

CHAPTER 2

redemptorist
p u b l i c a t i o n s

MEETING THE CONTEXT

AN UNEXPECTED JOURNEY

"For the wonder of who I am, I praise you."

(based on Psalm 139:14)

This line, from Psalm 139, has been a constant inspiration over the past twenty years, during which time I have worked as a disability adviser. It has been a privileged journey where I have met and accompanied many disabled people and their families, as they have sought to live out their lives and faith. During this time, I have spoken with many parents whose children have been disabled by a complex and generally inaccessible world. Parents have shared their stories about their child's journey to birth. Together we have spent honoured moments, remembering the pathways on which they found themselves. We have all agreed that they were times of "great love, anxiety, pain, prayer and expectations". In such times, encouraging people to remain in God's presence, know the wonder of who they are and feel God's hand in their life has always been at the centre of the pastoral support I have sought to share.

When parents receive the news that their unborn child has a medical condition and may experience disability, it is usually a time of great anxiety. Parents begin to feel different from their peers; they feel that they are set aside, presenting a problem to the medical professionals as well as to the world. Their pregnancy becomes a very lonely place to be. Medical diagnosis is usually surrounded by negative language which speaks of how their child's body or mind has "something wrong" or how "a problem has been found". Suddenly, what was to be a joyful journey is marked by a negative narrative; it becomes a problematic and unexpected pathway that they must travel. The life of their child is judged to have less worth than that of children whose life follows a "normal" pattern of development. Parents are made to feel that they are adding something problematic to a harmonious world; the life

of the child is not seen as gift; it is not felt to be good. The *BIA* approach challenges this negative starting point in a child's life and that of the child's parents. It does not accept the negative language that surrounds the pre-birth diagnosis. *BIA* invites you as an accompanier to focus on the knowledge that, within the creative activity of God, there is no norm for *being*, there is only a promise of belonging (Exodus 6:7), a knowledge that all life is good (Genesis 1:26-27) and teaching surrounding the richness of diversity (1 Corinthians 12:12-27). For however long a life lasts, in or out of the womb, all life is good in its diversity and all life is gift. This is the good news that we wish to share with parents. It is based on many years of attending to the stories, experience and requests of people who have been disabled and who have lived good and valued lives.

Before you move forward, take some time to reflect upon your personal and group approach to disability: what do you really think?

Scintilli of grace: BIA formation 2.1

Make a note of the immediate images or words that come into your mind when you see or hear the word:

Disability

Please reflect on the following and record your answer.

Notice how many of your words were negative and how many were positive.

The lives of some people, who are born within the goodness of God's rich diversity, have been disabled by negative attitudes, cultures, approaches and physical boundaries. If they have been born with a medical condition, with body shapes and ways of thinking that are not typical, their life is usually considered to be of less value than people who measure up to a typical way of being. Lack of access seems to follow them throughout their life

because the world is mostly designed for a typically shaped body and way of processing information. As they seek to live their life in all its fullness (John 10:10) this lack of access restricts them from getting around or from using their creative skills to learn. They become disabled people. Some disabled people, in whose stories I have shared, have expressed how it felt knowing their life was a “disappointment”, even before they were born. This has led them to live within a sense of loss, rather than experiencing their life as a gift.⁸ I have always found this dismaying, for I have never met any person who is anything less than wonderful and whose hand is not held in God’s. St John Paul II, himself a person who experienced being disabled, tells us how the human person is “unique and unrepeatable”.⁹ For St John Paul everybody “is capable of making visible what is invisible; the spiritual and divine”.¹⁰ Each body is “created to transfer into the visible reality of the world, the invisible mystery hidden in God, from time immemorial, and thus [is] a sign of it”.¹¹ Here, St John Paul reveals that each person is a sign of God’s mysterious love and presence in the world. God’s grace is God’s “loving communication with human existence”,¹² it is how God touches our life.

