**Communication Strategies and Intensive Interaction Therapy Meet the Theology of the Body: Bioethics in Dialogue with People with Profound Disabilities**

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**Abstract**

Academic bioethics does not appear to be interested in communication and its ethical concerns unless communication is to do with issues such as capacity, consent, truth telling and confidentiality. In contrast practitioners are interested in actually communicating with their patients and they are often particularly perplexed when it comes to people with profound disabilities where communication appears disrupted. Although some new and not so new communication strategies, and especially intensive interaction, are available, little has been written on either the ethical concerns these may present or the deeper concepts that underpin them. This article explores the practical applications of some of these communication strategies. By engaging these strategies with theology, and specifically Pope John Paul’s Theology of the Body, this article identifies and addresses some significant ethical issues that may arise, notably the risk of dualism and of objectifying the human person. Moreover it provides communication strategies with a rationale that goes beyond practicalities to one based on respect for human dignity, justice and solidarity.

**Key words**

Disability augmentative and alternative communication intensive interaction language of the body theology of the body ethics

**Introduction**

A glance at the contents page of many bioethical textbooks or courses offers what many perceive to be the structure of bioethics. Bioethics seems to be primarily constructed from two pillars: the pillar of issues at the beginning of life and the pillar of issues at the end of life. Then there is an arch encompassing ‘middle’ issues. However the ‘middle’ issues are not to do with middle of life. Rather they are to do with specific ethical issues: the ethics of autonomy, consent, truth telling, confidentiality, the doctor-patient relationship.

 Two things are perhaps significant. Firstly, disability, the issue that encompasses the beginning, middle and end of life, is in much the same situation as the elephant in the room. Disability is hidden in questions at the beginning of life especially the debate on genetic screening and pre-natal diagnosis. Disability is left simply implicit in end of life questions concerning withholding and withdrawing treatment. More often than not, it is avoided in the discussion on assisted dying as the conversation centres on the dignity of control, autonomy and choice. Even that most profoundly disabled patient, the person in a persistent vegetative state, is placed in the ‘end of life’ category rather than disability. Truth telling, confidentiality and decision-making issues briefly mention the criteria for capacity and competence and then move on to a discussion of the autonomous and verbally competent patient. Conversations about speciesism rarely speak about disablism yet these two ‘isms’ appear to collide. Secondly, very little attention is paid to communication itself. Beginning of life and end of life questions focus on the right to choose for those, of course, who can express choice or those who have made advance directives. Vigorous debate on whether autonomy has limits, consent and whether it is informed, the extent of the obligation to tell the truth, confidentiality, all centre on the significance of decision-making and being heard. However communication in bioethics is more than who has the final word in decision-making, what information needs to be given, and whether autonomy trumps paternalism. Most healthcare professionals are interested in developing better communication skills, in gaining expertise in understanding the patient before them. At the minimum, in knowing where it hurts. Communication, engaging with the patient, is a matter of seeing the patient as a person and not just a body to be examined, worked upon or fixed. So, for a ‘middle’ issue, what about communication and people with disabilities? And by disabilities here we are talking about the kind of intellectual disabilities that appear to disrupt communication.

**Communication**

In academic bioethics, communication between healthcare professionals and patients and their families is recognised as crucial - at least on the level of seeking consent, affirming autonomy and avoiding a charge of paternalism. ‘On the ground’ in a practical sense, health professional-to-patient communication is essential and this is why it is important to spend some time in looking at it in all its varied forms, especially the communication of, and with, people with profound disabilities. However there are at least two levels to this: at one level there are the different methods of communication including non-verbal and augmentative and alternative communication. Appreciating that there are methods of communication other than the verbal is not only valuable in practical terms. It also demonstrates respect. At another but deeper level, there is how the person with disabilities comes to make sense of himself and the world around him, how that person communicates, if you like, with himself. Learning how a person ‘ticks’, how he is as he is, can make all the difference. Although no one can fully come to know another person, knowing more about how that person is can help to break through some of the things that isolate people from each other. And in the case of profound disability it is often the isolation that causes the most barriers.

***Augmentative and alternative communication***

Taking a leaf out of pedagogy, recent research into teaching and learning has made great strides in reaching out to people with intellectual disabilities. This research has built upon the realisation that people learn in very many different ways. To begin with, people depend on their senses to process the information around them and most people will use one of their senses more than the others. The predominance of one particular sense can lead to the identification of a specific learning style: a visual learner learns by seeing, an auditory learner learns by listening and verbalising, read-write learners prefer the written word, kinesthetic learners use a hands-on, trial and error approach. In theory if the teacher can identify the learning style then not only is information transferred but also experiences are gained so that learning becomes internalised: these are knowledge and skills that the student wants to practice and master. A similar strategy can be used with people who do not use verbal communication. Human beings naturally use alternative communication through facial expressions, when they use gestures, when they use signs, pictures or symbols. In the case of communicating with some people with disabilities discovering a preferred method of communication and then following it up by using special tools such as makaton, picture boards, symbol boards, photographs and electronic devices like switches or even IT can be invaluable.

