JAROSŁAW L. MIKUCZEWSKI

DISABILITY AND COMPASSIONATE CARE:

IGNATIANUM UNIVERSITY PRESS

A NEW VISION FOR PERINATAL HOSPICE

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The domain of deontology may appear, especially today, as the most vulnerable in the field of medicine; but it is essential, and medical morality should always be considered by practitioners as the norm of their professional practice that deserves most attention and above all the greatest efforts for its defense.

John Paul II
(*Address to The World Medical Association*, October 1983)

INTRODUCTION

It might seem self-evident to say that our personal experiences leave indelible marks on who we are and how we think. Nevertheless, I feel compelled to begin with this thought, as events, encounters, and even mistakes possess the powerful ability to shape our understanding of ourselves and the world around us. One such pivotal experience for me was my time working as a chaplain in perinatal hospice care in Poland. This journey was not just a professional engagement; it was a deeply personal odyssey that taught me invaluable lessons about life, empathy, and the essence of human dignity.

During my tenure in Poland, I witnessed firsthand the critical importance of having healthcare teams who not only understand and support the desires of parents expecting children with terminal conditions but also recognize them as loving guardians of profoundly disabled children. These parents—who choose to bring their children into the world despite knowing their lives will be brief—demonstrate a remarkable blend of courage, love, and resilience. They require and deserve a care environment that acknowledges and supports their experience.

I quickly realized that this field of care inherently carries a particular understanding of human disability or illness. Whether consciously or unconsciously, this understanding markedly influences the nature and scope of care provided to vulnerable perinatal hospice patients. The quality and effectiveness of that care depend heavily on the caregivers' underlying anthropology and their view of human disability. This realization led me to explore the most influential contemporary narratives on human disability. My goal was to identify perspectives that could best respond to the needs of parents who choose to carry affected pregnancies to term, ensuring they receive comprehensive support consistent with the mission of Catholic perinatal hospice care. At the root of this mission lies a commitment to recognizing the inherent dignity of every human life, regardless of its limitations.

Understanding and addressing the complex needs of these parents requires a nuanced approach that considers their emotional, spiritual, and practical challenges. Healthcare teams must be equipped not only with medical expertise but also with deep empathy and respect for the parents' journey. This holistic approach fosters a supportive environment where parents feel valued and understood, enabling hem to navigate their challenging path with dignity and grace. Moreover, this exploration aims to bridge the gap between contemporary disability narratives and the practical aspects of hospice care. By integrating these narratives, we can develop care practices that are both compassionate and effective, providing parents with the reassurance that their children, despite their profound disabilities, are recognized and cherished as full members of the human family.

In summary, the interplay between personal experiences, conceptual understandings of disability, and practical caregiving forms the backbone of effective perinatal hospice care. This book aspires to deepen our understanding of these dimensions, with the ultimate goal of enhancing the support provided to parents and structuring it in accordance with the compassionate mission of Catholic perinatal hospice. Through this work, I hope to offer insights and guidance that will benefit healthcare providers, parents, and all those accompanying the sacred journey of caring for life, however brief it may be.

Adam's story

I was first introduced to the importance of perinatal hospice care through an encounter with the wonderful parents of a boy named Adam, who was diagnosed with microcephaly in the 16th week of pregnancy. I met them at the Office of Children's Hospice in Krakow, Poland. The couple was convinced that they wanted to bring Adam into the world and provide the necessary care for him to live, however brief his time with them might be. Despite their strong resolve, I could sense their struggle: a heavy burden of fear, uncertainty, disappointment, and anger. The couple was evidently searching for meaning in the midst of their first child's inevitable, profound intellectual impairment and eventual premature death.

In that search, Adam's parents turned to the perinatal hospice care team—of which I, as a chaplain, was a member—for assistance. It became clear that they were seeking a particular attitude of appreciation and validation of their son's life from us. They needed reassurance that Adam, despite his severe physical and neurological disabilities, would be acknowledged as fully human and his life valued equally. At the same time, they hoped to be seen and supported as loving and faithful caregivers of their unborn son. Responding appropriately to these parental expectations depends, I believe, on how the care team understands the nature and meaning of disability, particularly profound intellectual impairment. In this context, Pope John Paul II (JPII) emphasized on numerous occasions the importance of correctly understanding the human condition in the face of illness and disability. He also warned that "deontology is the most vulnerable field of today's medicine."[1]

Acknowledging the magnitude of this challenge, my book aims to contribute to the rediscovery of a proper anthropology and an understanding of profound human disability in the perinatal hospice setting, particularly from a Catholic perspective. I argue throughout that only by adopting such a framework can perinatal hospice teams offer the full measure of respect and appreciation for the human dignity due to unborn children with severe impairments, and support to the families who care for them. Although this work is primarily intended to enrich the practices of Catholic perinatal hospice centers, I believe it may also prove beneficial to non-Catholic centers and to anyone involved directly or indirectly in the care of individuals with profound intellectual disabilities. I am aware that my study is by no means exhaustive; much remains to be explored in the field of medical anthropology and disability within contemporary Western healthcare. Nevertheless, I hope that this book can serve as a starting point for further inquiry into these and underexamined issues.

Understanding and addressing the complex needs of these families requires a nuanced approach that considers their emotional, spiritual, and practical challenges. Healthcare teams must be equipped not only with medical expertise but also with deep empathy and respect for the journey of parents facing such circumstances. A truly holistic approach creates

1 John Paul II, *Address at the conclusion of the 35th General Assembly of the World Medical Association* (October 29, 1983).

an environment in which families feel seen, supported, and empowered to navigate their path with dignity and grace. Moreover, this exploration aims to bridge the gap between contemporary narratives about disability and the day-to-day realities of hospice care. By integrating these perspectives, we can develop care practices that are not only medically sound but also compassionate and responsive, providing parents with the reassurance that their children, even in the presence of profound disability, are cherished as full members of the human family.

In summary, the interplay between personal experiences, theological and philosophical understandings of disability, and practical caregiving strategies forms the backbone of effective perinatal hospice care. This book aims to contribute to a deeper understanding of these interconnected elements and enhance the support provided to families, in line with the compassionate mission of Catholic perinatal hospice. Through this work, I hope to offer insights and guidance that will benefit healthcare providers, parents, and all those who participate in the sacred calling of caring for life, however brief its earthly span may be.

Between anthropologies

The quest for an appropriate anthropology—one that offers a robust understanding and appreciation of profoundly disabled human life—must begin with an examination of the fundamental sources that have shaped contemporary Western narratives about disability. This project opens with an analysis of three such sources: (1) secular Disability Studies (DS), (2) the contemporary Catholic Church Magisterium as informed by the teachings of St. Thomas Aquinas, and (3) the writings and teachings of JPII, particularly his *Theology of the Body* (TB).

Each of these substantial sources presents a distinctive way of understanding human disability, shaped by the context of a particular community and its underlying social dynamics. As for the DS, its advocates promote what philosopher Hans Reinders describes as an "anthropology of political citizenship."[2]

2 Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: Eerdmans, 2008), p. 35.

In contrast, the Magisterium of the Catholic Church reflects what I refer to as a *ratio*-informed anthropology—one that emphasizes a rational appreciation of human dignity. Meanwhile, although JPII's anthropology is rooted in the Thomistic tradition, his perspective introduces a somewhat different emphasis, which I will describe as *relatio*-informed anthropology.

Accordingly, this project entails two stages. In the first, I will introduce the anthropologies proposed by DS and the Catholic Magisterium and explore their positive contributions to our perceptions of disability while also identifying significant limitations, especially regarding the recognition of dignity and full humanity in unborn children with profound intellectual disabilities. In the second stage, I argue that JPII's *relatio*-informed anthropology, especially as developed in *Theology of the Body*, contributes several considerations that are critical for a more complete appreciation and protection of unborn children living with profound disabilities. Consequently, I contend that this vision of the human person should be widely accepted as a solid foundation for perinatal hospice care in both Catholic and non-Catholic healthcare institutions.

Before proceeding further, it is important to clarify that the rationale behind this specific focus on profound intellectual impairment has to do with my experiences in the Krakow Children's Hospice and at Cardinal Glennon Children's Hospital in Saint Louis. In both places, I observed that such impairments were among the most prevalent conditions affecting children in perinatal hospice care. This reality gives rise to a unique set of concerns for parents navigating their child's diagnosis and care. There is substantial literature indicating that public perceptions of intellectual disability often create considerable burdens—not only for individuals with disabilities but also for their families and support networks. Since profound intellectual disability is not my main focus in this project, I will not discuss it in greater detail here; however, the issue certainly warrants separate and extended reflection.

I begin this work by sketching the historical and clinical context of perinatal hospice care. The upcoming chapter will trace its origins and development. I will explain how it has evolved into its current form and point to the distinctive multidisciplinary character of this practice, which calls for close collaboration across medical, psychological, pastoral, and ethical domains.

Ultimately, I will argue that perinatal hospice care embodies a unique set of values that are vital to the healthcare profession. Drawing on the narratives of mothers in perinatal hospice settings, I will demonstrate the importance of this practice in respecting and protecting not only the lives of perinatal children but also the integrity and dignity of their families. The first chapter will conclude by emphasizing the need to ground perinatal hospice practices in coherent and life-affirming anthropological concepts so that its noble mission of compassionate, ethically rooted care can be truly fulfilled.

CHAPTER ONE

PERINATAL HOSPICE CARE: CONTEXT OF CARE

Advances in prenatal screening and the routine use of ultrasound technology have resulted in increased diagnostic capacities for detecting rare and often significantly life-limiting conditions.[1] Although potentially beneficial in and of itself, these advances can also present distinct difficulties for prospective parents. Particularly troubling is the question of what to do when tests identify genetic anomalies or congenital defects. What course of action should they take? Should they opt to terminate the pregnancy in the belief that they are sparing the child from suffering, or continue the pregnancy and prepare for the potential hardships of caring for a child with profound needs?

Aaron D. Cobb, a philosopher and father of Samuel—a child with trisomy 18 who lived only five hours after birth—observes that

> typically, parents are forced to ask these questions at advanced stages of a wanted pregnancy, reflecting on their options in the shock that follows a devastating diagnosis. Any choice in this context is fraught with difficulty.[2]

Adam's parents, whom I met at a perinatal hospice in Kraków, faced a similarly complex and emotionally charged decision. Fortunately, they were able to find a safe and supportive environment for Adam's birth, but such services are sadly still not widely available in Poland. In most cases, the only option presented to parents expecting a child with a terminal diagnosis is termination of the pregnancy. In such situations, parents are often met with messages suggesting that both the baby and the family would

1 Aaron D. Cobb, *A Virtue-Based Defense of Perinatal Hospice* (New York, NY: Routledge, 2020), p. 2.

2 Ibidem.

be better off if the pregnancy were ended. After all, they are told, the child is going to "die anyway."[3]

The absence of alternative care options for pregnancies affected by severe diagnoses can leave parents feeling pressured into choosing termination. An important study by Kenneth B. Schechtman sheds some light on this particular issue. According to his findings, only 20% of families chose to continue a pregnancy after receiving a diagnosis of a lethal malformation.[4] However, the situation can change dramatically when parents are fully informed about alternative care options. Schechtman reports that 80% of families in his study chose to carry pregnancies with serious congenital diagnoses to term when they were told about the possibility of comfort care following birth.[5] Similar results are reported by Michelle D'Almeida, whose study found that 75% of families opted to continue pregnancies with serious diagnoses when they were made aware of supportive care options.[6]

1.1. Perinatal hospice care: filling the void

Perinatal hospice is a relatively new form of care for families who choose to continue a pregnancy after receiving a serious or life-limiting diagnosis. As Lis Townsend explains, this practice has the noble goal of supporting parents through the emotional turmoil that naturally accompanies the pregnancy and birth of babies diagnosed with severe, often fatal, disorders.[7] According to Townsend, perinatal hospice care "provides an alternative to the solution of abortion, a decision that often only heightens the guilt of parents who may already be blaming themselves for producing an imperfect child."[8]

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3 Liz Townsend, "Giving Terminally Ill Babies and Their Families an Alternative to Abortion," *National Right to Life News*, April 2001, pp. 20–21, p. 20.

4 Kenneth B. Schechtman et al., "Decision-Making for Termination of Pregnancies With Fetal Anomalies," *Obstetrics & Gynecology* 99, no. 2 (2002): pp. 216–222.

5 Ibidem, p. 219.

6 Michelle D'Almeida et al., "Perinatal Hospice: Comprehensive Care for the Family of the Fetus with a Lethal Condition," *Obstetrical & Gynecological Survey* 58, no. 11 (2003): pp. 718–719.

7 Townsend, 2001, p. 20.

8 Ibidem.

This model of care has emerged as a successful integration of three major sociomedical advances of the past four decades.[9] As Nathan J. Hoeldtke notes, these include advancements in accurate prenatal diagnostics, enhanced understanding and recognition of perinatal grief, and the rise of modern hospice care.[10] Prenatal diagnosis of fetal pathology was practically impossible before the second half of the 20th century. It was not until 1964 that anencephaly was first identified via ultrasound.[11] Following shortly thereafter in 1968 was the first prenatal detection of an abnormal fetal karyotype.[12] In the decades since these initial breakthroughs, the continued evolution of diagnostic imaging and molecular genetics has resulted in a wide range of conditions that can now be detected in the prenatal period.[13]

Unfortunately, advances in diagnostic capabilities for fetal conditions have far outpaced the development of viable treatment options. As Hoeldtke asserts, "prenatal diagnostic advances have not always been accompanied by equivalent advances in knowledge about the management of familial needs arising from foreknowledge of a significant fetal disorder."[14] He also acknowledges that "doctors are so uncomfortable in these situations, they don't know what to do. They think there's no risk with abortion, that the problem will be over."[15] In a similar tone, Townsend emphasizes that many physicians believe they are helping their patients by sparing them the grief of carrying a baby destined to die. However, she also argues that carrying the pregnancy to term can help parents deal with the inevitable grief. As she explains, "if they abort the baby, the parents will always wonder whether the diagnosis was correct, whether they murdered a healthy child."[16] Townsend concludes:

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9 Nathan J. Hoeldtke and Byron C. Calhoun, "Perinatal Hospice," *American Journal of Obstetrics and Gynecology* 185, no. 3 (2001): p. 525.

10 Ibidem.

11 Shreelata Datta, "Ultrasound in Obstetrics and Gynaecology," *Obstetrics, Gynaecology & Reproductive Medicine* 23, no. 7 (2013): pp. 202–207.

12 Myungshin Kim, Jong Chul, and In Yang, "Prenatal Diagnosis of Down Syndrome," *Genetics and Etiology of Down Syndrome*, 2011.

13 Hoeldtke, 2001, p. 527.

14 Ibidem.

15 Ibidem, p. 529.

16 Ibidem.

> but if the baby is born, they are able to hold the child, videotape him, baptize him, and even take him home if he lives for a short time. They know that they did everything they could. They gave God a chance to heal the baby, gave every opportunity for a miracle.[17]

Although, statistically speaking, stillbirth and neonatal death are relatively common, the first published report on the psychological impact of stillbirth did not appear until 1968.[18] Similarly, the first study examining parental responses to neonatal death was not released until 1970. Prior to these milestones, as Stanford Bourne points out, prenatal losses were typically seen as "non-events."[19]

Providentially, once this topic had been broached in the medical literature, a growing awareness of the grief associated with perinatal loss led to an increase in research that has culminated in the standards of care we have today. The first to implement a comprehensive program for parents electing to continue affected pregnancies was American gynecologist Byron C. Calhoun. His initiative exceeded the standards of existing perinatal bereavement management at the time and was specifically designed to support parents experiencing sudden and unexpected perinatal loss. Calhoun's program exemplifies how the understanding of end-of-life care has evolved over recent decades. In the context of perinatal hospice, parents are often confronted with a terminal diagnosis for their child at an early stage in the pregnancy. As Cobb aptly observes, the sudden and unexpected loss once associated with prenatal death has now been replaced by the equally shocking experience of receiving a devastating diagnosis: "instead of anticipating the arrival of a new baby, they contemplate the impending death of a loved one."[20]

17 Ibidem, p. 22.

18 Stanford Bourne, "The Psychological Effect of Stillbirths on Women and Their Doctors," *J R Coll Gen Pract.*, no. 16 (1968): pp. 103–112.

19 Ibidem, p. 110.

20 Cobb, 2020, p. 37.

1.2. Perinatal hospice: logic of functioning

The medical community's perception of end-of-life care was substantially transformed by the studies of Elisabeth Kübler-Ross, especially her seminal work on death and dying.[21] Similarly, modern hospice standards were shaped by her contemporary, Cicely Saunders, whose approach to caring for terminally ill patients and their families centered on providing holistic physical and emotional support.[22] In 1982, Jonathan Whitfield and his colleagues built on Saunders's work by applying the principles of hospice care at the Children's Hospital in Denver, where they developed the first neonatal hospice program for dying infants and their families.[23] Since then, the philosophy of hospice has continued to evolve and take shape through various institutions and models. Today, the hospice movement is a well-established global entity that has expanded to include the care of the families of terminally ill children.

Although neonatal hospice is still vital in and of itself, it is no longer sufficient to meet the needs of families of children with prenatal terminal diagnoses. This is because the increased capacity for early diagnosis of lethal congenital anomalies necessitates that care for grieving families start not at the time of the infant's death but at the moment the diagnosis is made.[24] Therefore, as Byron C. Calhoun explains, a new model of perinatal hospice care was created to provide continual support to families from the time of diagnosis until the death of the infant. In 1995, Calhoun formally established the first perinatal hospice care center at Madigan Army Medical Center in Tacoma, WA.

According to Calhoun, the experiences of families who choose to continue pregnancies in which the prenatal baby has received a terminal diagnosis are very similar to those of families in which an adult or child family member receives a similarly devastating diagnosis. He therefore believes

21 Kübler-Ross Elizabeth, *On Death and Dying* (Tokyo: Yomiuri shinbunsha, 1972).

22 Dame Cicely Saunders, "The Hospice: Its Meaning to Patients and Their Physicians," *Hospital Practice* 16, no. 6 (1981): pp. 93–108.

23 Jonathan M. Whitfield, "The Application of Hospice Concepts to Neonatal Care," *Archives of Pediatrics & Adolescent Medicine* 136, no. 5 (January 1982): pp. 421–424.

24 Byron C. Calhoun, "Perinatal Hospice: Should All Centers Have This Service?," *Neonatal Network* 16, no. 6 (September 1997): pp. 101–102.

that perinatal hospice care should be seen as a "logical step in the evolution of hospice."[25] He also points to important similarities between perinatal and adult hospice care, stressing that in both instances, the emphasis should be on:

> neither hastening nor prolonging death; affirming life by caring for the loved one while regarding dying as a normal process; stressing values that go beyond the physical needs of the dying one; and meeting the medical, emotional, and spiritual needs of the family by providing a multidisciplinary team that continues to follow them even after the death of the loved one, during the period of bereavement.[26]

According to Calhoun, perinatal hospice care centers on the people involved rather than on the fetal pathology and places the family at the heart of the caregiving process.[27] As such, hospice provides a continuum of support for the family from the time of diagnosis through death and beyond. Perinatal hospice also allows appropriate time for the necessary experiences of grief and emotional processing. As Calhoun describes, it is a "time for bonding, loving, and losing; time so that the entire course of living and dying is a gradual process that is not jarringly interrupted."[28]

1.3. Perinatal hospice: discovering the value

According to the pioneers of perinatal hospice care, Calhoun and Hoeldtke, parents of prenatal children with terminal conditions should be given the opportunity to consider all possible options—including the possibility of continuing the pregnancy within the perinatal hospice pathway. This is important for protecting the couple's reproductive autonomy. In a similar vein, Cobb argues that "the primary good served by prenatal hospice is that it respects the family's choice to continue an affected pregnancy."[29] It can also be helpful for families to understand that although their unborn child

25 Hoeldtke, 2001, p. 527.
26 Ibidem.
27 Ibidem.
28 Ibidem, p. 528.
29 Cobb, 2020, p. 4.

has a terminal condition, there are still many things that can be done to care for both their baby and their family. This empowers them to take control over some of the consequences and outcomes of their difficult situation.[30]

Similarly, Calhoun asserts that we need to reject the popular sentiment that "because the fetus has a terminal condition, there is nothing that can be done." On the contrary, he insists, "there are a great many things that can be done to care for these families."[31] Accordingly, he describes hospice as an "interactive and, at times, intense form of care."[32] Rather than simply letting nature take its course, perinatal hospice actively empowers families to take control of the situation. Parents who choose perinatal hospice can avail themselves of as much—or as little—of the available support as they wish.[33] Equally important is the existence of a viable, compassionate, and structured program that offers expecting parents a real alternative: a supportive context in which they can work through the implications of the birth and the impending death of their child.[34]

As Cobb argues, in addition to preserving reproductive autonomy, perinatal hospice also meets other important patient needs. For instance, as an alternative to abortion, it helps to protect the moral value of the unborn child.[35] He also advocates for understanding perinatal hospice as "a common project of care that manifests virtues essential to addressing substantive human needs."[36] For Cobb, perinatal hospice embodies "virtues crucial for identifying, recognizing, appreciating, and addressing the vulnerabilities and needs occasioned by a significantly life-limiting in utero diagnosis."[37] Accordingly, he focuses on four virtues in particular: hospitality, hope, solidarity, and compassion, explaining that each responds to specific human needs as its central object of concern. He writes:

30 Ibidem.
31 Hoeldtke, 2001, p. 527.
32 Ibidem.
33 Ibidem, p. 530.
34 Ibidem.
35 Cobb, 2020, p. 8.
36 Ibidem.
37 Ibidem, p. 9.

> the need for welcome is a focal concern of the virtue of hospitality. The need for meaningful possibilities worthy of pursuit is a focal concern of the virtue of hope. The need for human presence is a focal concern of the virtue of solidarity. The need for consolation in grief is a focal concern of the virtue of compassion.[38]

1.4. Perinatal hospice: a unique dynamic of care

Perinatal hospice necessitates a team-based approach to patient care, as no single profession can meet the full spectrum of needs experienced by families anticipating the death of a prenatal baby or neonate.[39] According to Charlotte Wool, the core perinatal hospice team typically includes the family, the primary physician, a social worker, and a nurse care manager trained in bereavement support.[40] This core team is often expanded to involve neonatologists, anesthesiologists, psychiatrists, psychologists, chaplains, bereavement counselors, labor nurses, and neonatal nurses.[41]

Depending on the family's preferences, some parents in perinatal hospice programs may elect to work with a broader range of support professionals, whereas others may prefer to engage with a smaller team. What is essential to the perinatal hospice model is that it encompasses antepartum, intrapartum, and postpartum care.[42] Each stage presents distinct emotional and medical challenges for both the expecting parents and the assisting medical team. Liz Townsend argues that the central focus of hospice is managing fear.[43] She notes that the fear of dying alone and the sense of abandonment in times of need are common experiences among hospice patients. In a similar way, families in perinatal hospice often fear isolation and abandonment as they face the loss of their child. They also fear the prospect of pain and suffering for their baby.[44]

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38 Ibidem.

39 Charlotte Wool, "State of the Science on Perinatal Palliative Care," *Journal of Obstetric, Gynecologic & Neonatal Nursing* 42, no. 3 (2013): pp. 372–382.

40 Ibidem, p. 373.

41 Wool, 2013, p. 375.

42 Ibidem.

43 Liz Townsend, "Giving Terminally Ill Babies and Their Families an Alternative to Abortion," *National Right to Life News*, April 2001, pp. 20–21.

44 Ibidem.

To address this reality, the first comprehensive perinatal hospice program, initiated by Calhoun in 1995, was designed to provide care and support throughout the period of gestation and delivery, with the goal of ensuring that the infant—if born alive—would be kept comfortable until the moment of death.[45] The program also aimed to reduce feelings of isolation and abandonment among parents through the constant availability of a multidisciplinary team to deal with concerns as they arose.[46] According to Emanuel Lewis, a critical task in working with families carrying a prenatal baby diagnosed with a terminal condition is preparing them for the grieving process. Grief following a perinatal loss differs from other forms of grief,[47] one key difference being the relative scarcity of memories associated with the child. In this context, Calhoun explains that:

> because building memories of their loved one is important for the grieving process, we provide parents with frequent ultrasonographic visualization of the fetus. We also encourage the presence of other family members, including grandparents and children, so they may visualize the fetus. The clear delineation of the existence of the "baby" helps not only the parents but also other family members to develop a concrete memory of the fetus, facilitating their grieving.[48]

Another crucial stage in managing an affected pregnancy is the facilitation of delivery. The logistics of delivering a terminally ill baby must be carefully planned. Every possible contingency should be discussed with the parents, including management of infant care in the event of a live birth.[49] Calhoun explains that he does not typically recommend fetal monitoring or other interventions during labor. However, there are situations in which families may request monitoring—or even cesarean delivery—if an intrapartum death appears otherwise inevitable.[50] One argument in favor of these interventions is the strong parental desire to see their baby

45 Wool, 2013, p. 378.
46 Ibidem.
47 Emanuel Lewis, "Mourning by the Family after a Stillbirth or Neonatal Death," *Coping with Physical Illness*, 1984, pp. 43–50.
48 Hoeldtke, 2001, p. 527.
49 Ibidem.
50 Ibidem, p. 529.

alive, even if momentarily. In such cases, parents may be willing to accept the increased maternal risks that accompany cesarean delivery.[51]

Once the child is born, the diagnosis is confirmed, and the infant is kept with the parents in order to maximize their time together. Calhoun and his team encourage the presence of other family members, including children, during this period. They believe that "being able to care for the newborn in even the smallest way allows parents to feel that they contributed something special to their offspring."[52] Not all children in perinatal hospice die immediately after birth. Some infants have conditions that are not immediately fatal and may be able to go home with their families before passing. In such cases, hospice care continues, often with increased involvement from the neonatal team to support the family during this time. Perinatal hospice care does not end with the death of the child either. Instead, it continues in the form of grief counseling and assistance with practical matters such as funeral planning or memorial services.[53] Contact with the perinatal hospice team is sometimes reestablished by the family during subsequent pregnancies, especially if they experience heightened anxiety. Calhoun notes that these lingering concerns may not always be openly expressed and thus require increased sensitivity and awareness from physicians and care providers during future pregnancies.[54]

1.5. Perinatal hospice: a mother's perspective

Any reflection on the experience of perinatal hospice would be significantly lacking without considering the needs and perspective of the mother. Only through this lens can the full spectrum of the emotional burden associated with perinatal hospice care—and the complex decision-making processes regarding the fate of the child—be fully appreciated in their entire complexity. The work of Anthony Lathrop and his team has been particularly important in giving voice to mothers who have experienced

51 Ibidem.
52 Ibidem, p. 530.
53 Ibidem.
54 Ibidem, p. 532.

perinatal hospice.[55] Their narrative study involved fifteen women who were presented with terminal diagnoses for their unborn children and still chose to continue their pregnancies.

The main goal of Lathrop's study was to broadly explore the experiences of women who elected to continue pregnancies affected by lethal fetal diagnoses, and "to develop knowledge useful to nurses and other healthcare professionals who provide perinatal hospice care."[56] For this research, Lathrop's team used a qualitative narrative analysis methodology, which is particularly well-suited for studies involving loss and bereavement. As Lathrop and VandeVusse explain, "creating and relating personal stories about significant life events is a basic means by which individuals organize their experience and construct sense and meaning."[57] Narratives, he adds, do not simply describe significant events—"they provide structure to experience and establish meaning in what may seem to be meaningless situations."[58] In addition, the analysis of personal narratives "can provide insight into important experiences in participants' lives."[59]

Lathrop and VandeVusse's study showed that perinatal loss is linked to bereavement-related experiences such as "grief, depression, anxiety, posttraumatic symptoms, guilt, and relationship difficulties."[60]

One recent, comprehensive study on bereavement focuses on the grief work hypothesis, which posits that recovery following a significant loss involves confronting the emotional pain of grief, severing emotional ties to the deceased, and returning to pre-loss functionality.[61] Other scholars in this field (such as Bowlby) describe four phases of response to loss: shock or numbness, searching and yearning, disorganization and despair, and reorganization.[62] However, more recent studies have begun to con-

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55 Anthony Lathrop and Leona VandeVusse, "Continuity and Change in Mothers' Narratives of Perinatal Hospice," *Journal of Perinatal & Neonatal Nursing* 25, no. 1 (2011): pp. 21–31.

56 Ibidem, p. 21.

57 Ibidem, p. 22.

58 Ibidem.

59 Ibidem.

60 Ibidem, p. 24.

61 Peter Wright, "Grief Theories and Models," *Journal of Hospice & Palliative Nursing* 10, no. 6 (2008): pp. 357–358.

62 John Bowlby, "Attachment and Loss," in *Loss: Sadness and Depression* (New York: Penguin, 1980).

ceptualize the bereavement process in a slightly different light by focusing on meaning reconstruction, continuing bonds, and posttraumatic growth.

In contrast to earlier models, "contemporary theories emphasize post-loss transformation of self and relationships, rather than a return to the pre--loss state."[63] These findings form the foundation of many programs dedicated to the care of women and families affected by terminal fetal diagnoses. They stress that the goal of perinatal hospice care is to "prevent suffering, preserve dignity, promote quality of life, and honor parental preferences."[64] Participants in Lathrop and VandeVusse's study strongly emphasized the importance of perinatal hospice care in helping them cope with the various struggles stemming from their loss. One key observation made by Lathrop and VandeVusse was "the experience of continuity and change in the mother's narratives."[65] For example, many mothers reported thoughts and feelings that remained constant despite the passage of time. As Lathrop and VandeVusse explain, many continued to experience "frequent thoughts about their babies, feelings of loss and pain, feelings of connection to their babies, and ongoing or recurrent feelings of grief."[66] At the same time, these mothers also noted changes in their emotional responses over the course of the study, including a decrease in the intensity of grief and perceptions of personal growth. One mother said that the loss of her baby led to profound personal growth. She asserted, "I'll never be the same… it really made me a lot more compassionate."[67]

> Another important facet of personal change reported by Lathrop's team was an increase in religious faith. This is illustrated by the testimony of one mother, who states that: "I just knew we would get through it. A lot of people in this kind of situation or any kind of a terminal illness realize strength that they didn't know they had. When you are about to lose it, you don't think you can do it, it's there again for you. And so, my faith is stronger than it ever was because I felt carried."[68]

These mothers' stories demonstrate that they valued and sought to preserve their feelings of family closeness, connection to, and love for their

63 Lathrop, 2011, p. 24.
64 Ibidem.
65 Ibidem, p. 25.
66 Ibidem.
67 Ibidem.
68 Ibidem, p. 26.

babies. Additionally, they stated that it was possible for them to "maintain meaningful emotional connections to their babies and to draw enduring lessons and meanings, even as the intense pain of their losses subsided."[69]

Another significant aspect of these mothers' narratives was the simultaneous sense of validation and invalidation of their motherhood. Lathrop and VandeVusse's findings reveal that the development of maternal identity was evident in many of the women's stories. Several described their intentional desire to become mothers, and some even used the term "emergency bonding" to characterize their urgent longing to form relationships with their babies during the limited time that they had together.[70] At the same time, these mothers also described various experiences in which they felt that their perceptions or emotions were invalidated. It therefore becomes critical to identify and understand the factors contributing to this sense of validation—or invalidation—of motherhood.

1.6. Validation and invalidation of perinatal hospice motherhood

As Lathrop and VandeVusse's study suggests, a mother's perception of herself as a mother can be challenged by the death of her baby. Additionally, many mothers expressed that they perceived a social bias that took the form of "an overt or unspoken tendency for others to devalue their babies or their status as mothers."[71] For example, some felt that because their babies were not expected to live very long, they were not expected to form strong attachments and should therefore get over it and recover quickly from their losses."[72] The implication that their affected children were somehow less important than healthy babies was particularly upsetting to these mothers.

Lathrop and VandeVusse's study also revealed that, because physicians have special authority in healthcare settings, their invalidating comments

69 Ibidem, p. 28.

70 Anthony Lathrop and Leona VandeVusse, "Affirming Motherhood: Validation and Invalidation in Women's Perinatal Hospice Narratives," *Birth* 38, no. 3 (2012): pp. 256–265.

71 Ibidem, p. 259.

72 Ibidem.

or attitudes could be especially painful for these women. They recount an instance in which one mother's physician remarked that there was no reality-based reason for her to continue the pregnancy and expressed his belief that she "only continued the pregnancy because she irrationally thought the baby would somehow survive."[73] Another mother described an interaction in which a physician suggested that, "as the baby was not expected to live very long, the mother would not become too attached and therefore would not grieve as much."[74]

The testimonies of these mothers also revealed that certain medical terminology can feel invalidating. They specifically cited the phrase "incompatible with life," a commonly used term in medical contexts to describe terminal conditions, as inappropriate and contradictory to their experiences.[75] One mother explained:

> the doctor said we have to terminate: "It is non-compatible with life." Who are they to say that? You know what I mean? Who are they to take all this wonderful, beautiful experience that we had away just because they feel it's non-compatible with life?[76]

Other health care experiences can be invalidating in more subtle ways. Some mothers recounted being struck by how sonographers or physicians withheld images of their babies or did not disclose the baby's sex once anomalies were identified.[77] These stories demonstrate that perinatal loss imposes substantial emotional burdens on mothers and families and that such situations require robust professional support. Perinatal hospice provides a safe space and comprehensive assistance necessary to care for prenatal life and to affirm the motherhood of women who choose to continue their affected pregnancies.

Lathrop's study aptly points to the moments in mothers' stories where they indicated the importance of affirming experiences and interactions. One example of such an affirming practice offered by perinatal hospice is the opportunity to have professional photographs taken of the baby.

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73 Ibidem, p. 260.
74 Ibidem.
75 Ibidem, p. 261.
76 Ibidem.
77 Ibidem, p. 262.

