**Disability and a Theology of Hope.**

I did not have to think long and hard about my title: Disability and a Theology of Hope. I lecture and work in the field of bioethics, healthcare, medical law, philosophy and theology. Here we talk about difficult and often contentious issues from the beginning of life to its end: abortion, and abortion up to term for a foetus that might be at risk of a disability; consent to treatment, and who decides for those who do not have the capacity to consent, those with profound cognitive disabilities, resource allocation when the needs of some people seem to be particularly high, end of life issues from refusing treatment to demanding assisted suicide, especially when the patient has a debilitating and disabling condition. And what is lying usually unspoken under all of this: disability. Plus a level of hopelessness that more often than not the first answer centres around the worthwhileness of a person’s life: is it worth treating this patient rather than is this treatment clinically indicated. At the same time I know people with profound, complex and multiple disabilities. People who even now are going wheelchair ice skating with their ventilators strapped to their wheelchairs, who enjoy simple things, who laugh and have fun, who look forward to the Christmas lights. People who come to Church and shout ‘Alleluia’ at the most inappropriate, yet obviously the most appropriate moments. A lived experience of joy, trust, fun and profound faith in what many people would see as an unlikely situation. A lived experience of hope and one that offers us all hope.

So, how do we work this out?

When we think about disability and in particular the actual lived lives of people with disabilities, for those who do not often come across people with disabilities, what comes first and foremost to mind? Well, just look at media reports. We are overwhelmed with dreadful and heart breaking stories. Not just about people who live lives of loneliness and poverty, with no work, lack of resources for special education, closing social facilities, closing special schools, institutional failures, always the cost to the taxpayer. Bullying. Hate crime. And countless descriptions of burdened carers whose own health suffers, especially as they grow older, burdened by the care of people with disabilities, people they love. Please note the negative language associated with many media reports. But it is not just these economic and social stresses. Much more seriously we hear about down-right abuse, cruelty, neglect especially of people with learning disabilities. People allowed to be put in unsafe and abusive situations – the girl with learning difficulties allowed to engage in unsupervised and random sexual activities so that she could ‘learn’ from her risky experiences; another young girl with learning disabilities, autism and extreme anxiety placed, with no regard for her parents wishes, in the equivalent of a padded cell in solitary confinement, fed through a hatch, because staff could not deal with her behaviour.

Simply out of our common humanity we should identify, point out and address these practices. We should challenge the language of ‘burden’ when applied to human beings. We do not need theology to realise that something is truly amiss here.

However it is all too tempting to begin and end a discussion on disability with decrying the problems and then pointing what could and indeed should be done in terms of social action. Or even simply pointing out that people with disabilities can live fulfilling lives.

Today I want to do something else. This is precisely because I think that if we view disability primarily as a problem – either a problem of attitudes and discrimination directed towards people with disabilities or a problem with people with disabilities or even as a problem that can be remedied by good and enabling care – we are really missing something. Yes there is a lot to be done and I commend very much those who are seeking to change attitudes. However I really do believe that people with disabilities can contribute significantly to formulating a theology of hope. Yes there should be hope that attitudes change. But the hope I am considering here is much more profound than social change. It is a real and certain hope, the kind of hope that we associate with building up the Kingdom of God.

To work this out I am going to look at some real problems we have, not problems associated with disability but problems that perhaps feed some of the discriminatory attitudes that are attached to lives of disability. I have picked out four problems, what I want to call dis-eases, feeling ill at ease: first, the dis-ease of loneliness; second, the dis-ease of idolising autonomy and power; third, the dis-ease of distrust of the heart; and fourth, the dis-ease of the search for ephemeral perfection. Problems that all contribute to a growing sense of hopelessness. Just to be clear, these are real problems that are had by people whether or not they have a disability. I am going to parallel each of these problems with an insight based on the experience of living with disability, and specifically intellectual disability, but an experience enriched by theology. I am going to offer a different perspective of people with disabilities, one that shows not only how people with disabilities can challenge today’s thinking but also how they can help save people from despair. This all may seem topsy-turvey, the wrong way round. But I really do think that we are missing something significant if we only focus on what is going wrong through society’s attitude to people with disabilities.

To be clear, I do not intend a ‘us and them’ discussion: this is neither what non-disabled people do or fail to do for people with disabilities; nor is it what people with disabilities can do for ‘us’, whoever the ‘us’ are. Having said that, I do think that every person should contribute to the flourishing of another, ‘do’ for another, and this is not a matter of using someone to make another person better. This is a matter of how each one of us is called to help the other become a better person in the same way as the other is called to help me grow as a person. Nor do I wish to romanticise or idealise the lives of people with disabilities: people with disabilities are just human beings who, like all human beings often live messy and difficult lives. In our common life on earth we are all on a journey towards holiness and this journey requires constant reflection and conversion. However I also think that some people are in a privileged place, they are ‘blessed’ if you like. And so they can give some really deep and rich insights into our common humanity.

