Caring for Persons with Intellectual and Developmental Disabilities

Ethical and Religious Perspectives

Edited by Jos V. M. Welie

Beyond Inclusion

Recognizing the Humanity of the Profoundly Impaired

Peter Comensoli, Bishop of Broken Bay, Pennant Hills, Australia

Abstract

Some theologians have recently argued that to fully recognize the humanity of the profoundly impaired we must propose a re-imagined Christian anthropology that involves, in part, adopting some form of a paradigm of inclusion. Here, that approach is summarized and given critical attention. In particular, the work of Hans Reinders is considered as a significant Christian theological position that holds such a view, but which is problematic. The Inclusion Paradigm is challenged by an account of human being that distinguishes between a human nature that is determined but not historically conditioned, and our existence, which remains undetermined while it is being lived out. This better builds an
anthropology that secures the profoundly impaired in their humanity, and takes seriously the condition in which they live out their lives.

Keywords: anthropology, developmental disability, friendship, inclusion, intellectual disability, personhood

Introduction

There are some human beings who live their lives at the extremes of the human condition because of some profound impairment to their human nature. This group of persons who suffer from severe intellectual or developmental disabilities (IDD) are identifiable by the fact that their faculties of reason, will, and self-awareness—all characteristics of a human being commonly associated with the moral status of being a person—are, or have come to be, severely undermined or entirely absent.

The nature of such impairment is often perplexing in the extreme, yet it is commonplace in most cultures to foster the dignity of the profoundly impaired and to attend to their wellbeing. It is by means of such practices that they are generally acknowledged as peers within the human community. This lends credence to the intuition that the profoundly impaired are recognizably persons among fellow persons.

There are those who would deny that the profoundly impaired are persons precisely because of their impaired condition, while there are others who would uphold the personal presence of the profoundly impaired precisely by sideling their condition. In both positions, it is the condition of the impairment that makes the difference and raises a question: is there something at stake for the profoundly impaired precisely in being the particularly conditioned human beings that they are?

There is a growing number of theologians who seek to re-imagine Christian anthropology from the perspective of the disabled. The aim is to secure their humanity without the condition of their humanity becoming an obstacle to their moral status. Key to this re-imagining is the adoption of a paradigm of inclusion around which the condition of human impairment is separated out from the question of human nature. Specifically, inclusion refers to the notion of full membership or attachment to a particular community that shares the same nature, that of humanity. In such a community, according to the account supported by some theologians, there remains an assumption of normativity regarding those who are not disabled, which helps to define the possibilities and limits of inclusion. This assumption requires critical attention. The profoundly disabled, so the argument goes, can be included in the community of persons when human nature is not defined in terms of the human capacity for reason and will. Their disability does not determine their claim to being human.

It is these two strategies—adopting a paradigm of inclusion, and separating out the condition from the status—that I want to examine in this paper. I will do so as a friendly critic: I think they make the right challenge, but I do not think their strategy adequately addresses the question of the anthropological and moral status of the profoundly impaired.
To state my own position up front: the condition under which the profoundly impaired live their lives is indeed central to the persons that they are, even while it is not determinative of them being human. There is something at stake for the humanity of the profoundly impaired precisely in their being the particularly conditioned human beings that they are; the condition of their humanity is indeed central to their claim to a personal presence among persons.

Of course, the category of “person” remains a contested point in contemporary discussion, reflecting much philosophical development since the Aristotelian-Thomistic understanding centered on reason. This is not the issue being examined. Rather, what is being questioned is the drive to separate out the specific condition from the status of personal presence. Rather than being tokens of respect, this drive actually undermines an important aspect of the particular way in which the profoundly disabled possess their humanity. But let us first examine in greater detail the alternative strategies that have been proposed.

**Reinders on Befriending the Disabled**

Hans Reinders proposes one such re-imagined anthropology in his major work, *Receiving the Gift of Friendship*. His thesis is this: the humanity of the profoundly disabled cannot be secured by the doctrine of the *imago Dei* – that is, the biblical notion that human beings are created in God’s image – because it is inaccessible to the profoundly disabled who do not have the personalizing capacities of reason and will. Therefore, we need to view human life without reference to intrinsic human agency so as to secure for the cognitively disabled their status within the human community.