One mother described how these images helped her overcome self-doubt: "I'm so glad I have those pictures because otherwise I'd think that really didn't happen to me. That that was just a bad dream. But the pictures are proof that the baby did exist."[78] Many perinatal hospices offer various ways of creating tangible mementos which, as Lathrop explains, are another way that these mothers seek to affirm the reality of their children. Castings of the baby's hands or feet are often cherished as physical reminders of the child's existence.[79] Another mother explained how such mementos can help dispel doubt:

> you're just kind of trying to hold on to something, because everything has slipped away, and that's all you have now. And so, if you're ever in doubt about what you went through, you can just go back and revisit it.[80]

Mothers interviewed by Lathrop's team also mentioned that, in addition to these types of mementos, the overall experience of physically caring for their baby played a key role in affirming their motherhood. In nearly every account, the mothers described the experience of physically caring for their deceased or dying infants.[81] Each of them mentioned caregiving behaviors such as dressing, bathing, and swaddling their babies. These activities were essential for them to acknowledge and validate their motherhood. Some mothers were frustrated by hospital practices that interfered with opportunities for personal caregiving and other similar forms of mother-baby interaction. Lathrop describes one story in which the mother, who gave birth via cesarean section, never got to hold or see her baby while he was still alive due to postoperative protocols.[82]

Another vital element in the validation of motherhood for these women was the recognition of their babies by family members. These mothers wanted their babies to be acknowledged as full members of the family. They mentioned that it was particularly gratifying when relatives came to visit them in the hospital and held their babies just

78 Ibidem, p. 261.
79 Ibidem.
80 Ibidem, p. 262.
81 Ibidem.
82 Ibidem, p. 263.

as they would a healthy child.[83] Such gestures provided validation that their family members shared in their perception of the significance of the baby's life.

Lathrop's study also revealed that these mothers appreciated being recognized as mothers by the health care team. One mother recalled enjoying her visits to the neonatal intensive care unit where her baby was staying because the staff acknowledged her role as a mother: I said, "Do you remember me?" As the nurse said "Of course, you're [baby]'s mom." And…I'm going to go back there just because I'm only [baby]'s mom. It's my identity, and I love it.[84] Talking about their babies is an important way for mothers to seek social legitimization, and health care professionals are particularly well-positioned to facilitate these types of essential, affirming interactions.[85] These mothers report that certain practices by health care staff contributed to feelings of validation, particularly "calling the baby by name, treating the baby like a person, saying that the baby was beautiful, attending to the baby's needs, and acknowledging the value of the baby's life."[86]

Mothers also appreciated practices such as being shown ultrasound images, being informed of their baby's sex, and being provided with mementoes such as professional baby pictures and hand or foot molds from their child. The stories of these mothers also reiterate the importance of being affirmed in their role as caregivers to their terminally ill babies. It was particularly meaningful for them to have unstructured time with their babies and to perform activities such as bathing and dressing them.[87] Many of these mothers expressed appreciation for experiences in which they felt that they were trusted to take good care of their children. Almost all mentioned that it was especially affirming to be recognized by nurses and other health care team members as good mothers. They also appreciated the way in which medical teams validated their maternal emotions by not imposing expectations about how they should

83 Ibidem.
84 Ibidem, p. 264.
85 Ibidem, p. 266.
86 Ibidem.
87 Ibidem.

feel in such a difficult situation. One mother appreciated that her providers were "comfortable with tears."[88]

Additionally, many women expressed gratitude for moments when they felt that the significance of their loss was acknowledged. They were also deeply affected by validation that came from physicians. Lathrop notes that "one mother described how her obstetrician, who was not on call when she delivered, came to the hospital on her day off to see and hold her baby."[89] Another mother emphasized her appreciation for a physician who returned to the hospital several hours after her baby's birth to attend a bedside memorial service. Lathrop recounts that many stories echoed the sentiments of one mother who urged providers, "we need you to be real, and, you know, take off that white lab coat and become a human."[90]

The narrative study conducted by Lathrop's team confirmed the complexity of the psycho-socio-spiritual dynamics faced by mothers who decide to continue affected pregnancies. Among the many factors that contribute to this complexity is the deep-rooted need for appreciation and validation. As shown above, appreciation was a critical element in several aspects of the perinatal hospice experience. First, mothers expressed a need for acknowledgment of their terminally ill prenatal or neonatal babies and assurance that the lives of their children, although profoundly disabled, were just as valuable as any other. Second, they demonstrated a strong desire for recognition of their autonomy, particularly through appreciation for their decision to continue affected pregnancies. Finally, they sought acknowledgment of their identity as caring and loving mothers, regardless of their babies' diagnoses or life expectancy.

To respond appropriately to the complex situations of mothers who choose to continue affected pregnancies, it is necessary to create an environment that incorporates a robust anthropology of human disability. Without such a framework, responses to the needs of mothers in perinatal hospice care risk being superficial and inadequate. Such situations could lead to discomfort, undermine their trust in healthcare providers, and ultimately reduce mothers' willingness to follow professional

88 Ibidem, p. 267.
89 Ibidem.
90 Ibidem.

recommendations. As Kathy Duckett explains, regaining patients' trust is a difficult task. It is therefore essential to build and maintain strong, trust-based relationships from the outset.[91]

In light of these considerations, there is a clear need for specialized care environments for mothers who elect to continue affected pregnancies. Moreover, it is imperative that these environments be staffed by healthcare providers who are guided by a robust anthropology of human disability. Only then can we adequately meet these mothers' needs for validation and appreciation. As I will argue, the most appropriate setting for this care is perinatal hospice. In order to fulfill its mission, however, it must be supported by an anthropology that facilitates a sound and comprehensive understanding of profound human disability.

1.7. Conclusion

Perinatal hospice is a space designed to meet the fundamental human needs of mothers in the midst of extraordinary difficulty. Although this form of care is specifically designated for families who choose to continue pregnancies with severe fetal diagnoses, it can also be seen as the next "logical step in the evolution of hospice."[92] There are three constitutive elements that contributed to the inception of perinatal hospice care. First, advances in prenatal diagnostic technologies now allow for the early detection of rare and often significantly life-limiting conditions. As a result, what were once unexpected instances of prenatal death are increasingly becoming cases of devastating early diagnoses. Second, there has been growing understanding of perinatal grief management and greater awareness of the unique suffering endured by couples who learn early in pregnancy that their child has a severe condition. Third, the advent of modern hospice care has provided a structure for meeting the needs of these families.

The convergence of these three factors points to a tangible need for robust and specialized multidisciplinary services tailored to families who choose to continue pregnancies after receiving an adverse diagnosis.

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91 Kathy Duckett, "Behind the Mask," *Home Healthcare Now* 38, no. 6 (2020): pp. 327–330.

92 Hoeldtke, 2001, p. 527.

Perinatal hospice care can also be a compassionate alternative to abortion. It is multidisciplinary by nature, and requires the collaboration of various specialists. The core hospice team usually includes the family, a primary physician, a social worker, and a nurse care manager trained in bereavement support. This team is often expanded to include representatives from other specialties, such as neonatologists, anesthesiologists, psychiatrists, psychologists, chaplains, bereavement counselors, labor nurses, and neonatal nurses.

Because of its interdisciplinary structure, perinatal hospice care is also a unique locus of virtues essential to addressing vital human needs—such as appreciation and validation of the lives of perinatal babies and the feelings of mothers who long to be recognized as loving, caring, present, and attentive guardians—just like mothers of healthy children. Accordingly, perinatal hospice care represents a necessary and crucial care paradigm, a space where families can be welcomed, appreciated, and supported with dignity. To fulfill this mission, however, it is necessary to first establish a well-grounded understanding of profound disability and illness based on corresponding anthropological principles. In order to accomplish these goals, I will examine various perspectives on human disability and attempt to identify the one which is most closely aligned with the mission of Catholic perinatal hospice care. In the following chapter, I begin by analyzing contemporary secular narratives of human disability so as to identify both their positive and negative implications for the practice of perinatal hospice care.

CHAPTER TWO

SECULAR DISABILITY STUDIES AND THE ANTHROPOLOGY OF POLITICAL CITIZENSHIP

The search for an anthropology capable of properly contextualizing profound human disability—and supporting perinatal hospice care practices, especially from a Catholic perspective—begins with an exploration of the field of contemporary disability studies (DS).

According to Hans S. Reinders, social constructionism is "a set of theories about how conceptual schemes are shaped by our language, what particular behavior they inform, and what specific social conditions allow them to exist."[1] In the case of human disability, social constructionism views it mainly as a conceptual scheme that mirrors the beliefs, prejudices, and assumptions present in the social world.

This chapter examines three distinct concepts related to human disability: (1) the social model of disability, (2) identity politics, and (3) the poststructuralist account, which is anchored in social constructionist logic. For each, I will attempt to identify the underlying narratives of human disability and evaluate which aspects may adequately inform perinatal hospice practices—particularly in Catholic settings, and best serve the needs of the pregnant woman, her terminally ill perinatal baby, and their family.

My overarching question, then, is whether social constructionist logic provides an understanding of profound human disability that is compatible with the needs of perinatal hospice mothers, including their desire for appreciation and validation. Can this framework affirm the humanity and dignity of profoundly intellectually disabled unborn babies like Adam? Furthermore, what kind of anthropology does it promote? I begin by considering the first concept: *the social model of disability*.

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1 Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: Eerdmans, 2008), pp. 54–55.

2.1. Social model of disability

My exploration of the field of DS begins with a look at the social model of disability. Historically, this model represents the first secular, scholarly attempt to examine human disability. British sociologist Michael Oliver played a pivotal role in developing these concepts in the early 1980s.[2] Physically impaired himself,[3] Oliver joined an international movement in the 1970s that sought to overturn what was then the dominant—and, in their view, discriminatory and oppressive—medical model of disability. Oliver's affiliation with The Union of the Physically Impaired Against Segregation (UPIAS), one of several disabled people's organizations that emerged in 1970s Britain, proved to be particularly influential.[4] The founding of UPIAS is closely associated with two key figures. The first was Paul Hunt, a disabled writer and activist who, while residing at the Le Court Cheshire Home, authored a landmark letter to *The Guardian*, published on September 20, 1972. In this letter, he called for the formation of a consumer group to represent those living in institutions.[5] Hunt had spent his childhood and much of his adult life in residential institutions. The primary focus of his activist efforts was to secure independent living, inclusive education, and welfare benefits for disabled individuals. In 1966, he served as the editor of *Stigma*, a collection of essays by disabled people reflecting on their experiences of prejudice and exclusion.[6] The second leading figure in UPIAS was Vic Finkelstein, a psychologist with a spinal cord injury who immigrated to Britain in 1968 as a political refugee following persecution by South Africa's apartheid regime for his civil rights activism. Through his personal experiences, he was able to draw connections

2 It is commonly held among scholars of Disability Studies that the "social model of disability," although referenced by Oliver as early as 1981, was more fully developed in the 1990s edition of his book *The Politics of Disablement*.

3 Michael Oliver (1945–2019) sustained a spinal injury in an accident in 1962 and subsequently used a wheelchair.

4 See Tom Shakespeare, *Disability Rights and Wrongs Revisited* (London: Routledge, 2014), p. 14.

5 See Shakespeare, 2014, p. 14.

6 Ibidem.

between the liberation struggles of Black South Africans and the difficulties faced by disabled people.[7]

2.1.1. Toward the liberation of the oppressed

The UPIAS initially concentrated on discussion and debate aimed at developing a political ideology of disability. Their first policy statement, adopted in December 1974, declared that a central goal of UPIAS was:

> replacement of segregated facilities with opportunities for people with impairments to participate fully in society, to live independently, to undertake productive work, and to have full control over their own lives.[8]

They also described disabled people as an oppressed group and elaborated on the barriers that they faced:

> we find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and lack of up-to-date aids and equipment.[9]

In the early UPIAS documents, the terms "physically impaired people" and "disabled people" were used interchangeably. However, explicit reference to physical disability was later strongly critiqued and ultimately rejected by Oliver and other advocates of the social model of disability.

Although the UPIAS statement called for alliances with other groups—including the mentally handicapped, the mentally ill, and non-disabled individuals—only people with physical impairments were eligible for membership in UPIAS.[10] According to Hunt, the fundamental problem for disabled people was the isolation and segregation that resulted from social and financial disparities. He explained it as follows:

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7 Ibidem, p. 15.

8 Ibidem, p. 19.

9 *Fundamental Principles of Disability: Being a Summary of the Discussion Held on 22nd November, 1975 and Containing Commentaries from Each Organization* (London: UPIAS/Disability Alliance, 1976), paragraph 1.

10 Shakespeare, 2014, p. 19.

> disability is a situation caused by social conditions, which requires for its elimination: (a) that no one aspect, such as incomes, mobility, or institutions, is treated in isolation; (b) that disabled people should, with the advice and help of others, assume control over their lives; and (c) that professionals, experts, and others who seek to help must be committed to promoting such control by disabled people.[11]

In the later part of the UPIAS statement, Hunt and Finkelstein presented their position on disability, stating that:

> In our view, it is society that disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.[12]

Several years later, Hunt reiterated his understanding of disability, emphasizing the distinction between physical impairment and disability, as he wrote:

> to understand this, it is necessary to grasp the distinction between the physical impairment and the social situation, called disability, of people with such impairments. Thus, we define impairment as lacking all or part of a limb or having a defective limb, organ, or mechanism of the body, and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments, and thus excludes them from participation in the mainstream of social activities.[13]

2.1.2. Overcoming a medical model and essentialist anthropology

By utilizing the logical framework of the UPIAS and viewing disability through the lens of social and economic disparity, Oliver developed a political manifesto known as the social model of disability. The primary objective of Oliver's approach was to oppose the dominant and influential medical model of disability. According to this medical model, human disability is understood as a failure of bodily function, defined in terms

11 UPIAS, 1976, p. 4

12 Ibidem.

13 Paul Hunt, *A Critical condition*, in P. Hunt (ed.) *Stigma*: *The Experience of Disability* (London: Geoffrey Chapman, 1982), p. 15.

of abnormalities or defects in physiological processes. Disability is perceived as a personal, health-related tragedy.

Consequently, the medical model legitimized the notion of defective citizenship for people with disabilities due to their limitations and located them on the margins of political agency. The social model, initiated by Oliver, sought to challenge this social injustice. As Tobin Siebers notes:

> the social model challenges the idea of defective citizenship by situating disability in the environment rather than in the body. In a society of wheelchair users, stairs would not exist; the fact that they are ubiquitous in our society reveals only that most of our architects are nondisabled people who care little about the problem of access. From this perspective, disability does not call for individual medical treatment but rather for changes in society.[14]

In contrast to the medical model, the social model, influenced by Marxist[15] ideology, argues that disability is the tragic result of a discriminatory and oppressive industrial capitalism that been imposed by an "able-bodied/minded" society upon its collective victims.[16] In such a capitalist society, a disabled person is perceived only from the perspective of their impaired body and diminished capacity to perform wage-earning labor. As Oliver points out, in an industrial capitalist system, labor has become commodified.[17] This represents a sweeping shift from the pre-industrial era, in which work was seen as more of a communal enterprise than an individual endeavor. In that earlier, more cooperative model of labor, people with

14 Tobin Siebers, *Disability Theory* (Ann Arbor: The University of Michigan Press, 2011), p. 12.

15 Michael Oliver openly acknowledged his adherence to Marxist ideology in his analysis of the oppression of disabled people by the able-bodied majority. He mainly blamed the capitalist free labor market for the discrimination and exclusion of disabled people, who are unable to compete with able-bodied workers for wage labor. Oliver drew parallels between the oppression of the working class by the wealthy bourgeoisie and the oppression of disabled individuals by able-bodied society. He argued that particular pressure comes from medical institutions, which view disability as an individual physical tragedy and impose limitations and barriers on people with impairments. According to Oliver, being disabled automatically places a person in an oppressed position. See Michael Oliver, *The Politics of Disablement* (Charlesbourg, Québec: Braille Jymico Inc., 2006), p. 177.

16 Michael Oliver, *The Politics of Disablement* (Charlesbourg, Québec: Braille Jymico Inc., 2006), p. 76.

17 Ibidem.

various impairments had more opportunities to contribute to the production of goods.

In the modern industrial capitalist system, disabled people are left entirely dependent on material support from various social agencies. However, viewing disability solely through the lens of economic oppression may overlook other significant contributing factors. Oliver explicitly rejects the notion of natural defects and maintains that being disabled conveys no objective truth about a person's humanity. As a result, he also rejects what is commonly referred to as essentialist anthropology.[18] Moreover, Oliver directly accuses essentialism of contributing to the oppressive dynamics of disability and reinforcing the "personal tragedy theory."[19]

The logic behind this position is that essentialism, which distinguishes between essential and accidental properties of the human being, asserts that certain attributes constitute human nature. Accordingly, if these essential attributes are somehow compromised, the consequence is unavoidably seen as a degradation of human nature and relegation of the individual to the category of disability.[20] As a result, due to limitations in natural conditions, some people experience unequal opportunities. Oliver argues that such logic leads to the social exclusion and oppression of disabled individuals based on their so-called "broken human nature."[21]

For those who advocate the social model of disability, the belief that objective natural defects contribute to the reality of human disability is regarded as little short of heresy. They argue that there is always a social convention underlying claims about human nature. For Oliver, the entire notion of a robust, stable human nature must be rejected. What he proposes instead is a socially constructed, fluid, and mutable set of conditions used to describe the human being. In this view, disability is not an objective condition that simply corresponds to bodily impairment. Rather, it is constructed through a complex interplay of factors, such as social constructs, cultural values, physical environments, and stigmatized impairments.[22]

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18 Deborah Marks, *Disability: Controversial Debates and Psychosocial Perspectives* (London: Routledge/Taylor & Francis Group, 2006), p. xi.

19 Oliver, 2006, p. 32.

20 Ibidem.

21 Ibidem, p. 35.

22 Reinders, 2008, p. 56.

2.1.3. A call to action

In the context described by Oliver, the primary mission of disabled persons is to overcome oppression by taking concrete action directed toward securing rights, ensuring equal access to public spaces, and achieving full inclusion in society. As Siebers explains, the social model of disability views people with impairments as quasi-political activists fighting for emancipation from capitalist social repression, using both intellectual and emotional resources.[23]

Oliver adds that the only way for a disabled person to overcome oppression and regain control over their life is to resist a disabling society.[24] He argues that "given the current situation, the idea of resistance may be the best approach for political activists committed to confronting disablement."[25] The main goal of such action must be a "radical structural change" that can be achieved by "developing tactics and strategies for confronting the disabling society."[26] For this mission to succeed, there must be a growing awareness of the need for the "self-empowerment" of disabled people, which can be seen as a "critical incidence of resistance."[27]

One way to achieve this self-empowerment is through participation in the disabled people's movement. Oliver explains that:

> the emphasis of the movement is on self-organization and a commitment to radical political action to promote change, improve the quality of disabled people's lives, and promote their full inclusion in society.[28]

Practically speaking, these political agendas focus on removing all social barriers that lead to the exclusion and oppression of disabled people. Since many of these barriers stem from "policies and practices based on the individualistic and medical approach to disability,"[29] their elimination must involve "gaining control over material resources and the range and quality

23 Siebers, 2011, p. 15.
24 Oliver, 2006, p. 163.
25 Ibidem.
26 Ibidem.
27 Ibidem, p. 166.
28 Ibidem, p. 173.
29 Ibidem.

of service."[30] This can be accomplished through the use of unconventional political tactics, including demonstrations, direct action, and civil disobedience.[31] According to Oliver's standard, a fully emancipated disabled person is one who actively participates in political movements and defends the principle "nothing about us without us."[32]

2.1.4. Imperfections in the social model

While acknowledging the good intentions and laudable achievements of the social model of disability (such as the Americans with Disabilities Act of 1990), there are some significant shortcomings inherent in this approach. To begin with, Tom Shakespeare notes that although the simplicity of the social model may have initially contributed to its appeal as a political ideology, this same simplicity, among other factors, simultaneously prevents it from being widely accepted as a rigorous academic framework for understanding disability.[33]

For instance, this model first emerged among a small group of activists, many of whom—like Oliver—had sustained spinal cord injuries or experienced a relatively limited range of similar conditions. This founding group was also composed exclusively of white men. The exclusion of other forms of disability, such as learning difficulties, mental health conditions, or profound impairments in infants, has led to a relatively narrow conceptualization of disability.[34]

Another major shortcoming of the social model is "the neglect of impairment as an important aspect of many disabled people's lives."[35] I will elaborate more on this issue in the next paragraph in relation to the concept of disability identity. One more contentious point is that the social model assumes what it needs to prove: that disabled people are oppressed.[36]

30 Ibidem, p. 174.
31 Ibidem.
32 Ibidem, p. 176.
33 Tom Shakespeare. "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 2017), p. 199.
34 See Shakespeare, 2017, p. 199.
35 Ibidem, p. 200.
36 Ibidem.

According to Shakespeare, this assumption represents a flawed oversimplification and carries a significant methodological bias.[37]

He also notes that the social model's rigid distinction between impairment as a medical reality and disability as a social construct fails to account for the authentic experiences of disabled people.[38] In practice, these factors are intricately intertwined, and it is difficult to draw a clear line between the effects of impairment and those of social barriers.[39] As such, Shakespeare argues that:

> if a person with multiple sclerosis is depressed, how easy is it to make a causal separation between the effect of the impairment itself; her reaction to having an impairment; her reaction to being oppressed and excluded on the basis of having an impairment; other, unrelated reasons for her to be depressed? In practice, social and individual aspects are almost inextricable in the complexity of the lived experience of disability.[40]

Shelley Tremain, a feminist and disability studies scholar, also acknowledges the weaknesses of the social model in "treating impairments as an unsocialized and universal concept, whereas, like sex, impairment is always already social."[41]

Another objective built into the social model of disability by Oliver and his colleagues is the creation of a barrier-free society. Although there is great merit in the aspiration to build a world in which disabled people are fully liberated from everyday obstacles, there are numerous practical impediments to achieving this vision. For instance, many aspects of the natural environment will remain inaccessible to people with various physical impairments. Mountains and beaches, for example, continue to pose significant barriers for wheelchair users. For people with visual impairments, the beauty of nature may remain largely inaccessible. In the case of profoundly disabled perinatal infants, the removal of barriers has little to no bearing on their lives, as it does not influence their condition or outcomes. Moreover, the notion of creating a world entirely free of physical

37 Ibidem, p. 201.
38 Ibidem.
39 Ibidem.
40 Ibidem, p. 202.
41 Shelly Tremain. "On the subject of impairment," in Marina Corker and Tom Shakespeare, *Disability/Postmodernity: Embodying Disability Theory* (New York: Continuum, 2002), p. 32.

and environmental hindrances is unfeasible. Michael Bury comments on Oliver's ambitions:

> it is difficult to imagine any modern industrial society (however organized) in which, for example, a severe loss of mobility, or dexterity, or sensory impairments, would not be "disabling" in the sense of restricting activity to some degree. The reduction of barriers to participation does not amount to abolishing disability as a whole.[42]

Advocates for a barrier-free world seek liberation from a disabling society through radical political action. They call for disabled people to emancipate themselves through political activism. As Shakespeare argues, Oliver's logic of resistance to a disabling society bears "the hallmarks of utopia."[43] This is also illustrated by Oliver's view of the future of the struggle against the oppression of disabled people, in which he states that oppression "will only end when the oppression of all is overcome, and that will only happen with major structural, economic, political and cultural transformation as well as resistance."[44]

But how realistic is the vision of a society completely transformed and free from all forms of oppression? From a Christian perspective (which is ultimately rejected by the Marxist and materialist dialectic underpinning the social model of disability), such a reality is conceivable and will be fulfilled only in the Eschaton, the future Kingdom of Heaven.

The strong emphasis on political activism as the sole path to liberation for disabled people, as Reinders rightly points out, reinforces the hierarchy of disability and exclusion of profoundly intellectually disabled people.[45] Many disabled people—such as severely intellectually disabled prenatal children—are simply incapable of taking political action, while many others may lack the cognitive ability to deliberately and consciously resist the pressures of a disabling society. Furthermore, not all disabled people view themselves as victims of capitalist oppression. All this points to the conclusion that Oliver's social constructionist approach to disability,

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42 Michael Bury, *Health and Illness in a Changing Society* (London: Routledge, 2006), p. 137.

43 Shakespeare, 2017, p. 78.

44 Oliver, 2006, p. 176.

45 Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: Eerdmans, 2008), p. 85.

while powerful, actually marginalizes many disabled individuals. This vision of political activism—in which liberation is tied to resistance, self-representation, and self-assertion—excludes certain groups, especially those with profound intellectual disabilities or unborn individuals like Adam.

The emphasis on resisting social oppression paradoxically leads to the further exclusion of the most vulnerable—those with profound intellectual disabilities. The social model of disability, which rejects essentialist views in favor of Marxist materialist logic, promotes what Reinders aptly terms an "anthropology of political citizenship."[46] According to this theory, a human person derives their dignity and value from their conscious and voluntary participation in political activism. Moreover, it is society—or its representatives—that allocates this dignity and value to the individual. Reinders argues that this perspective reinforces the hierarchy of disability and excludes people with intellectual disabilities.[47] For profoundly disabled unborn children in need of perinatal hospice care, the social model of disability—with its social constructionist logic and anthropology of political citizenship—seems entirely insufficient for affirming and safeguarding their personal humanity and dignity.

In fact, the social model offers little, if any, support for the practice of perinatal hospice care. Quite the opposite is true. As Patricia J. Rock insightfully observes, the logic underlying the social model places such a strong emphasis on political activism that it ultimately sidelines the most vulnerable group of people to the point of calling into question their very right to life.[48]

Although Oliver, who died in March 2019 after a distinguished academic career as a professor at the University of Kent, never directly criticized the concept of perinatal hospice care, he also did not contribute to the development of structures necessary for the recognition and support of profoundly disabled unborn children. It would be incredibly valuable to have a clear statement of Oliver's stance on oppressive social attitudes toward the most vulnerable disabled prenatal babies, especially those described by the term "incompatible with life."

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46 Ibidem, p. 91.

47 Ibidem.

48 Patricia J. Rock, "Eugenics and Euthanasia: A Cause for Concern for Disabled People, Particularly Disabled Women," *Disability & Society* 11, no. 1 (1996): p. 124.

Oftentimes, however, silence speaks louder than words. In this case, Oliver's silence sadly contributes to the marginalization and neglect of what may be the most defenseless group of disabled people: perinatal hospice babies. There is a painful irony in the thought that someone who spent his life fighting for the liberation and empowerment of disabled people may have overlooked those most visibly oppressed and marginalized by their medical condition. Could it be that he did not regard these children as full citizens? Unfortunately, that question must remain unanswered. In the next paragraph, I will look at another narrative paradigm for understanding human disability that continues to follow social constructionist logic and follows the pathway laid by the anthropology of political citizenship. Although this concept of disability identity can be seen as a refinement of Oliver's argument, it still contains some substantial anthropological shortcomings that merit close scrutiny.

2.2. Disability identity

The disability identity model is another way of viewing disability from a standpoint of social constructionist logic, although its proponents call for necessary revisions to the traditional social model of disability.[49] They argue that Oliver's perspective on disability fails to recognize the fact that impairment is an essential and inescapable part of many disabled people's lives. Liz Crow, a disabled artist and activist, stresses that the social model overlooks the highly individual nature of impairment. In describing her own experience, she contends:

> as individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability.[50]

49 Among the main figures are Tobin Siebers, John Swain, Liz Crow, Nancy Mairs, Sally French.

50 Liz Crow, *Renewing the Social Model of Disability* (Leeds: University of Leeds, 1992), p. 7.

2.2.1. Is it okay to be disabled?

In this same vein, the heralds of disability identity movement—such as Tobin Siebers,[51] John Swain, and Sally French[52] seek to demonstrate that although disability is shaped by social mechanisms, it is also inseparably linked to concrete, embodied impairments that affect daily life by introducing specific limitations. They also challenge Oliver's claim that all disabled people should be automatically seen as politically oppressed citizens. From their perspective, social oppression does indeed play a role in the experiences of some individuals with disabilities—but not necessarily all. Instead of upholding the rhetoric of "resistance against a disabling society," proponents of disability identity encourage embracing positive identity and engagement based on one's physical or cognitive differences.

Crow notes that the first step is recognizing one's physical impairments and integrating that awareness into a holistic experience of oneself as a unique individual human person.[53] Only then can they begin to affirm that disability is, at least in part, a defining aspect of who they are. This attitude is found, for example, in the sentiments of Cyndi Jones, editor of the disability magazine *Mainstream*, who contracted polio as a child. When speaking about her disability, she explains that if a cure were available, she would choose not to take it. She adds:

> the main thing disabled people need to do is claim their disability, to feel okay about it. Even if you don't like the way society treats you as a disabled person, it's part of your experience, it's part of how you become to be who you are.[54]

Although the disability identity model rejects a fundamental tenet of the social model—the belief that disability always equates to oppression—it nevertheless operates within the same social constructionist logic and draws on the same anthropology of political citizenship. To better understand this position, it is helpful to consider the notion of ownership in relation to disability.

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51 Tobin Siebers, *Disability Theory* (Ann Arbor: The University of Michigan Press, 2011).

52 John Swain et al., *Disabling Barriers, Enabling Environments* (Los Angeles: SAGE, 2000).

53 Crow, 1992, p. 8.

54 Quoted in Joseph P. Shapiro, *No Pity: Peoples with Disabilities Forging a New Civil Rights Movement* (New York: Times Book, 1993), p. 14.

2.2.2. Own your disability

Advocates of disability identity maintain that it is entirely valid for a person with a disability to embrace their condition as part of their identity. They also insist, however, that such a message would be inappropriate coming from an able-bodied person.[55] Nancy Meyers illustrates this logic by referring to herself as a "cripple" because of her multiple sclerosis. She adds, however, that she "would never refer to another person as a cripple. It is the word I use to name only myself."[56] According to Siebers, openly acknowledging one's disability enables reclaiming agency and control over one's own life.[57] Moreover, self-identifying as disabled can ascribe a positive meaning to the reality of one's condition and serve as a protective buffer against social discrimination based on physical or cognitive impairment.[58]

In recent history, there are several examples of terms that were originally intended as insults but have since become sources of pride due to changing social attitudes. One such example is the identification of individuals as "black." This term, once burdened with negative connotations—so much so that people in the United States began to identify instead as African American—was reclaimed, thanks in large part to the Black Consciousness Movements in the 1970s when it became an element of affirming expressions such as "Black is beautiful." Similarly, when Cyndi Jones was asked whether she would like to be cured of her disability, she responded that being disabled is part of what gives her life meaning.

These shifts in social perceptions of attitudes toward disability and disabled people undoubtedly mark valuable and important progress. However, the logic informing disability identity still does not go far enough in challenging the anthropology of political citizenship. Instead, it continues to adhere to the social constructionist dialectic, which rejects essentialist views of human nature in favor of an anthropology of political citizenship. Like supporters of the social model of disability, proponents of disability identity maintain that human nature is socially constructed rather than innately determined. In this context, the adoption of disability

55 See Reinders, 2008, p. 64.
56 Nancy Meyers, *Plaintext Essays* (Tucson: The University of Arizona Press, 1997), p. 11.
57 Siebers, 2011, p. 17.
58 Ibidem.

identity has led to an understanding of impairment as an objectively existing psychophysical condition, rather than simply a label of social oppression. Yet, from this perspective, only disabled persons are seen as having the legitimate authority to define and speak about disability.

This results in a form of subjective and authoritative language used in the discourse on human disability. Only the disabled person is viewed as having the right to define themselves and declare, "this is who I am." At the heart of disability identity logic is the principle that only a disabled person can choose to embrace or reject their identity as disabled.

2.2.3. Disability identity logic: a potential threat to the most vulnerable

Although disability identity logic was intended to empower disabled individuals, it still poses a potential threat to the most vulnerable members of this group. Similarly to the social model of disability, the disability identity framework can lead to the exclusion and marginalization of people with intellectual disabilities, especially those who are profoundly intellectually disabled, as well as unborn babies diagnosed with impairments. This is largely due to the emphasis within disability identity logic on self-identification as a means of embracing one's disabled identity. However, it is important to recognize that not every disabled person is intellectually and emotionally capable of such self-identification.

The ability to identify oneself as having a physical or mental impairment—and to affirm this identity in a positive way—is beyond the reach of many people with profound intellectual disabilities. As a result, disability identity logic tends to serve those who possess the necessary intellectual and emotional resources for this process. At the same time, it excludes individuals such as profoundly disabled unborn children, who lack the competence for self-identification or for taking ownership of their disability. This exclusion often occurs in the hospital setting. Profoundly disabled prenatal babies are evaluated by healthcare professionals who determine whether their impairment can be positively embraced as an element of a unique identity, or whether it should be perceived as an intolerable burden that justifies avoiding their birth altogether, including through the termination of pregnancy. Depending on the outcome of these judgments, these new human lives may be seen either as unborn children with disabilities or dismissed in pejorative terms as defective fetuses "incompatible with life,"

as described in the experience shared by Aaron Cobb.[59] The ways in which disability is perceived at these critical moments play a decisive role in determining the fate of these profoundly impaired unborn babies.

2.2.4. Not welcomed in society

Marsha Saxton, a feminist and disability rights scholar who has spina bifida, emphasizes in her work that the way society perceives disabled unborn babies is closely tied to decisions about whether or not to continue pregnancies following terminal diagnoses.[60] She also argues that in the U.S., medical practitioners and healthcare officials are primarily responsible for the dominant narratives surrounding prenatal disability. Patricia Rock, another critic of the negative perceptions that frequently accompany disability, argues that:

> disabled people know only too well they are not welcomed in society, but the active promotion of abortion on the grounds of disability and determining that euthanasia is a viable proposition for the disabled fetus/child—is fascism.[61]

According to Rock and Saxton, the emphasis on prenatal testing is motivated by a desire to avoid the perceived burden of caring for children with severe impairments. Consequently, if prenatal diagnostic tests detect conditions such as Down syndrome, spina bifida, muscular dystrophy, sickle cell anemia, or cystic fibrosis, the only "right and healthy" decision is often assumed to be termination of the pregnancy.[62] Ruth Hubbard argues that the social pressure placed on pregnant women to undergo such tests and to choose selective abortion in the case of anomalies—as if it were "the responsible thing to do"—amounts to a form of "unacceptable oppression"[63] and should be opposed. Hubbard writes:

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59 Cobb, 2020, p. 2.

60 Marsha Saxton, "Disability Rights and Selective Abortion," in *The Disability Studies Reader,* 5th Edition, ed. Lennard J. Davis (New York: Routledge, 2017), p. 73–86.