 While it is important for the practitioner to recognise and utilise different forms of communication there are other issues that may have to be factored in. Some people with profound disabilities rely on sense experience to make sense not only of the world around them but also to make sense of their own self. This is why in many special schools there is so much emphasis on a sensory approach to learning. For instance the topic of the sea side is brought to life and to mind by feeling sand, smelling seaweed, tasting fish and chips (as long as the person is able to eat orally), being splashed by water. In the healthcare situation there is much to be said for handling stethoscopes, touching bandages. However often there is a difficulty in the processing or the sense experience is somehow disrupted. The barrier to communication happens long before an attempt at communication is made.

 If the healthcare professional can identify the problem in the processing, recognise and pre-empt a possible barrier, then not only is it possible to gather more complete information it is also possible to be more creative with that information, to come to understand more fully, to grasp what is going on. In short, to make a connection and to communicate in a deeper sense than simply to exchange facts. Some people with disabilities may have a time delay. It takes time, often minutes, to process the simplest thing like the call of the person’s name, a request to ‘look’ or ‘listen’. If the request is made, the name is called, and before waiting for the response the request is made again, the name called again, then the processing is interrupted. The connections are not made. The person stalls at the first hurdle. The communication opportunity is lost just because of a failure to wait.

 Some people with disabilities have difficulties with perception. For some a change in the colour of the flooring may indicate anything from a step onto the same material, to the need to step up or down, to a complete change from solid to spongy ground. Until the step is taken the person does not know what he or she is confronting. The simple move from one place to another becomes a gamble, a matter of intense thought, at times, a matter of fear. No wonder the person is in no fit state to engage in more complex communication. Taking it slowly, reassurance, touch, a helping hand, may all go some way to alleviating anxiety. Giving time to recover may aid in making the next step. When the brain is not under pressure from trying to process, then it can work more effectively in other ways.

 For people with dementia visual perception may be affected and often it takes merely a creative strategy to address the issue. If a person is given a transparent glass filled with a clear liquid it should be of no surprise when that person does not pick it up and drink: the person probably does not see it. If a person eats from only one half of the plate then turning the plate around may let them see what is on the other half of the plate that was previously hidden to them. Asking a question may cause considerable confusion. This is because each question requires information to be processed and an adequate response to be formulated. Instead of a question, a simple statement may elicit a more coherent and less confused response. The question, ‘Have you been for a walk in the garden?’ is much more complicated to answer and potentially more threatening to the person’s sense of themselves as a thinking and remembering person than the statement, ‘the garden is looking lovely today’ which may bring about a discussion about going outside.

 Often people with profound disabilities are acutely aware of their own bodies or their bodies express something of what is going on inside, more so than the abled who can mask what they do not want to reveal or who are not conscious of the workings of the body unless it is to increase its function or efficiency. This is perhaps because the inner life of the profoundly disabled person very much seems to be focused in on the self. This may be obvious in people with breathing or eating difficulties. There is a concentration involved in these activities that simply passes the abled by. Where there are other physical problems as well, get the bodily position right and the whole person is at ease. Being careful about the body is also being mindful about the person.

 However there are some disabilities where communication becomes a much more perplexing issue. Undoubtedly the search to know at least partially how it is to live with certain disabilities has become a topical subject. There are books and internet sites speculating on what it is like to live with autism, saying how it feels to have Asperger’s syndrome, answering frequently asked questions about managing with Attention Deficit Disorder. But when it comes to people who do not appear to communicate then there is a further task, the task of seeking out deeper communication, and a useful starting point is communication that is non-verbal: non-linguistic body language.

***Body Language***

Intentional methods of communication that function to convey information and methods of communication (sometimes unintentional) such as body language that convey emotion are usually confirmed or checked by the responses they elicit from other people. We watch, check and reaffirm by looking and listening and responding to others. Nevertheless there are some people who do not seem to be able to engage in this reaffirming and confirming process. They appear to be isolated in their own world. More often than not people with severe disabilities engage in what seems to be meaningless and repetitive behaviour. However instead of dismissing this behaviour, research has been done to explore this behaviour as communication.

