

## *The Ethical Grounds for the Best Interest of the Child*

LYNNE BOWYER

**Abstract:** Managing a healthcare situation in accordance with the best interests of a child can be challenging for both parents and healthcare professionals. These challenges take different forms as the child grows and develops physically, emotionally, and cognitively. In this article I argue that a child's best interests cannot be construed in terms of a narrow conception of human beings as isolated, self-contained biological organisms, in which "health" and "illness" are understood in terms of physiological function and dysfunction. Such an approach overlooks the wider context in which the child grows into and comes to dwell in the world, continually enacting her life within her community. The health of a child is intimately connected to the ways in which she is involved in the world, through active and rewarding engagement with significant others. That embeddedness implies that acting in her best interests calls for others to nurture and integrate her into a sustainable human community so that she is supported appropriately throughout all the contingencies and vagaries of life that impact on her health.

**Keywords:** child health; best interest of child; child development

Each of us is an embodied Being born into a social, cultural, historical, familial, and parental moment that is unique. This matrix of circumstances constitutes the world that we are thrown into and share with others.<sup>1</sup> Our world is not an abstract, timeless physical space but a place of significance, a locus of human concern whose particular structure has been discursively constituted and patterned over time. These shared, discursive structures manifest a particular ethical orientation—that is, a particular ontological conception of things and the relations between those things—such that what we understand things to be and how we learn to deal with them are shaped by our patterns of discursively informed interaction. Our discursive structures of thought provide the background of intelligibility, a cognitive or conceptual framework that constitutes our particular form of life. Dwelling within a particular shared form of life, we develop an embodied understanding of the world, its possibilities, and our place within it. Thus, each of us is fundamentally a Being-in-the-world-with-others—the hyphenated word emphasizes that we are inseparable from "others" and that the "world" is a human life-world or conceptually structured place of significance of which we are a part.<sup>2</sup> Our diverse concepts, such as "play," "mother," "father," "friend," "our home," "my school," and so forth, ground us in the world in meaningful ways.

Our life with others is also continually under way, and who we become is constantly unfolding, taking shape and being dynamically held within our particular web of worldly relationships that make some things possible and close other things down. Thus, a child's interactions with others continually inform her dynamic potentiality to Be someone, somewhere. Relationships that are sustaining and nurturing hold one another well;<sup>3</sup> they hold open and enable all individuals to engage in worthwhile activities that contribute to one another's well-being. When these relationships involve children, significant others play a vital role in sustaining the

child in a way that (over time) equips her with the embodied techniques of living well. It is the work of this parenting role to enable the child to grow into the world, so that she can take up an appropriate place in her community and shape a life worth living. For that reason, the relationships that children have during the early stages of their life are crucial for their self-world understanding. Through favorable encounters in which the child is consistently guided by significant others, values associated with sharing, cooperation, respect, trust, and communal meanings are established, along with secure and healthy social bonds.<sup>4</sup> These relational facts mean that our ethical formation can be derailed in adverse social situations and debilitating interpersonal relationships. If confused, conflicting, or negative interactions become woven into a pattern of everyday activity that structures the possibilities open to a child, the coherence of self-world understanding can be threatened.<sup>5</sup>

Childhood is a time during which we are the most susceptible to the positive and negative encounters that inform our view of things and initiate us into the world. Because our Being is in-formed (formed within) by what happens to us and is inseparable from the webs of relational significance that constitute and support us, our actions are always interactions that draw on the way that others have shaped us.<sup>6</sup> Guided and supported by others, our potential to engage appropriately with things emerges progressively as we grow into the world. Thus, given a favorable learning environment, a child comes to intelligently integrate her cognitive world, making sense of herself and the things that she does. For example, a parent teaches a child that if she wants to be a friend and as a corollary have friends, she has to behave in certain ways and not others. The significance of friendship is conveyed by means of stories (for example, *Frog and Toad Together* and *Should I Share My Ice Cream?*) and songs (for example, "Aroha Is Love," "Stand by Me," and "With a Little Help from My Friends") that transmit the timeless messages of friendship and that are iterated throughout the young person's life. Such messages are conveyed in multiple ways: through appropriate interaction with animals, through dealings with siblings and peers, and by the way that she sees her parents behave toward their friends. The concept "friend" is, like all concepts, shared; it is rule governed and constituted by norms relating to the truth of what it means to be a friend and by which we can evaluate whether or not a particular act is one of friendship. Being a friend enters into what one values, in the sense that having friends elicits feelings of connection and significance in the lives of others, and one feels bereft when lacking the intimacy of friendship. The support and guidance that are required when we are learning how to become a friend calls for an attentive caregiver to respond in ways that empower the growing individual, as she learns a repertoire of actions appropriate for friendship. It is a learning situation in which the child, as a potentiality for Being-a-friend, is involved in-the-world-with-others, learning how to think and act appropriately in everyday, rewarding tasks.<sup>7</sup>