61 Patricia J. Rock, "Eugenics and Euthanasia: A Cause for Concern for Disabled People, Particularly Disabled Women," *Disability & Society* 11, no. 1 (1996): p. 124.

62 Saxton, 2017. p. 75.

63 Ruth Hubbard, *The Politics of Women's Biology* (New Brunswick, NJ: Rutgers Univ. Press, 1990), p. 197.

> women are expected to implement the society's eugenic prejudices by "choosing" to have the appropriate tests and "electing" not to initiate or to terminate pregnancies if it looks as though the outcome will offend.[64]

The practice of selective abortion, or as some disability activists have termed it, a new form of eugenic abortion, is a stark example of discrimination against disabled people. Adrienne Asch and David Wasserman, both scholars in disability rights, criticize what they describe as the synecdoche involved in trait-based selection:

> to reject a parental relationship with a future child on the basis of knowledge of a single characteristic is to allow that characteristic to obscure or eclipse all other features of the future child. Any trait-based selection conflicts with the ideals of unqualified welcome and inclusiveness to which prospective parents and society as a whole should aspire.[65]

An additional valuable perspective on society's misperceptions of disabled people comes from Andrew Solomon, an American writer who actively supports disability rights movements. According to him:

> most people with disabilities don't wish they had never been born; most people with disabilities contribute to the world they inhabit; most people with disabilities both give more to and get more from life than their nondisabled peers may be inclined to guess.[66]

Solomon provides a historical context on how social views of certain disabilities have resulted in the denial of the right to life for the most vulnerable group. He recalls the example of ethicist Joseph Fletcher, who in 1968 wrote in *The Atlantic Monthly* that there was:

> no reason to feel guilty about putting a Down syndrome baby away, whether it's 'put away' in the sense of hidden in a sanatorium or in a more responsible lethal sense. It is

64 Ibidem.

65 Adrienne Asch and David Wasserman, "Making Embryos Healthy or Making Healthy Embryos: How Much of a Difference between Prenatal Treatment and Selection?," in *The 'Healthy' Embryo: Social, Biomedical, Legal, and Philosophical Perspectives* (Cambridge: Cambridge University Press, 2010), p. 201.

66 Peter Catapano and Rosemarie Garland-Thomson, *About Us: Essays from the Disability Series of the New York Times* (New York: Liveright Publishing Corporation, 2021), p. x.

> sad, yes. Dreadful. But it carries no guilt. True guilt arises only from an offense against a person, and a Down's is not a person.[67]

In response to this shocking and callous statement, significant efforts were made to secure the rights of people with Down syndrome. Today, they live nearly twice as long as they did in 1968, and many are gainfully employed. Some are writers, actors, or models, and many live at least semi-independently. Despite these tremendous advancements, the general image of life with Down syndrome is still negative, especially among healthcare professionals.[68]

For Solomon, the question of how we perceive the experience of living with a disability has real, formative power. According to him:

> how we frame disability determines how we live it, and if it is defined as calamitous from the start, the job of finding meaning is steeper than it need be. The fact that you wouldn't have chosen something doesn't mean that you can't find joyful meaning in it.[69]

Solomon believes that disability is a valid identity and that "disability may coexist with shocking ability." Every human being, he argues, must come to terms with both their strengths and their limitations. For him, this requires accepting the whole person. As he aptly states:

> if I imagine myself without dyslexia, without ADD, without depression, without gayness, without nearsightedness, without orthostatic hypotension, without Jewishness, without white privilege, without prosopagnosia, then there's very little of me left. We are mostly an accumulation of strengths and weaknesses, of pathologized and non-pathologized conditions and identities.[70]

Are these sentiments not equally relevant to the reality experienced by profoundly disabled unborn babies, whose physical impairments coexist with the immense and inherent value of their lives? The failure to acknowledge this truth often leads to the oppression and marginalization of this most vulnerable group.

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67 Ibidem.

68 Saxton, 2013, p. 79.

69 Catapano and Garland-Thomson, 2021, p. xi.

70 Ibidem. p. xvii.

2.2.5. The profoundly disabled perinatal baby: an unheard voice

A recently published book, *About Us: Essays from the Disability Series of the New York Times*, explores the essence of disability identity logic and the ways in which it may uphold—or fail to uphold—the dignity and humanity of profoundly disabled prenatal children, particularly in the context of perinatal hospice care.[71] In the preface, Peter Catapano, one of the editors, proudly states that the book, which brings together roughly 60 essays originally published in *The New York Times*, is devoted to disability issues and is "the first of its kind: a platform in a major news publication devoted to writing by and about people living with disabilities."[72]

Catapano further highlights that the contributors to *About Us* represent a wide range of voices and experiences, including individuals with physical, motor, sensory, and cognitive differences. Unfortunately, not a single essay tells the story of a profoundly disabled prenatal baby who was allowed to be born. According to Catapano, the authors include "students, artists, scholars, poets, novelists, journalists, doctors, activists, and accomplished literary figures like the essayist Edward Hoagland and the neurologist and author Oliver Sacks." But none of these voices come from expectant parents of profoundly disabled prenatal children—people like Adam's parents or Aaron Cobb.

Rosemarie Garland-Thomson, the book's second editor, is a disability rights activist, bioethicist, educator, and humanities scholar who has a rare genetic condition: complex syndactyly. She echoes Catapano's accolades for the book, stating that:

> this book, *About Us and by Us*, harkens back to the unifying call of our civil rights movement—"Nothing About Us Without Us." Our stories are claims to self-representation and recognition that this slogan demands.[73]

As a passionate supporter of disability identity logic, she also notes that: "claiming an identity can be an act of self-knowledge and generosity

71 Ibidem, p. xi.
72 Ibidem, p. xix.
73 Ibidem, p. xiii.

toward our interlocutors, letting them know how we understand ourselves and who we believe we are."[74]

> Garland-Thomson's discourse on disability conveys a tone characteristic of disability identity circles, as she emphasizes that: our stories don't ask for sympathy, plead for inclusion, or extol tolerance—as does so much traditional disability advocacy or advice from therapeutic, clinical, or spiritual experts. We are the expert users of our own lives and makers of our own stories, self-advocates defining ourselves in all our distinctiveness and complexity.[75]

It is important to understand that Garland-Thomson's acceptance of disability identity logic came through her embracing of feminism. She often states that "feminism made me disabled." She further explains:

> so feminism made me disabled by showing me how positive identity politics could be mobilized in the service of the knowledge-building and dissemination project that is the academic mission. Most important for me as a humanities scholar, I learned from feminist studies the power of representation to shape the world. I recognized that both framing and enacting disability in the context of the positive identity politics which emerged from the civil and human rights and social justice understanding of disability was the route to dignity, equal treatment, and access for people with disabilities.[76]

Consequently, in her academic work, she argues that feminism—both as activism and as theory—overlaps harmoniously with disability studies.[77]

It can be argued that these two fields often collaborate successfully collaborate; however, when issues of reproductive rights are examined, potential disjunctures between feminism and disability come to light. One salient point of conflict is the question of protecting prenatal babies diagnosed with various disabilities. For feminist activists, access to abortion constitutes one of the most fundamental rights for women. Writing in *Signs*—one of the leading international journals in Women's Studies—just six years after the U.S. Supreme Court made abortion a constitutional right for women, Barbara Hayler opined that, "The right to choose

74 Ibidem.

75 Ibidem, p. xxvi.

76 Ibidem.

77 D.A. Caeton, "Choice of a Lifetime: Disability, Feminism, and Reproductive Rights," *Disability Studies Quarterly* 31, no. 1 (November 2011).

abortion—as part of a claim to reproductive self-determination—is central to the feminist movement."[78]

The nature of the potential clash between feminism and disability rights is well articulated by D.A. Caeton, who states:

> there is a key difference between the goals of the reproductive rights movement and the disability rights movement regarding reproductive freedom: the reproductive rights movement emphasizes the right to have an abortion; the disability rights movement, the right not to have to have an abortion.[79]

It is in this space that the interests of Garland-Thomson's feminist activism and disability activism generate significant friction. There appears to be a contradiction between her support for the positive self-identification of disabled people and her lobbying efforts for female reproductive rights that would permit the abortion of prenatal babies suspected of malformation or disability.

How can we reconcile Garland-Thomson's approval of eugenic abortion with her otherwise commendable assertion?

> becoming disabled demands learning how to live effectively as a person with disabilities, not just living as a disabled person trying to become nondisabled. It also demands the awareness and cooperation of others who don't experience these challenges. Becoming disabled means moving from isolation to community, from ignorance to knowledge about who we are, from exclusion to access, and from shame to pride.[80]

> It is a sad irony that a call to overcome isolation and embrace community is presented on the one hand, while the fundamental right of the most vulnerable group of disabled people to be born is called into question on the other. Commenting on this inconsistency, Caeton notes: by implication, then, it was held that the experience of giving birth to a child with severe fetal deformity would unjustly impair the emotional and psychological health of the mother. It is intriguing that health is deployed in such a strategic manner, where it becomes a quality so necessary for preservation that it can both invalidate a child as being human while at the same time affirming the humanity of the mother.[81]

78 Ibidem, p. 4.
79 Ibidem.
80 Catapano and Garland-Thomson, 2021, p. 8.
81 Caeton, 2011, p. 4.

Additionally, Caeton poignantly observes that endorsing a platform consistent with feminism and disability activism would necessitate embracing positions that are incompatible both legally and logically.[82] He rightly asks:

> how could, in other words, an individual woman's right to abortion never be questioned when it would have to be questioned in order to protect fetuses with deformities or other perceivable disabilities from being unfairly terminated? Can both the individual and a class of citizens be protected when we are dealing with the same issue?[83]

Another illustration of the inconsistencies between the disability rights movement—from a standpoint of disability identity logic—and support for selective abortion is provided by Jennifer Bartlett, a contributor to *About Us*. In her essay *Disability and the Right to Choose*, she shares a touching story of how, as a disabled woman (Bartlett has cerebral palsy), she had to fight against the objections of medical professionals in order to secure her right to give birth.

Today, her son is a healthy 15-year-old. Although she experienced firsthand the oppressive and marginalizing attitudes directed at disabled women who wish to become mothers, she still supports the right to terminate pregnancies with possible markers of disability. Bartlett attempts to reconcile this apparent contradiction by saying that:

> the right to legal and safe abortion is a core element of American feminism and the struggle for women's rights. This puts me in a strange position. When I think about this issue, I feel my very existence questioned. As a disabled woman, I have been told flat out, "I'd rather be dead than be like you." Even the Dalai Lama has said that aborting a fetus with a disability is understandable. How do I begin to hold this contradiction in my mind? That I am a valid, beautiful human being—as are all my friends, some of whom have much severer impairments—and that I also support women's right to choose, a right that logically must extend to a woman who ends a pregnancy because of the prospect of an extra finger? I don't know the answer.[84]

I will continue to examine this tension between disability identity logic and selective abortion, but first I need to address some potential inconsistencies

82 Ibidem.

83 Ibidem, p. 7.

84 Catapano and Garland-Thomson, 2021, p. 21.

in how advocates of disability identity fight for the liberation and inclusion of disabled people. What we saw in Garland-Thomson's argument seems to be a very representative picture of the mechanism of marginalization and oppression of the most vulnerable group of disabled people; that is, profoundly disabled prenatal babies. On the one hand, her approach to human disability seems to uphold the anthropology of political citizenship. On the other hand, it appears to reinforce a hierarchy of disability, in which the most severely impaired prenatal babies are denied the recognition and inclusion that disability identity activists like Garland-Thomson seek for others.

As with Oliver, Garland-Thomson, by virtue of her extensive personal and professional experience, could serve as a highly competent and credible advocate for the recognition and protection of disabled prenatal babies. Unfortunately, she has chosen not to seize this opportunity to champion the most vulnerable group among disabled people. Caeton rightly points out, "Until we embrace disability non-prejudicially, it will prove impossible to protect fetuses that exhibit traits of physical and cognitive alterity."[85]

2.2.6. Disability identity logic and the threat of a new eugenic abortion

The scope of this project, unfortunately, does not allow for an in-depth analysis of selective abortion. However, I would like to take a moment to discuss how disability identity logic may, in my opinion, contribute to supporting this practice.

First of all, we need to look at the messages conveyed by proponents of selective abortion—some of whom, as previously shown, also align themselves with disability identity logic. According to Saxton, this messaging reinforces a hierarchy of disability.[86] She notes that some medical professionals and public health officials:

> promote prenatal diagnosis and selective abortion with the intention to eliminate particular categories of disabled people—people with Down syndrome, spina bifida, cystic fibrosis, and fragile X—all of which are associated with mildly to moderately disabling clinical outcomes.[87]

85 Caeton, 2011, p. 9

86 Saxton, 2013, p. 79.

87 Ibidem.

These harmful narratives are subsequently disseminated across society, particularly targeting prospective parents of disabled unborn children like Adam's. Such messaging implies that certain impairments are more undesirable than others and therefore justify "extraordinary" measures such as selective abortion. Adrienne Asch emphasizes the powerful influence of this messaging as she states that:

> I believe it will be very difficult for most families to consider bringing children with diagnosable disabilities into the world if they know that the society believes their births should have been prevented.[88]

By portraying certain disabilities (e.g., Down syndrome) as incompatible with mainstream, able-bodied society, medical professionals send a clear message that such forms of impairment are excluded from the realm of positive disability identity. They also imply that prenatal testing—which aims to detect potential prenatal abnormalities—should be implemented as widely as possible as the best way of protecting the health of society. However, as Ruth Bailey points out, equating prenatal diagnosis with other forms of disease prevention is erroneous because:

> it obscures the fundamental difference between prenatal testing and any other way of preventing illness, namely that the "treatment" which follows prenatal testing—abortion—"cures" the condition by eliminating the fetus rather than by stopping the condition occurring in the first place.[89]

This messaging essentially suggests that it is better to be dead than disabled. It also "expresses a negative valuation of, or misrecognition or disrespect toward, the lives of disabled people."[90]

Disability identity logic, which promotes the subjective and authoritative recognition, or rejection, of particular human impairments, thus seems to be inadequate in safeguarding the lives of the most vulnerable disabled group, i.e., intellectually disabled unborn babies. The decision as to whether

88 Adrienne Asch, "Disability equality and prenatal testing: contradictory or compatible?" *Florida State University Law Review* 30, no. 2 (2003): p. 340.

89 Ruth Bailey, "Prenatal Testing and the Prevention of Impairment: a Woman's Right to Choose?," in *Encounters with Strangers: Feminism and Disability* (London: Women's, 1998), p. 149.

90 Bailey, 1998, p. 149.

their disabilities are socially acceptable or not is left in the hands of other non-disabled individuals or groups.

In this context, the involvement of medical professionals and public health officials raises legitimate concerns. Saxton argues that some of these decision-makers assert—based on their authority and subjective judgments—that people with Down syndrome or spina bifida will not be able to embrace their conditions positively and will experience only lives of suffering.[91] These views may also carry the implicit assumption that the birth of disabled children constitutes a form of oppression for women.

Saxton's own life proves just how thoroughly wrong these assumptions are as she affirms that her life is full of joy and personal fulfillment despite her profound disability.[92] Disability identity logic may also have an adverse effect on the dynamics of parenting disabled children. For instance, if the message that certain disabilities are incompatible with a positive sense of self persists long enough, it is not difficult to imagine how this could make the decision to bring a disabled child into the world extraordinarily difficult for many parents. It may even lead them to pursue what society implicitly signals as the more obvious and acceptable path: terminating the pregnancy in order to prevent future suffering and a perceived poor quality of life for the child.

From the perspective of virtue ethics, this kind of decision is incompatible with good parenting and can have serious moral consequences. According to Alasdair MacIntyre, choosing to continue a pregnancy affected by disability represents the highest expression of parental virtue.[93] He argues that a virtuous parent is oriented toward the needs of the child—whatever those needs may be—rather than their own: "Good parental care is defined in part by reference to the possibility of the affliction of their children by serious disability."[94]

For MacIntyre, the parents of disabled children embody the very paradigm of good parenthood and "provide the model for and the key

91 Marsha Saxton, "Disability Rights and Selective Abortion," in *The Disability Studies Reader*. 5th Edition, ed. Lennard J. Davis (New York: Routledge, 2017), p. 80.

92 Ibidem.

93 A.C. MacIntyre, *Dependent rational animals: Why human beings need the virtues* (Chicago: Open Court, 1999), p. 91.

94 Ibidem.

to the work of all parents."[95] According to him, the issue of selective abortion is ultimately a matter of parental moral character.[96] Disability identity logic, which reserves the right of positive self-identification to the disabled individual alone, mirrors the pattern observed in selective abortion. Just as disabled persons are seen as the sole authorities on defining and interpreting their own conditions, medical professionals and healthcare providers appear to hold exclusive authority over whether a particular impairment is deemed acceptable or compatible with life. Saxton warns that this arrangement is dangerous, as the medical system "takes a very narrow view of disease and the alleviation of suffering"[97] and "tends to underestimate the functional abilities and overestimate the burden and suffering of people with these conditions."[98]

Another important issue connected to selective abortion and disability identity logic is that abortion always has a broader impact. As anthropologist Rayna Rapp notes, although selective abortion is often presented in many doctors' offices as a "personal choice" or a "reproductive choice," its consequences are inevitably public. One such consequence is strengthening the common social view of what mental and physical traits are expected from a new human life conceived as a future member of society.[99]

The right that some medical practitioners claim to have to act as quasi quality-controllers of citizenship might raise a justifiable concern that:

> if a condition like Down's syndrome is unacceptable, how long will it be before experts use selective abortion to manipulate—eliminate or enhance—other presumed genetic, socially charged characteristics: sexual orientation, race, attractiveness, height, intelligence?[100]

Disability identity logic, which is founded on social constructionist premises, continues to operate within an anthropology of political citizenship. As

95 Ibidem, p. 92.
96 Ibidem.
97 Saxton, 2017, p. 81.
98 Ibidem.
99 Rayna Rapp, "Accounting for amniocentesis," in *Knowledge, Power, and Practice: The Anthropology of Medicine in Everyday Life*, ed. Shirley Lindenbaum and Margaret Lock (Berkeley: University of California Press, 1993), p. 56.
100 Rapp, 1993, p. 57.

a result, it allows space for oppressive and discriminatory practices, such as the selective abortion of profoundly disabled unborn children.

Although proponents of disability identity logic rightly argue that they work to eliminate the exclusion and oppression of disabled citizens, the harsh reality for profoundly disabled unborn babies is that they will have no share in this victory. On the contrary, the opposite is true. Under the umbrella of the disability identity paradigm, the most vulnerable members of the disabled population face a tragic reality in which their fates are decided by able-bodied medical professionals who, often unilaterally, decide whether those lives are socially acceptable based on their physical condition. Consequently, much like the traditional social model, disability identity logic fails to offer a robust anthropological framework that affirms and protects the dignity and humanity of perinatal hospice babies. The next section will explore the final major approach to disability in contemporary secular studies: one grounded in poststructuralist logic.

2.3. Poststructuralist account

The poststructuralist approach to disability is generally considered a distinctly American phenomenon, as opposed to British or European schools of thought.[101] As Lenard Davis points out, Britain and Europe have drawn on very different theoretical traditions mainly based on a materialist perspective.[102] In contrast, American disability studies of the 1970s were heavily influenced by functionalist and phenomenological paradigms, represented by scholars such as Safilios-Rothschild,[103] Albrecht,[104] and Zola.[105]

However, by the 1990s, the dominant viewpoint had shifted toward various theoretical movements loosely termed "postmodernism"

101 This view is shared by Lennard J. Davis and Tom Shakespeare.

102 Lennard J. Davis, *The Disability Studies Reader* (New York: Routledge, 2017).

103 Constantina Safilios-Rothschild, *The Sociology and Social Psychology of Disability and Rehabilitation* (Washington, D.C.: University Press of America, 1982).

104 Gary L. Albrecht, *The Disability Business: Rehabilitation in America* (Brantford, Ont.: W. Ross MacDonald School Resource Services Library, 2009).

105 Irving Kenneth Zola, *Missing Pieces: a Chronicle of Living with a Disability* (Philadelphia: Temple University Press, 1982).

or "poststructuralism" that were championed by figures such as Lenard Davis,[106] Rosemarie Garland-Thomson,[107] David Mitchell and Sharon Snyder, [108] Shelley Tremain,[109] Dan Goodley,[110] Fiona Kumari Campbell,[111] and, more recently, Robert McRuer.[112] The work of these scholars has been influenced by poststructuralist thinkers such as Michel Foucault, Judith Butler, Gilles Deleuze, and Félix Guattari. According to Tom Shakespeare, Foucault's approach to disability, in particular, played a key role in shaping this new, poststructuralist way of understanding human impairment.[113]

The next step, therefore, is to take a closer look at his considerations and evaluate whether a poststructuralist approach to disability can potentially offer robust protection for profoundly intellectually disabled unborn children and support practices such as perinatal hospice care.

2.3.1. Foucault and disability: deconstructing normalcy

As Oliver points out, Foucault's reflections on disability represent a clear turn away from an emphasis on material factors and toward a focus on culture, language, and discourse.[114] Accordingly, a crucial element of Foucault's approach to disability is the deconstruction of the concept of "*normalcy*."[115] To better understand this dynamic, we must examine the relationship between the social and natural determinants of human

106 Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (Kbh.: Nota, 1995).

107 Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture And Literature* (Columbia University Press, 1997).

108 David T. Mitchell, James I. Porter, and Sharon L. Snyder, *The Body and Physical Difference: Discourses of Disability* (Ann Arbor: The University of Michigan Press, 1996).

109 Shelley Tremain, *Foucault and the Government of Disability* (Ann Arbor: The University of Michigan Press, 2015).

110 Dan Goodley, Bill Hughes, and Lennard Davies, *Disability and Social Theory New Developments and Directions* (Basingstoke: Palgrave Macmillan, 2013).

111 Fiona Kumari Campbell, *Contours of Ableism: the Production of Disability and Abledness* (New York: Palgrave Macmillan, 2012).

112 Rob McRuer, Benjamin Reiss, and David Serlin, *Keywords for Disability Studies* (New York: New York University Press, 2015).

113 Tom Shakespeare, *Disability rights and wrongs revisited* (London: Routledge, 2014).

114 Michael Oliver, *The Politics of Disablement* (Charlesbourg, Québec: Braille Jymico Inc., 2006), p. 180.

115 Shelley Tremain, *Foucault and the Government of Disability* (Ann Arbor: The University of Michigan Press, 2015), p. 34.

disability and distinguish between the notions of *invention* and *discovery* in relation to health conditions. We must also ask, "whether a particular disability can be discovered independently from particular practical interests rooted in particular social conditions."[116] Some health conditions raise controversial questions about whether they are empirically observable natural phenomena discovered by medicine, or socially constructed innovations legitimated by political and cultural agendas.

One example of such uncertainty in the field of mental health is schizophrenia. As psychologist Mary Boyle emphasizes, there is ongoing debate among contemporary Western psychologists and psychiatrists about whether schizophrenia is in fact an objective condition "out there," or whether it is a culturally conditioned framework used to interpret otherwise incomprehensible behavior. A similar situation exists in the field of learning disabilities, particularly in the debate over whether ADHD (Attention-Deficit/Hyperactivity Disorder) is an objectively existing medical condition or simply a label for a cluster of behavioral issues. This question becomes even more complicated when we consider the clear vested interests that pharmaceutical companies have in the diagnosis of ADHD.[117]

For Foucault, however, the distinction between invention and discovery is misleading and should be dismissed.[118] Instead, he argues that we should focus on the specific rules that determine how certain objects are positioned within a particular system of knowledge. As Foucault explains, these objects—such as normality/pathology or disability/ability—

> are not waiting for their discovery by the discipline that is designed to understand them, as if they were exterior to its discourse and fully formed, only to be correctly described and classified by it. Rather, the reverse is true: discourses form the objects of which they speak.[119]

Following this logic, one would have to admit, as Reinders does, that "disability is an invention created by policing institutions and organizations

116 Ibidem.

117 Adam Rafalovich, *Framing ADHD Children: a Critical Examination of the History, Discourse, and Everyday Experience of Attention Deficit/Hyperactivity Disorder* (Lanham, MD: Lexington Books, 2008).

118 Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: Eerdmans, 2008), p. 74.

119 Ibidem, p. 75.

such as professional bodies and the nation-state."[120] Therefore, the distinction between discovery and invention in the context of disability is utterly misleading—because there is, in fact, no discovery at all, only invention.

2.3.2. Disability: an invention of governmentality

Shelley Tremain, one of the most prominent contemporary Foucauldian theorists, argues that, according to Foucault, "subjects are produced who 'have' impairments because this identity meets certain requirements of contemporary social and political arrangements."[121] Tremain maintains that Foucault viewed impairment as an invention of governmentality, a concept introduced in the eighteenth century to serve the interests of public hygiene. What distinguishes the Foucauldian approach to disability from Oliver's social model is his concept of power. Unlike Oliver, who theorizes power as a repressive force that regulates and controls the actions of human agents, Foucault conceives of power as something that "fabricates them in the discourses that produces information and knowledge of what they are."[122]

In terms of historical genealogy, Foucault argued that impairment is recognized as a distinct category "when the distinction between the 'normal' and the 'pathological' marks the beginning of modern biomedicine at the end of the eighteenth century."[123] This distinction, he claimed, "sustains disability as a form of power that both contributes to the formation of an identity and establishes impairment as its necessary and sufficient condition."[124] In other words, for Foucault, human impairments are medical fabrications that bring the category of disability into being.[125]

The consequences of this paradigm for disabled people are aptly captured by Bill Hughes, who writes:

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120 Ibidem.

121 Shelley Tremain, *Foucault and the Government of Disability* (Ann Arbor: The University of Michigan Press, 2015), p. 10.

122 Ibidem. p. 14

123 Bill Hughes, "What Can a Foucauldian Analysis Contribute to Disability Theory?," in *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2005), p. 82.

124 Ibidem. p. 83.

125 Ibidem.

> to be situated within a discourse of "pathology" is to be delegitimized. Insofar as disabled people have become an object of disciplinary power, they have also become the subject matter of professional groups, whose discourses of expertise have defined and redefined that subject matter. The outcome of these practices for disabled people has been the systematic closure of opportunities for agency. By the end of the nineteenth century, confinement, institutionalization, and dependency had become the reality of disabled people's lives. Disabled people became people who could not do things for themselves, who were a burden—a group in need of intensive and intrusive systems of surveillance.[126]

Although the Foucauldian analysis of disability possesses considerable explanatory power, Reinders points out that it also reveals a problematic nominalist tendency. This concern arises from Foucault's "uncompromising rejection of any suggestion that the language of impairment and disability refers to something 'out there,' a fact about the natural condition of human being that evokes a particular kind of response."[127] For Foucault, the only thing to which we truly respond is language. According to Foucauldian theorist Barry Allen, one possible explanation for this perspective is that "[Foucault's antirealism] rejects any suggestion of inherent structure."[128] This Foucauldian antirealism, when applied to human disability and impairment, reveals itself in the categorical denial of these realities existing independently of linguistic structures.

Following this logic, Allen asserts that "nobody is impaired on her own, through a naturally occurring deficit that [the] ... body bears as a biophysical property."[129] He also adds that impairment is not "something missing, not a lack or absence; it is something added, an unasked-for supplement contributed by disciplinary knowledge and power."[130] Commenting on Foucault's approach to disability, Allen argues that "impairment is not inscribed in the biological register of nature and merely given in the body.

126 Ibidem.

127 Reinders, 2008, p. 77.

128 Barry Allen, "Foucault's Nominalism," in *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2005), p. 99.

129 Ibidem, p. 94

130 Ibidem.

It is an artifact implanted in the body by the discipline that measures deviation."[131] He also states:

> impairment is real (as real as crimes or money), though not a naturally given abnormality, but rather an artifact of the knowledge that measures the deviation from the norm. Norms and normal cases are like statutory law and criminals: they exist, they are real—that is, effective—but only because people agree to take them seriously as objects of knowledge. It takes pedagogy to see some difference (which might otherwise be a matter of indifference) as a deficit, deficiency, or abnormal impairment. Impairment has no reality apart from the social mathematics of normalizing judgment.[132]

This line of reasoning is difficult for Reinders to accept. He argues:

> in view of my earlier example of human beings who do not understand the difference between "you" and "me," or between "now" and "then," or between "here" and "there," I doubt the possibility of a social order within which this inability would be a matter of indifference.[133]

Additionally, he contends that this kind of reasoning "conflates the distinction between knowing and being"[134] and stresses that "the norm does not constitute the condition of being impaired; it only constitutes the label that is attached to the condition within the context of a given social practice."[135]

2.3.3. An elusive self-representation

Consequently, Foucauldian nominalism with regard to human disability complicates the task of adequately describing actual cases of people with profound intellectual disabilities, such as Adam. Like other previously discussed social constructionist approaches to disability (the social model and disability identity logic), Foucauldian analysis seems to assume that the disabled person is a purposeful agent capable of competent self-representation. As discussed earlier, this logic leads to the solidification

131 Ibidem.
132 Ibidem, p. 96.
133 Reinders, 2008, p. 79.
134 Ibidem.
135 Ibidem.

of a hierarchy of disability in which those with profound intellectual disabilities remain at the bottom. To support this claim, it is important to examine Foucauldian theories of disability in order to discern how questions of human subjectivity and self-representation were conceived by Foucault himself. The poststructuralist approach to humanity (to which Foucault subscribed) seeks to demonstrate that subjectivity is not a given but is instead the product of language.[136]

Nirmala Erevelles notes that, for Foucault, the human subject does not exist outside the system of signs and signifiers constituted by language, and "thus the idea that human subjects can represent themselves by using language as a medium of transparent self-identification must be dismissed as a delusion."[137] Additionally, Foucault rejects the notion of the human individual as a pre-existing entity. Instead, he views subjectivity as "the result of the exercise of symbolic power."[138] In this same vein, human subjectivity is "not to be mistaken as an originary force but is to be understood as the constituted effect of knowledge regime."[139]

Given these considerations, we see that, from Foucault's point of view, emancipation for disabled people must be achieved by empowering them to participate in self-representation. But if this is the case, what role can people with profound intellectual disabilities play in this dynamic? For them, meaningful participation in this way seems entirely out of reach. Erevelles suggests that, in light of the Foucauldian interrogation of essentialized subjectivity, the challenge is to rethink agency without resorting to traditional notions of "essentialized subjectivity." She argues that it is particularly important for those involved in the disability rights movement "to reconstitute for themselves empowering subjectivities."[140]

In a similar vein, Licia Carlson, another Foucauldian theorist of disability, reflects upon the Foucauldian historical analysis of "mental retardation" in order to challenge "the self-evident nature of mental retardation as a particular

136 Ibidem, p. 80.

137 Nirmala Erevelles, *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic* (New York: Palgrave Macmillan, 2016), p. 17.

138 Ibidem.

139 Ibidem, p. 47.

140 Ibidem.

kind of problem to be solved."[141] In her work, she argues that the concept of "mental retardation" is influenced by "subjugated knowledges" imposed "from above." Carlson defines subjugated knowledges as institutional discourse, philosophical theorizing, and other forms of expert knowledge "produced about rather than by persons" who are labeled "mentally retarded."[142]

One example of this pattern of power/knowledge can be found in nineteenth-century scientific discourse, which created the category of "feeblemindedness" and predetermined that this particular group of people were destined for specific educational and developmental outcomes. This example helps Carlson "to expose the complex power relationship" that underlies the construction of categories such as "mentally retarded" in the Foucauldian sense—as subjects who both act and are acted upon."[143] But in theorizing how their subjectivity is constructed, Carlson says that we must take into account the fact "that certain individuals may be unable to participate in this form of philosophical and political discourse."[144] As she writes:

> a Foucauldian analysis need not lead to a denial of the lived realities of people who are labeled "mentally retarded," experiences that may be the result of their actual cognitive abilities, and/or the political, economic, and social consequences of being classified as "mentally retarded." Rather, the promise of a Foucauldian approach lies in the unmasking of certain power relations that directly affect the extent to which certain voices are silenced and exposing the dangers of defining and speaking for an entire class of individuals. Ultimately, Foucault's work calls upon us to consider how the very existence of mental retardation as a classification affects the process of self-determination and the conception of moral agency for individuals who are thus labeled.[145]

2.3.4. Foucault and the enduring resistance to power

Scott Yates observes that Foucault wants to empower people so they can resist the power of professionals and institutions in governing their self-image. He also warns of the dangers inherent in speaking for others

141 Licia Carlson, "Docile Bodies, Docile Minds: Foucauldian Reflection on Mental Retardation," in *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2005), p. 134.

142 Ibidem, p. 135.

143 Ibidem, p. 149.

144 Ibidem.

145 Ibidem, pp. 149–150.

or formulating resistance strategies on their behalf.[146] Foucauldian theorists similarly maintain that the liberation of human agency is "centered on the relationship of the self with the self."[147] The poststructuralist narrative of human disability—especially in Foucauldian thought—follows the same logic found in other social constructionist approaches to disability (e.g., the social model and disability identity logic); namely, that the underlying ethical framework that makes the inclusion of people with disabilities entirely dependent of their capacity for self-representation and self-affirmation."[148]

In a lecture delivered on January 7, 1976, Foucault argued that "power is not something that is exchanged, given, or taken back, but rather is exercised and exists only in action."[149] Consequently, the appropriate response for disabled individuals to the biopolitical practices of the state is to exercise a form of power that comes from self-affirmation. Through this, they can resist objectification and defend their subjectivity. However, such a mechanism remains inaccessible to people with profound intellectual disabilities—and even more so to unborn children with such conditions. Moreover, the Foucauldian project continues to reinforce a model of political citizenship in the way it conceptualizes the position of disabled individuals within the structure of power/knowledge.

Foucault provides a noteworthy interpretation of human disability by pointing specifically to ways in which social notions of disability can be seen as products of "policing" mechanisms enacted by professional organizations and state institutions. Still, his framework fails to offer an adequate understanding of profound intellectual disability which might otherwise facilitate deeper recognition and protection of profoundly disabled unborn children. As Bill Hughes notes, "while the incorporation of Foucault's analyses into disability studies will expand the theoretical menu of the discipline, as well as its intellectual arsenal, in the long run Foucault's

146 Scott Yates, "Truth, Power, and Ethics in Care Services for People with Learning Difficulties" in *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2005), p. 69.