 Phoebe Caldwell, a practitioner experienced in working with people with autism, has researched extensively in the field of severe learning disabilities. In addition to intentional functional methods of communication and emotional engagement every human being has what Caldwell calls “numerous and continuous conversations” between his brain and body. However on the whole the person is not aware of these conversations. Caldwell gives the example of breathing to illustrate this.[[1]](#footnote-1) In the case of people with disabilities who are unable to communicate effectively with the outside world and so are not able to draw outside confirmation, they often seem to develop further this internal conversation between brain and body as a way of self-confirmation. The person develops a personal language of activity that becomes meaningful for him. Caldwell uses this idea of the body’s conversation to explain the fixation that some people with disabilities have on a particular behaviour. Such behaviour acts to control the environment and cut out what would otherwise be overwhelming sensory experiences.[[2]](#footnote-2) When the therapist partner focuses on the bodily acts of the person that person is revealed as embodied and as expressing himself through the body. This happens even when the person’s actions suggest that his world is beginning to fragment or that the messages are scrambled. In order then for others to communicate with the person the first step is to discover how he is communicating with himself.

***Intensive Interaction: ‘Finding You Finding Me’***

Intensive interaction was developed by Caldwell, and the educationalists Dave Hewett and Melanie Nind. Hewett and Nind were teachers at the Harperbury Hospital School in Hertfordshire in the 1980s. They worked with people who had severe learning difficulties and they were interested in teaching the basics of pre-speech communication. Most of the students at the school were on the autistic spectrum. The students did not seem to understand speech; they appeared socially isolated. They lived in their own ‘little worlds’. Hewett, Nind and Caldwell based intensive interaction programmes on the approach of the psychologist Geraint Ephraim. Ephraim developed a technique he called augmented mothering, a technique based on body language and the interactions of babies with their mothers. In these interactions the focus is on closeness, on sharing behaviours, copying facial expressions and gestures, vocalising, eye contact and physical proximity; all the things that parents instinctively do with their young children.

 As Ephraim noticed, the relationship of mother and child involves a natural interaction of copying, mimicking and imitation and this is the basis of intensive interaction therapy.[[3]](#footnote-3) Through observing the interrelationship of mother and child Ephraim realised that a child recognises her own sounds and movements even if these movements and sounds are made by another person. If the child sees or hears similar movements and sounds then the child will start to attend to what is going on. The child’s sounds and movements have meaning for her, a kind of language, and by copying these the partner, be it mother or therapist, can engage in that language. In the natural way of things this is precisely what a mother instinctively does when she mimics her child’s noises or expressions and in return the child watches and copies her.

 Moving beyond the mother child relationship that characterised Ephraim’s approach, Caldwell opened up intensive interaction to the public as a person-centred approach to communication in her book *Finding You Finding Me* published in 2006. Caldwell’s main insight is that communication is a “two-way thing”: it is not just that some people cannot communicate with me; I cannot communicate with them.[[4]](#footnote-4) From this insight she maintains that participants are called “partners” rather than patients and therapists, or doctors, or teachers and learners[[5]](#footnote-5). It has long been recognised that the problem encountered by many healthcare professionals centres on how to capture the attention of the person who is withdrawn. Certainly in the usual healthcare setting there is a limited time for engaging with the patient and so inevitably the professional turns to the family or the carer, often by-passing the actual person who is the subject of the appointment. Nevertheless becoming aware of some of the techniques for creating the possibility of engagement can at least begin a conversation of sorts.

 Caldwell explores the world of those with cognitive impairment for whom the outside world does not make sense, whose world is at times confusing and painful and where outside events frequently seem to be hostile. Caldwell explains that this reality that is undoubtedly real for the person needs truly to be respected as “valid for them”. Without this respect there is a risk of sensory overload if the partner therapist demands that her own sensory reality takes precedence.[[6]](#footnote-6) The results of sensory overload are often catastrophic. The person may suffer the pain of experiencing a world that is falling apart. This in turn may lead to coping strategies of either fight or flight responses. Such responses can close the person in on himself as a form of protection.[[7]](#footnote-7) Commonly the person then tries to hold onto a sensation that can absorb the pain and he engages in some activity that has meaning for him, usually some form of apparently repetitive obsessive action.[[8]](#footnote-8) Repetitive actions offer a form of safety in an inner world of the self and an internal ‘conversation’ with the self, inner because communication is with the self and not with another. Through fixations and self-stimulation the person becomes conscious of his inner world and at least to begin with may feel in control even if this inner self becomes a painful place and he can no longer get out of it. As Caldwell explains, in some cases a person’s brain is “cluttered” with unprocessed images, sounds and information and notably in people with autism the sensory intake is scrambled.[[9]](#footnote-9) When a person fears fragmentation, that is when his world falls apart, then he will pay attention to limited objects as a protection.[[10]](#footnote-10)