Through the incarnation God becomes flesh, thus knowing and feeling what human existence entails. God desires to be with us and through Christ invites us into his company;¹³ God wants to be in relationship with God’s creation and to share in God’s life. We know this through the scriptures, the teachings of the Christian Church, the actions and words of Christ, as his spirit moves throughout history among everyday people in their everyday lives (John 1:14-15). Jesus’ human story leads us towards God; all our stories are part of this movement. We are orientated towards God’s gaze and love; we turn towards God and God is always turned towards us. In moments that are challenging we might feel as if God is not present. However, these are moments when we are called to be held by God and be present with Christ (John 14:9-11). Recognising God’s guidance in our human journeys, feeling the presence of Jesus, helps us to realise that in all things we are never alone; through uniting

our lives with Christ's we are always held in God's love.¹⁴ This is the essence of the Christian story. As I have travelled with families and individuals I have experienced how important it is to accompany people who find themselves on an unexpected path in their life and to support them as they "remain open to grace". In moments of extreme difficulty and grief, I have found that this has helped us to move forward. Reflecting on Christ's story helps us to realise that with every experience of the cross, there is always a resurrection.

Scintilli of grace: BIA formation 2.2

For personal or group reflection.

Think back into your own life. In difficult and joy-filled moments, how have you noticed God's presence at work in your life? How did God's touch reach into your life?

BIA formation 2.3

Reflections from the author and *BIA* parents

Parish accompaniment 2.3: insights

In my pastoral journeys, Psalm 139:1-18 has been a constant companion. The psalmists had a prophetic role in the Old Testament. As cantors and priests, their words and songs spoke for and to the people of God. Their poetic language served to express personal and collective experiences of spirituality, recording life's journey and mediating it to God. The psalms are therefore prayers from our ancestors in faith who have lived a life with God and whose words guide us and lead our own experiences and similar paths. Psalm 139 is a celebration of the human person and confirms that our God knows each one of us, just as we are. Each life has a purpose in God's plan; we each mirror God into the world. Throughout life, God and God's grace are our constant companions. God makes a profound yet simple promise for our existence: "I will be your God and you shall be my people" (Jeremiah 7:23). We are therefore never alone and we *all, always* belong to God.

When a child and their parents receive a pre-birth diagnosis of a possible disability or medical condition, they find themselves in a situation that seems completely impossible. You can imagine them being very frightened of the huge responsibility that they are being asked to bear. My friend and colleague Dr Pia Matthews, herself a mother of a daughter with Rett syndrome,¹⁵ tells us what she feels about the vocation of people with disabilities and gives an important message to parents:

"People with disabilities can bring from within themselves exceptional energy and values of great use for the whole of humanity so that he or she is not only to whom we give; he or she must also be helped to become one who gives to the best of his or her ability."¹⁶

Pia helps us to see that becoming a parent is not just about having a child. Parents are called to enable each gift of life, for however long they live, to fulfil their personal call to vocation and experience their unique purpose in God's plan. Each person has a role in helping to teach the world what love is.

Receiving and giving life is not always straightforward. We can never know what is going to be asked of us. The gift of being a Christian is that we can be sure that, as we live, we are each held in God's gaze, and that it is this assurance that helps us to live faithfully, when life provides us with challenges that seem overwhelming. As Pia tells us, each life brings energy to the world, we are each given as God's gift to the world. No matter how long a child's life lasts, either in or out of the womb, or whatever medical diagnosis finds, a child will always be totally unique and unrepeatable; they are gift from the moment of their conception.