**So some of today’s problems**

As I touched upon in my introduction there are some serious problems when it comes to the lived experience of disability: discrimination, isolation, loneliness, abuse. But now let us think further. What are some of the ‘dis-eases’ of today? Look at the news, but not this time at news specifically directed to the situation of people with disabilities. Many people are simply not at ease with themselves: dis-ease. Of course as St Augustine reminds us, our hearts remain restless until they rest in God. This is true. However, here I mean something different.

First, the dis-ease of loneliness. Society seems to be a collection of individuals placed side by side with no real bonds between them: there are so many lonely people. In October the UK government launched the first cross-government strategy to tackle loneliness. Loneliness has become one of the greatest challenges to public health. The government strategy involves not only what is called ‘social prescribing’ where GPs direct people to community support groups, but also initiatives such as teaching school children about loneliness and the value of social relationships. However, simply by providing support groups does not deal with the deeper issue of loneliness. As any widowed or bereaved person will tell you, you can be lonely in community. Loneliness is part of being human. Feeling redundant is a real fear for all of us.

Jean Vanier, the founder of L’Arche communities for people with intellectual disabilities has long grappled with the problem of loneliness. He points out that he only really found out about loneliness in L’Arche when he encountered people who had suffered acute loneliness. What Jean Vanier came to realise is that apparently strong people are able to submerge feelings of loneliness by the masks of busy-ness and seeking recognition and success.[[1]](#footnote-1) We may think also today of ‘retail therapy’, shopping, gaming, virtual relationships online, indeed virtual reality. People do not realise that they are lonely because of all of this activity, until loneliness crashes in on them usually at a time of crisis, when they can no longer take refuge in busy strategies. Think perhaps of the once active person who had previously thought herself self-sufficient and independent, who did not need others except for the occasional socialising, and who is now unable to do all the things she used to, unable perhaps even to go out on her own. And if she regains her independence that hole of loneliness will simply close over as if it never was, just a memory. That moment of loneliness was an aberration, a weakness, a failure. Until the next time. Solitary loneliness leads to fear and to hopelessness.

What insights can a life of disability give us here? In L’Arche communities Jean Vanier noticed that loneliness could still be present in community. Nevertheless he also saw that people with intellectual disabilities were more able to come through difficult situations. The openness and simplicity of their lives allowed them to cry out, to ask, to share, to seek friendship. There was no idea of self-sufficiency or pride in their own abilities to hold them back. They were not afraid or affronted by pride to acknowledge their dependence on others as opposed to independence from others. For Jean Vanier the L’Arche experience gives witness to the possibility of facing up to our shared human experiences, of not being afraid of the truth that we all go through times of loneliness and vulnerability. This is not a solitary loneliness. Unlike the mask of a social activity strategy that seeks to cover up social failure, this is a real solidarity and one that can give hope to the world. It gives hope because it points to the fact that human beings are not isolated units; we need each other. Healing can come through authentic relationships, of loving and being loved, of belonging, of being wanted. Pope John Paul II puts this in more explicitly theological terms: ‘The world you are inheriting is a world which desperately needs a new sense of brotherhood and human solidarity. It is a world which needs to be touched and healed by the beauty and richness of God’s love.’[[2]](#footnote-2) We are in a world ever in need of human solidarity, lasting solidarity and not simply at a moment of need. The lived experience of solidarity in communities such as L’Arche, in families where there is a disabled person, even in individual situations where a disabled person entrusts her care to another, can bring the healing touch of God and can also become a significant beacon of light for the world. However, and this is where I show I am not idealising the disabled community, if you do have a disability, think about how you entrust yourself to others, how you allow others to be generous. Does pride sometimes get in the way? Reflect also on how you are open to others in your community or family. How you yourself allow solidarity and how you show solidarity. Commitment to a constant conversion, to change and growth, to acceptance that each of us needs to be loved and is wanted for our own sakes, is part of the journey to becoming truly human, for all of us. Understanding this is a source of hope.