 This reaction to sensory overload is often isolating. According to Caldwell, in order to break through this isolation and reach the person living “on the inside” the partner therapist must “learn their language”. Language here refers both to how the person ‘talks’ to himself and to what is meaningful for him. By concentrating on this language the focus is hopefully taken off the things that may be disturbing one of the partners.[[11]](#footnote-11) While repetitive behaviour may act to freeze out overwhelming senses so that the “brain feels safe”[[12]](#footnote-12) it may also give an opportunity for the partner to break through isolation. Caldwell discovered that if she paid attention to what her partner was actually doing and attached significance to every action, then if she copied the repetitive behaviour, her partner became curious. He was drawn towards the one who was making the same sound or doing the same movement. Caldwell deduced that the person began to see that someone else was understanding and valuing his rules.[[13]](#footnote-13) Moreover Caldwell noticed a “surprise factor” as both she and her partner shifted attention from the self to the other by becoming “complicit”. Caldwell uses the example of a person turning a dial and the partner or therapist drawing clockwise then anticlockwise on the person’s hand.[[14]](#footnote-14) Caldwell calls this “sharing the joke”, it is finding pleasure in each other’s company, it is friendship.[[15]](#footnote-15)

 In analysing her own approach to this engagement Caldwell identified that the partner therapist often starts from bewilderment. However she says that it is necessary for the partner therapist to free herself from her own agenda in order to see her partner’s meaning in action. On both sides this is a personal interaction since the partner therapist is privileged by being allowed into another’s personal internal conversation and the other person begins to recognise what is being offered. As Caldwell puts it, “if you copy me I know it is me you are copying”.[[16]](#footnote-16) Notably for Caldwell this emptying of the self to engage with another is in itself an opportunity to find our own self more deeply.[[17]](#footnote-17) The partnership can then develop as the person begins to realise that there is a meaningful response to what he initiates and so in turn he starts to look for another response; there is expectation of a response to the response. Ultimately this leads to a desire to engage with the partner therapist and Caldwell notes that this engagement is more often than not characterised by excitement, a sense of sharing and above all a sense of humour.[[18]](#footnote-18)

 Like all methods intensive interaction has its drawbacks. Caldwell herself drew attention to the problem of the fittingness of mimicking and of age appropriate behaviour. However it appears that these shortcomings are usually seen from a practical point of view. Critics of intensive interaction ask whether the therapy respects age appropriateness, whether the actions it encourages fit the situation, whether it reinforces stereotypical behaviour, whether it is a source of embarrassment.[[19]](#footnote-19) Furthermore the therapy requires time so that a relationship can develop. Like many therapies intensive interaction is only as good as the practitioner. It relies on the practitioner’s skill, how resourceful she is in identifying communication and how creative she can be in sharing that communication. Inevitably, perhaps, since it is a therapy with specific goals in mind it is limited to being task oriented rather than focused on encounter. This means that the relationship and being open to the other is relevant only insofar as it serves the therapeutic aims.

 Simply looking at intensive interaction from a practical viewpoint does however neglect some more serious problems. The therapy encourages one of the partners precisely not to be herself. By asking the partner therapist to copy the actions of the other in order to break into the other’s world the partner therapist’s acts no longer reflect who she is. Moreover, it risks being intrusive instead of a way of ‘being with’ another in companionship. In addition there is the more significant risk that some practitioners of intensive interaction implicitly believe that the person with disabilities is a person or mind trapped in a crippled body as if the body is a useless or indeed limiting extra, and that it is the job of the therapist to reach out and free this person. To be sure Caldwell attempts to avoid the Cartesian split between mind and body. Nevertheless the risk remains. Moreover in the task of discovering how the person communicates with himself or expresses himself there is the temptation on the part of the partner therapist to view this discovery as merely an additional piece of knowledge: the practitioner learns how to read the signs of her partner in order to move onto the next stage of the therapy. Inevitably the situation of the person with disabilities is subject to the interpretations of the partner therapist and so the person becomes vulnerable to the other. In other cases the disabled person may remain isolated and unreadable and the partner therapist may conclude that the therapy has failed. Furthermore if the relationship is said to begin when there has been a response then it would seem that the practice of intensive interaction need not necessarily recognise and respect the dignity of each person. At times it does not seem to be able to avoid one person becoming an object for the other.

 Certainly any therapy must be approached care-fully to ensure that the dignity of each person is maintained and that each person is fully respected. However in order to lessen risks and temptations, to identify in advance possible pitfalls, it may help to reflect on a complimentary understanding of the language of the body, the one put forward by Bishop Karol Wojtyła before he became Pope John Paul II, that he developed into his perhaps best known work, the Theology of the Body. The resonance this theology has with some of the insights from intensive interaction demonstrates that it is a theology that can be appreciated on a philosophical as well as theological level. The work already done in theology can give the practical application of intensive interaction a more secure foundation as well as offering a corrective perspective.

