

*Well-Being***8.1 Introduction**

Value theory concerns what is good. More precisely, value theories are accounts of what things are intrinsically good and what things are intrinsically bad. *Intrinsically* means ultimately or in itself as opposed to instrumentally or as a means to something else. Value theory has various components that correspond to different sorts of things that might be thought to be good.¹ Some theorists believe that beautiful things have objective, intrinsic value, which they call aesthetic value. Others disagree, holding that beauty is subjective, residing “in the eye of the beholder.” Some thinkers hold that the good includes certain moral values. For example, Shelly Kagan holds that the good includes both well-being and desert – whether individuals get what they morally deserve.² Brad Hooker holds that the good includes both well-being and fair distribution of benefits, involving priority to the worst-off.³ This chapter focuses on the area of value theory that is concerned with the nature of prudential value or *well-being*.

While ethical theories offer differing guidance in relation to individual well-being, no one denies its importance. Even libertarians, who deny the existence of any obligations to promote others’ well-being independent of an agent’s past actions (see Chapter 6), recognize the principle of non-maleficence. As discussed in Chapter 4, this principle states that it is pro tanto wrong to harm others. Harming others, as harm is ordinarily understood, involves diminishing their well-being.

Well-being is closely related to a variety of familiar practical concepts in addition to harm. Just as harm involves diminishing well-being, *benefit*

¹ For an illuminating discussion, see Robert Audi, *The Good in the Right* (Princeton, NJ: Princeton University Press, 2004), chap. 4.

² Shelly Kagan, *The Geometry of Desert* (Oxford: Oxford University Press, 2012).

³ Brad Hooker, *Ideal Code, Real World* (Oxford: Clarendon, 2000).

involves increasing it. A *good* or *flourishing* life for the individual who lives that life – that is, a prudentially good life – is one largely characterized by well-being. It is, in other words, a life in which one fares well more than badly, flourishes more than languishes. Both harm and benefit are connected with the concept of an individual's *interests*. An individual's well-being is a function of their interests, considered together. Indeed, we may think of each interest – for example, someone's interest in gainful employment or their interest in getting enough sleep – as a component of someone's well-being.

Unlike ethical theories or principles, value theories are not explicitly action-guiding. While they tell us what is good, they do not tell us what to do about it. Utilitarians believe that well-being (or welfare) is the only thing that is intrinsically good. They also believe that agents have an obligation to act in ways that can be expected to maximize well-being, but this latter view does not follow from their theory of the good. A moderate deontologist could agree that well-being is the only intrinsic good, but hold, as we do, that we have only a *pro tanto* obligation to promote well-being and that we are subject to moral constraints on promoting it such as respecting individuals' rights. So the nature of the good is one thing: the topic of value theory. What to do about the good is another thing: a topic in ethical theory.

We begin this chapter with an examination of different theories of well-being. Following a discussion of the pros and cons of subjective and objective theories, we identify three challenges that any successful theory must meet. We sketch a subjective theory of well-being that we think can meet these challenges. According to our theory, both enjoyment and the satisfaction of narrative-relevant desires are prudentially good for an individual. Suffering and the frustration of narrative-relevant desires are prudentially bad for an individual. Reality has an amplifying effect, such that enjoyment is better when its object is real and the fulfillment of desires is better when the desires are rational and informed. The chapter then proceeds to three areas of practical concern: (1) disability in relation to well-being, (2) decision-making for impaired newborns, and (3) decision-making for patients in irreversibly unconscious states.

8.2 Subjective Theories

Contemporary philosophers generally divide accounts of well-being into three categories: *mental-state theories*, *desire-satisfaction theories*, and

objective theories (sometimes called *objective-list theories*).⁴ We locate the first two categories under the broader heading of “subjective theories,” since they understand well-being in terms of an individual’s mental life (invoking one sense of “subjective”) or in terms of what the individual wants (invoking another sense of “subjective”).

According to mental-state theories, an individual’s well-being consists in their having certain kinds of mental states or experiences. The most familiar version of this approach, *hedonism*, identifies well-being with happiness. Happiness, according to classical hedonism, consists in pleasure and the absence of pain. Importantly, the terms “pleasure” and “pain” are not restricted to *sensory* pleasures and pains.⁵ The pride you experience at a loved one’s graduation and the pleasing sensations of a warm bath both constitute pleasures, while the sorrow you feel upon learning of a loved one’s death and the experience of stubbing a toe are both pains. So we may think of “pleasure” and “pain” as referring to the full range of pleasant or agreeable experiences and the full range of unpleasant or disagreeable experiences.