Thus, our interactions with others establish a way of relating to the world; a way of Being and hence living and participating in a given social situation. Over time, through her thoughts, words, and actions, the child learns to integrate herself appropriately in-the-world-with-others, while simultaneously coming to understand her own particular way of Being. The webs of relational significance that she is part of sustain a reciprocal recognition of self and others, which grounds and embeds the child's identity as someone, somewhere. The child's encounters with significant others constantly validate who she is and what she can and cannot do. In this way she learns to be at home in the world (*heimlichkeit*),<sup>8</sup> anchored in a way

that enables her to respond appropriately to the ebb and flow of life's events, because she knows where she stands and what her life is about in this moment. Thus, supported and guided by others, she develops and enacts her autonomy, as she effectively synthesizes, integrates, and coordinates fitting and sustainable moves in response to the situations she is addressed by.

As it takes time to become adept in the culturally informed discursive practices that are necessary for dwelling responsively and response-ably in our lifeworld, we become autonomous in some situations before others. Learning to become an accomplished member of the community is a temporally extended phenomenon that requires becoming proficient in many discursive practices, or "language games" (as Wittgenstein calls them).<sup>9</sup> As our autonomy is temporally informed and situationally specific, it means that we require ongoing empowering interactions with others to position us well and guide us in situations with which we are unfamiliar. With others alongside to support us, we learn to navigate novel circumstances, becoming proficient in more and more aspects of our life, so that we come to competently extend our hold on our world.

As creatures who are continually under way, our Being is a continual movement, and thus our individual health is also part of the movement of our lived existence. Our health is integral to our unique, embodied performance and is part of the rhythm of our Being-in-the-world. It manifests itself differently in each of us, depending on our engagement in the historical and sociocultural situation in which we dwell. Gadamer has noted:

It is part of our nature as living beings that the conscious self-awareness (of health) remains largely in the background so that our enjoyment of good health is constantly concealed from us. ... Despite its hidden character, health none the less manifests itself in a general feeling of well-being. It shows itself above all where such a feeling of well-being means that we are open to new things, ready to embark on new enterprises and, forgetful of ourselves, scarcely notice the demands and strains which are put upon us. ... Health is not a condition that one introspectively feels in oneself. Rather it is a condition of being involved, of being in the world, of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks. ... It is the rhythm of life, a permanent process in which equilibrium re-establishes itself.<sup>10</sup>

Caught up in the flow of our worldly interactions, we are ordinarily unaware of our embodied, involved activity, such that the movements of our limbs and the work of our heart, our lungs, our eyes, and so on, ordinarily assume an inconspicuous familiarity. When we are no longer able to carry out our everyday dealings in the world, a breakdown occurs in our patterns of interaction. And when we can no longer attend to things in our usual way, our embodiment becomes strangely conspicuous. We become aware of our leg when the pain in our knee prevents us from walking up the steps to the shed; we are heedful of our eyes when the blurring of our vision makes it difficult to read the newspaper; pain in our fingers comes to the fore when we struggle to get the lid off the jam. This disruption in our ordinary dealings, whereby our familiar world collapses and everyday meaning recedes, opens up the mood of anxiety. We are *unheimlich*, no longer at home in the world, and the fundamental fragility and vulnerability of our human condition is made manifest through our illness situation. This fracturing of the world is at the same

time a fracturing of our self-understanding, of who we are and what we can do. In such situations, the webs of interactions in which we are engaged and that usually seem so strong and permanent can loosen and break, sometimes in the space of moments. Our plans and projects, our sense of place, our salient involvements in the world, and our range of possibilities are challenged, or even collapse, as our ordinary way of Being is disrupted. As adults, coping with such situations is often extremely difficult, and in the case of children, their inexperience can exacerbate this difficult situation even more. A child may not have developed the cultural forms of understanding needed to make sense of her illness situation. She may not have developed the resilience needed to find other ways of dealing with her helplessness and frustration when she can no longer respond to the call of the world in her usual way.