***The Language of the Body***

When he was a professor of ethics in Lublin, Karol Wojtyła delivered a series of philosophical and ethical lectures and papers later published in 1976 under the title *Person and Community.* He had already published a book in 1969 and its Polish title, *Osoba i Czyn*, actually translates as *Person and Act* rather than the usual title it is given, *The Acting Person*. Wojtyła begins with the fundamental premise that the body is a visible sign of an invisible reality, that acts express the person so from the outset Wojtyła is operating out of a Thomistic framework. After all, the idea that a person’s acts and behaviour express the person is not new nor is the realisation that there are certain actions that the person does without apparent awareness, like breathing. The structure of human action, though primarily in the context of the moral order, was considered at length by the thirteenth century Dominican St Thomas Aquinas, arguably the most significant Catholic theologian. The classic phrase *operari sequitur esse*, acts follow being, is a fundamental statement concerning the experience of acting. St Thomas takes aspects of Aristotle’s thinking and modifies it to make a clear distinction in human action. In the one human person St Thomas identifies what he calls *actus humani,* a human act, and *actus hominis,* an act of a human being. An *actus humani* proceeds from the person’s free will in the light of the end of the act iself; it has a moral dimension and carries with it responsibility for that action. An *actus hominis* is any action performed by a human being and this includes involuntary action like coughing or breathing, reactions to pain and emotions.[[20]](#footnote-20)

 Wojtyła takes up this Thomistic distinction in human acts not simply to describe what happens in human beings but in order to provide a critical response to philosophies of consciousness. According to Wojtyła these philosophies claim to centre on human experience yet at the same time they forget that that subject of experiences is a concrete human being. In bioethical terms this risks reducing the person to expressions of wants, desires and choices. Wojtyła thinks that inevitably this leads to a separation of the human being and the person. As he later explains in his encyclical *Evangelium vitae,* the Gospel of Life, when he becomes Pope, the body is no longer seen with a sense of the “mystery” of being. What now counts is the value of having rather than the value of being and the body becomes raw material that one has rather than being “a properly personal reality”.[[21]](#footnote-21)

 Undoubtedly there are connections between Wojtyła/Pope John Paul’s thinking and the insights to be gained from intensive interaction. Just as for Wojtyła/Pope John Paul *operari* includes the whole human dynamism that is, what merely happens in the human being and everything the human being does, so too for Caldwell are acts that merely happen in human beings part of the internal conversation. Along with Wojtyła/Pope John Paul it would seem that in the intensive interactive approach to people with disabilities bodily action has “the most basic and essential significance for grasping the subjectivity of the human being”[[22]](#footnote-22) whether it be an ordered and coherent subjectivity or one affected by fragmentation and overwhelming sensations. Moreover Wojtyła/Pope John Paul notes that in the inner conversation “each human being, myself included, is an ‘eyewitness’ of his or her own self – of his or her own humanity and person”.[[23]](#footnote-23) However in the distinction between *actus humani* and *actus hominis* the Thomistic theology of Wojtyła/Pope John Paul does not allow for any actual separation of the body and the person. There is no risk of seeing an ‘inner person’ waiting, as it were, to be liberated from a limited body. Furthermore, this Thomistic language of the body applies to all human beings whether abled or disabled. This means that it specifically points to a fundamental respect for all human beings as sharing in the same kind of human nature. There is no ‘them’ and ‘us’, there is only ‘we’.

***The Theology of the Body***

As Pope, Wojtyła builds the language of the body into his Theology of the Body. Many people associate his series of catechetical lectures, later written up as the Theology of the Body, almost exclusively with married life. This is due in part to a renewal of the way in which love and in particular married love, as expressed in an openness to children, has been presented. However Pope John Paul himself says that his Theology of the Body is relevant to all, whatever their state in life. In this theology he goes beyond human action and deeper into human experience. His reflections particularly on solitude and *communio* seem to have special resonance with the experience of people with disabilities.

 The Theology of the Body is partly a response to the problems that Pope John Paul finds in contemporary anthropology. According to the Pope modern anthropological thinking tends towards dualism, a separation of the spiritual interior and corporeal exterior aspects of the person, and towards the domination of forces of nature rather than self-mastery. Thus the body is treated as an object to be manipulated and the ‘real me’ is somewhere else. He calls this a “Manichaean mentality” in reference to the third century movement that saw the fallen soul as imprisoned in matter and only liberated by knowledge. In the modern Manichaeistic way of thinking the ‘problem’ becomes the physical body rather than the problem being located in the “lust in the heart”, or the interior attitudes people take towards the body.[[24]](#footnote-24) Certainly this understanding has resonance with some attitudes to disability where the ‘problem’ is seen solely in the apparently abnormal body and the solution is simply to reform the body until it meets the ‘norm’, or the attitude that sees the self as imprisoned in a broken body and longing to be freed even to the extent of embracing assisted dying, or the attitude that sees the profoundly intellectually disabled human being as merely a body that lacks the component of ‘person’. It is through these attitudes that the people with disabilities become subject to indifference, discrimination or hostility. The person with disability becomes the problem rather than part of the problem lying in the interior attitudes of others.

