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Disability: An Attempt to Think *With*

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The Challenge

The challenge for anyone who would try to reflect on the suffering of those who are described as disabled is that they must do so from the presumption that they are not disabled. As a result it is hard to avoid appearing pretentious and arrogant to those who are disabled, as well as those who care for the disabled. It is always a dangerous practice to write about others, to try to characterize the life of others, because it is too easy to project on their lives our fears and fantasies. Such projections become particularly dangerous when someone who, often with the best will in the world, tries to say what it means to be disabled as well as how those who are disabled should command our attention.

Note how even the challenge I've described is implicated by the grammar of the preceding sentence. To suggest, as that sentence does, that the disabled have no way to protect themselves from the power of those who try to say why and how the disabled should be understood and cared for presumes that those who are disabled are "helpless." That, of course, is not the case as anyone who has learned to live with someone whom we identify as disabled can testify. I will have more to say about what it means for us to live with one another, but I must first try to develop some categories for better understanding the challenge of the "with."

The problem is manifest in the presumption that the very category "disability" is a useful way to describe anyone. What it means to be deaf, blind, intellectually disabled, young, and old is so different, it seems to make little sense to lump these various conditions under a general category called "disability." It turns out that there is such variety in each of these designations, and more could easily be added, that it is by no means clear that we have learned anything useful by characterizing someone as deaf or intellectually disabled. That we learn little from such categorizations makes the use of the general description "disabled" all the more problematic.

That I have included in the list the young and the old is, of course, a gesture to help us think about our tendency to use the language of disability to create a world of "us" and "them." Xavier Le

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Pichon, in a powerful reflection on the significant work of Jean Vanier and Fr. Thomas Philippe, observes that they considered infancy and old age, with their proximity of death and its suffering, as the two golden ages of our lives. Vanier and Philippe did so because they thought a common characteristic of being young or old was a vulnerability that is forgotten or denied in the more active periods of our lives. Our experience of vulnerability they think is a resource for helping us understand the vulnerability of persons with disabilities.

According to Le Pichon, Vanier and Philippe identified these ages as golden because they think the vulnerability we experience by being young or old creates the condition that makes the work of the Holy Spirit possible. To be young or old is to lack the means, as the disabled do, to disguise our desire to be loved. Yet that “weakness” enables the Holy Spirit to act toward the young, old and the disabled in a special way. Le Pichon observes that the Holy Spirit makes the immense love of God present to those who suffer the lack of tenderness that only love can provide.”¹

To call attention to vulnerability in order to characterize the commonalities between those who suffer from intellectual disabilities, the old, and the young threatens, however, to make the general category of disability meaningless. That to be human is to be vulnerable sounds not only true but wise. However, it can be the kind of generalization that hides from us the different kinds of vulnerability that characterize particular lives. Le Pichon, however, is surely right to direct attention to the times in our lives when we find it difficult to hide from ourselves or others that we need help. In truth we are bodily creatures subject to illness and accidents at any time of our lives, but we are quite capable of suppressing knowledge of our finitude, (a suppression that I suspect is one of the reasons we are so intent to distance ourselves from those who are disabled).

I think Le Pichon is right to suggest that our desire to love and to be loved is the heart of the matter. In her recent book, Wandering in Darkness: Narrative and the Problem of Suffering, Eleonore Stump, drawing on Aquinas, develops an account very much like Le Pichon’s understanding of the relation between our desire to be loved and our vulnerability.² For example Stump calls attention to Vanier’s account of the loneliness engendered by shame, a shame that often pervades the lives of those described as intellectually disabled, that can only be overwhelmed by the love Vanier has learned to receive and give by living with his friends in L’Arche.³

Such love is constituted by narratives that make it possible for Vanier to know his friend is mentally handicapped without that

¹ Xavier Le Pichon, “The Sign of Contradiction,” in The Paradox of Disability, edited by Hans Reinders. (Grand Rapids: Eerdmans, 2010), p. 96.

² Eleonore Stump, Wandering in Darkness: Narrative and the Problem of Suffering (New York: Oxford University Press, 2010), pp. 90-97.