147 Reinders, 2008, p. 85.

148 Ibidem.

149 Tremain, 2015, p. 4.

work will provide few resources that could improve the lives of disabled people."[150]

2.3.5. Conclusion

The field of contemporary disability studies is extensive and multilayered. Growing awareness of the need for equal rights, opportunities, and access for people with disabilities has led to the hopeful expectation of continued academic progress in the coming years. These advancements are undoubtedly cause for optimism among those with physical, mental, and emotional limitations—as well as for those who care for them. Nevertheless, certain difficulties remain, especially when we examine the theoretical foundations proposed by leading and mainstream disability scholars.

Disability activists and advocates most commonly adopt a social constructionist paradigm. As discussed in this chapter, the troubling reality of this perspective is that it fails to grant the most vulnerable group of disabled people—profoundly intellectually disabled prenatal babies—a basic recognition and appreciation as equally valuable members of the human community. Furthermore, the underlying logic of social constructivism does not guarantee strong support for perinatal hospice care practices.

Following an examination of the social model of disability proposed by Michael Oliver, I have identified several significant shortcomings. As emphasized, a major weakness of this model is its tendency to overlook the fact that, for many disabled people, their impairment is a fundamental part of their lives. Additionally, proponents of the social model may mistakenly assume that all disabled individuals are inherently oppressed. This assumption represents a serious oversimplification and a considerable methodological bias.

An overemphasis on the need for disabled people to be involved in political activism as the sole path to liberation—as Reinders rightly points out—can reinforce a hierarchy of disability and exclude profoundly intellectually disabled individuals. Many disabled people, especially profoundly disabled prenatal babies, are simply not capable of this kind of political engagement. Not every disabled person has the cognitive ability

150 Bill Hughes, "What Can a Foucauldian Analysis Contribute to Disability Theory?" in *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2005), p. 80.

to consciously resist aspects of a disabling society. Moreover, not all disabled people necessarily view themselves as victims of capitalist oppression.

The social model of disability rejects essentialism and embraces a Marxist materialist logic by promoting what Reinders rightly calls an "anthropology of political citizenship." In this view, a person's dignity and value are contingent upon their conscious and voluntary participation in political activism. As argued in this chapter, certain flawed aspects of the social model can also be identified in disability identity logic. Although leading proponents such as Tobin Siebers and Rosemarie Garland-Thomson encourage disabled people to develop positive self-identification and engagement based on their own physical or mental characteristics, they nevertheless uphold the potentially harmful anthropology of political citizenship, which reinforces a hierarchy of disability and contributes to the exclusion of profoundly intellectually disabled prenatal babies.

As emphasized throughout this chapter, disability identity logic is founded on social constructionist principles and adheres to an anthropology of political citizenship. Consequently, it can justify oppressive and discriminatory actions toward the most vulnerable, such as the selective abortion of profoundly disabled unborn children. Additionally, by conflating loyalty to feminist activism with advocacy for disability rights, Garland-Thomson introduces a troubling contradiction: she simultaneously supports unrestricted access to abortion—particularly when the child in question exhibits signs of potential disability—while also purporting to advocate for the inclusion and protection of disabled individuals.

Finally, I have examined the poststructuralist approach to disability to assess its usefulness in protecting profoundly intellectually disabled prenatal children and supporting perinatal hospice care. Foucault does contribute a valuable viewpoint on human disability by exposing how the very notion of disability is often constructed by "policing" institutions and bureaucratic systems. Despite this, however, his work still falls short in providing an account of profound intellectual disability that could lead to greater recognition and protection of profoundly intellectually disabled unborn children. By remaining within the logic of social constructivism, Foucault, too, embraces the anthropology of political citizenship, which does not adequately address the needs or dignity of the profoundly disabled perinatal population.

Moving on from the secular discourse of disability studies, I now turn to the work of the medieval theologian St. Thomas Aquinas in order to explore how his views on human disability have substantially shaped—and continue to influence—the teachings of the Catholic Church. In the following chapter, I will demonstrate how Thomistic anthropology, especially Aquinas's understanding of profound intellectual disability, underpins the official purview of the Catholic Church and finds expression in key magisterial documents such as the *Code of Canon Law*, the *Catechism of the Catholic Church*, instructions issued by the Congregation for the Doctrine of the Faith, papal encyclicals, and others. I will also argue that what I term a "*ratio*-informed anthropology" that stems from Thomistic thought may still fall short in providing the full degree of protection needed for profoundly disabled prenatal babies. To substantiate this claim, I will begin by sharing a personal account from my time serving as a chaplain in a children's hospice in Kraków, Poland.

CHAPTER THREE

THE CATHOLIC CHURCH'S PERSPECTIVE ON HUMAN DISABILITY AND *RATIO*-INFORMED ANTHROPOLOGY

Following the teachings and example of Jesus Christ, the Catholic Church has strived for nearly two millennia to bear faithful witness to the dignity and sanctity of human life. Even during the time of the Roman Empire, the first Christian communities were recognized by pagan citizens of "the capital of the world" for their willingness to adopt and save the life of unwanted infants left at the Lactoria Columna (Milk Column) in one of the city's main squares.

Jesus' command to "love one another" (John 13:34, NRSVCE)[1] as He loved us, has deeply shaped the character of Christian charity and underscores the imperative to care for and protect human life. Prominent examples of this commitment include the founding of the first hospitals by religious orders. The Cistercians and Benedictines, for example, provided medical care to the poor, the elderly, and those who suffered from chronic conditions or old age and were unable to care for themselves.[2]

During the height of pilgrimages and other travel to the Holy Land in the 10th and 11th centuries, special chivalric orders (such as the Sovereign Military Hospitaller Order of Saint John of Jerusalem) were established to protect pilgrims and provide essential healthcare to travelers.[3] Even in modern times, the Catholic Church has consistently affirmed the necessity of respecting and protecting human life from conception

1 All Bible quotations are taken from the *New Revised Standard Version, Catholic Edition*, published by the National Council of Churches.

2 Gary B. Ferngren, *Medicine and Religion: a Historical Introduction* (Baltimore: Johns Hopkins University Press, 2014), p. 105.

3 Ibidem, p. 106.

to natural death. This teaching is upheld in numerous documents, declarations, and pastoral instructions issued by both past and current Popes.[4]

The Catholic Church is one of the most prominent and steadfast voices supporting pro-life initiatives worldwide, while consistently opposing pro-abortion legislation.

3.1. Profound intellectual disability: a difficult terrain for Catholic Church teaching

Despite its historic and ongoing commitment to affirming the sanctity of human life, there is still a need within the Church for improved pastoral guidance on issues related to profound intellectual disability. Without a doubt, the Church's teachings recognize the lives of profoundly intellectually disabled human life as being just as precious and sacred as those of able-bodied individuals. Furthermore, the Church clearly upholds the necessity of protecting these lives from potential threats such as selective abortion. Nevertheless, when it comes to addressing the specific pastoral challenges associated with this type of disability, Church teaching is often vague and lacks clear, explicit guidance in several areas. As a result, there are situations in which people with profound intellectual disabilities may feel excluded from full participation in the ecclesial community.

One example of this is the Church's teaching, as manifested in certain documents related to sacramental discipline (particularly the Roman

4 See "Conclusions of a Vatican Conference on the Family and Integration of the Disabled," Conference on the family and integration of the disabled, accessed September 28, 2020,http://www.vatican.va/roman_curia/pontifical_councils/family/documents/rc_pc_family_doc_20000304_integration-disabled_en.html. Also, "The Person with Disabilities: The Duties of the Civil and Ecclesial Community," Persons with disabilities, accessed September 28, 2020,http://www.vatican.va/jubilee_2000/jubilevents/jub_disabled_20001203_scheda5_en.htm. *Pastoral Statement of U.S. Catholic Bishops on Persons with Disabilities: Including the 1988 Resolution on the Tenth Anniversary of the Pastoral Statement on Persons with Disabilities* (Washington, D.C.: United States Conference of Catholic Bishops, 2001). *Welcome and Justice for Persons with Disabilities: a Framework of Access and Inclusion: a Statement of the U.S. Catholic Bishops* (Washington, D.C.: United States Catholic Conference, 1998). *Celebrate and Challenge: Tenth Anniversary: Pastoral Statement of the U.S. Catholic Bishops on Handicapped People* (Washington, D.C.: Board of Directors, National Catholic Office for Persons with Disabilities, 1988).

Catholic Code of Canon Law), which unintentionally creates what I refer to as a state of *quasi-Limbo Puerorum*. This term describes the condition of children with profound intellectual disabilities who may be unable to receive the sacraments of Eucharist or Confirmation, both of which, along with Baptism, constitute the Sacraments of Christian Initiation.

The concept of *Limbo Puerorum* originated with St. Augustine of Hippo, who defended the doctrine of original sin and maintained that infants who died without baptism must reside in a particular state, since they were incapable of committing personal sin.[5] St. Augustine believed that:

> such infants as quit the body without being baptized will be involved in the mildest condemnation of all. That person, therefore, greatly deceives both himself and others who teach that they will not be involved in condemnation; whereas the apostle says: "Judgment from one offense to condemnation," and again a little after: "By the offense of one upon all persons to condemnation."[6]

In the 12th century, the idea of *Limbo Puerorum* was furthered by Peter Abelard. He envisioned this state as existing somewhere between hell and heaven, in which unbaptized infants experienced no physical torment or positive punishment, but only the pain of loss at being denied the beatific vision.[7]

Contrary to the original concept, my rhetorical figure of *quasi–Limbo Puerorum* refers to a situation in which a child with profound intellectual disability, though baptized, is still not granted full access to the Ecclesial Community through reception of the other Sacraments of Christian Initiation (i.e., Eucharist and Confirmation). As a result, the lives of these babies appear suspended somewhere between inclusion in and exclusion from the Church.

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5 Michael Lofton, *Is My Baby in Hell?: Hope for Parents of Unbaptized Infants* (West Monroe, LA: R&T Press, 2020), p. 34.

6 St. Augustine, *The Merits and Remission of Sins and the Baptism of Infants* (Whitefish, MT: Kessinger Pub., 2005), ch. XVI.

7 *The Hope of Salvation for Infants Who Die without Being Baptised* (London: Catholic Truth Society, 2007), p. 22.

3.1.1. All are welcome? Intellectually disabled children and the sacrament of Eucharist

To support my claim that a dynamic resembling *quasi–Limbo Puerorum* is still present in contemporary pastoral practice of the Roman Catholic Church, I need to share another firsthand account from my time as a chaplain at a children's hospice in Poland. Shortly after I began my ministry, a number of parents of profoundly mentally and physically disabled children approached me to ask whether their sons and daughters could receive the Sacrament of the Eucharist. All of these children were between 9 and 11 years old, which is when children typically receive this sacrament for the first time.

My immediate response to the question was a firm yes. I was glad that these parents were taking seriously their responsibility for their children's spiritual well-being. What I did not know at the time was that they had already posed this question to their local parish priests and had been told it was not possible. When I later visited these priests and explained that I was willing to prepare the children to receive the Sacrament of the Eucharist, I was told that doing so would violate Roman Catholic Canon Law (*Codex Iuris Canonici*, CIC).

However, the explanation that I received was only partly true. The current version of the CIC, promulgated by Pope John Paul II on November 27, 1983, in the chapter entitled "The Most Holy Eucharist," states that:

> the administration of the Most Holy Eucharist to children requires that they have sufficient knowledge and careful preparation so that they understand the mystery of Christ according to their capacity and are able to receive the body of Christ with faith and devotion.[8]

In the following paragraph, the document specifies: "the Most Holy Eucharist, however, can be administered to children in danger of death if they can distinguish the body of Christ from ordinary food and receive communion reverently."[9] Another paragraph that is crucial to understanding

8 Code of Canon Law, c. 913, § 1, in *Code of Canon Law: Latin-English Edition* (Washington, DC: Canon Law Society of America, 1999), 130.

9 CIC, c. 913, § 2.

the possibility of restricting intellectually disabled children from receiving the Eucharist states that:

> it is primarily the duty of parents and those who take the place of parents, as well as the duty of pastors, to take care that children who have reached the use of reason are prepared properly and, after they have made sacramental confession, are refreshed with this divine food as soon as possible. It is for the pastor to exercise vigilance so that children who have not attained the use of reason or whom he judges are not sufficiently disposed do not approach holy communion.[10]

It was likely these passages that played a decisive role in the denial of the Eucharist to the profoundly intellectually disabled children whose parents had enlisted my help.

The rationale behind this position is relatively straightforward: if a child does not possess sufficient reasoning ability, they may not be able to distinguish "the body of Christ from ordinary food" (which is a very high expectation, even for a fully intellectually capable person). As a result, their reception of the sacrament could risk sacrilege, since they may lack the proper inner reverence and devotion. Additionally, the requirement of sacramental confession prior to receiving Holy Communion presents another insurmountable barrier for individuals with profound intellectual impairments, who are simply incapable of making a valid confession.

It is important to note, however, that this overly legalistic interpretation of the CIC text overlooks an important point that appears in the very first line of the same chapter: "Any baptized person not prohibited by law can and must be admitted to holy communion."[11] According to Canon Law, the persons who are prohibited from receiving the Eucharist are:

> those who have been excommunicated or interdicted after the imposition or declaration of the penalty, and others obstinately persevering in manifest grave sin are not to be admitted to holy communion.[12]

Clearly, the disabled children in question were entirely free from any form of excommunication or interdict. Moreover, they were also free from

10 CIC, c. 914.
11 CIC, c. 912, § 1.
12 CIC, c. 915.

grave or mortal sin, as they lacked the capacity for sufficient reason to perform a free and deliberate act and thereby satisfy the two conditions required for an act to be considered mortal sin. As the *Catechism of the Catholic Church* explains:

> for a sin to be mortal, three conditions must together be met: Mortal sin is sin whose object is grave matter, and which is also committed with full knowledge and deliberate consent.[13]

Therefore, baptized children with profound intellectual disabilities constitute a unique group of the faithful for whom distinct, specially adapted sacramental disciplines should be applied.

This awareness seems to be reflected in *Canon 913 §1* of the *Codex Iuris Canonici* (CIC), which states that sacramental discipline should be applied "according to [the children's] capacity." We must also remember that any pastoral action concerning the sacramental life of the faithful should be motivated by the responsibility entrusted to parents and local pastors to ensure that children receive all three sacraments of Christian initiation: Baptism, Eucharist, and Confirmation. The CIC is explicit in emphasizing the importance of receiving all these sacraments, saying that: "the sacraments of baptism, confirmation, and the Most Holy Eucharist are interrelated in such a way that they are required for full Christian initiation.[14]

In light of these directives, the position taken by the aforementioned parish priests was, at best, pastorally irresponsible and, at worst, seriously neglectful. My decision to prepare those disabled children for the sacrament of the Eucharist was based on the clear instructions of the CIC, which affirms:

> pastors of souls and other members of the Christian faithful, according to their respective ecclesiastical function, have the duty to take care that those who seek the sacraments are prepared to receive them by proper evangelization and catechetical instruction, attentive to the norms issued by competent authority.[15]

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13 *Catechism of the Catholic Church: Revised in Accordance with the Official Latin Text Promulgated by Pope John Paul II* (Ottawa: Canadian Conference of Catholic Bishops, 2006), no. 1857.

14 CIC, c. 842, § 2.

15 CIC, c. 843, § 2.

In my reading of this text, the parents of profoundly disabled children not only had the right but also the duty to seek full Christian initiation for their children through the reception of the Eucharist, followed later by Confirmation.

Another highly instructive text in this context is Pope Benedict XVI's post-synodal apostolic exhortation *Sacramentum Caritatis*. In the section devoted to the reception of Holy Communion by the sick, the Pope emphasizes:

> whenever possible, Eucharistic communion should be made available to the mentally handicapped, if they are baptized and confirmed: they receive the Eucharist in the faith also of the family or the community that accompanies them.[16]

It is important to recognize two key points in this excerpt. First, the Pope mentions the sacrament of the Eucharist in the context of the other two sacraments of Christian initiation: Baptism and Confirmation. This reinforces the earlier point that full integration into the Ecclesial community requires reception of all three sacraments, which should not be treated as entirely separate or unrelated. Second, Benedict indicates the importance of family and community in the spiritual lives of the intellectually disabled. This dynamic played a crucial role in the story I shared earlier.

I eventually received permission to begin preparing five profoundly disabled children to receive the sacrament of the Eucharist. The program lasted seven months, during which I held monthly meetings with their families in which we discussed various topics related to the Christian faith and celebrated the Eucharist in their homes. The children were always present for these gatherings. Despite the preparation, none of the five children were ultimately able to communicate or demonstrate an understanding of the Christian faith sufficient to distinguish regular bread from the Body of Christ. They also could not explicitly promise that they would receive the Eucharist with complete reverence. Nevertheless, none of us—including the families—doubted that they were ready to be fully welcomed into the Christian family.

The liturgy during which these children received Holy Communion for the first time was a particularly joyful occasion for their parents

16 Benedict XVI, *Sacramentum Caritatis* (Città del Vaticano: Libreria Editrice Vaticana, 2007), no. 54.

and loved ones. It was also an important moment for me—though bittersweet. On the one hand, I was overjoyed that these children would be fully integrated into the family of the Catholic Church through the sacraments of initiation. On the other hand, I was deeply disappointed that we were asked to organize the ceremony privately, apart from the main Sunday Mass celebration. This decision was a missed opportunity for the larger parish community as it could have provided an excellent pastoral example of the Church's "pro-life" commitment in a tangible, public way.

Being pro-life means standing up for all lives, especially the most vulnerable, and ensuring that they are fully welcomed and valued within the Church. If, as a Catholic community, we are to fully dedicate our energies to protecting unborn children from abortion, then it makes sense that we should also continue those efforts after birth. What could more meaningfully demonstrate the integrity of a truly pro-life position than ensuring that children with profound intellectual disabilities are able to receive all the sacraments of Christian initiation—and to do so in a setting in which the entire community can witness and celebrate that joyful occasion together?

This story clearly indicates that, although the CIC generally acknowledges the right of disabled children to be fully integrated into the Ecclesial community, it does not explicitly or precisely specify how this should or can be accomplished. Consequently, this imprecision can lead to situations in which children with profound intellectual disabilities are prevented from receiving the sacraments of Eucharist and Confirmation. I hope that growing reflection on the topic of intellectual disability will prompt Church teaching—such as that found in the CIC—to become more attentive and inclusive toward this particular group of the faithful.

3.1.2. An Orthodox perspective on sacramental discipline

To complete the broader picture of sacramental practice, it should be mentioned that the sacramental discipline described in the CIC applies only to the Roman Catholic Church. Substantially different regulations govern the Eastern Catholic Churches, which follow various Orthodox rites.[17]

17 The Eastern Catholic Churches (ECC), also known as the Oriental Catholic Churches or Eastern-rite Catholic Churches, comprise twenty-three Eastern Christian churches that are in full communion with the Pope in Rome. Unlike the Latin tradition followed

According to the *Code of Canons of the Eastern Churches* (*Codex Canonum Ecclesiarum Orientalium*, CCEO), the sacraments of Christian initiation are to be administered together:

> sacramental initiation in the mystery of salvation is perfected in the reception of the Divine Eucharist, and thus the Divine Eucharist is administered after baptism and chrismation with holy myron as soon as possible according to the norms of the particular law of each Church *sui iuris*.[18]

It is common practice in these Churches for the infant to receive all three sacraments—Baptism, Confirmation (Chrismation), and Eucharist—during the baptismal ceremony. The CCEO emphasizes that:

> with respect to the participation of infants in the Divine Eucharist after baptism and chrismation with holy myron, the prescriptions of the liturgical books of each Church *sui iuris* are to be observed with the suitable due precautions.[19]

In Eastern Catholic Churches, infants receive the sacrament of Eucharist in the form of a drop of consecrated wine. This practice predates the Roman Catholic Church's later norms and can be traced as far back as the 5th century. In one of his sermons, St. Augustine of Hippo testifies to the Western Church's practice of giving the Eucharist to infants from the Lord's Table.

> Those who say that infancy contains nothing for Jesus to save are effectively denying that Christ is Jesus for all believing infants. In fact, by insisting that there is nothing in infancy for Jesus to redeem, they are really saying that Christ the Lord is not Jesus for believing infants—that is, infants who have been baptized in Christ. But what does the name Jesus mean? Jesus means "Savior." Jesus is the Savior. If someone claims there is nothing in an infant to be saved, then for that person, Jesus is not a Savior. And if you can tolerate the idea that Christ is not Jesus for some of the baptized, then I'm not sure your faith aligns

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by the Roman Catholic Church, the ECC embrace five distinct liturgical rites: the Alexandrian Rite, the Armenian Rite, the Byzantine Rite, the East Syriac Rite, and the West Syriac Rite. The ECC are led by patriarchs and are governed according to the Code of Canons of the Eastern Churches.

18 Code of Canons of the Eastern Churches, c. 697, in *Code of Canons of the Eastern Churches: Latin-English Edition* (Washington, D.C.: Canon Law Society of America, 2001).

19 CCEO, c. 710, § 1.

> with sound doctrine. Yes, they are infants—but they are his members. They are infants—but they receive his sacraments. They are infants—but they partake at his table, so that they may have life in themselves.[20]

Fr. Robert Taft, S.J., comments on the history of infant Communion in the Western Church as he argues that:

> the practice [of communing infants] began to be called into question in the 12th century not because of any argument about the need to have attained the "age of reason" (*aetus discretionis*) to communicate. Rather, the fear of profanation of the Host if the child could not swallow it led to giving the Precious Blood only.[21]

Consequently, when the laity in the West were later denied access to the chalice, this change "led automatically to the disappearance of infant Communiontoo."[22]

According to Taft, this "was not the result of any pastoral or theological reasoning. When the Fourth Lateran Council (1215) mandated yearly confession and Communion for those who had reached the "age of reason" (*annos discretionis*), it was not affirming this age as a requirement for reception of the Eucharist."[23] Another compelling point Taft makes is that the decline of infant Communion in the West occurred gradually and was essentially complete by the 13th century, when:

> the "age of reason" theory advanced to support the innovation of baptizing infants without also giving them Communion. So, the "age of reason" requirement for Communion is a medieval Western pastoral innovation, not a doctrinal argument. And the true ancient tradition of the whole Catholic Church is to give Communion to infants. Present Latin usage is a medieval innovation.[24]

I am convinced that, based on Taft's theory of "medieval innovation," he would likely agree with my point that the Roman Church's

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20 Augustine, *Writings of Saint Augustine* (Washington: Catholic University of America Press, 1966), p. 174.

21 Robert F. Taft, *A History of the Liturgy of St. John Chrysostom* (Roma: Pontificium Institutum Studiorum Orientalium, 1978), p. 124.

22 Ibidem.

23 Ibidem, p. 125.

24 Ibidem.

sacramental discipline regarding the reception of Holy Communion, as stated in the CIC, unintentionally creates a situation in which children with intellectual disabilities are left in a state of *quasi-Limbo Puerorum* and are not fully integrated into the Christian community.

I hope that through this project and other subsequent work, the teachings of the Church will become increasingly attentive to the needs of profoundly intellectually disabled children, who constitute a distinct yet critically important segment of the faithful.

3.1.3. Catholic sacramental discipline and perinatal hospice care: an overlapping area

Before continuing, I want to propose a potential relationship between the practices of perinatal hospice care and the sacramental discipline of the Catholic with regard to the reception of Holy Communion as there is a possible connection that might not be immediately evident but is crucial to identify. If we consider a scenario in which Catholic healthcare institutions provide perinatal hospice care, it is likely that the medical professionals working with expectant parents of profoundly disabled unborn children will be, at least to some degree, familiar with the Church's sacramental guidelines regarding Holy Communion for those with severe intellectual impairments.

This familiarity could unintentionally send a mixed message to prospective parents of profoundly disabled children. On the one hand, they are assured that the life of their disabled unborn child is sacred, precious, and worthy of being welcomed into the world. On the other hand, they may perceive a contradiction: if their child will not be offered full integration into the Ecclesial Community through the sacraments of the Eucharist and Confirmation, then perhaps that life is seen, even subtly, as less complete or defective.

In some extreme cases, this painful realization could be the final emotional blow that leads expectant parents to reconsider their decision to bring their disabled unborn child into the world. Even if it does not cause them to terminate the pregnancy, it may still add unnecessary sorrow to an already painful and emotionally taxing experience. Therefore, this important link between Catholic sacramental discipline and perinatal hospice care could have significant consequences.

3.2. Catholic Church tradition and *ratio*-informed anthropology

Having demonstrated that the sacramental discipline outlined in the CIC creates the possibility for the discriminatory denial of the sacraments of Eucharist and Confirmation to intellectually disabled children, I now turn to another concern: the presence of an underlying ambiguity in the Catholic Magisterium's understanding of human nature. Specifically, there appears to be an overemphasis on *ratio* (i.e., reason) as a defining feature of human personhood, resulting in what I term a *ratio*-informed anthropology in certain teachings of the Catholic Church. As mentioned earlier, this type of anthropology may involve several shortcomings, especially when it comes to the pastoral and sacramental care for profoundly intellectually disabled children.

3.2.1. Are they human in the very same way?

For at least the past four decades, the perspective of the Catholic Church on the value of human life has been at the forefront of bioethical debates surrounding issues such as abortion, in vitro fertilization, embryo experimentation, and, more recently, stem cell research. The position consistently upheld by the Catholic Magisterium is unambiguous: human life is sacred from the moment of conception until natural death.[25] Human beings are endowed with inherent dignity and deserving of unalienable respect and protection.

In its teaching on human life, the Catholic Magisterium proclaims that human nature and personhood are present from the very moment of conception. To support these claims, the Church frequently turns to contemporary science, especially genetics. Current Catholic doctrine highlights the fact that even at the earliest embryonic stage—known as the *morula*—the developing human already possesses all the genetic information necessary to become a fully mature human person.[26] In other words, embryonic

25 *Catechism of the Catholic Church: Revised in Accordance with the Official Latin Text Promulgated by Pope John Paul II* (Ottawa: Canadian Conference of Catholic Bishops, 2006), 1700.

26 Germain Grisez, *Abortion: the Myths, the Realities, and the Arguments* (New York: Corpus Book, 1972), p. 46.

and fetal life is of the same biological kind as that of a full-grown adult, since both possess a complete and functional genotype.[27] For that reason, every organism of human origin must be regarded—and protected—as a human being.

The most prominent magisterial document that deals with this issue is *Donum Vitae*, issued by the Congregation for the Doctrine of the Faith on February 22, 1987. In this document, we read that:

> from the time the ovum is fertilized, a new human life has begun, which is neither that of the father nor of the mother; it is rather the life of a new human being with its own growth. It would never be human if it were not human already.[28]

The position that being human is biologically determined by being born of human parents reflects Aristotle's principle that "man is born from man."[29] Therefore, "if there is an issue about the humanity of some being, all you need to know is whether it is of human descent."[30]

Consequently, the question of whether people with profound intellectual disabilities are fully human can be answered quickly and simply based on their human origin. Despite the ease with which Catholic doctrine seems to be able to affirm whether a particular being is human, it is much more complex to determine how each unique human being realizes their humanity. For instance, although the Magisterium of the Catholic Church firmly teaches that people with profound intellectual disabilities are human, "are they human in the very same way as us, intellectually able?"[31] This is a question raised by Polish theologian Anna Maliszewska, who adds:

> if so, how can this fact be explained taking account of the Churches' statement regarding the rational nature of the human being, the rational human soul, the personal responsi-

27 Richard A. McCormick et al., "Abortion: Questions of Value and Procedure," in *Moral Theology: Challenges for the Future: Essays in Honor of Richard A. McCormick* (New York: Paulist Press, 1990), pp. 241–261.

28 Instruction *Donum Vitae* (Washington, D.C.: United States Conference of Catholic Bishops, 2013), p. 13.

29 Reinders, 2008, p. 91.

30 Ibidem.

31 Anna Maliszewska, "Fully Human. People with Profound Intellectual Disabilities in Light of the Teaching of the Catholic Church," *Studia Bobolanum* 29, no. 4 (2018): pp. 23–53.

bility of every human person, the inalienable freedom of every human being, the capacity for either acknowledging or rejecting God, etc.[32]

3.2.2. Between two different perspectives

The difficulty in answering this question may be due to the fact that Catholic doctrine on human nature seems to be simultaneously shaped by two different approaches, arising from two different perspectives.[33] According to Maliszewska, the consequence of this is that Catholic anthropology seems to contain internal tensions and discrepancies resulting from a pendulum-like movement between these lines of thought.[34]

When we examine Catholic teaching, we find statements that clearly affirm the human status of persons with profound intellectual disabilities, alongside others that seem to take no account of the intellectually disabled. In the previous paragraph, I provided an example of this reality through a quotation from the Roman Catholic *Code of Canon Law* and the *Catechism of the Catholic Church*. I also pointed out how people with profound intellectual disabilities can experience sacramental marginalization.

At this point, it is important to ask how it is possible that the Catholic Magisterium, which emphasizes the sanctity of every human life, still leaves room for the potential marginalization of profoundly intellectually disabled children. As Eberhard Schockenhoff argues, this anthropological ambiguity results from internal tensions between two different conceptions of human nature, both of which are upheld by Catholic doctrine. According to him, the term "human nature" suggests that human beings share a common nature, which is stable and knowable, and therefore not meaningfully open to question.[35] However, when we ask what it means to live in accordance with this nature, things quickly become more complex.

Schockenhoff argues that, historically, "living in accordance with nature" has been associated with the original state: genesis. This interpretation leads to conceptions of a Golden Age to which humankind should

32 Ibidem. p. 24

33 Ibidem, p. 27.

34 Ibidem.

35 Eberhard Schockenhoff and Brian Macneil, *Natural Law and Human Dignity: Universal Ethics in an Historical World* (Washington, D.C.: The Catholic University of America Press, 2003), p. 12.

return.[36] A second understanding of "living in accordance with nature" is connected to humanity's ultimate end (*telos*). According to this view, human beings will only fully live according to their nature in a future state of utopia and earthly existence is a kind of preparation for that reality. Based on Schockenhoff's distinction between these two theories of human nature (genesis vs. *telos*), the Magisterium of the Catholic Church can indeed be seen to vacillate between these opposing poles.

The position of *Donum Vitae*—that human personhood begins at conception because each human originates from human persons—seems to accord with the genesis viewpoint. Conversely, other passages from Catholic Canon Law that emphasize the necessity of proper intellectual formation in order to receive the sacraments of the Eucharist and Confirmation clearly support the *telos* framework.[37]

Apparent discrepancies between the priorities of these two poles may cause confusion and perplexity among the faithful. On the one hand, Catholic teaching embraces the genesis perspective in order to affirm that human personhood begins at conception and, as such, all human life is entitled to inalienable dignity and protection from practices such as abortion or embryo experimentation. At the same time, however, it upholds the *telos* perspective that overemphasizes the proper development of the faculty of reason as a necessary condition for receiving the sacraments of the Eucharist and Confirmation. This inconsistency is not only potentially confusing; it also creates the possibility for the sacramental marginalization of profoundly intellectually disabled children, who may be relegated to the state of quasi-*Limbo Puerorum*.

In the next section, I will explore possible origins of the Catholic Church's overemphasis on reason as a critical component of human nature.

3.2.3. Boëthius: the path toward reason

According to Robert Taft, a fundamental shift in the Magisterium of the Catholic Church's understanding of human nature occurred during the "age of reason," contemporaneous with the work of 13th-century

36 Schockenhoff, 2003, p. 13.
37 Reinders, 2008, p. 93.

theologian St. Thomas Aquinas.[38] Although I acknowledge the significance of the scholars of this period and their contributions, I suggest, following the work of Joseph W. Koterski,[39] that there was actually a much earlier turning point which marked the rise of interest in the faculty of human reason and will as essential components of human nature. I argue that this point can be traced to the period when early Christian thinkers began rediscovering Greek philosophy and attempting to define the term *persona*.

Among the most prominent figures of this time was Anicius Manlius Severinus Boethius, commonly known as Boethius, who lived and worked in the 6th century AD. Boethius was born in Rome to a patrician family around the year 480.[40] He lost both of his parents in childhood and was subsequently adopted by another patrician family, that of Quintus Aurelius Memmius Symmachus. Historian Noel Harold reports that Boethius' adoptive family instilled in him a love of literature and philosophy.

Boethius' ambition was to translate Plato's dialogues and all the works of Aristotle into Latin. He also intended to demonstrate that, despite their apparent discrepancies, the theories of Aristotle and Plato were internally compatible and could in fact complement each other.[41] Thanks to his extensive translation work, several important Aristotelian texts—such as *In Categorias Aristotelis*, *De Interpretatione vel Periermenias*, *Interpretatio Priorum Analyticorum*, and *Interpretatio Elenchorum Sophisticorum Aristotelis*—became available in Latin.

There is some dispute among contemporary scholars as to whether Boethius received his philosophical training in Athens or Alexandria. Both cities were, at the time, important centers of the Neo-Platonic school. According to Pierre Courcelle, it was probably in Alexandria that Boethius joined the Neo-Platonist philosopher Ammonius Hermiae.[42] A potentially decisive argument in favor of Alexandria is Boethius' Christian faith,

38 Taft, 1978, p. 124.

39 Joseph W. Koterski, "Boethius and the Theological Origins of the Concept of Person," *American Catholic Philosophical Quarterly* 78, no. 2 (2004): pp. 203–224.