 In contrast Pope John Paul keeps together the interior and exterior aspects of the human being so that the body is subjectively identified with the person. Person is not opposed to human being. Rather each person is a unique and concrete human being, and of course each human being is a person. Furthermore each human being is a sexual being since his or her body belongs properly to his or her person. This undivided human being is called into relationship with others and with God through the gift of the self to others. And by giving oneself the person finds herself, an insight reinforced by Caldwell’s own practical application in intensive interaction.

 Pope John Paul’s Theology of the Body begins, as does all of his theological reflection, with the teaching of Jesus. Perhaps paradoxically, in the case of the Theology of the Body the teaching is taken from the Gospels of St Matthew and St Mark and it concerns divorce.[[25]](#footnote-25) Jesus is the centre point and it is Jesus who looks back to the *Book of Genesis* and then ultimately forward to the resurrection of the body. Taking the account of the creation of humankind in *Genesis* as a narrative for the human condition Pope John Paul explains that Adam, the archetypal human being, finds himself aware of himself as a person and a being in the world. He realises that he is not merely a being among other beings. He is conscious of his own body and its meaning as well as aware of choice and self-determination. These insights come forward as God brings the non-human animals to Adam so that he can name them. Adam himself is “alone before God”.[[26]](#footnote-26) According to Pope John Paul all human beings are “in solitude”, alone in the visible world that expresses what he or she “is not”. However there is a second creation story. It is “not good” for man to be alone so God (in the *Genesis* story literally and metaphorically) opens Adam up to a being like himself, also a person in solitude, and they become a *communio,* a communion of persons.[[27]](#footnote-27) *Communio* is something more than community and it is formed as a result of the solitude of both persons: a double solitude.

 Significantly, for Pope John Paul solitude remains a personal dimension of every human being because solitude expresses what is unique and unrepeatable about each and every human being. In theological terms solitude expresses what the Church Fathers of the Second Vatican Council say about each human being, that “man is the only creature on earth that God has wanted for its own sake”.[[28]](#footnote-28) Again, significantly, for Pope John Paul each human being is constantly being called into deeper communion with others. This immediately gives a rationale for communication and for enabling communication with those who would otherwise be isolated. Moreover, *communio* does not represent an obliteration of the self nor does the person become an object for the other. Rather it is an affirmation of the person as a unique person, as another ‘I’. Theologically speaking this is an authentic expression of the nature of human beings made in the image of God where God is at once a unity and a communion of Three Persons.[[29]](#footnote-29) In eschatological terms this communion is realised in the community of saints.

 Of course the understanding of the human person as in solitude and seeing the other as another ‘I’ can be found in twentieth century philosophy, especially that of Emmanuel Levinas. Both Pope John Paul and Levinas think that a person can be in a relation with another person and yet remain distinct. Moreover this relation is not simply one of a being alongside another. As Levinas explains in terms that might seem familiar to practitioners of intensive interaction, “I do not only think that he is, I speak to him. He is my *partner* in the heart of a relation which ought only have made him present to me” (his italics).[[30]](#footnote-30) Nevertheless for Levinas, while the other is known through sympathy it is also specifically a non-reciprocal relationship in the sense that I have an ethical responsibility towards the other yet this responsibility does not expect anything in return. I can only act *for* the other. In contrast in Pope John Paul’s vision of solitude and *communio* I can also act *with* the other since each person is the other’s “helper”.[[31]](#footnote-31)

 Pope John Paul’s Theology of the Body also enables further reflection on solitude that is relevant for people with disabilities. According to the Pope solitude in its original meaning is not loneliness. Instead it expresses the reality that every human being is alone before God albeit also in solidarity with the human race. He then explains that the notion of solitude as loneliness seems to have entered into human history at the Fall when Adam disrupts the communion of persons by objectivising Eve, by no longer seeing her as another ‘I’ but instead as ‘an object for me’.[[32]](#footnote-32) Certainly the media has highlighted many cases where people with disabilities have become ‘objects’ for other human beings whether it is through discrimination, indifference or hostility. However the risk of objectivisation may also be present in intensive interaction when the therapy and its goals overtake the relationship, or when the person of one of the partners is lost through the dominance of the other. This may also apply to the partner therapist who adopts the obsessive behaviour of the other. It may also be found where the person is seen principally in terms of his or her diminished mental capacities or impairments rather than as this particular man or woman, or where there is the temptation to infantalise the person. In such cases not only may the person with disabilities be subject to the loneliness of isolation there may also be a second loneliness as a relationship that opened the person up now disappears. In a salutary reminder of these dangers Pope John Paul says that people with disabilities have the same need “‘to love and to be loved, they need tenderness, closeness and intimacy”. Nevertheless he recognises that this entails “authentic relationships in which they can find appreciation and recognition as persons”.[[33]](#footnote-33) In terms of therapies he notes that it requires treatment and rehabilitation that take into account “a complete vision of the human person”.[[34]](#footnote-34)