³ Stump, pp. 146-147.

knowledge becoming a form of domination. Thus for Vanier the name of his friend is more determinative for their relation than what may characterize the friend's "disability." That to know the name of someone who is also mentally disabled I take to be what it means to risk wanting to be loved even when we may think we suffer from a disability that makes it difficult for us to be loved.⁴

I do not pretend, however, that the vulnerability created by our desire to love and be loved "solves" what I regard as the insolvable and acute problem of labeling. Licia Carlson helpfully calls attention to the difference between the clinical and the social systems approach to describing and labeling mental retardation. The clinical or medical model views mental retardation as a condition of an individual that has pathological characteristics that transcend socio-cultural groups. In contrast the social systems approach sees retardation as a status entailed by a social system and the role played by a person in that system.⁵

Advocates of the social systems approach generally maintain that disability is a social construction. Applying this principle to the deaf, those who assume a systems approach argue, for example, that deafness not be considered a category of disability but rather the deaf are to be understood as a linguistic minority. Yet even if it is acknowledged that various forms of disabilities are socially constructed, it nonetheless remains the case that some categories exist in order that persons with severe intellectual and physical disabilities receive the care and support they need.⁶ The challenge is how that is to be done without the categories becoming self fulfilling or legitimating forms of discrimination.

Carlson helpfully suggests that a category like mental retardation is best understood as a contingent classification, which means it is not in the philosophical sense a natural kind, that is, it is not a name for an inevitable necessity. Accordingly the description of "mental retardation" rightly is a category that must change over time not only in reference to a class but also for individuals. It is quite possible, for example, that given a radical change in the environment an individual might no longer be thought to be "disabled."⁷ What must always be kept in mind, however, is that the categories used to characterize disabilities are "interactive," which means they "are applied to self-conscious individuals who are aware of these labels and may act and

⁴ Hans Reinders has developed a compelling account of the significance of friendship for understanding the relationship between the profoundly disabled and those who are not in his Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics (Grand Rapids: Eerdmans, 2008).

⁵ Licia Carlson, The Faces of Intellectual Disability: Philosophical Reflections (Bloomington, Indiana: Indiana University Press, 2010), p. 87.

⁶ Carlson, pp. 88-89.

⁷ Carlson, p. 93.

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react in such a way that in turn affects the nature of the classification itself; and they are affected by the discursive practices and institutions in which these labels are defined and maintain.”⁸

“Interactive” is, I hope to show, but another name for why it matters that the most compelling accounts we have concerning disabilities take the form of stories. For example, in her book, No Easy Choice: A Story of Disability, Parenthood, and Faith in an Age of Advanced Reproduction, Ellen Painter Dollar provides a well informed account of the moral ambiguities surrounding the use of the technology of preimplantation genetic diagnosis (PGD). She had used this technology once to try to avoid having another child that did not suffer, as she and her daughter do, from a brittle bone disease. That disease makes those who suffer from it extremely susceptible to broken bones. Dollar, however, decided after further reflection to abandon the attempt to use PGD but she nonetheless chose to have two more children who might have been born suffering from the same disease. Happily they were born free of the disease.

In her book Dollar reports on the ethical issues surrounding the use of PGD by drawing on the philosophical and theological resources available. Yet she is quite explicit that she does not regard that aspect of her book to constitute the primary argument of the book. Rather it is the story she has to tell of how she came to the decision not to use PGD that is the heart of her book. That is why her book is in the form of a memoir. It is so because she hopes by telling her story she might be of help to others in a similar situation. But equally important she argues that the narrative of her life is a form of moral deliberation that is particularly significant in the face of a life like her own.⁹

Some time ago I wrote a book on the suffering and death of children entitled, Naming the Silences: God, Medicine, and the Problem of Suffering. I did not think of the book as “my book” because the book consists primarily of stories I tell that are not unlike Dollar’s story of her struggle with her and her daughter’s illness.¹⁰ I argued that without such stories medicine threatens to be a technology shaped to no purpose other than the elimination of suffering and death. Yet Christians believe we are determined by a narrative that can make what we suffer purposeful. Note I did not say that the fact our lives can be narrated makes it possible to explain suffering. Rather I tried to show, and show is the operative word, in

⁸ Carlson, p. 95.