Hedonism has strengths. We generally regard pleasant experiences as making us better off and unpleasant experiences as making us worse off, other things being equal. Rewards generally consist of things that bring us some type of pleasure and punishments typically involve things that cause us some form of pain. The thesis that we are well-off to the extent that we are happy has a ring of plausibility.

Yet further reflection raises doubts about hedonism. What, after all, is pleasure? A natural answer is that pleasure is simply *the experience of feeling good*. But is this a single feeling or experience? If so, how is it distinguished from other feelings? The only experiential quality we seem able to ascribe to all pleasures is *pleasantness* – feeling good. But so many different types of experience feel good or can feel good. Maybe the term “pleasure” designates a wide variety of mental states, not just one. This conjecture seems plausible when contrasting the pleasing sensations of a warm bath to the pride felt upon achieving a major goal, to the intense sensations associated with sexual excitement, or to the quiet enjoyment of reading a good book. If pleasures comprise a variety of mental states, what do they have in common to make them all pleasures? A plausible answer refers not to the

⁴ Derek Parfit popularized this classification, with slightly different terminology, in *Reasons and Persons* (Oxford: Clarendon, 1984), Appendix I.

⁵ See Jeremy Bentham, *An Introduction to the Principles of Morals and Legislation* (Oxford: Clarendon, 1907; first published 1789), chap. V.

way they feel but to the fact that they are all *liked*, or *desired*, just for the way they feel. We might therefore understand pleasure as including all states of consciousness that are liked or desired just for the way they feel.⁶

This way of defining pleasure would enable the hedonist to explain *why* pleasure – or, more globally, happiness – should be thought to constitute well-being. The explanation is that pleasure is good for us *because we desire, prefer, or like it*.⁷ For those who are attracted to the idea that each mature person's values and priorities determine what is ultimately good for them, the fact that we desire pleasure will satisfactorily explain its contribution to our well-being. But this reasoning also opens the door to another theory.

In addition to desiring pleasure, human beings want things that are *not* states of consciousness. This is the main point of Robert Nozick's "experience machine" thought-experiment.⁸ Suppose you could plug into a machine that could give you any and all mental states you would like to have (varied pleasures, a sense of novelty, believing that you are achieving your life goals, and so on). For most people such a machine could not give them all they want out of life. In addition to agreeable experiences, most of us want such things as having good friends, accomplishing our ambitions, and learning about the world. And these sorts of things involve states of affairs beyond our own minds. In the case of having friends, for example, neither *believing* one has friends nor *experiencing good feelings* as a result of this belief delivers what we want: actually having friends. Mental-statism, it appears, construes well-being too narrowly.

Desire-satisfaction theories claim that we are well-off to the extent that we get what we desire. "Satisfaction" here means that what one wants to happen, happens; it does not require that one *feel* any satisfaction. This approach is subjective in the sense that each individual determines what is good for them – by desiring some things and not others. For example, if I desire to play ping-pong but not to read classic novels, then playing ping-pong contributes to my well-being but reading classic novels does not

⁶ This is Henry Sidgwick's idea in defining pleasure as "desirable consciousness" (*The Methods of Ethics*, 7th ed. [London: Macmillan, 1907], Bk. II, chap. 3). Another option is to construe pleasure and displeasure not as types of mental states but as reflecting a *dimension* of any conscious state: the degree to which it is pleasant or unpleasant (Shelly Kagan, "The Limits of Well-Being," *Social Philosophy & Policy* 9 [1992]: 169–189). By contrast, Aristotle understood *eudaimonia*, often translated as "happiness," in terms of a particular sort of active life rather than in terms of mental states (*Nicomachean Ethics*).

⁷ Here we assume that to like an experience for the way it feels involves desiring, other things being equal, that the experience continue.

⁸ *Anarchy, State, and Utopia*, 42–45.

(unless instrumentally). Many philosophers, economists, and laypersons find this general approach plausible.

A challenge confronting desire-satisfaction theories is to determine *which* of an individual's desires are such that their satisfaction makes that individual better off. Not all desires can count in this way. Suppose that while traveling you make a casual acquaintance with someone who tells you she hopes to get a particular job. You form the desire that she land the job, and then you go your separate ways, and later you do not think about her. A year later, unbeknownst to you, she gets the job. Your desire has thereby been satisfied, but it is dubious that this makes you better off – even though, had you found out, you would have been pleased.⁹ The problem this example reveals is that our desires can be about anything, including things far removed from our own lives. Unless restricted in some way, desire-satisfaction accounts construe well-being too broadly.