Second the dis-ease of idolising autonomy and power. Pope John Paul II called people of today Promethean people. In the ancient story of Prometheus, Prometheus steals fire from the gods in order to help weak and puny human beings who were left without protection, without sharp claws or fur or speed when his brother gave all these gifts away to other animals leaving human beings with nothing. Prometheus gives fire, the power of technology, to human beings and the result? Chaos and war. We may have technology but we do not have direction. This lack of direction, and at times downright wrong direction, has been carried through in our current medical ethics: in medical ethics whatever can be done is done with ethics lagging far behind; we seem to despise the weak and puny, we seek to edit out the apparently faulty gene of Down Syndrome, we scan out disability as if disability existed disembodied only in the womb or the glass dish but not in someone’s personal reality. We forget that the unborn disabled human being is already a daughter or son, brother or sister, an existing member of the human family. But what we are most afraid of is losing fire to others: we have pride in our own abilities and our own control, our power. Just look at healthcare: where everything is about choice, my choice even if in practice many things are in fact beyond my choice. Indeed we prize autonomy to such a point that if there is risk of losing autonomy and control we would rather lose life itself. And this is what is fuelling much of the debate on assisted suicide or dying. This debate is not about pain and suffering. Palliative care practitioners constantly tell us that suffering can be properly and ethically managed. If it is not properly managed in practice then the answer is to continue to improve and strive to provide good and better care. True, palliative care cannot always deal with one of the most difficult of suffering, soul pain, existential pain. If you take a look at the testimony of those who call for a change in the law for assisted dying much of the conversation is about soul pain: not wanting to be dependent, not wanting to be taken care of, not wanting someone else to feed or wash me or take me to the toilet. For these people their dignity is very much linked to their abilities to exercise choice and be in charge: without choice and control there is no dignity. Undoubtedly often the reasoning behind this is because there are so many instances of poor care and neglect, and people are often placed in undignified situations by failure to attend properly to their needs. The lived experience of people with disabilities bears this out. However the answer here is to provide better and more thoughtful care, not to eliminate the person. There is a clear distinction between human dignity that can never be lost and being in an undignified situation that can be remedied by overcoming thoughtlessness. Nevertheless there are still some people who view dependency with such horror that even the best care will not alleviate their dis-ease. Frequently comes the explanation, ‘I would not like to be like them’ or even ‘like that’: I do not want to be stuck in a wheelchair, stuck in a home, ‘shoot me before I lose my marbles’. Simply put, people are afraid. People have pride. When what people value most are speed, function and efficiency, people become acutely afraid of losing these capacities, of being thought of as a burden, redundant, useless. And alongside fear is a sense of hopelessness.

And this is perhaps where the witness of people with disabilities comes in. Of course what we do know is that as St Paul says, ‘God chose what is foolish in the world to shame the wise, God chose what is weak in the world to shame the strong.’[[3]](#footnote-3) From Moses the stammerer,[[4]](#footnote-4) to the man born blind,[[5]](#footnote-5) God works through people in their weakness and vulnerability, to challenge those who think they are strong, independent and invincible. Those people who equate their human dignity with choice and control forget that the reality and complexity of being human is more fully expressed when the human aspect of vulnerability and disability is included. Without acknowledging this reality we are tempted to despair. Moreover, as Pope John Paul points out ‘a society will be judged on the basis of how it treats its weakest members’.[[6]](#footnote-6) The realities of a life with disabilities is a real testimony to ‘respect for the inalienable dignity of every human being, a dignity which is intrinsic to life itself and not granted or conceded by any individual, group or state’,[[7]](#footnote-7) and this holds despite all the inadequacies of health and social care. As Pope John Paul reminds us, ‘the disabled are not different from other people which is why, in recognising and promoting their dignity and rights, we recognise and promote our own dignity and rights and those of each one of us.’[[8]](#footnote-8) And to show I am not idolising people with disabilities, people with disabilities are also faced with the temptation to the same pride in each one of us that tells us we should be strong, independent, autonomous and free rather than beholding to anyone else. We are all prone to think that an undignified situation equals a loss of dignity and so we are all subject to the same fears and despair. Nevertheless, according to Pope John Paul the disabled person forces us all to question ourselves and the mystery of being a human being. He says that ‘it is in the more difficult and disturbing situations that the dignity and grandeur of the human being emerges.’[[9]](#footnote-9) Human dignity that promotes both the uniqueness of each person and the solidarity of all regardless of condition or situation. Being truly human. This is real hope.