⁹ Ellen Painter Dollar, No Easy Choice: A Story of Disability, Parenthood and Faith in an Age of Advanced Reproduction (Louisville, Kentucky: Westminster/John Knox Press, 2012), p. 194 (manuscript).

¹⁰ Stanley Hauerwas, Naming the Silences: God, Medicine, and the Problem of Suffering (Grand Rapids: Eerdmans, 1990). Eerdmans second edition of the book used only the subtitle as the title for the book.

Naming the Silences that, in the absence of explanations for suffering, the story that makes us Christian provides a way to go on. It is that contention I now want to develop by drawing on Eleonore Stump's argument that the knowledge we gain through narratives is crucial if we are to know how to be with those we label as disabled. Such knowledge, moreover, is a knowledge made possible by love.

Why Stories Matter

Stump begins her account of narrative by quoting Isak Dinesen that, "All sorrows can be borne if you...tell a story about them." Stump confesses she is not sure Dinesen's claim is true, but Stump is sure that reflection on suffering is better with the help of a story.¹¹ Crucial to Stump's argument is the contention that there are things to be known by way of a narrative that cannot be known by more analytical modes of reasoning. The latter way of intending the world Stump characterizes as Dominican because it thrives on abstract properties and designations. In contrast a Franciscan mode of knowledge divides up and describes the world on the basis of typologies that require the acquaintance with stories and persons. (pp. 40-41) Of course, to distinguish between ways of knowing by a naming the alternatives Dominican and Franciscan is an exemplification of a Franciscan way to think.

According to Stump the Dominican way of knowledge consists in having an attitude toward a proposition. It is to know *that*. Such knowledge is not to be dismissed because it is extremely important for sustaining our lives. It is knowledge that draws on first and third person avowals. (pp. 49-50) By contrast Stump claims that there is a kind of knowledge of persons that is not reducible to knowledge of *that*. This is second person knowledge that requires that we actually have interaction with another person to have the knowledge we say we possess. (p. 53)

Stump helpfully illustrates the variety of this latter kind of knowledge by calling attention to its expression in sentences such as, "Joseph knew that the men he saw in front of him in the crowd were his brothers," or "Thomas Aquinas knew the presence of God in the Eucharist." (pp. 53-55.) Stump observes that such sentences make clear that one could not hope to characterize the knowledge implied without the narratives that make those sentences make sense. Thus to "know" why it is significant that Joseph recognized his brothers we need to know that they had tried to kill him. That Aquinas knew God is present in the Eucharist entails the story of God in Christ.

Moreover it is within such narrative contexts we begin to understand that the problem with the assumption that there is

¹¹ Stump, p. 26. Hereafter references to Wandering in Darkness will appear in the text.

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something called *the* problem of suffering is the singular *the*.¹² The stories we tell and stories we are told identify different kinds of suffering and raise different kinds of questions and beg for different kinds of responses. So the narratives that constitute the lives of those who suffer matter for determining the kind of challenge raised by stories such as that of Job, Samson, Abraham, and Mary of Bethany. Different though they may be, however, Stump helps us see how each of these stories in quite different ways involves our desire to be loved and to love.¹³

Accordingly Stump argues that any account of the challenges suffering raises entails narratives of our relations with one another. To develop this point she calls attention to the challenge of those who suffer from autism. She does so because those who suffer from autism seem to be unable to sustain second person interactions that make the kind of knowledge narratives constitute possible. The social isolation, lack of eye contact, and the absence of empathy so often associated with autism are the conditions that make their knowledge of the world and other persons problematic.