40 Noel Harold Kaylor and Philip Edward Phillips, *A Companion to Boethius in the Middle Ages* (Leiden: Brill, 2012).

41 Kaylor and Phillips, 2012, p. 37.

42 Pierre Courcelle and Harry Ezekiel Wedeck, *Late Latin Writers and Their Greek Sources* (Cambridge, MA: Harvard University Press, 1969).

which was an extremely important part of his life. It is worth noting that the Roman Catholic Church officially recognizes Boethius as a saint.[43]

The Neo-Platonic school in sixth-century Athens was known for its anti-Christian stance, which ultimately led to its closure in 529 by Emperor Justinian.[44] In contrast, Alexandria was known for the relatively peaceful coexistence of Christians and pagans. Conrelie de Vogel also theorizes that while studying in Alexandria, Boethius became familiar with Origen's school and drew on Origen's understanding of *ousia* and *hypostasis* in relation to the Holy Trinity while developing his own definition of a person, *persona*.[45] In *Contra Eutychen et Nestorium*, Boethius explains that the Greek word *hypostasis* can be translated into Latin as *persona*, meaning *naturae rationalis individua substantia* ("an individual substance of rational nature").[46]

This definition earned Boethius a prominent place in the history of Christian philosophy and theology. One factor that contributed to the significance of his definition was the fact that it fit so well with the essential Christian commandment "to love one another" (John 13:1). This exhortation naturally entails an attitude of respect and care for others, recognizing them as uniquely individual sons and daughters of God.[47]

Consequently, as Koterski points out, the concept of the person as an ontological category first gained prominence in Christian culture.[48] Boethius' timeless contribution to the Christian understanding of the human being is seen both in the appreciation of the individuality and uniqueness of every person and in his stress on the faculties of reason and will. According to Koterski, Boethius can rightly be considered one of the earliest and most influential Christian thinkers. He exerted a major influence on the course of Christian anthropology through his deeper appreciation for the human faculties of reason and will[49]as defining elements of the human person.

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43 Ibidem.

44 John Marenbon, *Boethius* (New York: Oxford University Press, 2003), p. 13.

45 Cornelia J. de Vogel, *Greek Philosophy: a Collection of Texts* (Leiden: E.J. Brill, 1967).

46 Boethius et al., *The Theological Tractates* (Cambridge, MA: Harvard University Press, 1978).

47 Koterski, 2004, 210.

48 Ibidem.

49 Ibidem, p. 215.

3.3. St. Thomas Aquinas and the empowerment of *ratio*

Further reflection on the faculties of reason and will resurfaced in Christian thought after several centuries, most notably in the 13th century, through the work of St. Thomas Aquinas. In his monumental work, the *Summa Theologica*, Aquinas sought to address nearly every essential subject related to the Christian faith. For this task, he drew on the works of Aristotle and, as Norris Clarke puts it, "made a fundamental option for Aristotle and against Plato."[50] In the section of the *Summa* dedicated to the nature of the human being, Aquinas reaffirms Boethius' definition: "'Person' signifies what is most perfect in all nature, that is, a subsistent individual of a rational nature[51]." Thus, Aquinas continued the tradition of earlier Christian thinkers by approaching the nature of human personhood through the lens of the faculties of reason and will.

The influence of Thomistic thought on the contemporary Catholic Magisterium is unquestionable. The prominence of Aquinas' view on crucial aspects of Christian life, including the understanding of the human being, was endorsed by the dogmatic constitution *Dei Filius*, which was issued by the First Vatican Council and signed by Pope Pius IX on April 24, 1870. This document focuses on the relationship between faith and reason and refers to Aquinas as the *Doctor Angelicus*. Accordingly, in *Dei Filius*, we read:

> not only can faith and reason never be at variance with one another, but they also bring mutual help to each other, since right reasoning demonstrates the basis of faith and, illumined by its light, perfects the knowledge of divine things, while faith frees and protects reason from errors and provides it with manifold knowledge.[52]

This statement from the First Vatican Council directly refers to the teaching of St. Thomas, especially his famous claim that "believing is an act

50 William Norris Clarke, *Explorations in Metaphysics: Being, God, Person* (Notre Dame, IN: University of Notre Dame Press, 2008), p. xi.

51 *Sum. Theol.*, I, q.29, a.3.

52 Béchard Dean Philip and Joseph A. Fitzmyer, *The Scripture Documents: an Anthology of Official Catholic Teachings* (Collegeville, MN: Liturgical Press, 2002), p. 16.

of the intellect assenting to the divine truth by command of the will moved by God through grace."[53]

It is also necessary to mention another important document that bears witness to the significance of Thomistic thought within Catholic doctrine: Pope Leo XIII's encyclical *Aeterni Patris*, issued on August 4, 1879, which focused on "The Restoration of Christian Philosophy in Catholic Schools in the Spirit of the Angelic Doctor, St. Thomas Aquinas."[54] This document exhorts continued adherence to Thomistic thought and asserts that:

> among the Scholastic Doctors, the chief and master of all, towers Thomas Aquinas, who, as Cajetan observes, because "he most venerated the ancient doctors of the Church, in a certain way seems to have inherited the intellect of all." The doctrines of those illustrious men, like the scattered members of a body, Thomas collected together and cemented, distributed in wonderful order, and so increased with important additions that he is rightly and deservedly esteemed the special bulwark and glory of the Catholic faith.[55]

Pope Leo XIII continues his praise of the Angelic Doctor, arguing that:

> with his spirit at once humble and swift, his memory ready and tenacious, his life spotless throughout, a lover of truth for its own sake, richly endowed with human and divine science, like the sun he heated the world with the warmth of his virtues and filled it with the splendor of his teaching.[56]

The importance of Thomistic thought in the context of the contemporary Catholic Magisterium is also emphasized in another strong statement from *Aeterni Patris*:

> domestic and civil society even, which, as all see, is exposed to great danger from this plague of perverse opinions, would certainly enjoy a far more peaceful and secure existence if a more wholesome doctrine were taught in the universities and high schools-one more in conformity with the teaching of the Church, such as is contained in the works of Thomas Aquinas.[57]

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53 *Sum. Theol.*, II, q.2, a.2.

54 Pope Leo XIII, *Encyclical Letter On the Restoration of Christian Philosophy Aeterni Patris* (Boston, MA: Daughters of St. Paul, 1979).

55 Ibidem, no. 17.

56 Ibidem.

57 Pope Leo XIII, *Encyclical Letter On the Restoration of Christian Philosophy Aeterni Patris* (Boston, MA: Daughters of St. Paul, 1979), no. 28.

Because of the prominent influence of Thomistic thought on contemporary Church teaching, it is crucial to examine how Aquinas understood human beings with physical and intellectual disabilities.

3.3.1. Intelligibility and goodness

Clarke emphasizes that two basic principles lie at the foundation of the entire Thomistic vision of the universe: namely, the intelligibility and the goodness of being.[58] Consequently, all spirits, including the human spirit, are "intrinsically oriented by [their] very nature toward being, i.e., [they] have a natural aptitude and drive to know all being (being as intelligible) and to be fulfilled by it (being as good)."[59] Being itself also possesses an intrinsic disposition to unveil itself to the mind and to fulfill the spirit's drive toward its own self-perfection. This allows for the "unfolding of the entire intellectual life in all its forms, including the whole enterprise of science, and the entire practical and moral life in the human search for happiness."[60]

The ideas that being is intelligible and good in itself are the two main pillars upon which the entire Thomistic understanding of the world and humanity is built. Clarke calls these two pillars "the secret dynamo" energizing the entire movement of Thomistic thought.

It is important to remember that St. Thomas framed his vision of the universe—and of the human beings within it—as a theologian who drew from Christian Revelation. Accordingly, he grounded his reflections in the doctrine of the creation of all things by God as *Logos*. Thus, all being is intelligible because "the Source of all being is identically both the fullness of being and the fullness of intelligence, and all other beings proceed from God by an act of free creative intelligence and love."[61]

Aquinas explains the goodness of being in a similar way. His conception of being carries two important characteristics. The first, as Clarke points out, is "its uncompromisingly existential character," and the second is "the close link of action with being, so that action flows naturally from

58 William Norris Clarke, *Explorations in Metaphysics: Being, God, Person* (Notre Dame, IN: University of Notre Dame Press, 2008), p. 3.

59 Ibidem.

60 Ibidem, p. 4.

61 Ibidem.

any actually existing being."[62] For St. Thomas, the constitutive structure of real being is a synthesis of essence as the determining mode and the act of existence (*esse*) as the central core of perfection in every being.

Aquinas emphasized the act of existence as the ultimate intrinsic principle of perfection in every being, and writes "*de causis dicitur, prima rerum creatarum est esse*" ("the first of all created things is the act of existence").[63] This emphasis on *esse* marked a completely new approach in the field of metaphysics and deviated from traditional Aristotelian views that focused more on being in terms of substance, form, matter, change, and efficient and final causes.[64]

St. Thomas' approach to being had a profound influence on later Christian theology, philosophy, and especially anthropology. As Clarke aptly points out:

> for the first time, the fact of actual existence as immanent act and perfection is formally and technically integrated into the metaphysical analysis of the constitutive structure of being—being thereby "unveiled" as constituting the very root of all the ontological perfection within a being, including its intelligibility.[65]

In short, through his existential conception of being, St. Thomas understands action as the natural self-manifestation of being—both of its presence (*existence*) and its mode of presence (*essence*).[66] Accordingly, he often reminds us that *agere sequitur esse* ("action follows being"). For Aquinas, real being is conceived as a dynamic inner act of presence. Moreover, this presence possesses natural aptitudes and tendencies to realize activity proportionate to its innate nature.[67] Every act, says St. Thomas, is naturally communicative of its own perfection, according to the degree to which it is enacted, as "it is in the nature of every actuality to communicate itself as far as it is possible."[68]

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62 Ibidem, p. 5.

63 *De Veritate*, q. 1, art. 1, ad 3. Thomas Aquinas, *Quaestiones disputatae de veritate.* English, accessed October 15, 2020, https://isidore.co/aquinas/QDdeVer1.htm.

64 Clarke, 2008, p. 6.

65 Ibidem, p. 7.

66 Ibidem.

67 Ibidem, p. 8

68 *De Potentia*, q. 2, art. 1.

3.3.2. Aquinas and the question of personhood

Another important element of St. Thomas' reflection on being is the question of personhood. As previously mentioned, Aquinas, in the context of his reflections on the "divine persons," endorses Boethius's definition of *person* when he writes:

> person signifies what is most perfect in all nature—that is, a subsistent individual of a rational nature. Hence, since everything that is perfect must be attributed to God, for as much as His essence contains every perfection, this name "person" is fittingly applied to God; not, however, as it is applied to creatures, but in a more excellent way; as other names also, which, while giving them to creatures, we attribute to God; as we showed above when treating of the names of God.[69]

St. Thomas holds that personhood is not just a peculiar mode of being added externally. Rather, it is a natural state of perfection to which being aspires, unless prevented by circumstances which might fragment its act of presence into parts external to one another.[70] Consequently, drawing on insights from Karl Rahner, Clarke observes:

> the fullness of being, which is act of presence, is of its very nature personal, or self-possessing presence, and the nature of the person, on its side, is nothing else than to be an active self-possessing presence, present both to itself and to others-to the whole world, in fact, if its act of presence is intense enough.[71]

Although Aquinas introduced a new way of understanding being as intrinsically self-communicative and relational through action, he never explicitly applied this thematized concept to his philosophical notion of the person.[72] Clarke suggests that this may be due to the fact that other, more pressing controversies, especially Trinitarian and Christological disputes, absorbed his attention. The extensive efforts of 13th-century theologians to articulate the two central Christian doctrines of God's Triune nature and Christ as the God-man resulted in a situation in which "discussions of the metaphysics of personhood tended to get fixated

69 *Summa Theologica*, I, q. 29, a. 3.
70 Clarke, 2008, p. 15.
71 Ibidem, p. 17.
72 Ibidem, p. 211.

on the technical problems of the 'incommunicability' of the person, i.e., what makes it distinct in some way from the rational nature which always accompanies it."[73]

As a result of this theologically-oriented approach to questions of human nature, the relational and self-communicative dimensions of personhood remained relatively underdeveloped for many centuries. Aquinas's limited attention to these relational aspects, coupled with his emphasis on *ratio*-informed logic as the primary means by which human beings realize the *imago Dei*, has significantly influenced how the contemporary Catholic Magisterium perceives human personhood—especially in relation to persons with profound intellectual disabilities.[74]

St. Thomas's relational insight had to wait until the advent of personalist phenomenology in the 20th century, which renewed interest in the relational and interpersonal dimensions of the human person. Among the scholars working within this new framework was the Polish priest and philosopher Karol Wojtyła (later Pope John Paul II), who considered the nature of the human being through the dynamics of interpersonal relationship in his *Theology of the Body*.

In many ways, the work of John Paul II (JPII) can be seen as a "creative completion" of St. Thomas's anthropology. Later sections of this study are devoted to a more in-depth examination of that contribution, but first we must complete the present exploration of Aquinas's relational notion of being.

For Cardinal Joseph Ratzinger (later Pope Benedict XVI), the distinct lack of development of a relational notion of human personhood in Christian philosophy represents a serious shortcoming that he attributes to St. Thomas and other Scholastic thinkers. Instead of taking the opportunity to create updated or at least more fully integrated modalities of thought, they simply upheld the traditional Boethian definition of the person as "an individual substance of a rational nature." Ratzinger comments that St. Thomas failed to recognize that in the relational dynamic of personhood, as developed within Trinitarian theology,

73 Ibidem.
74 Ibidem.

> lies a concealed revolution in man's view of the world: the undivided sway of thinking in terms of substance is ended; relation is discovered as an equally valid primordial mode of reality... and it is made apparent how being that truly understands itself grasps at the same time that in its self-being it does not belong to itself; that it only comes to itself by moving away from itself and finding its way back as relatedness to its true primordial state.[75]

Another possible reason why Aquinas's understanding of the human being never took on a distinctly relational character was his personal view of what constitutes the perfection of being.[76] St. Thomas emphasizes that "every substance exists for the sake of its operations"[77] and that "each and every thing shows forth that it exists for the sake of its operation; indeed, operation is the ultimate perfection of each thing."[78] Consequently, in every being—including the human being—there is an innate dynamism that seeks to pour into self-expression its own perfections through its operational capacities. The perfection of being manifests itself in relation to its ultimate goal—its *telos*—as St. Thomas asserts that:

> the ultimate end of man, and of every intellectual substance, is called felicity or happiness, because this is what every intellectual substance desires as an ultimate end, and for its sake alone. Therefore, the ultimate happiness and felicity of every intellectual substance is to know God.[79]

Aquinas also explains the relationship between this teleological impulse and the act of knowing God. He says that:

> since all creatures are ordered to God as to an ultimate end, all achieve this end to the extent that they participate somewhat in His likeness. Intellectual creatures attain it in a special way, that is, through their proper operation of understanding Him. Hence, this must be the end of the intellectual creature, namely, to understand God.[80]

In these excerpts from St. Thomas's account of the human being and its innate capacity for self-expression through reason and will, the relational

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75 Joseph Ratzinger, *Introduction to Christianity* (New York: Herder and Herder, 1970), p. 132.
76 Clarke, 2008, p. 213.
77 *ST*, I, q. 19, a. 2.
78 *ST*, I, q. 105, a. 5.
79 *Summa contra Gentiles*, III, ch. 24.
80 *SG*, I, ch. 26.

character of personhood remains notably absent. In order to complete a fuller picture of Aquinas's understanding of the human being, the next section will explore his view of human disability.

3.3.3. Aquinas and the reality of *amentia*

Aquinas did not write any treatises specifically focused on issues of human disability. Although disabilities, illnesses, and other pathologies are inevitable aspects of human life, he never connects these conditions with his concept of the human being as created *imago Dei*—in the image and likeness of the Triune God. Instead, it appears that, for Thomas, bodily infirmity and illness exist only as a consequence of original sin, resulting from the disobedience of our first parents. St. Thomas states that "bodily ills properly result from original sin, which took away original justice."[81]

According to Aquinas, the human creature lived in a state of graced intimacy with God before the Fall. One privilege of this state was that God's grace "overflowed" from the soul into the body.[82] A physical result of this overflow of grace, as Aquinas understands it, was the inability of human beings to suffer bodily infirmities.[83] After their first act of disobedience, however, humanity was deprived of this supernatural grace, and the human body entered a state of disorder in relation to the soul. As a result, the human body no longer operated according to its grace-elevated nature and became susceptible to damage, dysfunction, and decay as a direct consequence.[84] In all such instances of infirmity, Aquinas asserts that a certain good is lacking and that these conditions can rightly be understood as *malum*, or evil.[85]

However, he does distinguish between *malum poenae* ("affliction" or "evil suffered") and *malum culpae* ("evil of fault"), which Miguel J. Romero roughly equates with contemporary notions of "natural evil" and "moral evil."[86] When St. Thomas speaks of bodily infirmity as *malum*, he also makes it

81 *De Malo*, 5.4.

82 *DM*, 5.1.

83 Miguel J. Romero, "Aquinas on the Coporis Infirmitas: Broken Flesh and the Grammar of Grace," in *Disability in the Christian Tradition* (Grand Rapids, MI: Wm. B. Erdmans Publishing Co., 2012), pp. 101–152, p. 107.

84 *ST*, I, q. 81, a. 1.

85 *ST*, I, q. 14, a. 2.

86 Romero, 2012, p. 107.

clear that this evil does not signify any actual being or form of creaturely existence. Rather, it should be understood as a "parasitic reality" imposed upon a more determinative good.[87]

Consequently, Aquinas argues that to suffer bodily infirmity is to experience evil, but he firmly rejects the notion that the afflicted person becomes inherently "defective." This distinction is essential in light of the aforementioned tendency to view profoundly disabled people as occupying a secondary category of existence—or, as Romero terms it, an "anthropological minor-league."[88] Still, the ways in which Aquinas appears to describe the reality of mental disability, along with his pastoral advice regarding this group, may give rise to legitimate concerns. Of particular relevance to this work is the possibility that his perspective might justify discriminatory practices, such as withholding the Sacrament of the Eucharist from profoundly intellectually disabled children.

In his work, St. Thomas identifies a variety of conditions analogous to what we today would likely refer to as mental illness. Romero lists several such conditions described by Thomas, such as mindlessness (*amentia*), violently disposed madness (*furor*), generally unhealthy states of mind (*insanes*), unusual alienation from faculties considered crucial for normal cognition (*alienates a mente*), arrested mind (*captus mentis*), and so on.[89] St. Thomas also refers to persons who seem to completely lack mental capacity as "half-wits" and "fools," stating that "the majority of men have sufficient knowledge for the guidance of life, and those who have not this knowledge are said to be half-witted or foolish."[90] Despite this, Aquinas distinguishes between culpable foolishness and natural foolishness as he refers specifically to the condition of lacking the use of reason (*amentia*) and the person who is affected by it (*amens*).[91]

The children from the Kraków children's hospice whom I prepared for the Sacrament of the Eucharist were *amens*. According to his understanding, St. Thomas regards *amentia* as a bodily infirmity in which the powers necessary for the operation of reason are diminished and thus fail

87 *ST*, I, q. 49, a. 3.
88 Romero, 2012, p. 109.
89 Ibidem, p. 111.
90 ST, I, q. 23. a. 7.
91 ST, II, q. 44. a. 5.

to cooperate properly with the immaterial intellect in carrying out the act of understanding. Accordingly, Aquinas writes:

> just as bodily blindness is the privation of the principle of bodily sight, so blindness of mind is the privation of the principle of mental or intellectual sight. Now this has a threefold principle. One is the light of natural reason, which light, since it pertains to the species of the rational soul, is never forfeited from the soul, and yet, at times, it is prevented from exercising its proper act, through being hindered by the lower powers which the human intellect needs in order to understand—for instance, in the case of imbeciles and madmen.[92]

To be clear, St. Thomas believes that *amentia* cannot negate the active image of God in human persons or their participation in the supernatural life. He also maintains that this physical condition cannot prevent a human being from responding to God's grace or from achieving their ultimate good: knowing and loving God. As such, it should be acknowledged that these views actually cast his perception of the profoundly intellectually disabled in a rather positive light. However, it is when St. Thomas discusses the sacramental life of the Church, particularly aspects of the Eucharist, that he introduces certain remarks which seem to conflict with this otherwise positive outlook. Aquinas recognizes that God can and does objectively communicate with the human being—including *amens* in the sacramental life of the Church.[93] People with intellectual disabilities still participate in the divine nature through their membership in and participation in the Body of Christ.[94] This participation begins with the Sacrament of Baptism.

For St. Thomas, the effects of baptism are twofold. First, baptism restores harmony in the relationship between the human being and God.[95] Second, it acts as a conduit for the distribution of supernatural grace and virtue.[96] Consequently, Aquinas insists that "imbeciles (*amentes*) who never had, and have not now, the use of reason, are baptized, according to the Church's intention, just as, according to the Church's ritual they believe and repent."[97]

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92 ST, II, q. 15. a. 1.
93 *ST*, II, q. 45. a. 5, *De Veritate*, q. 11. a. 3.
94 *ST*, III, q. 73. a. 3.
95 *ST*, III, q. 69. a. 1–2.
96 *ST*, III, q. 69. a. 4–5.
97 *ST*, III, q. 68. a. 12.

Romero points out that St. Thomas presupposes that grace makes possible a supernatural life through infused virtue that operates independently of one's bodily condition and corresponding level of self-consciousness, as might be the case with profoundly intellectually disabled persons.[98]

In a manner similar to his treatment of the Sacrament of Baptism, Aquinas dedicated an entire article to the issue of the Eucharist and "those who lack the use of reason," in which he addressed the objection that those who "lack the use of reason" should not receive the Eucharist.[99] In his response, Aquinas introduced a distinction between those who are said to absolutely never have had the use of reason (*amens in principle*) and those who seem to lack it in various ways and to differing degrees (*amens in fact*).[100]

The first group, the *amens in principle*, includes those who have absolutely never had the use of reason at any point since birth. Of these, St. Thomas asserts that even if they are baptized, they should not receive the Eucharist.[101] The rationale behind Aquinas' position is the "impossibility" of the *amens* to exercise proper devotion toward the Sacrament. St. Thomas explains it in this way:

> in another way men are said not to possess fully the use of reason. Either, then, they never had the use of reason, and have remained so from birth; and in that case this sacrament [Eucharist] is not to be given to them, because in no way has there been any preceding devotion towards the sacrament.[102]

According to Catholic teaching, it is important that one have the proper disposition before receiving Holy Communion, as those who consume the Eucharist without devotion or reverence for the real presence of Christ do so to their own condemnation.[103] Proper devotion, according to Aquinas, consists in surrendering oneself to the service of God through the interior act of conscious attention on God, known as adoration.[104]

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98 Romero, 2012, p. 115.
99 *ST*, III, q. 80. a. 9.
100 Romero, 2012, p. 116.
101 *ST*, III, q. 80. a. 9.
102 Ibidem.
103 *ST*, III, q. 80. a. 4; 1 Cor. 11:29.
104 *ST*, II, q. 84. a. 2.

In the act of adoration, the person is required to exercise two critical faculties: reason and will. A person must be able to recognize the real presence of Christ in the consecrated bread by means of reason and, subsequently, must freely desire to receive this gift with their whole heart through the exercise of the will. These specific conditions, as mentioned earlier, are still upheld in Catholic sacramental manuals, which exhort priests to ensure that children possess sufficient reason to distinguish between ordinary bread and the Body of Christ before they are permitted to receive their First Communion.

It should be noted that St. Thomas does not exclude all persons with intellectual disabilities from receiving the Sacrament of the Eucharist. His position permits those who "were not always devoid of reason" to receive the sacrament because, as he states, "those lacking the use of reason can have devotion toward the sacrament."[105] Accordingly, Aquinas only opposed giving the sacrament to those who have never possessed the use of reason (*amentibus qui nunquam habuerunt usum rationis.*[106] This distinction—although perhaps unintended by Aquinas—could potentially result in what Hans S. Reinders refers to as a "hierarchy of disability," in which the most profoundly intellectually disabled children are the most vulnerable to discrimination and exclusion, even within the Catholic Church.

A distinction between those who have never (*nunquam*) had the use of reason and those who once had it should be irrelevant in determining who is eligible for full integration into ecclesial life. If such a distinction is maintained, a *ratio*-informed anthropology takes precedence over the logic of human relationship that underlies the human experience of bodily infirmity and disability. Consequently, although Aquinas's work yields profound insights into the human being as self-communicative and relational through action, he also strongly emphasized the importance of intelligibility as manifested through the faculties of reason and will. This emphasis, reinforced over the centuries, has contributed to discriminatory sacramental practices within the Catholic Church, such as the denial of the Eucharist and Confirmation to profoundly intellectually disabled children.

105 *ST*, III, q. 80. a. 9.
106 Ibidem.

3.4. Contemporary voice of *ratio*-informed dynamic

Some influential contemporary Catholic thinkers subscribe to this Thomistic understanding of the human being. A prominent example is the German philosopher Robert Spaemann, who seems to uphold the *ratio*-informed model of anthropology. His understanding of the human person is based on the "teleological axiom," which he explains as follows:

> we know fully what something is only when we know what it is in its final perfection. This is true, at least, for human beings. We know fully what a human being is only when we know what he is called to be. This axiom is diametrically opposed to the axiom which dominates our scientific culture, and which say: what something is, and therefore also what the human being is, we understand when we know what it is made of and how it came to be.[107]

Spaemann argues that the life of human persons reveals the very meaning of life itself, which is the capacity of transcending oneself and aspiring to be "higher than other beings living on the earth."[108] As self-transcending beings, human persons occupy the highest place in the hierarchical order of creation because they are capable of ordering nature according to reason. Additionally, Spaemann notes:

> to be capable of truth constitutes the dignity of the human person. Only truth liberates man from being trapped in himself, from the inverted centeredness in oneself characteristic of all not-personal living beings. By their actions, human beings are capable to do justice to the things as they are; i.e., they are able to transcend themselves. Self-surrender, self-transcendence, and that is to say: love, is the highest form of life. In this human being realize themselves as persons.[109]

Spaemann's vision of human beings as the "highest form of life," perfected through rational capability, presents certain difficulties when we consider people with profound intellectual disabilities. The condition

107 Robert Spaemann, "On the Anthropology of the Encyclical «Evangelium Vitae»," in *Evangelium Vitae: Five Years of Confrontation with the Society: Proceedings of the Sixth Assembly of the Pontifical Academy for Life: Vatican City, 11–14 February 2000* (Città del Vaticano: Libreria Editrice Vaticana, 2001), p. 129.

108 Ibidem, p. 134.

109 Ibidem.

of human disability, Spaemann explains, differs significantly from animal infirmity. He writes: "The severely disabled are not, as animals are, at one with their nature, their mode of existence. They 'have' a nature; but because their nature is imperfectly realized, so is their way of having it."[110]

In other words, a human being can never be called defective per se, but only in the way they possess human nature. Although this statement seems to maintain the distinction between the person and their predicates, it raises further questions about the grounding of human nature in general. Spaemann takes the position that what makes human nature unique and distinct from other forms of life is its "practical and theoretical intentionality."[111]

In supporting this view, he appears to deviate from a traditional Christian anthropological axiom that originated with Aristotle and was reinforced by St. Thomas: that "men are born from men." Spaemann explains his position by proposing a thought experiment:

> let us imagine a creature born to human parents but very unlike other human beings. Let us suppose its conduct gives no suggestion of any kind of mutually reinforcing practical and theoretical intentionality. Let us conceive, furthermore, that this creature seems quite healthy, moving through the world normally and functioning as an animal equipped with all those instincts for survival that mankind characteristically lacks. It stands in need of no external assistance to survive. It is uninterested in, and of course incapable of, communicating with other human beings. Since it shows no signs of sickness, such a creature will inevitably present the appearance of a new and hitherto unknown variety of animal. It will not be a person, will not belong to the human race.[112]

From this excerpt, we clearly see the importance that intentionality plays in recognizing a nature as human nature. Spaemann concludes his reflection by emphasizing that the "severely disabled are different"[113] because they belong to the human race and "participate in the community of persons simply as recipients of physical and moral support."[114] But why, then, do the disabled belong to the human race? Is it because they were born to human parents, or because they are capable of intentionality? The

110 Ibidem.
111 Ibidem.
112 Spaemann, 2017, p. 244.
113 Ibidem.
114 Ibidem, p. 245.

latter seems to correlate with Spaemann's logic. Following this line of reasoning, it becomes difficult to avoid the conclusion that an overemphasis on the human faculties of reason and will in defining human nature will eventually lead to reinforcement of the hierarchy of disability.

However, Spaemann seems not to share this concern. He strongly opposes any marginalization or discrimination of disabled people. Moreover, he believes that disabled people give more than they receive. Their contribution, he writes, is "bringing to light the deepest meaning of a community of persons."[115] According to Spaemann, a disabled person may lack certain personal properties, and "it is by lacking them that they constitute the paradigm for a human community of recognizing selves, rather than simply valuing useful or attractive properties."[116] Disabled people "evoke the best in human beings; they evoke the true ground of human self-respect. So, what they give to humanity in this way—by the demands they make upon it—is more than what they receive."[117] Although I agree with this sentiment, I feel that Spaemann's message of appreciation for the lives of disabled persons would be more compelling and consistent if it were grounded more in the relational logic of human existence, rather than in the actualization of the rational soul.

The parents of Adam, whom I introduced at the beginning of this book, were in need of a meaningful narrative to help them make sense of their son's profound disability—a narrative to guide them as they took the first steps in understanding an immensely difficult situation. A narrative that would assure them that their severely intellectually impaired son was not a "manifestation of natural evil" or a "defect of nature."[118] A narrative that would give them confidence that their son would be fully valued and welcomed by both their human and ecclesial families. I sincerely doubt that Spaemann's thought experiment of a creature born to human parents while lacking intentionality would offer any comfort to Adam's parents or would give them the courage and strength to welcome this most vulnerable life into the world.

115 Ibidem.
116 Ibidem.
117 Ibidem, p. 246.
118 Reinders, 2008, p. 119.

In fact, I think it is quite possible that the opposite could be true. An intense focus on the human faculties of reason and will—and the decisive role of intentionality in drawing distinctions between legitimate human personhood and mere animal nature—might only add to the already significant burden that Adam's parents were facing. Might this continual emphasis on "practical and theoretical intentionality" lead them to think along the following lines: "If only our son had some mental capacity, wouldn't his entire situation be different? He could be definitively recognized, without a shred of doubt or hesitation, as a person. But since he's anencephalic, the possibility of recognition, appreciation, or integration into the community of human beings is riddled with uncertainty for him."

Is this not a stark example of what Hans R. Reinders calls the "hierarchy of disability"? Is this not a situation in which people with profound intellectual disabilities represent the lowest and most vulnerable group of the human race? From this standpoint, Spaemann's claim that severely disabled people give more than they receive should be supported by a *relatio*-informed anthropology rather than one based solely on ratio, which focuses only on the actualization and perfection of the higher faculties of reason and will. As Reinders aptly points out, "If it is true that human beings do not lose their dignity even when their capacities for reason and will are undeveloped, then it cannot be true that the perfection of these capacities is the ultimate ground for that dignity."[119]

3.5. A critique of *ratio*-informed perspective

Several Christian disability theologians have recently voiced criticism of *ratio*-informed perspectives on human disability.[120] Like Thomas Reynolds, they emphasize that disability is not inevitably the result of sin

119 Ibidem, p. 100.

120 Elizabeth L. Antus, "Disability at the Heart of Theology: On Marginality, Method, and Overcoming 'Best-Case Anthropologies,'" *Journal of Religion, Disability & Health* 17, no. 3 (2013): pp. 244–262, https://doi.org/10.1080/15228967.2013.809879; Molly Claire Haslam, *A Constructive Theology of Intellectual Disability: Human Being as Mutuality and Response* (New York: Fordham University Press, 2012), Thomas E. Reynolds, *Vulnerable Communion: a Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008).

or something unequivocally evil, but rather something capable of reflecting God's desire for diversity in all of creation.[121] Although this stance seems to challenge Aquinas's traditional perspective on bodily infirmity, I will attempt to demonstrate in later sections that it shares a common vision with the teachings of JPII.

Additionally, these scholars assert that Church teaching can take on an oppressive character toward intellectually disabled people. As such, they argue for the formulation of an entirely new anthropological paradigm—one that would be truly inclusive of all people and not leave the profoundly intellectually impaired at the margins of ecclesial and social life. To this end, Elizabeth L. Antus proposes adopting a disability theology-based anthropology that begins with the embodied experiences of disabled persons and seek to accommodate them. This new perspective stands in contrast to the current model, which simply incorporates people with disabilities into a pre-existing anthropology.[122] She also contends that attempting to "fit" disabled people into this pre-existing "definition of humanity" still leads to the conclusion that "even people with disabilities can still be considered fully human."[123]

According to Antus, the problem with the current perspective on human disability in the Catholic Magisterium is that it upholds a kind of discriminatory and exclusivist mentality in which disabled life, especially that which is profoundly intellectually impaired, is viewed as occupying the lowest rung on the ladder of human capability.[124] In contrast, the top of this ladder is reserved for those who possess the highest-functioning faculties of reason and will. Molly Haslam, another disability theologian, argues that human beings should be defined not by the primacy of reason (understood as the capacity for intellectual faculties and verbal communication), but by their capacity for relationship. This perspective signals a new and essential direction for understanding the nature of the human being, especially for those affected by severe impairment.

121 Thomas E. Reynolds, *Vulnerable Communion: a Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), pp. 59–63.

122 Antus, 2013, p. 245.

123 Ibidem.

124 Ibidem, p. 250.

In addition, Haslam's perspective aligns with the theological intuition of JPII, which I will explore in greater detail in the next chapter. For Haslam, the human being is essentially a relational being, manifested through active engagement in mutual responsiveness with another subject. She refuses to define human persons by their abilities, including the capacity to use concepts or make free choices.[125] However, Haslam acknowledges that her concept is essentialist to a certain degree, as it assumes a specific capacity for responsiveness inherent in the human being. As mentioned, Haslam's project converges with JPII's own theological anthropology, although the Pope's *relatio*-informed perspective on the human person is built upon a biblical foundation rather than a psycho-sociological one. I will address these issues in greater detail in subsequent sections.

The views expressed by contemporary disability theologians are a clear indication of the need for a new way of looking at disabled human beings within the Catholic Church. There is also a need for a new language to describe the reality of those experiencing profound intellectual disability. In addition, there is a deep need to create a welcoming and appreciative space for these individuals within the Church. I am convinced that these needs are felt by Catholic healthcare institutions that minister to people with various disabilities, especially perinatal hospice care centers.

A renewed approach to human disability is also necessary to confront what JPII calls, in his encyclical *Evangelium Vitae*, a "culture of death."[126] This phrase refers in particular to the acceptance of abortion and euthanasia as legitimate medical practices in many Western countries. Consequently, JPII argues that a new vision of the human person must be hinged upon the "Gospel of Life," a gospel according to which Christ has come so that we may have life, and have it abundantly."[127] The Pope also reminds us in this document that the mystery of the human being resides in the mystery of the incarnate God. Accordingly, human beings are not just biologically living organisms; they are called to the "fullness of Life" by "sharing the very life of God."[128]

125 Molly Claire Haslam, *A Constructive Theology of Intellectual Disability: Human Being as Mutuality and Response* (New York: Fordham University Press, 2012), p. 53.

