be offered *for* the sake of love *through* the free love of the innocently crucified Man whose sacrifice has been received and accepted by his merciful and all-loving Father.



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# Humanum

Issues in Family, Culture & Science

BOOK REVIEW

## A Mother's Love

NICK BAGILEO

**Elena Kilner**, *Letters to John Paul: A Mother Discovers God's Love in Her Suffering Child* (Moorings Press, 2014).

John Paul Kilner lived a short but inspiring life. He died when he was 14 months old from a neuromuscular disease called Spinal Muscular Atrophy (SMA). SMA is a genetic disease which is the number one killer of children under the age of two. This progressive and terminal disease is caused by the lack of a protein which controls nerve-to-muscle communication. This lack results in muscle weakness and ultimately atrophy. The first groups of muscles affected are the skeletal muscles and the lung muscles. John Paul's life was impacted at two months of age. In one day he underwent three significant surgical procedures, including a tracheostomy to help him breathe and two gastrointestinal interventions to keep him nourished. Having accompanied their son through every moment of his physical suffering, John Paul's parents, Pat and Elena, have provided us with the gift of his life story.

The book *Letters to John Paul: A Mother Discovers God's Love in Her Suffering Child* has two main sections. The first contains the *CaringBridge* postings from Elena to her family and friends. (*CaringBridge* is a non-profit blog where parents or friends can keep others informed on the condition of hospitalized loved ones.) The second section of the book includes letters Elena wrote to John Paul.

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**The Kilners help us to realize that to follow Christ is to see your life through the eyes of God and that our family life is a school of virtue where "God's way of loving becomes the measure of human love."**

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The witness the book provides is timely. As St. John Paul II noted many times in his pontificate, there are significant parts of our culture that have undergone a "crisis of meaning," the loss of the meaning of human life. Elena chronicles just such a crisis, as she records the attitudes of

certain health care professionals toward her son.

The doctors indicated that with SMA patients, they don't encourage the G-tube because it involves surgery, and since the prognosis is so bad, it's not worth the trouble. When I asked, "Well how do you feed them – obviously you don't starve the kid?"

The doctor's response: "Well, starvation' is a hard word..."

As the discussion progresses about the care John Paul will need at home, Pat and I have been encountering more and more nurses and doctors who question our eagerness to keep him living, and thriving as much as we can. Little by little John Paul will teach them the value of his little life, even if he isn't able to move and eat and breathe the way we do in this life. He will still learn, love, and be loved. And in heaven he will have the body of a professional soccer player.

John Paul's life story inspires us because it is an example of the redemptive value of suffering. He endured more suffering in his short life than many people experience in decades. It is hard to imagine the suffering of his parents and siblings as they watched John Paul endure the numerous medical procedures and fight for his life each day. Yet, the book is full of hope because it provides a witness to the intrinsic dignity of each human life. In one of her letters to John Paul, Elena expressed the meaning of his suffering:

I definitely cried until my eyes were swollen shut the day I learned your diagnosis. But suffering is a necessary part of our life on earth, and we should be grateful for it, because it is the way we will be able to get to heaven someday. It is what we do with our suffering that is most important. Do we hide from it or try to avoid it at all costs – or at others' cost? Do we get angry about it? Or do we see it for what it is – an opportunity? John Paul, suffering is an opportunity. It is an opportunity to love God, to love others, and to grow in virtue. (76–77)

The book allows us to see John Paul's life within the whole truth about man. It shows us that John Paul's life had meaning because he was a member of a family and he was incorporated into the Body of Christ, the Church. His life on earth was not his final destiny. As St. John Paul II said, "The life which God bestows upon man is much more than mere existence in time. It is a drive towards the fullness of life; *it is the seed of an existence which transcends the very limits of time.*"[i] Through his smiles and eye-to-eye contact with his family and friends, he knew he was part of something bigger than himself, a family he loved and who loved him. In these common human experiences we realize Love is our final end. This is an experience so many of our young people today yearn for but have somehow missed.

The impact this little boy had on his family and friends and their response to his suffering is a shining example of the new evangelization. As Cardinal Ratzinger noted "Evangelizing is not merely a way of speaking, but a form of living: living in the listening and giving voice to the Father."[ii] This requires a conversion of heart, which for Benedict XVI entails nothing less than "to question one's own and common way of living; to allow God to enter into the criteria of one's life; to not merely judge according to the current opinions." The Kilners help us to realize that to follow Christ is to see your life through the eyes of God and that our family life is a school of virtue where "God's way of loving becomes the measure of human love." [iii]

The book would be a marvelous addition to high school and college courses by providing young people with a living example of the new evangelization and the family life we are called to by the Gospel. Benedict XVI said,

I have often affirmed my conviction that the true apology of Christian faith, the most convincing demonstration of its truth against every denial, are the saints, and the beauty that the faith has generated. Today, for faith to grow, we must lead ourselves and the persons we meet to encounter the saints and to enter into contact with the Beautiful.[iv]

Let me be clear that I am not saying the Kilners are saints, but what I am saying is that their way of life is a path that is conducive to sanctity and continues to be a witness to the power of the Gospel which is the source of true joy.

As I finished the book it reminded me of something Malcolm Muggeridge wrote in 1981 where he noted that governments will find it impossible to resist the temptation of euthanasia.

The temptation will be to deliver themselves from this burden of looking after the sick and imbecile people or senile people by the simple expedient of killing them off. Now this, in fact, is what the Nazis did. And they did it not, as is commonly suggested, through slaughter camps and things like that, but by a perfectly coherent decree with perfectly clear conditions. And, in fact, it is true that the delay in creating public pressure for euthanasia has been due to the fact that it was one of the war crimes cited at Nuremberg. So, for the Guinness Book of Records, you can submit this: that it takes just about thirty years in our humane society to transform a war crime into an act of compassion. That is exactly what has happened.[v]

I wonder what will happen to families like the Kilners in thirty years. Our culture is becoming so dehumanized that I fear that they would be put in jail for trying to save their child's life. I pray that the example the Kilners have provided will help all to see that each human person is of infinite worth. Benedict XVI reminds us, "We are not some casual and meaningless product of evolution. Each of us is the result of the thought of God. Each of us is willed. Each of us is loved. Each of us is necessary."[vi]

[i] John Paul II, *Evangelium Vitae*, 34.

[ii] Joseph Cardinal Ratzinger, Address to Catechists and Religion Teachers, 12 December 2000. Available at [http://www.ewtn.com/new\\_evangelization/Ratzinger.htm](http://www.ewtn.com/new_evangelization/Ratzinger.htm).

[iii] Benedict XVI, *Deus Caritas est*, 11.

[iv] Cardinal Ratzinger, "The Beauty and the Truth of Christ": Address to CL in Rimini, 24 August 2002. Available at <http://www.ewtn.com/library/th...>

[v] Malcolm Muggeridge, *Christian Married Love* (San Francisco: Ignatius Press, 1981), 28.

[vi] Benedict XVI, First Homily of His Holiness Benedict XVI, 24 April 2005. Available at [http://www.vatican.va/holy\\_father/benedict\\_xvi/messages/pont-messages/2005/documents/hf\\_b-en-xvi\\_mes\\_20050420\\_missa-pro-ecclesia\\_en.html](http://www.vatican.va/holy_father/benedict_xvi/messages/pont-messages/2005/documents/hf_b-en-xvi_mes_20050420_missa-pro-ecclesia_en.html).