Autism, moreover, Stump suggests, is rooted in our biology. She is impressed by recent findings involving the significance of the mirror neurons in the brain that are crucial for our knowledge of other persons. These neurons fire in the brain both when “one does some action oneself *and also* when one sees the same action being performed by someone else.” (p. 68) Mirror neurons, therefore, seem to be the biological conditions that make it possible for babies to experience someone else as a person. To the extent autistic children are deficient in their knowledge of the mental states of other people that deficiency is not because they lack knowledge of the *that* but rather they are impaired because they lack the capacity of the kind of knowledge that is not reducible to the *that*. (p. 67)

Stump even suggests that the discovery of mirror neurons confirm Wittgenstein’s remark, “We *see* emotion—As opposed to what?—We do not see facial contortions and *make the inference* that he is feeling joy, grief, boredom.” (p. 71) The mirror neuron system, while capable of being described in first and third person perspectives, is generated by second person experiences. Accordingly

¹² This way of putting the matter reflects more my understanding of Stump. I should like to think she might be in agreement, but I do not want to attribute to her my interpretation. Though Stump sometimes suggests Wanderings in Darkness to be a book dealing with “the problem of evil,” I do not think in fact that is the primary subject of the book. Suffering, not evil, is her primary theme.

¹³ The heart of Stump’s book is a close reading of the story of Job, Samson, Abraham, and a Mary of Bethany. She refuses, for example, to separate the prologue and epilogue of the book of Job from the poetic parts of the book on grounds that the epilogue and prologue manifest God’s desire to redeem through love even Satan.

second person experience cannot be reduced to first or third person experience without remainder. (p. 78)

That is why second person expressions take the form of a story which makes second person experiences available to us in a manner that they can be shared by a wider audience. Stump puts it this way: “a story gives a person some of what she would have had if she had had unmediated personal interaction with the characters in the story while they were conscious and interacting with each other, without actually making her part of the story itself. The re-presenting of a second person experience in a story thus constitutes a second person account. It is a report of a set of second person experiences that does not lose the distinctively second person character of the experiences.” (p. 78)

To be a person is to find through others the possibility of a life that can be storied. There is, therefore, an interrelation between the storied character of our lives and the character of love. Drawing on Niko Kolodny’s account of love, Stump suggests that our love for another is not without reason but the reason is constituted by the lover’s relationship with the beloved. Such a relationship, moreover, is historical because whatever relationship in which I may stand with someone at any given time depends on our pasts. Therefore one of the reasons for loving another is the ongoing history one shares with them. (p. 88)

Stump enriches this account of love by calling attention to Aquinas’s understanding of love as requiring the interconnected desires of the good of the beloved as well as the desire for union with the beloved. (p. 91) These two desires are not independent of one another, particularly when the ultimate good that binds those that love one another is the desire for union with God. To be capable of such love requires that we desire the good for ourselves and thus to be in union with ourselves. Therefore the good requires internal integration because without the ability to rightly love ourselves we cannot love another rightly. (p. 100-101)

According to Stump the worst thing that can happen to a person from Aquinas’s perspective is to become permanently psychically fragmented, making possible alienation from oneself, from others, and God. God has through Christ made himself known in history in a manner that makes God’s desire to be close to us sure. So nothing can separate us from the love of God, even when we will to pursue that which is not our good with the result we are divided against ourselves. Such a “willed loneliness” is unfortunately the condition in which we find ourselves making our lives incoherent narratives of distorted loves. (pp. 129-150) But we are not without hope because through forgiveness regeneration is possible, thus making possible lives with the capacity to love and be loved, that is, to share a common story.

We suffer from our determination to love and be loved on our terms rather than desiring that which is our true good, but no matter

how alienated we may be from God “to one degree or another God is always present to every sufferer. No sufferer is isolated from the love of omnipresent God; and to the extent to which the sufferer is open to it, the presence of God to the sufferer comes with shared attention and closeness, for the consolation of the sufferer.” (p. 411) Given our sin, therefore, that world, a world in which the mystery of individual suffering must remain unexplained, is governed by God, who has not abandoned us.

Therefore for Aquinas even the worst and apparently hopeless suffering has a point. It is a mistake to think the point will be or can be made apparent at the time. Nor does he claim that in recognizing that suffering has a point, indifference can be justified in the face of suffering. Stump argues that, although God can use suffering for our good, it does not follow that that gives us permission to remain indifferent to our suffering or the suffering of others. (p. 477) Our suffering, the suffering of others, can be the occasion for interaction that makes possible the impossibility of telling the stories of our lives independent of one another. Such interdependence, moreover, is the reality love names.