126 John Paul, *Encyclical Letter Evangelium Vitae* (Vatican City: Libreria Editrice Vaticana, 1995).

127 Ibidem, p. 4.

128 Ibidem.

This eschatological perspective is also fundamental to understanding the reality of human disability. The papal document clearly states that human life is a unified composite of both temporal and eschatological existence, which, "unexpectedly and undeservedly, is enlightened by the promise and renewed by the gift of divine life."[129] This theological explanation sheds new and important light on the issue of undeveloped human capacities, particularly if the ultimate end of human life is not dependent on these capacities but is, in fact, simply a gift. The "holy innocents," whose capacities for reason and will remain undeveloped, are perhaps the least likely to "underserve" the gift of God, since they cannot misuse these capacities to do evil.[130]

Consequently, the Pope's perspective on human disability makes it clear that fulfilling the ultimate end of being human is God's gift. This means, as Reinders notes, "that human fulfillment is ecstatic, that is, 'from elsewhere'—namely, from God the Father, which is the same as saying that the final destiny of being human is not of our making."[131] The unique modality of JPII's understanding of bodily infirmity and disability is deeply shaped by a biblical perspective which sees human life as an unconditional gift from God, intended to culminate in eternal happiness in the Heavenly Kingdom. A full understanding of the redemption of human beings, including their bodily weaknesses and disabilities, becomes possible only through the self-sacrificial offering of Jesus Christ. Consequently, JPII's anthropology is fundamentally both eschatological and Christological; only through these two lenses can the relational character of human nature be fully and adequately understood.

3.6. Conclusion

The Magisterium of the Catholic Church, which is definitively oriented toward the protection of human life and emphasizes its sanctity from conception until natural death, evinces certain internal tensions and inconsistencies

129 Ibidem.
130 Ibidem.
131 Reinders, 2008, p. 115.

in its pastoral and sacramental policies concerning people with profound intellectual disabilities. As Maliszewska argues, "While asserting the humanity of persons with intellectual disability, at the same time the Catholic Church defines the essence of humanity through categories incongruous with the actual capacities and abilities of the persons in question."[132]

By upholding this type of perspective, the Catholic Magisterium overemphasizes a single dimension of human uniqueness, namely, the *telos*-oriented view in which ultimate fulfillment and happiness depend on the actualized agency of reason and will. In other words, the problem lies, in my opinion, in the ways that the Catholic Magisterium, often unintentionally, embraces a *ratio*-informed anthropology. The consequences of such a paradigm are grave and particularly troubling. The lack of robust appreciation and recognition for people with profound intellectual disabilities—and their potential marginalization through discriminatory sacramental and pastoral practices—appears to stem from an overemphasis on the human faculties of reason and will. While the Magisterium of the Catholic Church, following Aquinas' teaching, does promise the future perfection of impaired human bodies in the Eschaton,[133] in the "present time" the profoundly intellectually disabled face many obstacles and restrictions to full recognition and integration in the ecclesial community.

An unfortunate example of this reality, still present in the Roman Catholic Church, is the practice of restricting severely intellectually disabled children from receiving the Sacraments of the Eucharist and Confirmation. Accordingly, although baptized, children with profound intellectual disabilities are often not granted full access to the ecclesial community through reception of the other Sacraments of Christian Initiation, namely, the Eucharist and Confirmation. Consequently, these children live a suspended existence, somewhere between inclusion and exclusion from the ecclesial community. Such a situation represents a clear example of what might be described as a state of quasi-*Limbo Puerorum*.

Overemphasizing the faculties of reason and will while neglecting the *genesis* dimension is, as Schockenhoff argues, the root of this anthropological

132 Maliszewska, 2018, p. 24.

133 Bryan R. Cross, "A Thomistic, Non-Ableist Conception of Impairment and Disability," *The National Catholic Bioethics Quarterly* 20, no. 2 (2020): p. 240.

ambiguity in the Catholic Magisterium. I believe that this diagnosis is legitimate, even while recognizing that it does not fully capture the entire picture of the Catholic perspective on the human person. I am, therefore, convinced that there is another, better source of anthropological reflection within the Catholic Magisterium. The promotion of a different, more relationship-informed perspective could bring a healthier balance to our understanding of human nature.

Additionally, this alternative source of anthropological reflection could facilitate a fresh perspective on instances of human disability and bodily infirmity. As previously mentioned, my search for a proper anthropology—one that is inclusive of and appreciative toward intellectually disabled life, especially unborn children, and capable of providing support for perinatal hospice care teams and families—involves drawing on the works of JPII.

In the upcoming chapter, I will focus on JPII's writings that are dedicated to human disability, as well as his *Theology of the Body*, while attempting to demonstrate how the human being is biblically understood and situated within an eschatological and Christological context that emphasizes relational character. Furthermore, I will argue that this *relatio*-informed anthropology addresses the need for a proper understanding of profoundly intellectually disabled life and provides sufficient ground for both its appreciation and inclusion within the human and ecclesial communities. I will finally argue that the anthropology upheld by JPII creates a proper space for receiving and responding to the profound, unique desires of perinatal hospice parents, such as Adam's, to be fully recognized as loving guardians of their unborn children.

CHAPTER FOUR

JOHN PAUL II AND *RELATIO*-INFORMED ANTHROPOLOGY

Since the pontificate of John Paul II, the Magisterium of the Catholic Church has increasingly spoken out on behalf of persons with intellectual disabilities. This should come as no surprise to those familiar with Karol Wojtyła's (later Pope John Paul II) philosophical works. As a professor of ethics at the Catholic University of Lublin (KUL), he passionately worked on a synthesis of traditional Thomistic teaching with the personalism of German phenomenologist Max Scheler.

The result of these efforts was a unique approach to Thomas's philosophy known as "phenomenological Thomism" or "Thomistic personalism."[1] This distinctly personalist perspective is noticeably present throughout Wojtyła's academic work and later in his papacy. In particular, his emphasis on the uniqueness and mystery of the human person—especially in the context of bodily infirmity and disability—was a central element of his teaching. In addition to his academic contributions, his personal example speaks volumes about his reverence for the dignity of human life, regardless of physical or mental condition.

The final years of JPII's life were indelibly touched by the progression of Parkinson's disease. The world will long remember the image of the greatly fatigued Pope during the *Agnus Dei* prayer on Palm Sunday in 2005, just two weeks before his death on April 2. He was too weak to address the crowds that gathered in St. Peter's Square in Vatican City and was only able to quietly stand at the window of his library and gently wave. This was the image not only of a body slowly ravaged by a relentless disease, but also of incredible spiritual strength and eschatological hope.

1 George Weigel, *Witness To Hope: the Biography of Pope John Paul II* (New York: Harper Perennial, 2020), p. 23.

On the First Annual World Day of the Sick, on October 21, 1992, JPII declared that "pain and illness are great mysteries," and that "in the light of Christ's death and resurrection, illness no longer appears as an exclusively negative event; rather, it is seen as a visit by God, an opportunity to release love, in order to give birth to works of love towards the neighbor, in order to transform the whole of human civilization into a civilization of love.[2]" As he sat by his library window that Palm Sunday, these sentiments were expressed without the need for words.

4.1. Human disability and the voice of JPII

Questions of suffering, pain, and illness were central to JPII's dialogue with a contemporary Western civilization that had embraced a "culture of death"[3] in which practices such as euthanasia and abortion had become normalized. This "culture of death" asserts that human weaknesses of body and mind manifested through various illnesses and disabilities, are entirely unacceptable and should be eradicated by any means necessary, including the termination of life.

For JPII, a proper understanding of bodily infirmities and disabilities presupposes a robust and coherent anthropology. Without a proper understanding of the human person, it is impossible to construct a meaningful narrative through which to approach the reality of illness or disability.

This chapter will begin by presenting JPII's views on bodily infirmity and disability, as found in various papal texts. Each of these reflects his unique vision of the human person and encourages further reflection on the meaning of bodily weakness. They also contain a specific moral appeal: to deepen respect, acceptance, and appreciation for people with various forms of disabilities, especially for profoundly intellectually disabled unborn children, such as Adam, who hold a privileged place in this vision.

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2 John Paul II, *I World Day of the Sick*, 1993, accessed November 10, 2020, http://www.vatican.va/content/john-paul-ii/en/messages/sick/documents/hf_jp-ii_mes_21101992_world-day-of-the-sick-1993.html.

3 John Paul II, *Encyclical Letter Evangelium Vitae* (Vatican City: Libreria Editrice Vaticana, 1995), no. 12.

In the following section, I will delve into a fundamental text of JPII that focuses on discovering the deeper meaning of the human person: *Theology of the Body* (TB). This work is deeply rooted in the biblical narrative of the creation of the first human being and proposes a unique understanding of the human person through the lens of the "original triad": original solitude, original unity, and original nakedness. The Pope's description of this triad reveals a profoundly relational dynamic at the heart of human existence.

This anthropology—anchored in a reflection on original solitude, unity, and nakedness—makes evident the radically relational character of human life. According to the vision presented in *Theology of the Body*, human beings mirror their Creator above all through their capacity for relationship, rather than—as emphasized in the *ratio*-informed dynamic—through the faculties of reason and will. In the upcoming section, I propose that JPII's *relatio*-informed anthropology offers a narrative of profound human disability that has long been awaited by perinatal hospice parents and medical professionals. Additionally, I argue that it supports the appreciation and full inclusion of disabled persons, especially profoundly intellectually disabled perinatal babies like Adam.

4.1.1. Disabled persons: one of us

JPII's writings contain numerous statements that describe people with intellectual disabilities as being equal in dignity to those who are fully intellectually able. In one particularly significant passage, we read that "the disabled are not different from other people,"[4] and that "even when disabled persons are mentally impaired or when their sensory or intellectual capacity is damaged, they are fully human beings and possess the sacred and inalienable rights that belong to every human creature."[5] Throughout these papal messages addressing the impact of bodily and mental infirmities or disabilities, there is a consistent emphasis on the inalienable dignity of the mystery of pain and suffering. This section will focus on three

4 John Paul II, *Document of the Holy See for the International Year of Disabled Persons. To All Who Work for the Disabled* (Boston: St. Paul Editions, 1981), p. 15.

5 John Paul II, *Message to the Participants International Symposium on The Dignity and Rights of the Mentally Disabled Person* (January 8, 2004).

documents from JPII that are dedicated to the subject of disability, specifically the reality of mental impairment.[6]

In one of his earliest texts—his address on the occasion of the International Year of Disabled Persons in 1981, JPII reminds us of a fundamental truth about the Christian theology on disability, saying that:

> The first principle, which is one that must be stated clearly and firmly, is that the disabled person (whether the disability be the result of a congenital handicap, chronic illness or accident, or from mental or physical deficiency, and whatever the severity of the disability) is a fully human subject, with the corresponding innate, sacred, and inviolable rights.[7]

The Pope's account is based on the firm recognition that every human being possesses a unique dignity and intrinsic worth from the moment of conception, at every stage of development, and regardless of physical condition.[8] Additionally, JPII believes that "when we are faced with a disabled person, we are impelled to approach this mystery with respect and love."[9] The proper response to this reality should be marked by an attitude of solidarity to help these people "to take their place in society in all aspects and at all levels, as far as is compatible with his or her capabilities."[10] These actions must entail creating psychological, social, familial, educational, and legislative conditions and structures that favor the proper acceptance and full development of the disabled individual.[11]

JPII's perspective on disability seems to stand in contrast to that often seen in contemporary Western culture, in which profoundly disabled individuals—especially those with mental disabilities—are subject to various forms of marginalization and discrimination. As he emphasizes,

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6 I will draw upon these three documents by JPII: (1) *Document of the Holy Farther for the International Year of Disabled Persons. To All Who Work for the Disabled.* (Boston: St. Paul Editions, 1981), (2) *The Mentally Ill Are Also Made in God's Image The Holy Father's Address*, in *In the Image and Likeness of God: Always?" Disturbances of the Human Mind* (Vatican City: Editrice VELAR, 1996), pp. 7–19, (3) *Message to the Participants International Symposium on The Dignity and Rights of the Mentally Disabled Person* (January 8, 2004).

7 John Paul II, *Document of the Holy See for the International Year of Disabled Persons. To All Who Work for the Disabled* (Boston: St. Paul Editions, 1981), no. 1.

8 Ibidem.

9 Ibidem, no. 3

10 Ibidem.

11 Ibidem.

"the quality of society and civilization is measured by the respect shown to the weakest of its members."[12] There is no doubt that one of the most vulnerable groups is represented by profoundly intellectually disabled unborn children like Adam.

The foundation for acknowledging and appreciating disabled persons, as the Pope suggests, must be grounded in the awareness that "a disabled person is one of us, a sharer in the same humanity."[13] Consequently, "by recognizing and promoting that person's dignity and rights, we are recognizing and promoting our own dignity and our own rights."[14] The tendency to exclude and marginalize disabled individuals must be overcome, as JPII proposes, through the principles of integration, normalization, and personalization.

Integration must go beyond an attitude of mere tolerance and should involve a commitment to "make the disabled person a subject in the fullest sense, in accordance with his or her capacities, in the spheres of family life, school, employment, and, more generally, in the societal, political, and religious communities."[15] The principle of normalization must be implemented by employing every available means to support the full rehabilitation of the disabled person. As for the principle of personalization, the core tenet is to always remember in all therapeutic and rehabilitative efforts, that "it is always the dignity, welfare, and total development of the handicapped person, in all his or her dimensions and physical, moral and spiritual faculties, that must be primarily considered, protected and promoted."[16]

The papal document also takes up the issue of fetal disability and strongly condemns the practice of "selective" or "eugenic" abortion. According to JPII, this practice "springs from an attitude of pseudo-humanism, which compromises the ethical order of objective values," and furthermore, "represents a breach not only of medical ethics but also of the fundamental, inalienable right to life."[17] JPII is convinced that when medicine targets life instead of disease, it loses its title of nobility. As such, selective abortion is

12 Ibidem.
13 Ibidem, no. 4.
14 Ibidem.
15 Ibidem, no. 5.
16 Ibidem.
17 Ibidem.

never the proper response to the implications of profound human disability. Instead, "the respect, the dedication, the time and means required for the care of handicapped persons, even of those whose mental faculties are gravely affected, is the price that a society should generously pay in order to remain truly human."[18]

A particularly important message in this document seems directed toward the parents of profoundly disabled unborn children like Adam. In it, JPII stresses the great importance of "the help to be offered at the moment when parents make the painful discovery that one of their children is handicapped."[19] According to JPII, the presence of early assistance and adequate support in these situations is crucial to preventing both parents and disabled unborn babies from potentially "very unfortunate consequences."[20] One can easily recognize that these papal words are highly applicable to the practice of perinatal hospice care. Although perinatal hospice care was still a new and relatively localized initiative (in Great Britain and the United States) at the time that JPII uttered these words, his insights had already outlined the future mission of such centers around the world.

Also significant in this vein is JPII's conviction that "one should not rest content with only making the diagnosis and then leaving the parents abandoned."[21] Instead, it is necessary "for families to be given great understanding and sympathy by the community and to receive from associations and public powers adequate assistance from the beginning of the discovery of the disability of one of their members."[22] This mission is fulfilled today by numerous perinatal hospice care facilities, especially those run by Catholic health care providers. The dignity of a disabled person, both from a communal and social perspective, can be strengthened by cultivating a healthy balance between giving and receiving.

Accordingly, "the disabled person must be urged not to be content with being only the subject of rights, accustomed to receiving care and solidarity from others with a merely passive attitude."[23] Rather, the opposite attitude

18 Ibidem, no. 9.
19 Ibidem.
20 Ibidem, no. 10.
21 Ibidem.
22 Ibidem.
23 Ibidem.

should be promoted through the awareness that "he is not only a receiver; he must be helped to be a giver to the full extent of his capabilities."[24] JPII indicates that a crucial element in the empowerment of disabled people is the awareness of their dignity and worth, while simultaneously recognizing that "something is expected from him, and that he, too, can and should contribute to the progress and well-being of his family and community."[25]

All of these efforts have one key goal: allowing the disabled person to see themselves as a "person capable of responsibility and able to exercise his own will and to collaborate with others."[26] The papal document (an address given on the occasion of the International Year of Disabled Persons in 1981) offers important insights into the unique dynamic of working with disabled individuals and provides valuable guidance for those who work in this field. This guidance is also applicable to the context of perinatal hospice care. Accordingly, in this document, JPII teaches that "those who commendably dedicate themselves to the service of the disabled should have scientific knowledge of their disabilities, but they should also comprehend with their hearts the person who bears the handicap."[27]

JPII also acknowledges that the reality of human disability requires care providers to learn how to be sensitive to the unique signs through which the disabled express themselves and communicate. Accordingly, "they should acquire the art of making the proper gesture and saying the right word."[28] JPII also advises that they should learn how to accept with "calmness possible reactions or forms of emotion and learn to dialogue with the parents and families of the disabled."[29]

Caring for disabled individuals also requires appropriate moral and spiritual dispositions. Particularly important in this regard are "attentiveness, sensitivity, and particular respect for everything in the human person that is a source of weakness and dependence."[30] Through all these attitudes, the care and support of disabled persons can be seen as "a school

24 Ibidem.
25 Ibidem.
26 Ibidem, no. 12.
27 Ibidem, no. 14.
28 Ibidem.
29 Ibidem, no. 16.
30 Ibidem.

of genuine humanity, a demanding school, a noble school, an uplifting school."[31] Growth in understanding the disabled person, including their dignity and rights, should foster sincere and active love for every human being in their uniqueness and concrete situation.[32]

4.1.2. A call to appreciate human uniqueness

It is important to briefly describe the ways in which JPII perceives and describes instances of human disability. He presents disability within the broader context of human individuality and acknowledges such conditions as qualities that contribute to a person's unique identity. In his address to the Symposium on the Dignity and Rights of the Mentally Disabled Person, held in Vatican City in 2004, JPII emphasized that "the diversity that is due to a person's disability can be integrated into his respective unique individuality."[33] This recognition is essential, especially for those who care for disabled individuals. In this message, JPII provides new insights not previously present in earlier documents, as this reflection focuses specifically on the dignity and rights of mentally disabled persons.

JPII explains in this message that the starting point for any reflection on disability should be rooted in the fundamental conviction of Christian anthropology that:

> even when disabled persons are mentally impaired or when their sensory or intellectual capacity is damaged, they are fully human beings and possess the sacred and inalienable rights that belong to every human creature. Indeed, human beings, independently of the conditions in which they live or of what they are able to express, have a unique dignity and special value from the very beginning of their life until the moment of natural death.[34]

Additionally, the reality of human disability—with all the limitations and suffering that "scar" disabled persons—compels all of us "to question ourselves, with respect and wisdom, to the mystery of man."[35] JPII upholds

31 Ibidem, no. 17.

32 Ibidem.

33 John Paul II, *Message to the Participants International Symposium on The Dignity and Rights of the Mentally Disabled Person* (January 8, 2004).

34 Ibidem, no. 2.

35 Ibidem.

a certain essential logic with regard to human infirmity and suffering. He recognizes that "the more we move about in the dark and unknown areas of human reality, the better we understand that it is in the more difficult and disturbing situations that the dignity and grandeur of the human being emerges."[36]

JPII also describes the reality of human disability in terms of "wounded humanity" and plainly acknowledges that "the disabled challenge us to recognize, accept and promote in each one of these brothers and sisters of ours the incomparable value of the human being created by God to be a son in the Son."[37] For some scholars, the notion of the "wounded humanity of the disabled" evokes a certain reluctance. For instance, Maliszewska expresses concern that this term might imply "that the humanity of a person with an intellectual disability is not intact but in some way compromised," and that, consequently, people with intellectual disabilities might not be perceived as being endowed with the fullness of humanity. This, in turn, could lead to their marginalization.[38]

Although this concern may be legitimate in some respects, JPII appears to dispel such doubts by emphasizing that "the disabled are not different from other people, which is why, in recognizing and promoting their dignity and rights, we recognize and promote our own dignity and rights and those of each one of us."[39] According to JPII's vision, "a society that made room only for its fully functional, completely autonomous and independent members would be unworthy of the human being."[40] In his message to the participants of the International Symposium on the Dignity and Rights of the Mentally Disabled Person, JPII unequivocally condemned any form of discrimination based on effectiveness, calling such practices "disgraceful" and comparing them to racial, gender, or religious discrimination.[41] According to JPII, "justice calls for continual and loving attention to the lives of others and a response to the special and different

36 Ibidem.

37 Ibidem, no. 3.

38 Maliszewska, 2018, p. 29.

39 John Paul II, *Message to the Participants International Symposium on The Dignity and Rights of the Mentally Disabled Person* (January 8, 2004), no. 4.

40 Ibidem.

41 Ibidem.

needs of every individual, taking into consideration his or her abilities and limitations."[42]

As mentioned earlier, JPII approaches disability from a broader perspective, in which "the diversity that is due to a person's disability can be integrated into his respective unique individuality."[43] In this same vein, he maintains that 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."[44] To address the needs of disabled people, "sincere commitments are needed" from all members of society, particularly those with power and authority. The need to protect and support disabled individuals is especially urgent in the case of mentally and intellectually disadvantaged groups, who "perhaps need more attention, affection, understanding, and love than any other sick person: they cannot be left alone, unarmed and defenseless, as it were, in the difficult task of facing life."[45]

What is particularly exceptional in this papal text is that it signals the need for robust and comprehensive attention to the emotional and sexual dimensions of mentally disabled persons and avoids both simplification and ideology in this regard. Instead, "the sexual dimension is a constitutive dimension of the human being as such, created in the image of the God of Love and called from the outset to find fulfillment in the encounter with others and in communion."[46] Additionally, he emphasizes that disabled people have the same deep need and desire for love as other, able-bodied individuals. JPII reminds us that "they too need to love and to be loved, they need tenderness, closeness and intimacy."[47] His text is explicit in stating that "despite the damage to the mind and the interpersonal dimension, disabled people seek authentic relationships in which they can find appreciation and recognition as persons."[48]

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42 Ibidem.
43 Ibidem, no. 5.
44 Ibidem.
45 Ibidem.
46 Ibidem.
47 Ibidem.
48 Ibidem.

JPII also points out that specific Christian communities have succeeded in creating welcoming and supportive environments for intellectually disabled people. Although he did not name a particular organization, commentators on this papal text agree that he was referring to the L'Arche community founded by Jean Vanier. It is in places like these that disabled people can receive:

> an intense and stimulating community life, continuous and discreet educational support, the fostering of friendly contacts with properly trained people, the habit of channeling instincts and developing a healthy sense of modesty as respect for their own personal privacy.[49]

As a result of these efforts, "the emotional balance of persons with mental disabilities can be restored and lead them to live enriching, fruitful and satisfying interpersonal relationships."[50]

According to JPII, the only way to show disabled people that we love them is to show them that we value them. This can be realized in very practical ways, as emphasized in the address to the Symposium on the Dignity and Rights of the Mentally Disabled Person, by adopting attitudes such as "attentive listening, understanding their needs, sharing their suffering, [and] patience in guidance."[51] The aim of all these actions is to introduce disabled individuals into a human relationship of the communion of persons (*communio personarum*) in order to help them perceive their value and become aware of their capacity to receive and to give love.[52]

4.1.3. Disabled person: living icons of the crucified Son

The particular importance of the papal message to participants of the Symposium on the Dignity and Rights of the Mentally Disabled Person is that it provides a unique perspective on human disability. In this address, JPII begins by acknowledging that "in revealing the fundamental frailty of the human condition, the disabled person becomes an expression of the tragedy

49 Ibidem, no. 6.
50 Ibidem.
51 Ibidem.
52 Ibidem.

of pain."[53] In JPII's teaching, this connection between pain and human tragedy appears frequently. He makes clear that pain in and of itself carries no positive value. On the contrary, pain is viewed as a manifestation of evil and tragedy. The only way that this reality of pain can be placed in a positive context is through the redemptive suffering of Jesus Christ.[54] Without this perspective, pain remains a purely negative, shameful, and marginalized reality. Consequently, as JPII emphasizes, "the difficulties of the disabled are often perceived as a shame or a provocation, and their problems as burdens to be removed or resolved as quickly as possible."[55]

The ideal attitude toward disabled persons, according to JPII, is one that involves awareness and acceptance of the fact that disabled people are "living icons of the crucified Son."[56] His view on disabled individuals is characterized by a readiness to discover and recognize in them "the mysterious beauty of the One who emptied himself for our sake and made himself obedient unto death."[57] Furthermore, he entrusts to disabled people a sacred mission: to "show us, over and above all appearances, that the ultimate foundation of human existence is Jesus Christ."[58] It is evident that disabled people hold a unique and privileged place for JPII, as they are described as "humanity's privileged witnesses."[59] Additionally, they are not destined to be merely passive recipients of the goodwill of society, but rather have a vital mission:

> to teach everyone about the love that saves us; they can become heralds of a new world, no longer dominated by force, violence, and aggression, but by love, solidarity, and acceptance—a new world transfigured by the light of Christ, the Son of God who became incarnate, who was crucified and rose for us.[60]

For JPII, in our interactions with disabled people, especially those with intellectual disabilities, we should remember that God is always on the side

53 Ibidem, no. 8.
54 Ibidem.
55 Ibidem.
56 Ibidem.
57 Ibidem.
58 Ibidem, no. 6.
59 Ibidem.
60 Ibidem.

of the lowly, the poor, the suffering, and the marginalized.[61] God's preferential option for the poor and afflicted was revealed when, "by making himself human and being born in the poverty of a stable, the Son of God proclaimed in himself the blessedness of the afflicted and shared—in all things save sin—the destiny of man, created in his image."[62]

What is especially important in JPII's narrative of disability is his interweaving of these profoundly challenging human experiences with the redemptive suffering of Christ. This connection opens us to a perspective of hope and transformation in the face of profound disability. Furthermore, he asserts that "after Calvary, the Cross, embraced with love, becomes the way of life."[63] The perspective of the Cross also "teaches each one of us that if we know how to travel with abandoned trust the exhausting, uphill road of human suffering, the joy of the Living Christ which surpasses every desire, and every expectation will blossom for us and for our brothers and sisters."[64]

4.1.4. Disability and the Image of God

To complete the picture of JPII's reflections on human disability, particularly mental impairment, it is important to consider one additional document in which he focuses on the question "whether the mentally ill are also made in God's image."[65] In this relatively short text, published in 1996, JPII once again concisely yet powerfully presents the Christian theology on the human person, as well as on physical and mental affliction. This reflection, published nearly two decades after his first document on human disability (*Message for the International Day of Disabled People*, 1981), yields a deeper understanding of the topic.

The timing of this papal reflection is also significant, as it coincided with the period when JPII began experiencing early symptoms of Parkinson's disease. Undoubtedly, the impending reality of physical fragility

61 Ibidem.

62 Ibidem, no. 7.

63 Ibidem.

64 Ibidem, no. 8.

65 Pope John Paul II, "The Mentally Ill Are Also Made in God's Image The Holy Father's Address," in *In the Image and Likeness of God: Always?" Disturbances of the Human Mind* (Vatican City: Editrice VELAR, 1996), pp. 7–19.

brought on by Parkinson's, along with his earlier intensive medical treatment following the assassination attempt in May 1981, enabled him to engage in a more profound and intimate reflection on human suffering, illness, and disability. JPII's 1996 reflection was addressed to participants of a symposium dedicated to issues surrounding intellectual impairment and was entitled: *In the Image and Likeness of God: Always? Disturbances of the Human Mind*.

This symposium was attended by researchers, scientists, biomedical specialists, theologians, moralists, jurists, psychologists, sociologists, and healthcare professionals.[66] The group represented "a heritage of humanity and wisdom, of science and experience, which can produce very useful advice for the understanding, treatment, and care of the mentally ill."[67] Three years prior to the symposium, JPII firmly proclaimed in his encyclical *Veritatis Splendor*:

> man, made in the image of the Creator, redeemed by the blood of Christ, and made holy by the presence of the Holy Spirit, has the ultimate purpose of his life: to live for the praise of God's glory, striving to make each of his actions reflect the splendor of that glory.[68]

During the 1996 symposium, JPII added to this statement that it retains its truth "even when man's mental faculties seem severely limited and even impeded by a pathological process."[69] He emphasized that "the whole man, not just his spiritual soul, including his intelligence and free will, but also his body, shares in the dignity of the image of God."[70] This acknowledgment of the importance of the human body is critical because it allows for a deeper understanding of the nature of human disability and helps provide a more accurate and compassionate narrative of this reality. The experience of the human body and its significance in all existential dimensions,

66 John Paul II, 1996, p. 7.

67 Ibidem.

68 Pope John Paul II, *Encyclical: Veritatis Splendor* (Washington: CNS Documentary Service, 1993), no. 10.

69 John Paul II, 1996, p. 7.

70 Ibidem, p. 8.

including disability, is accorded a privileged place in JPII's anthropology and is particularly developed in his work entitled *Theology of the Body*.

The next chapter will reflect more extensively on *Theology of the Body*, but first, I must conclude my commentary on this papal address to the symposium participants. In his remarks, JPII explained the importance of the human body by emphasizing that "in fact, the human body is a human body precisely because it is animated by a spiritual soul, and it is the whole human person that is intended to become, in the body of Christ, a temple of the Spirit."[71] That "temple of the Spirit" must be treated with particular dignity and respect because "every individual man is an end in himself and can never be used as a mere means of reaching other goals—not even in the name of the well-being and progress of the community as a whole."[72]

Recalling the foundations of Christian anthropology in his address to the symposium, JPII reminds us of a fundamental text, *Gaudium et Spes*, issued by the Second Vatican Council in December 1965. This document describes the human being through "a certain parallel between the union existing among the divine persons and the union of the sons of God in truth and love."[73] In describing the uniqueness of the human person, JPII points to the fact that when:

> God turns his gaze on man, the first thing he sees and loves in him is not the deeds he succeeds in doing, but his own image, an image that confers on man the ability to know and love his own Creator, to rule over all earthly creatures, and to use them for God's glory.[74]

That image, as JPII explains, persists regardless of any physical or mental conditions that may affect the human body.[75]

Another crucial element of JPII's reflection to the symposium participants is his emphasis that the concept of man as the image and likeness of God is not confined mainly to the Old Testament narrative. On the contrary, he asserts that New Testament revelation greatly enriches this interpretation. To support this point, he recalls the words of St. Paul: "But

71 Ibidem, p. 8.
72 Ibidem.
73 *Gaudium et Spes*, no. 24.
74 Pope John Paul II, 1996, p. 9.
75 Ibidem.

when the time had fully come, God sent forth his Son, born of woman, born under the law, to redeem those who were under the law, so that we might receive adoption as sons" (Gal 4:4–5). Accordingly, as JPII points out, it is by grace that man truly shares in this divine sonship and becomes a child of God in the Son.[76]

JPII also cites another document of the Second Vatican Council, *Gaudium et Spes*, which states that Christ is "the image of the invisible God (Col 1:15); therefore He is the perfect man who has restored in the children of Adam that likeness to God which had been disfigured ever since the first sin."[77] Consequently, as the text continues, "human nature, by the very fact that it was assumed, not absorbed, in him, has been raised in us also to a dignity beyond compare. For, by his Incarnation, the Son of God has in a certain way united himself to each man."[78] On this point, we recall the title of the symposium—*In the Image and Likeness of God: Always?* and contemplate how unsettling the question "always?" can feel. JPII acknowledges that the question is provocative by nature, as it can be asked not only at the ontological level—where "faith and reason converge in recognizing the full human dignity of the mentally ill"[79]—but also at the deontological level, where "one can in fact ask whether the way a mentally ill person is treated by his peers in daily life corresponds fully and adequately to what he is in God's plan."[80]

Consequently, for JPII, the question "always?" should stir both personal and collective conscience to engage in sincere introspection regarding our behavior toward those with mental illnesses or disabilities.[81] In his encyclical letter, JPII again warns that people with mental or intellectual disabilities are often victims of indifference, neglect, exploitation, and abuse. To combat this sad reality, he invites us to cultivate "all those daily gestures of openness, sacrifice, and unselfish care which countless people lovingly make in families, hospitals, orphanages, homes for the elderly, and other

76 Ibidem, p. 9.
77 *Gaudium et Spes*, no. 22.
78 Ibidem.
79 Pope John Paul II, 1996, p. 10.
80 Ibidem.
81 Ibidem.

centers or communities which defend life."[82] This list could also include perinatal hospice care, which, in very practical ways, provides care and support for the most vulnerable people: profoundly disabled unborn babies.

JPII also reminded symposium participants that attitudes of care for the weak and disabled were emblematic of the first followers of Christ. He notes that "the disciples of the Lord, precisely because they were able to see the image of the 'suffering' Christ in all people marked by sickness, opened their hearts to them, spending themselves in various forms of assistance."[83] JPII concluded his reflection with a strong, insightful remark, pointing out that "Christ took all human suffering on himself, even mental illness. Yes, even this affliction, which perhaps seems the most absurd and incomprehensible, conforms the sick person to Christ and gives him a share in his redeeming passion."[84]

The narrative of human disability, particularly intellectual disability, that emerges from the above texts is clear and resolute: "whoever suffers from mental, intellectual or physical illness, always bears God's image and likeness in himself, as does every human being."[85] Furthermore, these persons always possess the inalienable right "not only to be considered as an image of God and therefore as a person, but also to be treated as such."[86]

JPII's special care for the vulnerable is always accompanied by an explicit call to practical action. As such, for JPII, everyone must make an active response to "show that mental illness does not create insurmountable distances or prevent relations of true Christian charity with those who are its victims."[87] Additionally, all are called to adopt a "particular attentive attitude towards these people, who are fully entitled to belong to the category of the poor to whom the kingdom of heaven belongs."[88]

82 *Evangelium Vitae*, no. 27.
83 Pope John Paul II, 1996, p. 10.
84 Ibidem.
85 Ibidem.
86 Ibidem, p. 9.
87 Ibidem.
88 Ibidem.