Another challenge is that desires can be misinformed or distorted. If a cult member's desires are based on systematically false beliefs, her well-being might not be promoted by satisfying those desires. If an addict's life is dominated by craving one fix after another, even to the neglect of basic necessities and formerly affirmed priorities, his current desires provide a dubious guide to his well-being. And long-term deprivation can depress expectations and, with them, desires. For example, a political prisoner might gradually lose hope of freedom and stop desiring it, yet regaining freedom would seemingly contribute to her well-being.¹⁰ Such reflections reinforce the idea that a plausible desire-satisfaction theory must qualify the desires whose satisfaction counts in an assessment of someone's well-being.

Informed-desire (or *rational-desire*) theories are motivated by the idea that desires can be prudentially faulty: for example, because misinformed, contradictory, dampened by deprivation, or based on overgeneralization.¹¹ So an informed-desire theory focuses on ideal or hypothetical desires rather than actual desires. It asserts that one's well-being consists in the satisfaction of the desires one *would* have if one were adequately informed, logically consistent, free of prejudice, and so forth. Such a theory can avoid problems stemming from the fact that our actual desires are sometimes prudentially faulty. In order to be viable, however, an informed

⁹ Cf. Parfit, *Reasons and Persons*, 494.

¹⁰ Amartya Sen, "Well Being, Agency, and Freedom," *Journal of Philosophy* 82 (1985): 191.

¹¹ Explaining why desires based on overgeneralization would not count, R. B. Brandt proposes that only desires that would survive cognitive psychotherapy are ones whose satisfaction would make us better off (*A Theory of the Good and the Right* [Oxford: Clarendon, 1979], Part I).

desire theory must satisfy two demands. First, it must *justify* the sorts of corrections of an individual's actual desires the account will countenance. Otherwise, we might doubt that the account is actually grounding individual well-being in an individual's own priorities. Second, it must rein in the desires that count in view of the enormous range of things about which we can have desires; those that count must be sufficiently relevant to our lives.

A final challenge confronts desire-satisfaction theories however they respond to those two demands. Just as we asked what it was about pleasure that made it important to well-being, leading us to the idea of being desired, we may also ask what it is about *being desired* that makes satisfaction of a desire contribute to well-being. Some philosophers contend that the satisfaction of a desire *per se* doesn't contribute to well-being.¹² Consider these scenarios. Jaime has no desire to listen to hip-hop but, when music from this genre surrounds him at a party, finds that he enjoys it immensely. Kaitlin wants to learn about linguistics but, upon taking a class in the subject (satisfying her desire to learn about it), finds that it leaves her cold. The lack of desire and therefore desire-satisfaction in the hip-hop case and the presence of desire-satisfaction in the linguistics case seem irrelevant to whether Jaime and Kaitlin have beneficial experiences. Meanwhile, the presence or absence of an *enjoyable experience* seems quite relevant. Such observations seem to support mental-statism. While Jaime and Kaitlin surely have a desire for enjoyable experiences, this desire is distinct from desires to hear hip-hop and to learn about linguistics; and the absence and presence of these two desires in the cases under consideration, one might maintain, are irrelevant to our assessments of well-being.

A different line of response to the question of why the satisfaction of a desire contributes to well-being leads in another theoretical direction. Recall that satisfaction of *informed* or *rational* desires seemed more promising as an indicator of well-being than satisfaction of actual desires. One possible explanation of why we tend to believe this is that some possible objects of desire – such as friendships or achievement – seem valuable independently of whether they are actually desired by a particular person. If so, then it is the objects themselves that determine whether they are conducive to well-being, in which case desire, whether actual or

¹² This idea is developed in T. M. Scanlon, "Value, Desire, and Quality of Life," in Martha Nussbaum and Amartya Sen (eds.), *The Quality of Life* (Oxford: Clarendon, 1993), 185–200. See also L. W. Sumner, "Welfare, Preference, and Rationality," in R. G. Frey and Christopher Morris (eds.), *Value, Welfare, and Morality* (Cambridge: Cambridge University Press, 1993), 74–92.

hypothetical, is irrelevant. This line of reasoning leads away from desire-satisfaction accounts of well-being toward objective accounts.