Stump uses Claiborne Park’s story of her care of Jessy, her fourth child who suffered from autism, to illumine the relation between love and the storied character of our lives. Claiborne Park, who confesses to having no faith in God, describes herself as an intelligent and intuitive person who was proud of the three lovely children she had raised. Her pride, however, was challenged by the suffering, pain, and sheer exhaustion that came with the birth of her fourth child, Jessy, who is autistic. Yet Park writes that it is true “that one grows by suffering. And that too is Jessy’s gift. I write now what fifteen years past I would still not have thought possible to write: that if today I were given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands—because out of it has come, for all of us, an unimaginable life. And I will not change the last word of the story. It is still love.” (p. 470)

Stump wisely does not try to use Park’s story to suggest that Park *really* believes in God. But she does observe that Park has grown through suffering just to the extent that her life has been integrated by her goodness through love. Park came to see “even the suffering of her life as gift.” By writing her book Park gives voice to how through the “alteration affected in her by suffering, by her heartbreak over her daughter’s autism, she found her heart’s desire anyway, only in a way much different from that in which she had originally sought it. As she herself testifies, in the bitter largesse of that gift—from her daughter, from a giver unacknowledged by a breather of thin, faithless air—she found something she cared to have more than she cared to have what she lost in the suffering.” (471)

Yet Stump’s account of Park’s love story seems to ignore the question, “But what about Jessy?” Jessy suffers from autism. Jessy

does not seem to have a life that can be storied as she has made it possible for her mother's life to be storied. Stump acknowledges that the account of the relation of love and narrative she develops as a response to suffering is one limited to "fully functioning adult human beings." It is not meant to apply to human beings who are not adult, who are not fully functional mentally, or to non-human animals. One cannot help but think, however, that more needs to be said.

Alex Sider, in a paper on disabilities, calls attention to his godson, Martin, who has a hard time communicating in the world in which he lives; words make it difficult to interact with others. Sider quotes from Martin's mother's blog about Martin's being appointed "leader of the day" in his class at school. His mother writes that "Martin's willingness to compromise so that he can be the leader reminds me that the poor kid is just trying to feel in control of at least one thing in his life. That world has established routines and people, but it can't be so predictable and established by adults that he feels no sense of freedom."

Sider observes that it is a good thing that Martin's appointment as class leader may help him develop a sense of belonging and acceptance, but it is also a vivid reminder of how out-of-control Martin's life remains. Sider confesses, therefore, that though he wants Martin to be Martin, that he wants him to be free and competitive with typically developing children, means that Sider does not "want him to have his disability." Sider suggests, moreover, the thought that he does not want Martin to have his disability rightly challenges some of the romantic reflections on disability legitimated by some theological accounts of disability. How are we to rightly regard the Martins of our world as precious creatures of God and yet wish they might not suffer from their disability? That question I take to be an intensification of questions surrounding the labeling of the disabled.

On Being With

Sam Wells and Marcia Owen, in a book that deals with the development of liturgies for families and friends of murder victims in neighborhoods of Durham, North Carolina, develop categories that I think can help us think about how at least some response to Sider's challenge is possible. The book is entitled, Living without Enemies: Being Present in the Midst of Violence and tells the story of how Marcia Owens found a way to respond to the murders through gatherings shaped by prayer. She recognized that there was nothing that could be done to make those who had been murdered return to life, but a response was possible even when it seemed any response could not avoid being painfully inadequate.

Wells begins their book, therefore, by characterizing four responses to the question elicited in such circumstances, that is, "How can I help?" The first response is that of the professional with

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well trained skills who think of themselves as “working for” those that need help. These professionals who are often philanthropists with the best will in the world can, by the way they intervene, rob those they desire to “help” of any voice. As an alternative way to think about how one might help, Wells identifies with those who seek to “work with” those identified as disadvantaged. In contrast to those who work *for* those in need, people who work *with* those needing help abandon any pretention of “expertise” in order to help others discover their own solutions based on their understanding of the “problem.”¹⁴

“Being with” describes a way not oriented to providing solutions because it is assumed more important is the formation of companionship amid struggle and distress. Wells identifies Jean Vanier’s work with L’Arche and the hospice movement as paradigmatic forms of “being with.” Jean Vanier’s discovery of his vulnerability in the process of being with the vulnerable is the kind of insight Wells expects “being with” makes possible. In a similar fashion learning to be with the dying turns out to be a reminder of our common humanity.