4.2. Theology of the Body and the relational character of existence

The unique vantage point from which JPII perceives human persons affected by illness or disability clearly emerges from the above-mentioned texts and stems from his distinctive anthropology. The fundamental question of human personhood is one that permeated the work of JPII—first as the philosopher Karol Wojtyła, and later as Pope John Paul II. A distinctive source that bears witness to his committed study of the question of personhood is his work entitled *Theology of the Body* (TB). This extensive text is a thorough and insightful analysis of the human person and may also be used as a unique tool for better understanding the complex reality of profound disability.

Moreover, by emphasizing the relational character of human existence, JPII offers a viable alternative to both political conceptions of citizenship and *ratio*-informed anthropologies. Consequently, the anthropology that takes shape in TB offers an inclusive and appreciative theoretical basis for addressing the needs of intellectually disabled persons, especially unborn babies. Furthermore, with its relational emphasis, TB has the potential to better support perinatal hospice care teams and families like Adam's.

4.2.1. Theological clock bomb

As part of his Wednesday audiences between 1979 and 1984, JPII delivered a series of catecheses on marriage that later came to be known as *Theology of the Body*—a term that he frequently used during these teachings. American author, political analyst, and social activist George Weigel described TB as "one of the boldest reconfigurations of Catholic theology over the centuries."[89] He also referred to it as "a kind of theological clock bomb, whose explosion, with dramatic consequences, will take place somewhere in the third millennium of the Church."[90]

It is easy to agree with Weigel's sentiment, as we find that TB continues to have a creative influence on both Catholic and non-Catholic thinkers

89 George Weigel, *Witness To Hope: The Biography of Pope John Paul II* (New York: HarperCollins, 1993), p. 343.

90 Ibidem.

today. This work of JPII also has its critics, however. Those most critical of TB argue that it says nothing new, is ambiguous, or is fatally idealistic.[91] Some feminists also find the messaging of TB offensive. One feminist critic even composed an entire book of political poetry in opposition to it.[92] Other critics have noted that while they appreciate aspects of TB, they nonetheless question the ways in which these texts have been presented to popular audiences.[93]

As Susan Windley-Daoust points out, the most fundamental claim of TB is that human beings, both men and women, were created as a sign pointing to union with God.[94] The ensouled human body also serves as a "pre-given language of self-giving and fruitfulness,"[95] as well as a revelation of the pattern of love by which God created and sustains the universe. In this dynamic, marriage is the primordial sacrament of God's love and a mode of participation in his endless, lavish love. At the same time, the call to celibacy is "a call to sacrifice the earthly sign of joining for union with God, which becomes another sign that points us to God's sustaining gift of Godself."[96] In short, TB calls humanity to see, "through the help of the Redeemer, the ensouled body via the lens of the law of the gift."[97]

JPII's TB can be divided into two fundamental parts. The second part—which attracts most of the controversy and popular critique—focuses primarily on moral theology, sexuality, and marriage. The first part, however, seeks to answer a more fundamental question: What does it mean to be human? Accordingly, I will focus my attention on the first half of TB in order to present JPII's views on the human being. These perspectives from the first half of TB are particularly insightful for the present project,

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91 Luke Timothy Johnson, "A Disembodied 'Theology of the Body' John Paul II on Love, Sex & Pleasure," *Commonweal* 128, no. 2 (January 26, 2001): pp. 9–25, p. 11.

92 Donora Hillard, *Theology of the Body* (Boston, MA: Gold Wake Press, 2010).

93 Alex Bush, "Christopher West Debate Continues: Schindler Responds to Smith and Waldstein," LifeSiteNews (LifeSite, December 31, 1969), https://www.lifesitenews.com/news/christopher-west-debate-continues-schindler-responds-to-smith-and-waldstein.

94 Susan Windley-Daoust, *Theology of the Body, Extended: the Spiritual Signs of Birth, Impairment, and Dying* (Hobe Sound, FL: Lectio Publishing, LLC, 2014), p. ix.

95 John Paul II and Michael Waldstein, *Man and Woman He Created Them: a Theology of the Body* (Boston, MA: Pauline Books & Media, 2006), p. 171.

96 Windley-Daoust, 2014, p. x.

97 Ibidem.

as they flow from JPII's conviction that "the body, in fact, and only the body, is capable of making visible what is invisible: the spiritual and divine,"[98] and that "it has been created to transfer into the visible reality of the world the mystery hidden from eternity in God, and thus to be a sign of it."[99]

I am convinced that the reflections of JPII within TB can serve as a unique lens that allows for a fresh look at the pattern of love and self-gift that inherently exists within the created world, as well as the innate *relatio*-informed dynamic of human existence. TB's understanding of the human person could also potentially function as a "clock bomb" for the practices of perinatal hospice care practices. To fully grasp JPII's unique view of the human person as presented in TB, it is crucial to first explore the intellectual sources that shaped his thinking. Accordingly, the following paragraphs examine some of the ways that JPII was influenced by both phenomenology and Carmelite spirituality. Next, I propose a distinctive dynamic of *relatio*-informed anthropology and demonstrate that it is rooted both in the two biblical accounts of the creation of the first man and in what JPII refers to as the prelapsarian triad of original solitude, original nakedness, and original union. Finally, I argue that JPII's relational understanding of the human person could prove extremely helpful in properly navigating issues related to profound intellectual disability and creating a culture conducive to the full appreciation and inclusion of affected persons—especially perinatal babies.

4.2.2. Between Scheler and Marcel: phenomenological and personalistic influences on JPII's work

In his teaching, JPII consistently argues that, rather than embracing a kind of anti-corporeality, Christian revelation affirms the body in all its beauty as created by God.[100] Perceiving that beauty, however, requires the right interpretation—the "right sight." For JPII, the importance of "seeing" undergirds much of his theological reflection. As a professor of philosophy in Kraków, Poland, Karol Wojtyła was deeply influenced by the early 20th-century phenomenological philosopher Max Scheler. In

98 JPII, 2006, p. 164.
99 Ibidem.
100 Windley-Daoust, 2014, p. 4.

his habilitation dissertation, *An Evaluation of the Possibility of Constructing a Christian Ethics on the Basis of the System of Max Scheler*, Wojtyła wrote:

> the theologian should not forego the great advantages that the phenomenological method offers his work. It impresses the stamp of experience on works of ethics and nourishes them with the life-knowledge of concrete humanity by allowing an investigation of moral life from the side of its appearance.[101]

For JPII, the ability to see the body carries fundamental theological importance. He shares this intuition with other 20th-century phenomenologists and personalists such as Max Scheler, Gabriel Marcel, Martin Buber, and Emmanuel Levinas.[102] According to JPII, "seeing" constitutes and enables the phenomenological attitude, which, as Scheler explains, is "an attitude of spiritual seeing in which one can see or experience something which otherwise remains hidden."[103]

In this dynamic of experiencing and seeing the other, the critical element—what Scheler calls the "spiritual posture"—is a disposition of openness to what the person sees. This posture is a necessary preparation for philosophical inquiry, which Scheler believes is rooted in the open encounter of the act of loving, "a love-determined movement of the inmost personal self of a finite being toward participation in the essential reality of all possible."[104] For Scheler, love is the act that reveals the essential value of the other. To see another in love is to see much more than merely to view them through objectification. JPII builds on Scheler's insight when he says that to "see in love is to see as Christ sees."[105]

Gabriel Marcel, another philosopher who greatly influenced JPII, described this phenomenological reality from a slightly different angle. Marcel approached reality through the phenomenological attitude by introducing the concepts of *primary reflection* (scientific reflection on problems to be

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101 Peter Hebblethwaite, "Husserl, Scheler And Wojtyła: A Tale Of Three Philosophers," *The Heythrop Journal* 27, no. 4 (1986), p. 44.

102 Thomas McGovern, "The Christian Anthropology of John Paul II: Overview," *Josephinum Journal of Theology* 8, no. 1 (2001): p. 134.

103 Max Scheler, *Selected Philosophical Essays* (Evanston: Northwestern University Press, 1973), p. 137.

104 Ibidem, p. 140.

105 McGovern, 2001, p. 40.

solved) and *secondary reflection* (the state of wonder before mystery).[106] For Marcel, mystery is not purely the unknowable, but rather the space in which the distinction between subject and object begins to lose its clearly defined boundaries. Accordingly, he writes that "a mystery is something in which I am myself involved, and it can only be thought of in a sphere where the distinction between what is in me and what is before me loses its meaning and its initial validity."[107] Instead of Scheler's "spiritual posture," Marcel introduces the term "availability" which he describes as:

> the attitude of availability is dispositionally opposed to an attitude which seeks "to dispose of" persons and things. "To dispose of" is to exercise a power over having. We can dispose of only what we have power over, of whatever we have at our disposal: methods, instruments, information, categories...We can never dispose of presence, if we treat persons as things over which we have powers of disposal, they will invariably withhold their presence from us...Availability is an opening upon the presence of another, not a way of access to certain goods he possesses.[108]

Marcel's notion of availability plays an essential role in his famous distinction between *being* and *having* as opposing modes of defining the human person. This insight also influenced Karol Wojtyła's understanding of the human being, as expressed in his early work *Love and Responsibility*[109] and later in the three papal encyclicals *Evangelium Vitae*, *Laborem Exercens*, and *Centesimus Annus*. In all of these texts, JPII reiterates Marcel's famous distinction and warns of the dangers of approaching humanity through the logic of having rather than being.

Thus, *Theology of the Body* resonates in a very particular way with many of the themes found in the work of both Scheler and Marcel. This is especially discernible in JPII's personalist focus on "the fundamental dimension of man's existence, which is always a co-existence."[110] It is also apparent "in his definition of humanity created to the image of God as a capacity

106 Windley-Daoust, 2014, p. 13.

107 Gabriel Marcel, *Being and Having; an Existential Diary* (New York: Harper & Row, 1965), p. 117.

108 Ibidem, p. 230.

109 See Pope John Paul II, *Love and Responsibility* (San Francisco: Ignatius Press, 1981).

110 Pope John Paul II, *Crossing the Threshold of Hope* (London: Jonathan Cape, 1994), p. 35.

for relationship to God, and his emphasis on approaching the human other through the eyes of love and value, not use."[111] The phenomenological character of TB is clearly visible in the way that JPII describes the moment when Adam first saw Eve. The Pope explains that in this experience, Adam's sight was filled with the light of God, and his expression was one of wonder in which one being says to another, "this is one I can love."[112]

Unlike Marcel and Scheler, however, JPII treated phenomenology not as an end in itself but as a method for understanding human experience in service of theological interpretation. After all, JPII emphasizes that the theologian *qua* theologian is not a phenomenologist, but can and should work out of a phenomenological attitude. As such, JPII points out that:

> in all of this, the phenomenological method plays only a secondary role. At the same time, these investigations convince us that the Christian thinkers, especially the theologian, who makes use of phenomenological experience in his work, cannot be a Phenomenologist.[113]

4.2.3. Contemplative attitude and the Theology of the Body

JPII's TB was shaped not only by his phenomenological methodolody but also, as Mary Timothy Prokes notes, by his contemplative attitude.[114] It was through this attitude of contemplation that JPII was able to bridge the gap between phenomenology and theology.[115] The contemplative attitude is defined as "a decision to put aside self-interest and distractions, and [to] turn attention to God, who is present in the moment."[116] Similar to the perspectives of phenomenology and personalism, "seeing" or "gazing" plays a critical role in this contemplative encounter.[117]

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111 Windley-Daoust, 2014, p. 15.
112 JPII, 2006, p. 183.
113 Ibidem, p. 196.
114 Mary Timothy Prokes, *Toward a Theology of the Body* (Edinburgh: T & T Clark, 1996), p. 135.
115 Windley-Daoust, 2014, p. 20.
116 Ibidem.
117 Ibidem.

JPII frequently uses these terms throughout TB, emphasizing that *gazing* refers to a focused attention held in wonder that is often referenced in Scripture.[118] Patricia Byrne writes that:

> to gaze, therefore, has a passive as well as an active dimension. When one gazes, one has the sense of being drawn in, and in this way being held by someone or something. Gazing is an activity that takes time; it cannot be rushed. It needs space, and there must be some element of distance if one is to gaze, to contemplate. Perhaps there is a paradox here—of being absorbed in and, at the same time, apart from.[119]

Another vital aspect of the contemplative attitude is its emphasis on the fullness of reality through the notion of *presence to another*. It is often said that the contemplative attitude is "a long, loving look at the real."[120] This perception harmonizes with Marcel's insight, in which he acknowledges that the act of beholding the presence of another is so consequential that it is "the exchange which is the mark of all spiritual life."[121]

In his seminal book *On Presence*, Ralph Harper explains that:

> all Presence has authority, a force, and radiance, unreserved yet unpredictable. One whose Presence makes others come alive is one who is alive and real. Real life has its marks: immediacy, fullness, and something like the annulment of time.[122]

Similar to those who embrace phenomenological attitudes, those who adopt a contemplative attitude evoke the first sight at creation, which was, as Marcel observes, "spiritual seeing."[123]

The need for "spiritual seeing," a contemplative vision promoted by St. John of the Cross and Carmelite spirituality in general, fundamentally influenced JPII's personal philosophy and, subsequently TB. Although this

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118 Prokes,1996, p. 137.

119 Patricia Bryne, "The Gift of Presence: The Elusive Core of the Spiritual Direction Relationship," *East Asian Pastoral Review* 38, no. 1 (2001): p. 15.

120 Windley-Daoust, 2014, p. 25.

121 Gabriel Marcel, *Homo Viator: Introduction to a Metaphysic of Hope* (New York: Harper & Row, 1962), p. 50.

122 Ralph Harper, *On Presence: Variations and Reflections* (Baltimore, MD: Johns Hopkins University Press, 2006), p. 4.

123 Marcel, 1962, p. 27.

fact is unknown to many, JPII was actually a Third Order Carmelite.[124] The spiritual theology of St. John of the Cross was introduced to him by a layperson, Jan Tyranowski, even before he entered an underground seminary in then Soviet-controlled Poland. Years later, JPII's doctoral dissertation in theology was titled *The Question of Faith According to St. John of the Cross*."[125]

The formative influence and insights of Carmelite spirituality are distinctly recognizable throughout JPII's work. According to Michael Waldstein, Wojtyła saw in phenomenology a Carmelite sensitivity to the lived experience of personal subjectivity, and in St. John of the Cross, a phenomenology of mystical experience.[126] From Windley-Daoust's insights, it can be inferred that "JPII's TB is his effort to live out the calling of the Third Order Carmelite and make present the riches of Carmelite mysticism for all people, especially laypeople."[127]

Another distinctive element of Carmelite spirituality is its emphasis on generosity. JPII incorporates this into his TB by describing it as the "free offer of oneself to God through offering oneself to the one whom you were called by God to marry, to be united in one flesh—or through offering yourself directly to God for the kingdom of heaven."[128] Through this generous self-offering to others, we create room for what JPII terms the "irradiation" of the Holy Spirit. He elaborates on this at the beginning of TB, where he writes:

> the reality of the gift and of the act of giving, which is sketched in the first chapters of Genesis as the constitutive content of the mystery of creation, confirms that the irradiation of Love is an integral part of the same mystery. Only Love creates the good, and in the end, it alone can be perceived in all its dimensions and its contours in created things and, above all, in man. Its presence is the final result of the hermeneutics of the gift. This consistent giving bears witness to rootedness in Love. The first verses of the Bible speak of it so much that they remove all doubt. They speak not only about the creation of the

124 JPII mentioned this affiliation in a letter to Cardinal Ballestrero, OCD, dated September 14, 1981.

125 The dissertation was published in English under the title *Faith According to Saint John of the Cross* (San Francisco: Ignatius Press, 1981).

126 *Man and Woman*, Waldstein introduction, p. 81.

127 Windley-Daoust, 2014, p. 18.

128 Ibidem, p. 21.

> world and about man in the world, but also about grace—that is, the self-communication of holiness, about the irradiation of the Holy Spirit, which produces a special state of "spiritualization" in that first man.[129]

Thus, whenever JPII uses the language of "the law of the gift," "the law of *ekstasis*," or "hermeneutic of the gift,"[130] he is in fact presenting Carmelite charisms to a largely secular audience.

4.3. Theology of the Body and hermeneutics of the gift

Having demonstrated the two fundamental influences on the thought of JPII and his TB, we can now shift focus to the primary purpose of that text. As Michael Waldstein aptly argues, the overarching goal of TB is to "show the divine plan for human spousal love, to show the goodness and beauty of the whole sexual sphere against its cheapening in the objective, scientific way of looking at nature." Waldstein also adds that TB emphasizes that "God's plan and its renewal by Christ, the Redeemer, is imprinted deeply within the bodily nature of the person as a pre-given language of self-giving and fruitfulness."[131]

Accordingly, throughout TB, JPII strongly asserts that human beings are called to commit themselves fully to covenantal relationship, whether embodied in sacramental marriage or through a celibate life ordered toward union with God.[132] Through this "spousal meaning of the body," the body reveals the reciprocal dynamic of the gift. JPII argues in TB that as ensouled bodies, we are created to receive God in word, sacrament, and prayer. Also, as creatures similar in nature to Christ, we are called to offer ourselves wholly and entirely to God the Father. Furthermore, because we speak a "language of the body"[133] and even a "gospel of the body"[134] that

129 Ibidem, p. 190.
130 Pope John Paul II and H. T. Willetts, *Love and Responsibility* (San Francisco: Ignatius Press, 1981), p. 126.
131 JPII, 2006, p. 105.
132 Windley-Daoust, 2014, p. 25.
133 JPII, 2006, p. 105.
134 Ibidem.

reflects God's Trinitarian communion and love, human beings cannot be understood apart from the "hermeneutics of the gift."[135]

JPII's recognition that the human being is fundamentally created within the dynamic of reciprocal gift is supported by his robust theological analysis of the original state of man. The starting point for this reflection is the biblical passage in which Jesus discusses marriage, as recorded in the Gospels of Matthew and Mark (Matt. 19, Mark 10). In these two accounts, Jesus defends the indissolubility of marriage by appealing to man's original state and emphasizing that "from the beginning, it was not so" (Matt. 19:8). Accordingly, to correctly understand the human being, it is necessary to carefully read the biblical accounts of the creation of the first man.

The human being, as JPII argues at the beginning of TB, is not a "lonely island" or a "nomad without windows," but "a being already placed and bestowed with a specific family relationship dynamic."[136] JPII understands man through his primordial vocation as part of a fundamental *communio personarum*, or "community of persons." The basis for this *communio* is the indissoluble marital union designed by the Creator "from the beginning." In the dialogue on marriage described in both Matthew and Mark's Gospels, Jesus refers twice to "the beginning." JPII explains that "by doing so, he clearly refers to the relevant words of Genesis, which his interlocutors also know by heart."[137]

The passage to which Jesus refers is Genesis 1:27, where we read: "God created man in his image; in the image of God, he created him; male and female he created them." A little later, Jesus refers to Genesis 2:24 when he says, "For this reason a man will leave his father and his mother and unite with his wife, and the two will be one flesh." By stating that "therefore what God has joined, let man not separate," Jesus asserts the principle of unity and indissolubility of marriage as the content revealed by God in this most ancient revelation.[138]

The truth about the human being as it was "from the beginning" includes, as JPII emphasizes, a particular prelapsarian triad: original solitude, original

135 Ibidem, p. 108.
136 Ibidem, p. 132.
137 Ibidem, p. 133.
138 Ibidem.

nakedness, and original union. Only through the lens of this prelapsarian triad can the human being be adequately understood and a sufficiently robust anthropology be formulated. To fully grasp this triad, we must briefly comment on the two different accounts of the creation of man: the Yahwist and the Elohist. I will briefly describe both narratives and explore their anthropological implications in the following sections.

4.3.1. First account of the Creation of Man

From the standpoint of biblical criticism, the first account of creation is actually more recent than the second. It is also more theologically developed with respect to the concept of God's image and the essential truths it presents about the human being. As JPII reminds us, this account stems from the priestly, "Elohist" tradition, derived from the term *Elohim*, which is used to name God.[139] JPII asserts that this narrative establishes a distinct cosmological character, including the creation of male and female and the seven-day rhythm of creation. [140]

In this account, man is created alongside the earth as part of the visible world, but at the same time is ordered by the Creator to rule over and subdue it. Despite man's connection to the visible world, the biblical narrative does not emphasize any likeness between man and other creatures, but rather his likeness to God Himself. Consequently, we read that: "God created man in his image; in the image of God he created him" (Gen. 1:27). In the creation of man, JPII notes a dynamic that differs from the creation of the rest of the visible world. He writes:

> in the cycle of the seven days of creation, a precise step-by-step progression is evident, man, by contrast, is not created according to a natural succession, but the Creator seems to halt before calling him to existence, as if he entered back into himself to make a decision, "Let us make man in our image, in our likeness."[141]

Thus, according to JPII, in the process of the creation of man, we find that the definition of man is based on his relationship with God

139 Ibidem, p. 134.
140 Ibidem.
141 Ibidem, p. 135.

and the resulting inherent impossibility of reducing man to the "world."[142] Consequently, as JPII states, "man can neither be understood nor explained in his full depth with the categories taken from the 'world,' that is, from the visible totality of bodies."[143] At the same time, JPII also reminds us that "man too is a body."[144] This essential truth is particularly manifest in the creation of two genders, male and female: "God created man in his image…; male and female he created them" (Gen. 1:27). This is reinforced by the words of the first blessing: "God blessed them and said to them, 'Be fruitful and multiply, fill the earth, subdue it, and rule'" (Gen. 1:28).

JPII explains that the first account of man's creation has a theological character with "powerful metaphysical content" because "it has become the source of the deepest inspirations for the thinkers who have sought to understand being and existing."[145] In this account, man is defined in a way that is more metaphysical than physical. Additionally, "in this metaphysical context of the description of Genesis 1, one must understand the entity of the good, that is, the aspect of value."[146]

In the first narrative account of the creation of man, goodness is repeatedly manifested on all the days of creation and reaches its fullness with the creation of man, as we read: "God saw everything that he had made, and indeed, it was very good" (Gen. 1:31). For JPII, this text forms an "incontrovertible point of reference and solid basis of metaphysics and also for an anthropology and an ethics according to which being and good are convertible. All this has its own significance for theology as well, and above all for the theology of the body."[147]

4.3.2. Second account of the Creation of Man

The second Creation account, believed to be the most ancient divine revelation, is often defined as "Yahwist" because God is consistently referred to as "Yahweh" throughout. This text has a different character from

142 Ibidem, p. 135.
143 Ibidem.
144 Ibidem, p. 136.
145 Ibidem.
146 Ibidem.
147 Ibidem, p. 137.

the first account and includes the original innocence of humankind, their original happiness, and the Fall. JPII considers this passage to be "the oldest description and record of man's self-understanding and the first witness of human conscience."[148] This account also contains "almost all the elements of the analysis of man to which modern, and above all contemporary, philosophical anthropology is sensitive."[149] Particularly important in this regard is the theme of man's subjectivity. By comparing the first and second accounts of Creation, it is important, as JPII suggests, to recognize that this subjectivity corresponds to the objective reality of man created "in the image of God."[150]

In TB, JPII illuminates the significance of the second account, in which the first human being is called *man* (*'ādām*). It is only after the creation of the first woman that he is referred to as *male* (*'iš*), in relation to *woman* (*'iššâ*), because she has been taken from the male (*'iš*).[151] The second account also states that "both were naked, the man and his wife, but they did not feel shame" (Gen. 2:25). This moment acts as the boundary line between original innocence and the Fall, as Genesis 3 then proceeds to recount the narrative of the first sin and the encounter with the "tree of the knowledge of good and evil."

JPII argues that in order to understand the state of "historical" sinfulness, we must refer back to the state of original and fundamental innocence. Consequently, "historical man is rooted in his revealed theological prehistory; and for this reason, every point of his historical sinfulness must be explained, both in the case of the soul and of the body, with reference to original innocence."[152] Additionally, both historical and contemporary man participates not only in the history of human sinfulness but also "in the history of salvation realized in Christ and through Christ."[153] It is important to remember that this redemptive perspective includes the body, and that "precisely this perspective of the redemption of the body guarantees the continuity and the unity between man's hereditary state of sin

148 Ibidem. p. 139.
149 Ibidem.
150 Ibidem.
151 Ibidem, p. 140.
152 Ibidem, p. 143.
153 Ibidem, p. 144.

and his original innocence, although within history this innocence has been irremediably lost by him."[154]

In the process of uncovering the truth about human bodily nature, we must, as JPII reminds us, appeal to experience, because bodily man is perceived by us above all in and through experience.[155] Additionally, "our human experience is in some way a legitimate means for theological interpretation and, indeed, it is an indispensable point of reference."[156]

4.3.3. Prelapsarian triad: Original Solitude

Having briefly described the two accounts of man's creation in Genesis, we are now ready to reflect upon the prelapsarian triad and explain how, according to JPII, it can help broaden our understanding of the nature of the human being. As JPII notes, the first element of the triad is original solitude. "It is not good that the man should be alone; I want to make him a helper similar to himself" (Gen. 2:18). JPII argues that this passage is fundamental for properly grasping the reality of the original solitude of the human being.

This text comes from the second account of the creation of man and thus from the Yahwist tradition. In this context, it is important to recall that the first man (*'ādām*) was created from the "dust of the ground" and is described as male (*'îš*) only after the creation of the first woman. Consequently, "when God-Yahweh speaks the words about solitude, he refers with them to the solitude of 'man' as such, and not only to that of the male."[157] Therefore, original solitude refers to the experience of both male and female.

According to JPII, original solitude has two meanings: "one deriving from man's very nature, that is, from his humanity, and the other deriving from the relationship between male and female."[158] Additionally, the "first meaning of man's original solitude is defined based on a specific test or on an examination that man undergoes before God."[159] The nature

154 Ibidem.
155 Ibidem, p. 145.
156 Ibidem.
157 Ibidem, p. 146.
158 Ibidem.
159 Ibidem.

of this test is explained in the passage in which we read: "When the Lord God formed every kind of animal of the field and all the birds of the air, He brought them to the man to see what he would call them" (Gen. 2:19).

Through God's test, "man gains the consciousness of his own superiority—that is, that he cannot be put on a par with any other species of living beings on the earth."[160] The essence of the test is that "the man gave names to all cattle, and to the birds of the air, and to every animal of the field; but the man did not find a help similar to himself" (Gen. 2:19–20). This passage carries the profound implication that "the created man finds himself, from the first moment of his existence before God, in search of his own being, as it were; one could say, in search of his own definition; today one would say, in search of his own identity."[161]

An important part of that identity is the capacity for self-definition and self-knowledge. These capacities presume the presence of consciousness, which "reveals man as the one who possesses the power of knowing with respect to the visible world."[162] Through this knowledge, man "reveals himself to himself in all the distinctiveness of his being."[163] Consequently, JPII explains that "man is not only essentially and subjectively alone."[164] In fact, he continues, "solitude also signifies man's subjectivity, which constitutes itself through self-knowledge."[165] JPII finally argues that "man is alone because he is different from the visible world, from the world of living beings."[166]

Furthermore, this process of seeking a definition of himself leads man to the "first delineation of the human being as a human person, with the proper subjectivity that characterizes the person."[167] Accordingly, the concept of original solitude includes elements of both self-consciousness and self-determination. JPII is explicit in stating that only when we fully recognize the fact that man is "alone" will we be able to understand

160 Ibidem, p. 148.
161 Ibidem, p. 149.
162 Ibidem.
163 Ibidem.
164 Ibidem.
165 Ibidem.
166 Ibidem, p. 150.
167 Ibidem.

the "next words which constitute the prelude to the creation of the first woman: 'I want to make a help."[168] JPII is further convinced that "without that deep meaning of man's original solitude, one cannot understand and correctly interpret the whole situation of man, created in the image of God, which is the situation of the first, in fact, primeval covenant with God."[169] Again, the proper way of understanding original solitude is to recognize that "man, through his own humanity, through what he is, he is at the same time set into a unique, exclusive, and unrepeatable relationship with God himself."[170]

A fundamental truth about the human being that JPII expresses in TB is that man belongs to the visible world and represents the body among bodies. Consequently, the body, through which man participates in the visible, created world, simultaneously provides him with the awareness of being alone.[171] The first man did not recognize any true similarity to other living beings and came to the conviction that he was alone. In this context of original solitude, man discovered the "awareness and consciousness of the meaning of his own body."[172] He also realized that, because of this ability for self-distinction, he was able to fulfill God's command to "cultivate the earth" (Gen. 2:5) and to "subdue it" (Gen. 1:28). This awareness brings with it "a particular perception of the meaning of one's own body, which emerges precisely from the fact that it is man's task to 'cultivate the earth' and to 'subdue it."[173]

Additionally, the structure of the human body allows for the execution of genuine human action. In this activity, the body expresses the person. What is also important in the context of man's original solitude is the emergence of the concepts of death and immortality, which are associated with the mystery of the tree of knowledge. This is seen in the following excerpt from Genesis: "You may eat of every tree of the garden, but of the tree of the knowledge of good and evil you shall not eat, for when you eat of it you shall certainly die" (Gen. 2:16–17). The fate of death and dying thus

168 Ibidem, p. 151.
169 Ibidem.
170 Ibidem.
171 Ibidem, p. 152.
172 Ibidem.
173 Ibidem, p. 154.

depends on the decisions and free choices of the first man. Consequently, JPII argues that "the alternative between death and immortality has entered from the very beginning into the definition of man, and that it belongs from the beginning to the meaning of his solitude before God himself."[174] JPII also explains that the original meaning of solitude, "permeated by the alternative between death and immortality, also has fundamental significance for the whole theology of the body."[175]

4.3.4. Bodies among other bodies

In this state of original solitude, man gained his identity and sense of otherness from the rest of the created world. Through the task given by God—naming the created world—the first man gained consciousness of his own superiority and discovered his otherness from the rest of creation. He recognized himself as a body among other bodies, yet simultaneously as the unique body that longs for relationship with a like body. Only after the first man discovered this otherness was he able to recognize and express his solitude through his inability to find "a fitting help for him." Accordingly, we can say that original solitude is a *sine qua non* condition for discovering unique human identity.

A crucial element of this identity is the openness to and need for relationship with other human beings. Within the context of perinatal hospice care and the experiences of profoundly disabled unborn babies, this inherent capacity for relationship with others plays a fundamental role. It explicitly shows that, in contrast to other created beings in nature, what constitutes human uniqueness is the capacity for interpersonal relationship—*communio personarum*. Regardless of physical or mental condition, every human being "from the beginning" carries the same indispensable dignity, grounded in the capacity for relationship with other people. Even profoundly disabled prenatal children participate in this relationship through their physical connectedness to the mother via the placenta and umbilical cord. Though there may be no verbal or conscious communication, *communio personarum* already exists.

174 Ibidem, p. 156.
175 Ibidem.

The dynamic of original solitude manifests itself in the life of every human being in some way. It is particularly recognizable in those moments when people become aware of their otherness in relation to the created world and experience a longing for relationship with another person. It is also present whenever a person needs "a help similar to himself." Applied to the context of prenatal life, we find that, by the very nature of human development, every person has an organic need for "a help similar to themself."

A prenatal baby needs a mother's womb in which to grow and develop. Later, it requires a person to feed and nurture it. By evoking original solitude, JPII emphasizes that human mutual dependency is not a marginal or undesirable condition but is, in fact, a foundational element of our human dignity and uniqueness. Recognizing this truth in the practice of perinatal hospice care is a fundamental task—one that will ultimately lead to a more robust appreciation and integration of profoundly disabled lives like Adam's.

Original solitude should be understood as an introductory and preliminary step toward the next prelapsarian reality: original unity. The next section will explore this topic in greater detail.

4.3.5. Prelapsarian triad: Original Unity

The words of Genesis, "It is not good that the man should be alone" (Gen 2:18), can be treated as a prelude to the account of the creation of woman. In this way, as JPII notes, the meaning of original solitude flows into and becomes part of the meaning of original unity.[176] In another foundational text regarding original unity, we read: "A man will leave his father and his mother and unite with his wife, and the two will be one flesh" (Gen 2:24).