Such situations do not only affect the child herself; they also affect the world of others in which she plays an integral part. Barbery notes: "When illness enters a home, not only does it take hold of a body, it also weaves a dark web between hearts, a web where hope is trapped."<sup>11</sup> Although our interdependent situation means that this existential situation is true for everyone at times of illness, it is intensified in situations involving children, whose lived reality is very much informed and held within the context of the home and the ways in which things and events are understood within the milieu of the family. As the phenomenon of illness is not an isolated, internal state but permeates our way of Being-in-the-world-with-others, surmounting an illness situation also requires finding appropriate ways of inhabiting a shared world. The family must work to restore (re-story) an appropriate place in the home for the child who is ill, so that she has supportive ways of negotiating her world, learning to engage in worthwhile activities in ways that she can manage, and that can be realistically sustained. A community of care must hold an individual well, regardless of her illness situation, continually working to provide her with a meaningful place to Be. The form that this place takes will be dependent on the form that her illness takes, and on the lifeworld that she is part of.<sup>12</sup>

It is important to include the child herself in the discussions relating to decisions about her care from the time that she is able to ascertain some understanding about her illness situation.<sup>13</sup> As previously discussed, learning to understand our world and make fitting and sustainable moves in response to the situations we find ourselves in is a measure of our autonomy in that circumstance. As autonomy is temporally extended and situation specific, the child's autonomy in relation to her illness situation is continually developing as she becomes able to understand and grasp the implications of her illness, possible treatments, and good ways forward. Her lived experience of her illness and the treatment she receives put her in a unique situation to contribute to the discussions about her care, and her ability to contribute is improved if she has been attended to respectfully and given age-appropriate information along the way.<sup>14</sup> Working with the child's developing autonomy in this way positions her as a Being that *matters* and goes a long way toward her healing. Giving her a place and a voice in the highly significant conversation about her life helps to allay her anxiety, fears, and distress, while also protecting and safeguarding her in areas in which her understanding is still unsteady. Such an inclusive approach can also attend to the fears and unease that many parents have regarding their child's illness situation, as the clinician can simultaneously work with their understanding and distress,

so that there is a bringing together of concerns and judgments, with a view to healing all concerned.<sup>15</sup>

Healing requires that a child be sustained in practices that enable the dynamic equilibrium of health to restore itself, which in turn impacts on the life of those intimately concerned with and involved with her. This means that ways of dwelling in the world with a child who is ill must also be sustainable for the family members who are entrusted with her care, as it is also their reality. For their own health, they too must be able to abide within durable patterns of interaction that hold the family well. Embedded in webs of interdependent relations, people have a particular understanding of what they can realistically do in the lifeworld of which they are part. The health of a child is caught up within a matrix of interdependencies involving complex relations of power and unique sets of demands. For instance, Peter is six years old, the eldest son in a family of three children. Ten months ago he sustained head injuries in a car accident, which have left him physically and intellectually dependent on others for sustaining him in his daily activities. His uncle, who was driving the car at the time, and his aunt, who was a passenger in the front seat, were both killed. Peter's cousin Layla, who is five, was also in the car, and she suffered multiple fractures and a punctured lung, which have healed well. Layla went to live with her aunt and uncle, Peter's parents, after her parents were both killed. Dealing with this family trauma meant that Peter's father had to give up his full-time employment. He is currently holding down three part-time jobs on short-term contracts. Peter's mother is at home caring for Peter's two other siblings, who are four and two, and now of course Layla as well. Peter's four-year-old brother, Nathan, has chronic asthma. What is realistically possible regarding the care of Peter within this family dynamic, situated in a wider socio-political context, is unique to his existential situation. Therefore, acting in the best interests of any child must be family encompassing and not just child directed; we cannot attend to the child's best interests without also attending to her lifeworld situation.<sup>16</sup>