Wells thinks there is one other way to respond to the question of how we can be of help when it seems that there is nothing that can be done to help. He calls this “being for” those in need. This way of responding Wells suggests may seem to be “a poor relation” to the other three approaches because it may seem to “do nothing.” Wells argues, however, that the work of those who teach in universities, work which may not address explicitly issues of justice, nonetheless can rightly hope that their work, as well as their lives, make a difference to those who are disadvantaged. In a similar fashion the prayers of monastics for the poor may be a singular way of being of service to the poor.¹⁵

Wells explores each of these responses to expose their strengths and weaknesses. The “working for” model tends to dominate the imagination of many who seek to be of service, and no doubt much good is done by those who undertake the task of trying to help those less fortunate. The problem with those who work for others, however, is a relationship of inequality is assumed that can be humiliating, making friendship impossible. “Working with” the disadvantaged has the advantage of trusting the disadvantage, recognizing that how one achieves a goal is as important as the goal itself.¹⁶

To “be with” may seem indistinguishable from “working with” but to be with the disadvantaged means you must experience in your own life the disempowerment associated with the disadvantaged. To

¹⁴ Samuel Wells and Marcia Owen, Living Without Enemies: Being Present in the Midst of Violence (Downers Grove: IVP Books, 2011), pp. 26-30.

¹⁵ Wells and Owen, pp. 30-32.

¹⁶ Wells and Owen, pp. 34-36.

be with requires that the experience of poverty in its many forms shapes your body in a manner that a commonality of trust is made possible. For those shaped by the strategies of working for and with, the stance of being with seems hopeless because those who are so determined do not see those for whom they care as a problem to be solved. To “be for” runs the risk of being so sensitive and knowing it can end by leaving those who are disadvantaged alone.¹⁷

Wells suggests that these alternative ways of engagement can be used to display the character of Jesus’ life and ministry. Jesus certainly worked for and with Israel, but Wells argues it is a mistake to fail to remember that before his ministry in Galilee Jesus spent thirty years in Nazareth. That he did so, Wells suggests, makes clear that Jesus’ work for and with us was made possible because he spent the years in Nazareth being with us. Wells asks what difference that might make for how we approach engagement with the socially disadvantaged. He answers by suggesting that the work of Christ has made it possible for those who would follow him to work with and to be with those we care for because we believe that is the way God is with us.¹⁸

Put in terms identified by Stump, Wells’s account of being with and for helps us see that we have the time to discover that through Christ we share a common story with those we mistakenly assume do not have the ability to narrate their lives. For in truth, none of us has the ability to know what stories we are living out until our lives are connected with other lives, our bodies are touched by other bodies, making possible a common story rightly called a love story. The presence of those identified as the disabled is but a prismatic exemplification of how we learn to be human beings by learning one another’s name.

I noted above that I know of no satisfactory way to deal with the problem of labeling the disabled. But I hope by calling attention to Stump’s account of narrative and Wells’s understanding of modes of intervention we can at least imagine how to be of “help” without our “help” only contributing to the problem. Labeling is a strategy that seems necessary if we are to “work for” the disadvantaged. Much that needs to be done is made possible by the labels that legitimate interventions meant to aid those in need. But working for can make us forget that we must know how to work and be with those whom we would aid.

I suspect we are tempted to take the stance of working for the disadvantaged because too often those we would help both frighten and frustrate us. They frighten us because we fear the acknowledgment of a common humanity. They frustrate us because too often there does not seem to be anything that can be done to “make things better.” But that is to fail to see that there is always something that can be done. What can be done is, as Stump suggests,

¹⁷ Wells and Owen, pp. 38-40.

¹⁸ Wells and Owen, p. 43.

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to love and be loved making possible a common story. Such a love may be difficult and hard, but that is how we know it is of God.

Sider is right to wish that Martin was not autistic. Dollar was right to wish her daughter had not been born with brittle bone disease. Dollar was right to rejoice that her other children did not suffer from her disease. But let us rejoice that Sider and Martin have one another, that the Dollar family exists, for without stories like theirs we would not know what love looks like.