It is important to note that the basis of this original unity, as Scripture suggests, is rooted in the creation of humankind as male and female. The Yahwist text in Genesis 2, unlike its Elohist counterpart in Genesis 1, introduces the reality of the duality of sexes. This additionally indicates that embodiment and sexuality are not identical concepts. JPII comments on this issue and rightly points out that in its normal construction, "the human body carries within itself the signs of sex and is by its nature male

176 Ibidem, p. 158.

or female."[177] Furthermore, he argues that the fact that man is a body "belongs more deeply to the structure of the personal subject than the fact that in his somatic constitution he is also male or female."[178]

Accordingly, the original solitude which can be attributed simply to "man" fundamentally precedes original unity, which is based on masculinity and femininity. These two sexes are "two different incarnations, that is, two ways in which the same human being, created in the image of God, is a body."[179] For JPII, the circle of human solitude is broken because the "first man reawakens from his sleep as male and female."[180] One particularly important aspect of this occurrence is what JPII calls the "dimension of homogeneity."[181] The narrative of Genesis 2, in which the woman is made "with the rib" that God-Yahweh had taken from the man, points to the homogeneity of the whole being of both. JPII emphasizes that this homogeneity refers above all to the body—the somatic structure—and is confirmed by the man's first words to the newly created woman: "This time she is flesh from my flesh and bone from my bones" (Gen 2:23). Homogeneity also refers to the more foundational aspect of the human being and thus, "the woman is created in a certain sense based on the same humanity."[182]

The profundity of this homogeneity is emphasized by the man's joy—even exaltation—for "which he had no reason before, due to the lack of a being similar to himself." As JPII notes, "joy for the other human being, for the second 'I,' dominates in the words the man (male) speaks on seeing the woman (female)."[183] This element of joy, born from the appearance of the "second I," is particularly important to recognize and cultivate within the context of perinatal hospice. So often in this setting, parents are left in an acute state of sorrow and despair following devastating prenatal diagnoses. In such critical moments, it could be extremely helpful for perinatal hospice care teams to implement JPII's "dimension of homogeneity" and point to the fact that the prenatal baby, although affected by genetic

177 Ibidem.
178 Ibidem.
179 Ibidem.
180 Ibidem, p. 160.
181 Ibidem.
182 Ibidem.
183 Ibidem, p. 161.

abnormalities and related ailments, embodies a profound and unalienated similarity to its parents. This fact should inspire a particular kind of joy, which JPII refers to as the "joy of the second I."[184]

4.3.6. Communio personarum

From the narrative in Genesis, we discover that the "definitive" creation of man consists in the creation of the unity of two beings. This unity represents the identity of human nature, while its duality simultaneously "shows what, on the basis of this identity, constitutes the masculinity and femininity of created man."[185] For JPII, this ontological dimension of combined unity and duality has an axiological meaning. This is clearly seen when we read that "God saw everything that he had made, and indeed, it was very good" (Gen 1:31). This original unity is defined, following Vatican II, as *communio personarum*. Consequently, the man's solitude in the Yahwist account presents to us "the discovery of an adequate relation to the person, and thus as opening toward and waiting for a communion of persons."[186]

This *communio personarum* should be understood as the existence of the person for another person. Moreover, the communion of persons could only exist "on the basis of a double solitude of the man and the woman, or as an encounter in their distinction from the world of living beings (*animalia*), which gave to both the possibility of being and existing in particular reciprocity."[187] The narrative of Genesis 2 reveals that the complete and definitive creation of man expresses itself in giving life to *communio personarum* in the form of Adam and Eve.[188] Therefore, we can conclude that "man becomes the image of God not only through his own humanity, but also through the communion of persons, which man and woman form from the very beginning."[189]

As a result of this dynamic, man exists as an image of God not so much in the moment of solitude as in the moment of communion. He is, from

184 Ibidem, p. 163.
185 Ibidem.
186 Ibidem, p. 162.
187 Ibidem.
188 Ibidem, p. 164.
189 Ibidem.

the beginning, "not only an image in which the solitude of one Person, who rules the world, mirrors itself, but also and essentially the image of an inscrutable divine communion of Persons."[190] This refers to the Trinitarian concept of the *imago Dei*, which TB says is the "deepest theological aspect of everything one can say about man."[191]The narrative of Genesis 2:24 also states that this original unity, "through which they become one flesh has from the beginning the character of a union that derives from a choice."[192] This union carries within itself a "particular awareness of the meaning of that body in the reciprocal self-gift of the person."[193]

Consequently, JPII asserts that "in every conjugal union of man and woman, there is a new discovery of the same original consciousness of the unitive meaning of the body in its masculinity and femininity."[194] He also argues that "each union of this kind renews in some way the mystery of creation in all its original depth and vital power."[195] Original unity thus unveils the fundamental character of the human being, which is the need for relationship. The nature of these relationships is based on the dynamic of reciprocal self-gift of the person, in which each individual is simultaneously both giver and gifted. The person brings his or her whole being to the relationship, which is manifested in embodiment that encompasses both the corporeal and spiritual dimensions of the individual. The corporeal dimension reveals itself through masculinity and femininity, which together serve as the basis for God's promise of fruitfulness.

This original unity, as depicted in TB, demonstrates that man's readiness for a relationship of reciprocal self-gift—rather than his cognitive or volitional faculties—is what first constitutes his uniqueness as a human being. This awareness is a crucial factor in my search for an appropriate anthropology that is both inclusive and appreciative of intellectually disabled life, and that could be implemented to facilitate improved support for perinatal hospice practices. Following JPII's reflection regarding original unity, the inalienable dignity of a profoundly intellectually disabled

190 Ibidem, p. 165.
191 Ibidem, p. 166.
192 Ibidem, p. 168.
193 Ibidem, p. 169.
194 Ibidem.
195 Ibidem.

unborn baby like Adam is based on the fact that he was called into existence in a uniquely specific body and given the masculine gender. Additionally, from the very moment of his conception, the unique existence of his personhood participated in the dynamic of relationship as reciprocal self-gift. This dynamic is fundamentally located within a particular family in which this new life was conceived.

JPII points out that the family dimension intimately resembles and reflects the Trinitarian dynamic. Accordingly, man's *imago Dei* represents an "image of an inscrutable divine communion of Persons."[196] The human dignity that flows from original unity can never be entirely destroyed, although various abuses may substantially diminish it. Consequently, JPII reminds us that every human life, regardless of its bodily or intellectual condition, carries within itself the indelible mark of original unity.[197] This unity precedes every other characteristic of human being.

Within the realm of perinatal hospice care, an emphasis on original unity as the basis for the inalienable dignity of human life can help medical teams and families more fully appreciate and protect the lives of profoundly disabled unborn children. Additionally, it can allow the parents of these children to feel more fully recognized as loving guardians of their profoundly disabled babies and provide access to that particular joy that is found in the existence of the "second I." Original unity, as expounded by JPII in TB, points to the value and importance of relationships based on mutual self-gift, especially those formed and nurtured within family life.

The life of a profoundly intellectually disabled perinatal baby like Adam also participates in this reciprocal dynamic of giving and being given. Although this existence is still at a prenatal stage—and physical conditions might prevent it from being born—by virtue of its existence, it is already included in a family relationship that mirrors the dynamic of the Trinity. As such, this life is inherently precious and should be cherished as a welcome member of the human family. In the following section, I will reflect on the final element of the prelapsarian triad: original nakedness.

196 Ibidem.
197 Ibidem.

4.3.6. Prelapsarian triad: Original Nakedness

One of the constitutive elements of man's original experience, as referenced in the first chapters of *Genesis*, is original nakedness. When we speak of the original human experience, we have in mind, as JPII explains, "not so much their distance in time, as rather their foundational significance," and we recognize that they are "always at the root of every human experience."[198] JPII's reflection on original nakedness is based on an analysis of *Genesis* 2:25, which states, "Now both were naked, the man and his wife, but they did not feel shame." This relatively brief passage presents a key element of original revelation. It describes the state of consciousness experienced by the first human beings—or, as JPII emphasizes, "their reciprocal experience of the body, that is, the man's experience of the femininity that reveals itself in the nakedness of the body and, reciprocally, the analogous experience of masculinity by the woman."[199]

This state of mutual experience of the body was, as *Genesis* says, without the feeling of shame. Shame appears only after the breaking of the first covenant, when "the eyes of both were opened, and they realized that they were naked" (Gen 3:7). This new awareness brings with it "a new content and a new quality of the experience of the body," where shame is not only one of man's original experiences but is also a boundary experience."[200]

4.3.7. Shame of the disabled body

The question of shame, particularly the shame associated with a disabled body, is highly relevant to the field of perinatal hospice. Dan Goodley argues that contemporary Western culture views the disabled body as lacking, which in turn creates significant emotional burdens for those living with physical impairments and for those who care for them.[201] Commonly, the questions asked by parents expecting profoundly disabled children have to do with the appearance of their baby's body and the extent to which

198 Ibidem.

199 Ibidem, p. 171.

200 Ibidem, p. 172.

201 Dan Goodley and Katherine Runswick-Cole, "The Body as Disability and Possability: Theorizing the 'Leaking, Lacking and Excessive' Bodies of Disabled Children," *Scandinavian Journal of Disability Research* 15, no. 1 (2013): pp. 1–19.

the impairment will affect it.[202] JPII emphasizes that the shame of the body is a consequence of the first disobedience to God the Father, but that it can be healed through the rebuilding of trust and faith in God. This perspective can help provide perinatal hospice parents with a fuller and healthier understanding of the physical disabilities experienced by their baby.

In his reflection on original nakedness, JPII points out that it was only after original sin that the first man and woman realized that they were naked. This awareness did not result simply from a transition from "not knowing" to "knowing," but rather from a "radical change in the meaning of the original nakedness of the woman before the man and of the man before the woman."[203] This change and the accompanying sense of shame are the products of the new consciousness that came about after eating the forbidden fruit: "Who told you that you were naked? Have you eaten from the tree of which I commanded you not to eat?" (Gen 3:11). In the experience of shame, JPII explains that "the human being experiences fear in the face of the 'second I,' and this is substantially fear for one's own 'I[204]'." Furthermore, through shame, the human being "instinctively" manifests the need for affirmation and acceptance of the self according to its proper value.[205]

The absence of shame in the state of man's original nakedness is substantially more than just the lack of a particular reaction or emotional state. Rather, it indicates a specific "fullness of consciousness and experience, above all, the fullness of understanding the meaning of the body connected with the fact that 'they were naked."[206] Thus, following the Yahwist narrative, the emergence of shame—especially sexual shame—is tied to the loss of that original fullness. At this point, one might ask, "With what fullness of consciousness and experience, and with what depth of understanding of the meaning of the body, does the meaning of original nakedness correspond?"[207] JPII answers by saying that it corresponds to the fullness of the truth of being in which man and woman were originally given

202 JPII, 2006, p. 173.
203 Ibidem.
204 Ibidem.
205 Ibidem, p. 174.
206 Ibidem, p. 175.
207 Ibidem.

to each other. In this state of original innocence, the human body "expresses the person in his or her ontological and essential concreteness, which is something more than individual, and thus expresses the human, personal 'I,' which grounds its 'exterior' perception from within."[208]

Through its visibility, JPII emphasizes that "the body manifests man and, in manifesting him, acts as an intermediary that allows man and woman, from the beginning, to 'communicate' with each other according to that *communio personarum* willed for them in particular by the Creator."[209] Accordingly, original nakedness becomes a *sine qua non* condition for full and robust interpersonal communication. Genesis 2:25 speaks about such a relationship, in which the words "they did not feel shame" indicate an "original depth in affirming what is inherent in the person."[210]

JPII's reflection on original nakedness, particularly his emphasis that the body, regardless of its physical condition, "expresses the person in his or her ontological and essential concreteness," could be especially meaningful in the field of perinatal hospice care.[211] This idea can offer valuable and long-awaited support to parents by showing that the life of their disabled children, though marked by bodily dysfunction or deformity, is equally precious. Similarly, it demonstrates that the shame of a disabled body can—and should—be overcome by reclaiming a total acceptance of one's body, as was present in the prelapsarian state of original nakedness.

The original triad of solitude, unity, and nakedness provides the foundation for an anthropology that seeks to understand and interpret the most essential elements of our humanness. First, we see that humankind, created by God to be both "male and female," bears the divine image infused within the human body. Second, created life is a freely given gift from God. As JPII emphasizes, "God reveals himself above all as Creator."[212] Consequently, every creature bears within itself a sign of the original and fundamental gift. The divine motive for creation is love, because "only love, in fact, gives rise to the good and is well pleased with the good" (1 Cor. 13).

208 Ibidem.
209 Ibidem.
210 Ibidem, p. 176.
211 Ibidem, p. 179.
212 Ibidem.

God's gift of human life is unique because it is realized "only by existing with someone and by existing for someone."[213] This mode of existence highlights just how fundamental and constitutive the relational communion of persons is for humanity.[214] As JPII emphasizes, "a communion of persons means living in a reciprocal 'for,' in a relationship of reciprocal gift."[215] In light of these words, we can clearly see how JPII's understanding of the human being, as articulated in TB, can provide tremendous support for perinatal hospice care. In particular, by emphasizing that all human life is a gift, regardless of its biological condition, it calls for acceptance and extends an invitation to establish a *communio personarum*, a communion of persons.

Additionally, as JPII points out, "the affirmation of the person is nothing other than welcoming the gift, which, through reciprocity, creates the communion of persons."[216] As such, this communion "builds itself from within, while also taking into itself man's whole 'exteriority,' that is, all that constitutes the pure and simple nakedness of the body in its masculinity and femininity."[217] Welcoming the life of a profoundly disabled perinatal baby is a deeply significant manifestation of accepting the gift of personhood. At the same time, this acceptance can become the starting point for a reciprocal relationship—a beginning of *communio personarum*. Even while still in the mother's womb, the baby contributes to this relationship by the simple fact of its existence. The nature of *communio personarum* does not depend on the exercise of rational or volitional faculties. Consequently, even a profoundly disabled perinatal baby like Adam is already a fully integrated partner in this relationship. Having explored JPII's understanding of the human being as expressed in TB and explained the importance of the prelapsarian triad for shaping a proper vision of human personhood, I wish to add one final note on JPII's conception of the impaired body.

213 Ibidem, p. 182.
214 Ibidem.
215 Ibidem.
216 Ibidem.
217 Ibidem.

4.4. The *relatio*-informed logic and the impaired body

Human beings, by definition, are limited. That we experience our bodies as limited should be self-evident. In fact, this limitation is a fundamental aspect of what it means to be embodied. Various approaches to impairment have attempted to establish parameters for which human limitations are considered acceptable—whether those limitations result from illness, disability, or injury. Some of these perspectives have even led to ruthless eugenic practices targeting the most vulnerable populations. In recent decades, this rejection of bodily limitation has extended to prenatal life and now poses a very real threat to the lives of profoundly disabled unborn babies like Adam.

JPII's reflections on human disability bring necessary support and hope amid these distressing realities. Of particular significance are those sections of TB in which he emphasizes that the human body "cannot be prevented, due to atypical genetic code, mental illness, physical illness, or injury, from being a pre-given sign of self-giving and fruitfulness."[218] He also notes that the "ensouled body living with impairments often serves as both call and witness, a witness to the work of the Holy Spirit, a witness to the passion of Christ, and a witness to our vocation to union with God, where weakness and vulnerability are the subversive way to life in God."[219]

4.4.1. Christ's impaired body

Windley-Daoust points out that, according to JPII, the proper way to conceptualize the reality of a disabled body is, first and foremost, Christocentric.[220] JPII reminds us that the weakness of Jesus Christ, as revealed in His life and death, is a natural sign of being human.[221] Reflecting on human disability, Stanley Hauerwas writes, "Christian humanism is determined by the Father's sending of the Son to be one of us. So, humanism must

218 Ibidem, p. 223.
219 Ibidem.
220 Windley-Daoust, 2014, p. 120.
221 Ibidem.

always begin with Jesus's humanity. When that isn't the case…compassion becomes a way to say certain people would be better off dead."[222]

In light of Hauerwas's insights, we can further assert—following Windley-Daoust—that the Passion of Christ is the ultimate sign of limitation: an intentional sign in which the Son of God willingly yields His life to the Father for the good of His brothers and sisters.[223] This sign of limitation, the Incarnation, points to the very essence of what it means to be human, especially when we encounter impairment. In such circumstances, we come to recognize a relational logic in which Christ's impaired, suffering body is understood through a Trinitarian, relational logic.

According to this logic, God the Father allows His only begotten Son to become man in order to reconcile humanity both to Himself and to one another. As the prophet Isaiah foretold regarding Christ: "He was being wounded for our rebellions, crushed because of our guilt; the punishment reconciling us fell on him, and we have been healed by his bruises" (Is 53:5). Likewise, in his first letter, St. Peter expresses a deep awareness of Christ's body being crushed and impaired for the sake of our salvation: "He was bearing our sins in his own body on the cross, so that we might die to our sins and live for uprightness; through his bruises you have been healed" (1 Pt 2:24).

According to JPII, Christ's impaired body acquires its redemptive meaning only within this relational logic, in which the gift of the body is first received and then offered back to the Father as a sacrificial offering.[224] Christ's self-limitation—His *kenosis*—thus presents, first and foremost, a relational dynamic. As JPII consistently reminds us throughout his theological work, especially in TB, the human being cannot be perceived from an isolationist viewpoint.[225] Rather, it is "about the visible lived experience of the call to love and the response to love, of relationship to God and others. It is about the divinely ordained witness to love."[226]

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222 Stanley Hauerwas and Jean Vanier, *Living Gently in a Violent World: the Prophetic Witness of Weakness* (Downers Grove, IL: IVP Books, an imprint of InterVarsity Press, 2018), p. 53.

223 Windley-Daoust, 2014, p. 121.

224 Pope John Paul II, *Crossing the Threshold of Hope* (London: Jonathan Cape, 1994), p. 232.

225 JPII, 2006, p. 34.

226 Ibidem.

4.4.2. *Relatio*-informed imago Dei

A novel magisterial development offered to Catholic theology in TB is JPII's account of the *imago Dei* as best manifested through relationship. This insight is particularly significant when we recall that the *imago Dei* tradition was shaped through the careful synthesis of Neoplatonism and Hebrew thought and envisioned that the image of God is located primarily in the human mind. As Windley-Daoust observes, "rationality, as eternal, reflects (as images do) the eternality of God, whereas the created body destined for aging and decay certainly is not the image."[227]

In previous chapters, I have explored the many unfortunate consequences that can result for disabled people when the faculties of reason and will are overemphasized in discussions of human nature. Now, I would like to argue that JPII's interpretation of the *imago Dei*, which relies on *relatio*-informed logic, allows for a more accurate and compassionate understanding and appreciation of disabled human beings, including profoundly intellectually disabled perinatal babies like Adam.

Windley-Daoust argues that JPII locates the doctrine of the *imago Dei* within the doctrines of universal redemption and sanctification.[228] Accordingly, she explains that we are created in the image of God for relationship—with God and with one another—and that it is through these relationships that we grow in holiness.[229] As a result, the creation of the image "is no longer a static honorific, nor a nod to rationality, but a dynamic call."[230] As mentioned earlier, the communion of primordial man reflected the *relatio*-informed *imago Dei* and is, according to JPII, founded upon the spousal meaning of the body. Through this initial gift of spousal union—which points to the Trinitarian life of God—holiness entered the world.[231] The natural consequence of that union, as JPII explains, is fruitfulness, which manifests itself first in the birth of children and also in the love that we share with our sons and daughters, mothers and fathers, brothers and sisters.[232]

227 Windley-Daoust, 2014, p. 128.
228 Ibidem, p. 129.
229 Ibidem.
230 Ibidem.
231 Ibidem, p. 130.
232 JPII, 2006, p. 207.

JPII reminds us that through the redemption of Christ, we are all brothers and sisters. In many ways, this is especially true when we encounter profoundly disabled persons, particularly prenatal babies.

Thomas E. Reynolds, a pioneer in the theology of disability and the father of two sons—one with multiple disabilities—openly acknowledges his debt to Gabriel Marcel and to JPII's TB as particularly valuable resources for understanding and addressing the needs of disabled people. Reynolds expertly explains the use of *relatio*-informed logic in the context of caring for a disabled person. He draws on the notion of *disponibilité*, or availability, in encounters with individuals with disabilities. Reynolds describes availability as a "moral fabric"[233] of love and, as such, a natural negation of the cult of normalcy.

He explains that the practice of availability is expressed through the "interrelated postures" of respect, fidelity, and compassion.[234] Consequently, availability "marks a morally charged willingness to participate in and undergo—that is, to suffer—the presence of another."[235] This attitude is not mere tolerance but "an availing of oneself that risks vulnerable openness to another's vulnerability. It is disposing oneself to the other for their sake and on their terms, binding together a relation of mutuality."[236] Jean Vanier rightly points out that entering a "binding relation of mutuality"—or, in my words, a *relatio*-informed reality—engenders a particular fear: the fear of encountering our own limitations and impairments as human beings, and the frightening call to move beyond them in response to the call to family, the call to love."[237]

As Windley-Daoust observes, "in fear, we realize that we are broken when we encounter a profoundly disabled person."[238] She adds that the natural human tendency in such moments is to attempt to hide what is imperfect, deformed, or impaired: "only instead of hiding ourselves from God, we take and hide the disabled Other: in an institution, in the back

233 Thomas E. Reynolds, *Vulnerable Communion: a Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), p. 123.

234 Ibidem.

235 Reynolds, 2008, p. 123.

236 Ibidem, p. 124.

237 Jean Vanier, *Becoming Human* (New York: Paulist Press, 2008), p. 74.

238 Windley-Daoust, 2014, p. 132.

of the church, in abortion. And we then place ourselves before God saying nothing is amiss."[239] The experience of fear in the face of human disability can, as Windley-Daoust reassures us, be "swallowed up" in faithful love when one lives one's limitations and vulnerability as part of the call to self-gift, openness to receiving others, and union.[240]

The experience of fear, as JPII explains in TB, is closely related to the experience of shame, which arises from the realization that the person does not desire God and does not place their trust in Him. As such, he writes:

> "I was afraid, because I am naked"—these words reveal a certain constitutive fracture in the human person's interior, a break-up, as it were, of man's original spiritual and somatic unity. He realizes for the first time his body has ceased drawing on the power of the spirit, which raised him to the level of the image of God. Its shame bears within itself the signs of a certain humiliation mediated by the body.[241]

In the context of caring for a disabled person—especially within perinatal hospice care—the experience of fear and shame may arise for prospective parents upon realizing that they do not feel strong enough to face such an incredibly difficult situation, and that they may not be mentally or spiritually equipped to navigate it properly.

Similarly, fear and shame may be triggered by the awareness that social attitudes, particularly in the medical field, are often not welcoming or inclusive toward profoundly disabled lives. Prospective parents may experience what Aaron D. Cobb describes: a tacit pressure from medical professionals to terminate a pregnancy because the child is described as "incompatible with life."[242] These emotions may be intensified by spiritual distress, in which the prospective parents of profoundly disabled children feel abandoned by God or otherwise left alone to face an incredibly difficult situation. In such moments, a *relatio*-informed understanding of the human person, as presented by JPII in his writings—especially in his TB—can offer necessary and valuable support.

239 Ibidem.
240 Ibidem.
241 JPII, 2006, p. 244.
242 Cobb, 2020, p. 9.

First, JPII emphasizes that human beings were created by God in His image, according to the *imago Dei*. He also states that "man becomes the image of God not only through his own humanity, but also through the communion of persons, which man and woman form from the very beginning."[243] JPII reminds us that this *communio personarum* is itself patterned on "an inscrutable divine communion of Persons."[244] Accordingly, human communion is meant to reflect a divine, Trinitarian dynamic.

Being created into a *communio personarum*, man is always placed in a specific circle of relationships: a particular sphere of *communio*. This may include close family, friends, or even a faith community. Because of this, the human person is never truly alone or abandoned, even if certain circumstances might give that impression. Ultimately, there exists a universal dimension of relationship: a *communio* of brothers and sisters who are sons and daughters of the Triune God. Secondly, the *relatio*-informed understanding of the human person—especially of disabled persons—presented by JPII, particularly in his TB, offers the potential to overcome experiences of shame and fear tied to societal perceptions of disability. It does so by emphasizing that all human beings are fundamentally and originally related to one another and are mutually interdependent. JPII illustrates this clearly in his reflection on original unity, where he introduces the "dimension of homogeneity."[245]

This *homogeneity* refers first and foremost to the somatic structure of the body and, as JPII notes, is confirmed by the man's first words to the newly created woman: "This time she is flesh from my flesh and bone from my bones" (Gen 2:23). However, *homogeneity* also runs deeper, referring to more fundamental aspects of the human person, such as the fact that "the woman is created, in a certain sense, based on the same humanity."[246] We can extend this understanding to the reality of disability and argue that JPII's "dimension of homogeneity" calls for the abolition of all harmful and unjust policies of discrimination and marginalization based on bodily or mental condition.

243 JPII, 2006, p. 164.
244 Ibidem
245 Ibidem, p. 165.
246 Ibidem.

Finally, we can argue that JPII's *relatio*-informed logic initiates a process by which the discriminatory lines between "them" and "us," between the able-bodied and the disabled, between the "compatible with life" and "non-compatible with life," begin to disappear. With the proper application of *relatio*-informed logic to our understanding of the human person, initial experiences of fear and shame give way to a new reality of solidarity and hope.[247] It is precisely this sense of belonging to one another, rooted in responsibility and care, that engenders a profound and healing sense of hope and joy in the face of the difficulties, divisions, and marginalization often experienced by disabled individuals.

Relatio-informed logic also creates space in which the lives of profoundly disabled perinatal babies are already seen as precious and worthy of full recognition and inclusion. Within this dynamic, the essential need of perinatal hospice parents—to be recognized as loving and caring guardians of their profoundly disabled children—is also fulfilled. This happens through the proper valuing and appreciation of the bonds they share with their prenatal babies. By understanding the elementary and primordial *communio personarum*, the communion between parent and child can be affirmed even when the baby is still in the womb and, due to the physical consequences of their disability, may never be born.

247 Ibidem.

CHAPTER FIVE

CONCLUSION

The reality of human disability, especially the profound intellectual impairment of perinatal babies—calls for a robust understanding of these crucial human experiences. The combination of a sound anthropology with a strong perspective on human disability allows for a more adequate response to the needs of profoundly disabled prenatal babies like Adam, as well as their parents. A proper anthropology, first and foremost, enables the recognition and appreciation of the full humanity and dignity of a profoundly disabled person. Second, it addresses the need to welcome and embrace such life within the larger community. Finally, a proper anthropology, together with a robust perspective on human disability, supports the needs of prenatal parents as they are recognized as loving and caring guardians of their profoundly disabled babies.

In light of this, my book has taken the form of a meticulous quest for appropriate anthropology that might positively inform the practice of Catholic perinatal hospice care and support one of the most vulnerable groups of people: profoundly intellectually disabled prenatal babies. I began this project by situating it in the historical context of the evolution of perinatal hospice care and its inherently multidisciplinary dynamics. I also argued that perinatal care requires a distinct set of values. Through the exploration of perinatal hospice mothers' narratives, I demonstrated the importance of implementing best practices that respect and protect not only the prenatal baby's life, but also the well-being of the entire family. Furthermore, I firmly maintain that, in order to fulfill its noble mission, the practice of perinatal hospice care must be firmly grounded in an appropriate anthropological framework—especially in Catholic healthcare settings.

In my pursuit of such an anthropology, I first delved into the secular field of Disability Studies and evaluated both the positive contributions and the limitations of its perspectives on human disability, particularly profound perinatal disability. My analysis focused on three specific

approaches: the social model of disability, identity politics, and the post-structuralist account. As demonstrated in this work, all of these approaches are anchored in a social constructionist logic. Furthermore, I argue that while much of the advocacy work within secular Disability Studies—such as promoting equal rights, opportunities, and access for disabled persons—is laudable, its anthropological assumptions are flawed. Most prominent disability studies scholars and activists, including Oliver, Foucault, Siebers, Crow, Garland-Thomson, and Catapano, promote social constructionist views of the human person. Consequently, their paradigms leave no room for a robust understanding of human nature, and rely instead on a Marxist-materialist logic.

As emphasized in this book, such views result in what Reinders rightly calls an *anthropology of political citizenship*, in which a human person derives their dignity and value from consciously and willingly participating in political activism and resistance to a disabling society. As articulated in my work, this vision of humanity is critically flawed, because not every disabled person—such as profoundly intellectually disabled prenatal babies like Adam—can participate in these required activities. Moreover, not every disabled person possesses the mental capacity to consciously resist a disabling society or to seek self-representation and self-affirmation.

Finally, not every disabled person identifies as a victim of capitalistic oppression. The constructionist perspective on human disability reinforces a hierarchy of disability, in which the lives of profoundly intellectually disabled persons constitute the lowest and most marginalized tier of the societal structure. In observing instances of social constructionist logic at work in contemporary Disability Studies circles, I firmly assert that such logic can lead to dangerous outcomes, where the most vulnerable individuals—profoundly intellectually disabled prenatal babies—are denied fundamental recognition and appreciation as equally worthy members of the human community. As such, social constructionist logic does not, and cannot guarantee any kind of robust support for the practice of Catholic perinatal hospice care.

Subsequent attempts to identify an appropriate anthropology capable of informing Catholic perinatal hospice care led me to explore the teachings of the Magisterium of the Roman Catholic Church. After analyzing several texts on sacramental discipline, I examined specific cases in which

profoundly intellectually disabled children were restricted from receiving the Sacraments of Christian Initiation—namely, the Eucharist and Confirmation. On this basis, I argued that the current Magisterium may be unintentionally responsible for creating what I call a *state of quasi–Limbo Puerorum*.

As explained, in contrast to the original *Limbo Puerorum*, the *quasi–Limbo* refers to situations in which babies with profound intellectual disabilities, though baptized, are not granted full access to the Ecclesial Community through the reception of the other Sacraments of Christian Initiation. Consequently, the lives of these children represent a form of suspended existence, in which their status lies ambiguously between full inclusion and exclusion from the Ecclesial Community.

Identification of these discriminatory and marginalizing sacramental practices required me to reflect on the origins of such situations. As discussed, a partial explanation for some of these discriminatory practices toward profoundly intellectually disabled children can be linked to instances in which the proper use of reason and will is overemphasized in discussions of human nature. I also argue that these tendencies stem from the strong influence of Thomistic thought on the contemporary Church Magisterium—particularly Aquinas's understanding of the essence of humanity through the categories of reason and will.

Aquinas's perspective on the human being can be interpreted in a way that reveals a kind of *ratio*-informed logic. As explained, this logic seems to lack a robust appreciation and recognition of persons with profound intellectual disabilities and may contribute to their marginalization and exclusion from the sacramental life of the Church. Moreover, this view of the human person does not have the capacity to adequately support or inform the practices of Catholic perinatal hospice care, where the majority of cases involve profoundly intellectually disabled children.

My identification of the weaknesses present in certain Magisterial texts and pastoral practices is not intended to undermine Church doctrine. Quite the opposite, in fact. I am firmly convinced that the answers to my search for an appropriate anthropology that might robustly inform the practice of Catholic perinatal hospice care are to be found within the Catholic theological tradition itself. To that end, I have analyzed JPII's reflections on the human person, particularly as presented in his *Theology*

of the Body and in other writings dedicated to disability. In these sources, I have identified consistently substantive accounts of the human person. Furthermore, I have demonstrated that the distinctive character of these accounts arises from a *relatio*-informed logic of human existence.

In his efforts to provide substantial insights into married life, JPII offered careful analyses of the biblical narratives concerning the creation of the first man, and sought to illuminate God's original plan for humanity. According to this plan, he emphasizes, man and woman were created as a sign pointing to union with God. Within this relational scheme, the ensouled human body functions as a "pre-given language of self-giving and fruitfulness"—a revelation of the pattern of love by which God created and sustains the universe. For JPII, even the most profoundly disabled body never ceases to be an image of God, the *imago Dei*. As demonstrated throughout my work, by emphasizing the bodily aspect of human existence, JPII reminds us that it is through the body that the human person is capable of existing within a relational logic—as a self-gift to others. Furthermore, because we speak a "language of the body," even a "gospel of the body," which reflects God's Trinitarian communion and love, the human person cannot be understood apart from the hermeneutics of the gift. As presented, JPII understands the human person through their primordial vocation to be part of a fundamental *communio personarum*, or community of persons. This particular insight discloses, as I have argued, his connection to 20th-century phenomenologists such as Scheler and Marcel.

JPII further explains the relational character of human existence in his reflection on the prelapsarian triad, comprised of original solitude, unity, and nakedness. As stated earlier, each of these three original states contains strong references to a *relatio*-informed logic of human existence. Moreover, they contain additional valuable concepts that can be applied to the practice of Catholic perinatal hospice care. In the state of original solitude, the first man recognizes himself as a body among other bodies, but simultaneously as a unique body that longs for relationship with the same. In the context of our reflection upon the perinatal hospice space and the reality of profoundly disabled unborn children, this inherent capacity for relationship with other human beings becomes critically important.

Through original solitude, JPII emphasizes that human mutual dependency is not a marginal or undesirable condition, but in fact a foundational

element of human dignity and uniqueness. As previously asserted, I believe that implementing this model within the perinatal hospice space is a fundamental task—one that will eventually allow for a more comprehensive appreciation and integration of profoundly disabled persons like Adam. JPII's reflection on original unity also contributes valuable insights for the practice of perinatal hospice care. As I have argued, his notion of the *dimension of homogeneity* is essential and, in the context of devastating prenatal diagnoses, can help parents like Adam's to understand that their unborn child—although severely affected by genetic abnormalities—still represents a profound and unalienated similarity to the humanity of their own personhood. As I claim in my work, this fact can potentially be the source of a unique kind of joy, which JPII calls the *joy of the second I*.

Furthermore, original unity demonstrates the human person's inherent need and readiness for a relationship of reciprocal self-gift, rather than being defined solely by cognitive or volitional faculties. Consequently, as emphasized, the lives of profoundly intellectually disabled perinatal babies like Adam are also included in this reciprocal dynamic of giving and being given. Even when human life is still in the prenatal stage and physical or bodily conditions might preclude birth, the very fact of existence already includes the child in a family relationship that mirrors the Trinitarian dynamic. Therefore, such life is precious and should be welcomed as a member of the human family.

The final element of the prelapsarian triad—original nakedness—contains JPII's essential reflection on shame. As demonstrated, this can play a vital role in the context of perinatal hospice care, in which the shame associated with the disabled prenatal body can become a significant concern. JPII emphasizes that the shame of the body is a consequence of the first disobedience to God the Father, and that this shame can be overcome through the restoration of trust and faith. This insight has the potential to offer parents of profoundly intellectually disabled children a fuller and more healing perspective.

Contemplation on original nakedness also carries other helpful implications for the practice of perinatal hospice care. As JPII observed, original nakedness depicts the state of the truth of being in which man and woman were originally given to each other. In a certain sense, the relationship of parents to their prenatal baby may bear similarities to that unique

and precious original relationship—particularly in the sense that the baby, although affected by a terminal genetic condition, is given to its parents to form the unique relationship of *communio personarum* willed for them by the Creator. In this *communio*, the dignity and humanity of these profoundly disabled babies are fully recognized, and perinatal hospice parents are affirmed as loving and caring guardians of their children.

In conclusion, I have shown throughout this book that the anthropology presented by JPII in his writings upholds a noticeably *relatio*-informed logic. Additionally, I have argued that this understanding of the human person—unlike the anthropology of political citizenship or one that is strictly *ratio*-informed—offers a robust vision of disabled human beings, particularly profoundly intellectually disabled prenatal babies like Adam. Furthermore, I have claimed that JPII's understanding of the human person carries the potential to positively inform the practice of Catholic perinatal hospice care, thus allowing it to respond robustly to the needs of profoundly disabled prenatal babies and their parents—needs that must be fully respected and appreciated. I firmly hope that my book will contribute to the growth and development of Catholic perinatal hospice care centers. I also believe that this discussion may prove beneficial for non-Catholic healthcare institutions as well.

Finally, I hope that my project will inspire others to become involved—both directly and indirectly—in caring for persons with profound intellectual disabilities by listening to and responding to the needs of these most vulnerable individuals. I am aware that this study is by no means an exhaustive treatment of the issue, and that there remains a great need for further work on these topics. Nevertheless, I hope that my work will serve as an invitation for others to continue these important discussions.

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