 Although in Caldwell’s vision the two people involved in intensive interaction are called partners rather than patient and therapist, it seems difficult to describe this relationship other than by saying, as Caldwell does, that communication is a two way thing, that both partners need to learn how to communicate. After all, it seems that the person with communication difficulties comes or at least is brought with his need to a therapist whose goal it is to make connections. The risk is always that disability becomes merely a way for the therapist to practice and develop her skills and techniques or to demonstrate she has a particular sensitivity to the less fortunate. However, theological insights may once again be useful. In “authentic relationships” it is not a question of simply performing a good deed for another nor is there an element of pity in the sense of creating an imbalance in the relationship or giving from what one person already has in abundance to one who is lacking. Rather, in an authentic relationship the personal dignity of both partners is foundational. The focus is placed on a shared humanity, and empowerment and enabling come from justice, *agape* and solidarity.

 Again, as Caldwell recognises, by emptying herself the therapist does indeed find herself more fully. This idea of finding the self through a gift of the self is current in theology. Nevertheless, it may suggest that disability simply offers a way of allowing the non-disabled to look in admiration back at themselves; in general terms disability provides them with an opportunity to learn to be better therapists or more sympathetic human beings. This reflects one of Pope John Paul’s main concerns, the human tendency to make the other into an object ‘for me’, although often a very special object, and forgetting or simply not seeing that the other is ‘an other’, a Christ. However theology goes further. Self gift is the foundation of *communio*, being a person in relationship, seeing the other as a person not as an object for me. If *communio* is building up the other as a person then that is precisely what the disabled do by being entrusted to others for their care.

***In dialogue with Bioethics***

Augmentative and alternative communication, intensive interaction, methods of communication that seek to break through the isolation of people with disabilities are significant components of successful healthcare. They belong in the conversation of bioethics because at the heart of bioethics is the call to see the patient as a person. Moreover, for people with disabilities it is not only an issue of practical sense, it is also a matter of justice. For those who think that in the case of people with profound disabilities where there is no verbal or obvious communication, nothing meaningful is going on it is easy to conclude that this human being is non-acting, not living much of a life. In the worst case this human being is merely an organism with reactions. By reflecting on different ways of communication and by researching into ways to reach people it is becoming apparent that people with disabilities may be living out a rich life, even if it is one that others cannot grasp. Indeed a failure of therapies to break through to a person in no way diminishes that person’s dignity nor does such a failure allow for that person’s inner life to be dismissed

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 While for the most part human beings now regard activity, functionality, purpose and efficiency as the marks of a worthwhile life, the person whose life does not reflect this may indeed help others to rediscover some of the meanings of what it is to be human. For many who are profoundly disabled the key to unlocking and making sense of the world is found in sensory experience. Using sight, hearing, touch, taste and smell is not a new way of living but it is one that is often forgotten in the busy-ness of daily life. Staying still, being apparently passive and allowing experience to come is a profoundly human activity. Thinking about a creative use of alternative methods of communication provides the opportunity to reconsider the narrowness of placing primacy in autonomy or self-rule seen as merely desires and wishes or providing informed consent. It demonstrates that there can be fundamental respect for the person and not merely his or her choices, desires and consent.

 The idea that the body is a visible sign of an invisible reality is a truth for the person with profound disability even where it seems impossible for the body to express that reality in ways that can be understood by another. Pope John Paul points out that when St Paul reminds the Corinthians to “use your body for the glory of God”[[35]](#footnote-35) this also applies to people with disabilities: we are all ‘temples of the Holy Spirit’. As Pope John Paul explains an apparently different life does not mean a less important life nor a life with less potential for holiness or for contributing to the world.[[36]](#footnote-36)