To do this, Reinders offers an extrinsic solution: that of “being chosen as a friend” by God. It is only in being befriended that someone who is profoundly disabled can come to transcend the impaired condition of his or her life, and so be seen as a full member of the human community. Friendship, not personhood, is the only sure way of securing the humanity of the profoundly impaired.

There are four key steps in Reinders’ project:

1. People with profound intellectual disabilities are people just like other people.
2. Whatever it is that distinguishes people as human beings, it cannot be (the exercise of) the human faculties.
3. The philosophical notion of personhood – of creatures who, by nature, reason, and will – cannot carry the weight of these two claims.
4. Therefore, the foundation on which the humanity of the profoundly disabled is to be secured cannot be that of intrinsic human agency, but must be extrinsic: that of receiving the gift of friendship (from God).

Two points are worth highlighting about Reinders’ project. First, his position stands or falls on finding a way in which the profoundly disabled can be fully included in the human community as friends (since they cannot be included as persons). Second, his project depends on separating out the condition in which the profoundly impaired find themselves – in particular their lack of certain capacities – from their status as human beings.
The Inclusion Paradigm

The notion that inclusion should be the one sought-after good necessary for securing the humanity of the profoundly impaired is itself questionable. The Lutheran theologian, Bernd Wannenwetsch, offers a helpful theological insight into the ambivalence of inclusion:

We are tempted to understand the predication of a disabled human being as “person” as a kind of benevolent stretching of the concept from the usual case toward the unusual. In other words, we are led to think of this “including” of the disabled within the protected zone which we inhabit – “even the disabled!” – as a required moral act. . . I wish to call attention to the mistaken assumption on which [this notion] is based: the need for an act of inclusion that, in turn, rests on an abstract and preconceived concept of personhood that is to be merely applied to disabled human life, instead of being won from a perceptive understanding of the phenomenon [of personal life] itself (183).

Wannenwetsch’s remarks point to a fairly simple idea: the mistaken assumption in a paradigm of inclusion is that it calls for the impaired to be incorporated into a notion of personhood as it applies to someone who is unimpaired. This presupposes that in determining someone’s personal presence among the community of persons, some are on the inside and some are on the outside, and that the insiders have some kind of power over who is chosen to enter the fold. Such an approach defines those on the outside by their lack or what they have lost, and so the paradigm of inclusion works as nothing more than a form of kind-hearted benevolence. A paradigm of inclusion – which assumes a normative desire to participate in an un-impaired world – risks always starting from the perspective of lack or loss. If one’s inclusion derives only from one’s personal achievement or activity, then a paradigm of inclusion will always be necessary for the profoundly impaired, who have no access to such possibilities. The profoundly impaired will never make it on their own merits.

“Inclusion” can be experienced both as a good and as an evil, as something creative and as something destructive. It certainly raises questions about the value of expressing the humanity of the profoundly impaired within the context of a paradigm of inclusion. Because of the failure of the paradigm of inclusion in constructing an anthropology that might recognize the humanity of each human individual, it can be suggested that what is needed is a means of thinking and acting “beyond inclusion” in securing their claim to humanity.

Where, then, are we to go, if we are to leave behind the notion of inclusion? Jean Vanier has often written about the need for the strong and powerful, those who stand at the top of the social ladder, to descend that ladder to the place where the weak and broken find themselves. Rather than assuming a position of power and include persons with IDD, Vanier appears to suggests that the powerful should exclude themselves so as to join those who are already on the outside. He argues that it is only by descending this metaphorical ladder that human beings will come to discover their humanity.

Vanier wants to distance our understanding of God – and the understanding of ourselves who are made in God’s image – from society’s obsession with categories of mastery and autonomy. While notions of inclusion and friendship are present in Vanier’s
picture, he uses the ladder metaphor to indicate that befriending and including do not make the human being, but presume a vision of human life which is not dominated by notions of capacity, autonomy, and the like.