Third, the dis-ease of distrust of the heart. Many people today are afraid of being manipulated and they are afraid that someone might take advantage of them. We cannot be open, transparent, trusting because that subjects us to the power of others. The heart becomes a place either of weakness or of fear, where there is no hope. In contrast, as Jean Vanier says, people with intellectual disabilities essentially live ‘by the heart’.[[10]](#footnote-10) This is because people with intellectual disabilities do not seek out autonomy or a setting up of the self in opposition to others. Rather they look for relationship, connection. They are more inclined to say sorry, to make the first move, to hold out a hand or give a hug. They are happy with the simple things, the walk in the park, sitting together. However, and not to idolise people with disabilities, as with all people the ego sometimes steps in and we seek out inauthentic relationships that manipulate others. Reflect on the times when our relationships have not been marked by trust and openness. Accepting when we fall short and really living by the heart is a way of becoming truly human. This way of living is a call to hope.

Fourth, the dis-ease of the quest for perfection. ‘Perfect people’. Perfect hair, perfect skin, the perfect look, the perfect dress for the perfect occasion. Of course we all know that all the air-brushing in the world is not going to make us perfect: it just masks the realities. But this quest for perfection is a symptom of a particularly difficult lack of ease. A discomfort with my body, and sometimes even with who I am. A temptation to treat the body as raw material to be manipulated and moulded according to my own desires. A temptation to idolise the perfect body and youthfulness as if growing older can only mean decline. And since we cannot halt the passing of time, since we cannot live up to an apparent physical and mental perfection, eventually we give up hope. Of course difficulty with the body, the body that does not do what I want it to do, that seems to let me down when I need it, that appears to be ugly or misshapen, that is failing and causing suffering, this difficulty is no stranger to people with disabilities. And perhaps it is this difficulty that requires the most from people with disabilities. New thinking in disability studies have urged a move away from thinking in terms of norms: people with disabilities are not deficient, abnormal or less than normal. The ‘problem’ with disability does not lie in the person. It lies in discriminatory attitudes, practices and everyday barriers that people with disabilities face. But the very real suffering of some people in their bodies and minds cannot be ignored.

Yet the Christian tradition has always maintained a respect for the body-liness of human existence: that is in part what the Incarnation is about, and our belief in the resurrection of the body. My body is good and it is my own personal reality. I, in my very self, am a gift from God. In the Christian tradition as expressed by the Fathers at the Second Vatican Council, each human being is unique and unrepeatable and each human being in their very being, alone before God, is wanted by God for their own sake.[[11]](#footnote-11) Pope John Paul explains, ‘for God and before God, the human being is always unique and unrepeatable, somebody thought of and chosen from eternity, somebody called and identified by his own name’.[[12]](#footnote-12)And, as St Paul puts it in his letter to the Romans, ‘something that was made, can it say to its maker: why did you make me this shape? A potter surely has the right over his clay to make out of the same lump either a pot for special use or one for ordinary use’.[[13]](#footnote-13) Moreover each human being is a gift to others. It is important to realise that no human being is a mistake, an aberration, or a deficiency. Diversity and differences belong to God’s plan.[[14]](#footnote-14) This has been appreciated since the time of the early Christians, after all God sent his Son to save all people.[[15]](#footnote-15) In the miracle of the loaves and fish Jesus, who is never swayed by people’s appearances,[[16]](#footnote-16) feeds all the people present whoever they are and regardless of characteristics.[[17]](#footnote-17) As St Augustine says, God does not make mistakes he knows what he is doing. God loves the child born with disabilities personally and with special tenderness.[[18]](#footnote-18) The human family is made up of diverse and fragile human beings. God leaves no one untouched and God draws each person closer to himself. This of course is what human beings who think that strength, independence and autonomy are what make human beings more perfect do not understand: that God made us and loves us in our fragile human nature for as St Paul tells us when we are weak we are strong because God’s grace is enough for us.[[19]](#footnote-19)

Of course God loves us simply for who we are: his children. Nevertheless, God may love us for who we are, but he does not want to leave us where he finds us. And this is where perfection comes in. True perfection. The perfection of holiness. The perfection of holiness is not physical or even mental perfection in terms of a perfect and attainable ‘norm’, the ‘perfect’ person. The way of holiness is unique for each person, it is to be the person that God wants each one of us to be and conformed in our own special way to the likeness of his Son. For St Thérèse of Lisieux ‘perfection consists in doing His will, in being what He wills us to be’ and this involves doing the smallest things with love.[[20]](#footnote-20) And as Pope John Paul explains, ‘for disabled people, as for any other human being, it is not important that they do what others do but that they do what is truly good for them, increasingly making the most of their talents and responding faithfully to their own human and supernatural vocation’.[[21]](#footnote-21)All human beings, whatever their situation, need God’s grace to grow in holiness. If we look at the lives of some of those ‘perfect people’ the lives of the saints, we will find that quite a number of saints had disabilities, and that includes physical, mental or cognitive disabilities. The lives of disabled saints show that, as St Augustine put it, grace blows where God chooses, and grace ‘does not pass over any kind of capacity’.[[22]](#footnote-22)

To show that I am not idealising people with disabilities, do you live your life to the full and with joy? Do you witness to the gift of yourself and simply being alive? How do you glorify the Lord by your life? Recognising that every human being is a gift for others, and rejoicing in the gift that is you, yet always mindful of who you are called to be, is a true example of hope.