Some of the pathways that we travel are ones that we might have expected, and some take a different route. The birth of a child with a disability, the death of a child due to a medical condition, asks us to love. We are asked not to think of the child as a possession but as a person whose story we have been asked to nurture, to care for and to love. I have found that in the face of great suffering, choosing love as the driving force helps us spend time with an unborn child in a way that honours the child's story as well as the parents'. This does not, for any second, minimise the difficult path that they must follow, or the heart-wrenching experiences they will encounter. They will be facing issues of life and death and dealing with emotions that they had never thought to deal with. One of our parents shares his thoughts with us:

"Everything seemed to be in slow motion, minute by minute and yet time passed so fast. From the scans we knew the physical challenges that our child would face, if he lived, so we knew what he had and through the scans we began to know who he was – a fighter. We thought about wheelchairs and the different

ways in which he would have to move, and our first thoughts were, can we do this, what sort of life will we have, what sort of life would he have? Speaking with my family helped me bring some perspective to his story. We placed love at the centre rather than fear. We began to see the wheelchair as the tool to enable him and that if we thought of his life as his life and not an extension of ours, new plans emerged, and we began to feel less frightened. Living in a wheelchair, or if he died in an operation would never change how much we loved him right now, as he grew in his own way.”

Another family shared how they just could not decide what to do in the face of a life-threatening medical condition and how their visit to the priest helped them to keep focused on love:

“We talked with the priest. I thought that he would be the first to condemn us for considering a termination in such impossible circumstances but there was nothing like that. He did not tell us about suffering but recognised that there would be no painless option and that we needed to decide on the life of our child out of love for him and for ourselves. Thanks to our priest we met a person to accompany us with love. Thanks to the care for us, spiritual support and presence during the hard times, we are still together and trying to find God’s love in all of this, trying to see the space for us in the Church.”

Please read chapters 2 and 4 of the BIA parents’ resource.

This is a time of intense formation for the **BIA** team. You can read individually or you may decide to invite one or two people to read and provide the team with a summarised presentation of the main insights. The information in each chapter will give you a full understanding of some of the issues and dilemmas

that a child with a disability or medical condition faces as well as the challenges and hopes that parents may experience. The information and insights from this chapter will help you gain the “language of accompaniment” that you will need as you travel along the pathways with them. You will notice that:

1. The information and stories are written directly to the children and their parents.
2. Chapters 1, 3, 5 are often referred to during each chapter. These chapters are an imaginative remembering of the story of the unborn Christ child and the people who have been chosen to accompany his life and mission. The unique nature of this activity is that we have merged the experiences of the *BIA* parents with that of Christ’s family by placing the words of the parents directly into the imaginative dialogue of Mary and Joseph.

We gently recommend that you read these chapters if you would like to deepen your ability to accompany.

In this chapter we have met the experience of the unborn child and his or her parents as they face human, faith and moral dilemmas in their life. We have reflected upon the issues and mind-sets that they face in times of pre-birth diagnosis of a medical condition and possible experience of disability. We have invited you to meet and note your personal concept of disability as well as Christian teaching surrounding the dignity and value of life. We have suggested that Christian teaching assures a place of belonging for people who have been disabled by negative stereotypes and that within the promise of God and the body of Christ, everybody has a place. This chapter provides the base for the *BIA* approach and journey. It is the formation for the accompaniment you will give. We have highlighted how true Christian accompaniment is founded on love and not judgements or imposition of ideas and beliefs. We believe that through a witness to Christian teachings and love we are able to help families in challenging times.

Before you move forward please undertake the following activity.

Scintilli of grace: BIA insights and formation 2.4

Group discussion or individual reflection

Christian accompaniment requires us to bring a gentle energy into their life of others. It invites us to hold love of the neighbour at the centre of all we do.

Please discuss:

1. What has struck you the most from this chapter and that of the *BIA* parents' resource?
2. What are your main insights?
3. List the main issues you feel parents face.
4. How will you respond with love?

Bring all of your reflections into a time of prayer, where you will breathe with God and rest in God's company.

As we travel forward in the *BIA* journey, chapter 3 will invite you to spend some time becoming familiar with the *BIA* pathways that parents must follow. We will explain the main experiences that have been shared by *BIA* parents. You will be asked to read thought chapter 6 of the *BIA* parents' resource and become familiar with the advice that is shared.