Our humanity is most truly itself through an act of self-emptying, he would say, of giving up what we cling to, and thereby of opening up to a similarly self-emptied life. The view of friendship and inclusion from the bottom of the ladder, therefore, is one where I am free to be with others, which is a reversal of the image from the top of the ladder where I consent that others may be with me.

**Living One’s Condition between Human Nature and Existence**

Vanier’s insight is that the true measure of our humanity is not to be found in ascribing personhood to others but in accepting that we are persons in virtue of the life we are called to live, in the condition under which we are living it – be it impaired or unimpaired. If the profoundly impaired are truly personally present in exactly the same way as every other human being, then this must be evident in the lives they are living under the condition of their impairment.

So, what does it mean to say that the profoundly impaired are truly personally present in the human community through the impaired lives that they are living? It means that the profoundly impaired are the human beings that they are in the condition under which they are living their humanity. There is no way of being human outside of the condition in which that humanity is lived.

It is of the nature of human being that we each have the project of our own individual lives to pursue, precisely as a personal project for life. Thus, both a determinate and an indeterminate principle marks our humanity. We are ordered towards fulfilling that which we are, yet we are free not to attain that goal. Therefore, it is our human nature that is determined, although it is not historically conditioned, because it is the nature that we have been given; whereas it is our existence, which remains undetermined while it is being lived out, that is historically conditioned, because it is the having or living of the nature conferred. In this sense, our existence is the opportunity to have or to live the nature that is presupposed. Human nature cannot be historically conditioned because it is determined fully already; but this nature takes on the form of a project to be lived out in particular circumstances of an individual’s life. The actual condition under which the project of one’s life unfolds is both necessary and sufficient for the actual living out of that life.

This plays out in the lives of the profoundly impaired in this sense: the condition under which they exist and live their lives is integral to their own human project. Their claim to being human is contingent upon nothing else other than their being in existence in the condition under which they find themselves. The human essence of the profoundly impaired does not exist hidden behind or underneath or beyond their human condition; it exists as the very condition under which they live. They are, quite uncomplicatedly, ordinary human beings, who are not excused from living out their humanity just because they are impaired.

Consequently, the profoundly impaired are not exempt from living out the nature that they have; their having their nature remains as bound up with qualitative considerations as does every human life, otherwise they would only ever be seen as different or special. They
are ordinary human beings: nothing more or less. One’s condition has to do with the task of living, which one does in virtue of his or her humanity. You do not have to have a certain “condition” – say, a particular level of rationality or volition – so as to achieve humanity. Rather, the condition of our humanity is the concrete state in which we are human.

**Concluding Remarks**

Why should we expect this to make a difference to how we recognize the humanity of the profoundly impaired? Recall the intuition with which we began: the practices of care towards the profoundly impaired are a sign that they are recognizably persons. What is particular about this intuition is that the measure of it has to do with the lives being lived, and not some status extended to them as an act of inclusion. It is not the condition of their humanity that determines their moral status; rather, it is the recognition of their personal presence that prompts us to attend to their condition.

The measure of our humanity, therefore, is not determined by the condition of it; it is not something to be achieved, either by the capacities we already have or by an act of moral inclusion when we do not have those capacities. One’s humanity is not determined via an invitation into the club of being one of us. Yet the condition of our humanity is the only means we have by which we live out our humanity; personhood is always a lived reality, not a category. The moral claim that the profoundly impaired make upon us is made via the condition of their humanity: their “all of me,” so to speak. It is not about finding ways in which they might first be included as one of us, before extending to them a moral status.

It has always been the case for the profoundly impaired that the condition under which they live their lives is the issue that matters. What we have come to, however, is a point where we may say that the condition of their impairment is both sufficient and necessary for answering the question of their personal presence and moral status within the human community. It is sufficient because the condition of their impairment is simply the concrete particular expression of their humanity; and it is necessary because their impairment is the only location, as it were, in which they may live the humanity that they have.

By implication, the profoundly impaired are both secure in their humanity and still need to continually live out the project of their lives just like every other human being. For the profoundly impaired, it is not a matter of including them as one of us, but that we and they may discover together the extent to which we live well “all of me” in the condition in which we live our lives.

**Bibliography**

Reinders, Hans S.


Vanier, Jean

Wannenwetsch, Bernd