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1. Phoebe Caldwell, *Finding You Finding Me* p.101 [↑](#footnote-ref-1)
2. Phoebe Caldwell, *Finding You Finding Me* p.102 [↑](#footnote-ref-2)
3. Phoebe Caldwell, *Finding You Finding Me* p.14 [↑](#footnote-ref-3)
4. Phoebe Caldwell, *Finding You Finding Me.* (London: Jessica Kingsley Publishers, 2006), 64. [↑](#footnote-ref-4)
5. Phoebe Caldwell, *Finding You Finding Me* p.15 [↑](#footnote-ref-5)
6. Phoebe Caldwell, *Finding You Finding Me* p.18 [↑](#footnote-ref-6)
7. Phoebe Caldwell, *Finding You Finding Me* pp.28-29 [↑](#footnote-ref-7)
8. Phoebe Caldwell, *Finding You Finding Me* p.37 [↑](#footnote-ref-8)
9. Phoebe Caldwell, *Finding You Finding Me* p.135 [↑](#footnote-ref-9)
10. Phoebe Caldwell, *Finding You Finding Me* p.123 [↑](#footnote-ref-10)
11. Phoebe Caldwell, *Finding You Finding Me* p.99 [↑](#footnote-ref-11)
12. Phoebe Caldwell, *Finding You Finding Me* p.103 [↑](#footnote-ref-12)
13. Phoebe Caldwell, *Finding You Finding Me* p.105 [↑](#footnote-ref-13)
14. Pia Matthews, *Pope John Paul II and the Apparently ‘Non-Acting’ Person* (Leominster: Gracewing, 2013) p.159 [↑](#footnote-ref-14)
15. Phoebe Caldwell, *Finding You Finding Me* p.109-111 [↑](#footnote-ref-15)
16. Phoebe Caldwell, *Finding You Finding Me* p.119 [↑](#footnote-ref-16)
17. Phoebe Caldwell, *Finding You Finding Me* p.123 [↑](#footnote-ref-17)
18. Phoebe Caldwell, *Finding You Finding Me* p.125 [↑](#footnote-ref-18)
19. For an instance of an analysis that focuses on practicalities see G. Firth, H. Elford, C. Leeming and M. Crabbe, ‘Intensive Interaction as a Novel Approach in Social Care: Care Staff’s Views on the Practice Change Process’ in Journal of Applied Research in Intellectual Disabilities 21 (2008), pp.58-69. [↑](#footnote-ref-19)
20. St Thomas Aquinas, *Summa Theologiae* (London: Spottiswoode, 1970),I.II.q.1,a 3. [↑](#footnote-ref-20)
21. Pope John Paul, *Evangelium vitae* (London: Catholic Truth Society, 1995) #22, 23 [↑](#footnote-ref-21)
22. K. Wojtyła, The Person: Subject and Community (1976) in *Catholic Thought from Lublin Vol.IV Person and Community*  (New York: Peter Lang, 1993) p.224 [↑](#footnote-ref-22)
23. K. Wojtyła, ‘Subjectivity and the Irreducible in the Human Being’ (1975) in *Catholic Thought from Lublin Vol.IV Person and Community* p.214 [↑](#footnote-ref-23)
24. Pope John Paul II, *The Theology of the Body: Human Love in the Divine Plan.* (Boston: Pauline Books, 1997) pp.165-166 [↑](#footnote-ref-24)
25. Matthew 19:5, Mark 10:6-9; Matthew 5:28; Matthew 22:30; Mark 12:25; also Luke 20:35 [↑](#footnote-ref-25)
26. Pope John Paul, *Theology of the Body,* pp.37-39 [↑](#footnote-ref-26)
27. Pope John Paul, *Theology of the Body,* pp.45-48 [↑](#footnote-ref-27)
28. Second Vatican Council, Pastoral Constitution On the Church in the Modern World, Gaudium et Spes, (7 December, 1965) in *Vatican Council II: The Conciliar and Post Conciliar Documents.* Ed Austin Flannery (Leominster: Gracewing, 1992 pp.903-1001)#24. [↑](#footnote-ref-28)
29. Pope John Paul, *Theology of the Body,* p.273 [↑](#footnote-ref-29)
30. Emmanuel Levinas, Is Ontology Fundamental? in *Basic Philosophical Writings*  Eds. A. Peperzak, S. Critchley, R. Bernasconi (Indianapolis: Indiana University Press, 1996) p.7 [↑](#footnote-ref-30)
31. Pia Matthews *Pope John Paul II and the Apparently ‘Non-Acting’ Person* p.73 [↑](#footnote-ref-31)
32. Pope John Paul, *Theology of the Body,* p.41 [↑](#footnote-ref-32)
33. Pope John Paul II, *On the Occasion of the International Symposium on the Dignity and Rights of the*

*Mentally Disabled Person* (5 January 2004), 5. [↑](#footnote-ref-33)
34. Pope John Paul II, Homily *Jubilee of the Disabled* (3 December 2000), 5 [↑](#footnote-ref-34)
35. *1 Corinthians 6:20* [↑](#footnote-ref-35)
36. Pia Matthews, *Pope John Paul II and the Apparently ‘Non-Acting’ Person* pp.125-126; p.164; pp.168-169 [↑](#footnote-ref-36)