At this stage we may wish to ask how can we do this? Specifically how can people with disabilities, especially perhaps cognitive disabilities… be such powerful witnesses to hope? The answer to this comes through the Old Testament Hebrew word ‘anawim’. Anawim means those who are ‘bowed down’. They were people in difficult situations because of their poverty and marginalisation, the voiceless, those without earthly power, but those who remained faithful waiting for God to fill them, those of Mary’s Magnificat in Luke 1:46-55, those who put their trust in God. They are the blessed. Essentially if you are nearly empty there is more room for God. However, people do not grow all on their own. People with disabilities are not like the angels, they are human beings. Like all human beings people with disabilities are in need of salvation, are called to holiness, are called to worship and take their place in their Church community. Each person with or without disabilities has a unique and specific vocation. Therefore the Church has the same duties to people with disabilities as she has towards all the faithful. So what are we doing as Christian communities in our catechesis, in our formation to help form people with disabilities?

So, how to understand loneliness, how to rescue human dignity from the mistaken belief that dignity equals being autonomous, how to live life in a deeper way by the heart, how to appreciate what perfection means for each one of us: people with disabilities, especially intellectual disabilities can give really promising insights into all of these difficulties and to a certain extent we do not need theology to work this out. However, we have also seen that the tendencies that lead to these difficulties are present in each one of us. Just like all people, people with disabilities need help to be able to live out their vocation and particularly their vocation of bringing hope. Apart from the very fact of our common humanity, this is why everyone should address the discriminatory attitudes and often scandalous treatment directed at people with disabilities. However, it does not stop there. This is why it is important that people with disabilities have the opportunities to grow in every dimension: not just in skills and function but also as human beings, as spiritual beings and as human beings who have a significant part to play in building up the Kingdom, a Kingdom of hope. And the world is truly in need of hope.

1. Vanier, *Becoming Human* Ch.1. [↑](#footnote-ref-1)
2. Pope John Paul II, *Homily,* 17th World Youth Day, 28 July, 2002, 3. [↑](#footnote-ref-2)
3. 1 Corinthians 1:27. [↑](#footnote-ref-3)
4. Exodus 6:13, 30. [↑](#footnote-ref-4)
5. John 9. [↑](#footnote-ref-5)
6. Pope John Paul II, *Address to the New Ambassador of New Zealand to the Holy See,* 25 May, 2000. [↑](#footnote-ref-6)
7. Pope John Paul II, *Address to the New Ambassador of New Zealand to the Holy See,* 25 May, 2000. [↑](#footnote-ref-7)
8. Pope John Paul II, *On the Occasion of the International Symposium on the Dignity and Rights of the Mentally Disabled Person,* 5 January, 2004, 3. [↑](#footnote-ref-8)
9. Pope John Paul II, *On the Occasion of the International Symposium on the Dignity and Rights of the Mentally Disabled Person,* 5 January, 2004, 2. [↑](#footnote-ref-9)
10. Jean Vanier, *Becoming Human* (London: Darton, Longman and Todd, 1998), 63. [↑](#footnote-ref-10)
11. Gaudium et spes, 24. [↑](#footnote-ref-11)
12. Pope John Paul II, *Urbi et Orbi Message* 25 December, 1978. [↑](#footnote-ref-12)
13. Romans 9:20-21 [↑](#footnote-ref-13)
14. Catechism 1937. [↑](#footnote-ref-14)
15. John 3:16. [↑](#footnote-ref-15)
16. Mark 12:14. [↑](#footnote-ref-16)
17. Matthew 15:32-38. [↑](#footnote-ref-17)
18. *Vatican Conference on the Family and Integration of the Disabled* 1999. [↑](#footnote-ref-18)
19. 2Corinthians 12:9-10. [↑](#footnote-ref-19)
20. St Thérèse of Lisieux in *The Fire and the Cloud, An Anthropology of Catholic Spirituality,* p.307 [↑](#footnote-ref-20)
21. *On the Occasion of the International Symposium on the Dignity and Rights of the Mentally Disabled Person* 5 January, 2004, 4. [↑](#footnote-ref-21)
22. Saint Augustine, *On the Merits and Remission of Sins,* I,32. [↑](#footnote-ref-22)