Consequently, responding appropriately to serve the best interests of the child requires that a clinician works to understand the unique individual assailed by illness, and the distressed interrelational situation that she is part of. Working with an individual's relational situation is vital for her healing. Although this is the case regardless of the age of the individual, it is more pronounced in situations involving children, due to the inherent dependencies that children have on their family situation. Respecting, attending, and responding to an individual's distinctive situation are vital for grasping the truth of her circumstances and working effectively with her. For example, responding appropriately to a child with deteriorating vision can take many forms depending on her circumstances. She can be provided with written text in large print, prescription spectacles, contact lenses, a surgical procedure, or any combination of these things. If her vision continues to deteriorate, attending to her best interests might require her living space to be organized in a way that contains textures, sounds, and smells that she can use to guide her around that space. She can be taught how to use braille text to extend her engagement in the world. Depending on her unique situation and the capabilities and commitments of those around her, it may be in her best interests to provide a guide dog or a cane. Caring friends and relations that can provide and sustain fitting ways for her to Be-in-the-world are also crucial for the restoration of her health. Choices and decisions will need to be informed by the web of relations that are

constitutive of who the individual is (becoming) and the lifeworld of which she is part. In this way we can make appropriate adaptations to the world, which includes the physical space and the opportunities for reworking this space to encompass the child's changing needs. We can also attend to and ask questions about the social space she inhabits: Does she go to school, and where is her classroom located? Does she have her own bedroom or share with siblings? Does she attend activities such as music classes or swimming classes? What moves must we make to accommodate her in the various aspects of her social realm? We can open up our ways of thinking so that we do not block her possibilities and the possibilities of those who are caring for her through rigid ways of thinking that fail to engage with the child's unique situation. The child, her family, her social world, and the structures of thought that embed us in the world can all adapt in various ways in order to find mutually sustaining practices that will enable the child to appropriately reintegrate herself into the world. In this way the dynamic equilibrium of her health restores itself as a sense of wholeness and connection—not perfection—is established.

The dynamic equilibrium of health is integral to the ongoing activity of Being somebody, somewhere. Health cannot be reduced to biological function and dysfunction—it must also include a person's psychosocial adaptation and her significant relationships that hold her in Being.<sup>17</sup> The restoration of health, like all activities, is a unique achievement of an embodied Being-in-the-world-with-others, requiring appropriate reintegration into the world. It is something that goes beyond what biomedical/biotechnological intervention—in the form of pharmacology or surgery—can offer, although in many healthcare situations these too can play a role. Health is not something that can be brought about *solely* by the techniques that result from biomedical science, nor can it be referenced against generalized, statistical norms. The latter is something that has also been pointed out by Aristotle, who argues that there can be no generalizable form of health, as health manifests itself differently in each of us; thus a doctor should study the "health of a particular man; (as) it is individuals that he is healing."<sup>18</sup> When we are concerned with the health of a child, we must take this ideographic approach even further, particularizing our advice and broadening our vision so as to encompass the child's unique familial situation, in order to act in a way that enables all concerned to attain "a new equilibrium of performance."<sup>19</sup>

## Conclusion

As a constant achievement of an individual-in-the-world-with-others, health is a particular response that elicits "a responsible performance in a social script."<sup>20</sup> Therefore, understanding and responding to individual health and what is in that individual's best interest requires attending to the lifeworld in which she is situated and the relations with others that sustain her Being. Restoring health requires that we are able to provide a meaningful, worthwhile place in which people can dwell, being part of a web of relationships that can nurture, guide, sustain, and accept who we are (becoming) and that can celebrate our individual contribution to family and community, no matter how small or how fleeting that might be. These things are intensified for a child, as the relational threads that hold her in Being may be constituted only by her immediate family and their support networks. It is therefore vital that significant people in the life of a child have the artistry, the skillful imagination, to discern the child's developing needs in times of illness,

and to prepare the physical and social space that will both motivate her and enable her health to restore itself, by holding her well as a Being-among-others. To act in the best interests of the child means that others must ensure that the world is less of a barrier to the restoration of her health, transforming oppressive or inequitable spaces into places in which she can become part of a rich repertoire of meaningful possibilities that will nurture and sustain her as somebody, somewhere, throughout the contingencies and vagaries of her life.

