

2014 - Issue Three

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.

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 Tippett, 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).

Ellen Roderick recently received her Ph.D. from the John Paul II Institute in Washington, D.C. Her dissertation was on childhood and its significance for the meaning of human freedom in theological anthropology of Hans Urs von Balthasar.

[i] The Templeton Foundation, available at http://humbleapproach.templeton.org/Learning_from_the_Disabled/vanier.html.