## Notes

1. Heidegger M. *Being and Time*. Macquarrie J, Robinson E, trans. Oxford: Basil Blackwell; 1962, at 264–5, 173–4, 82–4.
2. See note 1, Heidegger 1962, at 98.
3. Lindemann Nelson H. What child is this? *The Hasting's Centre Report* 2002;32:29–38.
4. Bowyer L. Autonomy and why you can never let me go. *Journal of Bioethical Inquiry* 2014;11:139–49. doi:10.1007/s11673-014-9533-4.
5. In their paper Cynthia L. Battle and colleagues show that a range of adverse childhood experiences are implicated in a variety of disordered ways of Being: see Battle CL, Shea MT, Johnson DM, Yen S, Zlotnick C, Zanarini MC, et al. Childhood maltreatment associated with adult personality disorders: Findings from the collaborative longitudinal personality disorders study. *Journal of Personality Disorders* 2004;18:193–211. See also note 1, Heidegger 1962, at section 26.
6. Heidegger 1962, at 154–61.
7. Lev Vygotsky discusses the dynamic relationship between thought and language developed through the guidance and support of community. See Vygotsky LS. Thinking and speech. In: Vygotsky LS. *Collected Works*. Vol. 1. Rieber R, Carton A, eds. Minick N, trans. New York: Plenum; 1987:39–285.
8. See note 1, Heidegger 1962, at 233.
9. Wittgenstein L. *Philosophical Investigations*. 3rd ed. Anscombe GEM, trans. Oxford: Basil Blackwell; 1958, at #7, #19.
10. Gadamer H-G. *The Enigma of Health: The Art of Healing in a Scientific Age*. Gaiger J, Walker N, trans. Stanford, CA: Stanford University Press; 1996, at 112–14. This dynamic equilibrium of health and illness has also been discussed by other thinkers; see Danzer G, Rose M, Walter M, Klapp BF. On the theory of individual health. *Journal of Medical Ethics* 2002;28:17–19. This dynamic equilibrium is also recognized in the healing practices of other cultures, for example, the continual balancing of yin and yang in traditional Chinese medicine and the maintenance of the harmonious structure of *iki* in traditional Japanese cultural practices.
11. Barbery M. *The Elegance of the Hedgehog*. Anderson A, trans. New York: Europa Editions; 2008, at 69.
12. Many forms of life have healing ceremonies that are performed by holy people (referred to as *tohungas* or shamans in some cultures) on those who are afflicted by illness, and those practices are part of the healing and reintegration of the individual, finding her a place in the world to Be.
13. McMurdo M, Gillett G. Consent, competence and lies to children: Veracity in paediatric care. *Journal of Law and Medicine* 2013;21:265–72.
14. See note 13, McMurdo, Gillett 2013, at 268–70.
15. See note 13, McMurdo, Gillett 2013, at 270–1.
16. The importance of recognizing, understanding, and working with an individual's unique situation is thoughtfully laid out in Anne Fadiman's book: Fadiman A. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. New York: Farrar, Straus and Giroux; 1998. Her account explores the ways in which the biomedical approach reduces a young Hmong child to an analyzable collection of symptoms in order to provide optimal "care," but in the process the doctors involved systematically fail to tailor her treatment in such a way that it engages with the family's reality. Thus, they are unable to work effectively together in the best interests of the child in her familial situation.
17. See note 3, Lindemann Nelson 2002.
18. Aristotle. *The Nicomachean Ethics*. Ross D, trans. Oxford: Oxford University Press; 2009, at 1097a, 11–14.
19. See note 10, Danzer et al. 2002, at 18.
20. Illich I. *Medical Nemesis: The Expropriation of Health*. New York: Pantheon Books; 1976, at 129.