8.3 Objective Theories

Objective theories of well-being claim that some conditions or activities in themselves make human life go better. A plausible list of these *intrinsic goods* might include autonomous living, deep personal relationships, understanding, aesthetic enrichment, accomplishment, enjoyment, and physical and mental functioning (or health).¹³

Whatever it includes as intrinsic goods, a plausible objective account will also include at least one intrinsic *bad*: suffering. Suffering is intrinsically negative for a subject and is not merely the absence of something good. Perhaps the same is true for some other conditions such as physical and mental dysfunction (or illness) and personal failure (the opposite of accomplishment). On the other hand, some objective theorists might regard these as simply the absence of certain intrinsic goods, an absence that often causes suffering.

An objective theory of well-being along the lines we have described makes several concessions to subjective theories. The inclusion of autonomous living leaves a lot of space to the individual to determine what is worth doing and pursuing. The inclusion of enjoyment does the same – since people enjoy different things – while also capturing the hedonist’s plausible idea that experiences we like or find desirable tend to make our lives go better. Identifying suffering as something bad is also a concession to hedonism. Meanwhile, again, the approach does not present a single prescription for a good life, instead allowing for different mixes of goods for different individuals. Finally, all of these items are things that most people tend to want in their lives, at least if they are reasonably informed, and tend to find satisfying.

¹³ All of these items except health and aesthetic enrichment appear in the list proposed in Griffin, *Well-Being*. For examples of objective accounts that construe health or physical and mental functioning as intrinsically – not just instrumentally – valuable for their possessor, see Amartya Sen, “Capability and Well-Being,” in Martha Nussbaum and Amartya Sen (eds.), *The Quality of Life* (Oxford: Clarendon, 1993), 9–29; and Martha Nussbaum, *Women and Human Development* (Cambridge: Cambridge University Press, 2000), 70–96. Strictly speaking, Sen and Nussbaum regard *capabilities* for functioning, rather than functioning itself, as objective prudential goods, a complexity we ignore here. For examples of theorists who include aesthetic experience among objective, intrinsic goods, see John Finnis, *Natural Law and Natural Rights* (Oxford: Clarendon, 1980); and Alfonso Gomez-Lobo, *Morality and the Human Goods* (Washington, DC: Georgetown University Press, 2002).

Perhaps the greatest challenge to objective theories, even those making significant concessions to the insights of subjective accounts, is the charge that they are not flexible enough. Suppose Tushar is not interested in accomplishment. Clear in his mind about what accomplishment is, he picks several weighty and worthwhile goals, succeeds in accomplishing them, but is not impressed. Is it plausible that accomplishment is in Tushar's interests? Would he really be better off, other things being equal, if he accomplished a lot more but became somewhat less happy? Intuitions may differ here. At any rate, the challenge is for the theory to be sufficiently responsive to individual differences in temperament and proclivities.

8.4 Three Challenges for Theories of Well-Being

Given our discussion of the pros and cons of subjective and objective theories of well-being, we think there are three challenges that any plausible theory of well-being should be able to meet. Identifying these challenges will help to motivate the subjective theory we develop in the next section.

The first challenge is *to anchor judgments of well-being plausibly in an individual subject's experience or life*. Some scholars endorse an Experience Requirement: a state of affairs can affect one's well-being only if it affects one's experience. This requirement strikes some as plausible on its face – “What I don't know, can't harm me” – and has plausible implications for cases like the travel acquaintance mentioned above, in which the acquaintance's later success does not make the traveler better off. Note, further, that the Experience Requirement does not *reduce* well-being to experience or mental states, since what affects our experience (e.g., having friends) may involve states of affairs outside our minds.

If the Experience Requirement is warranted, then it poses a serious challenge to objective theories and desire-satisfaction theories, which imply that our well-being can sometimes be affected by factors that do not affect our experience. But the Experience Requirement is controversial. Suppose a hospitalized elderly man lapses into an irreversible vegetative state, surviving in this condition for several months before dying. During this time, he is maintained on a respirator and fed through an intravenous line – despite the fact that (unknown to hospital staff) he had a deeply felt, enduring preference *not* to be maintained by artificial life support in a condition of irreversible unconsciousness. Due to his unconsciousness, he does not experience this affront to his dignity. But it does affect his body.

Proponents of the Experience Requirement will deny that maintaining this patient on artificial life support harms him. Some will disagree, judging (as we do) that harm occurs despite the patient's obliviousness. Those who find the Experience Requirement too restrictive in this way may prefer an Individual Requirement: a state of affairs affects an individual's well-being only if it affects the individual – that is, their mind *or body*.¹⁴

Neither the Experience Requirement nor the Individual Requirement seems able to explain our judgments in other cases. Suppose Sanaa, a medical researcher near the end of her life, is searching for a way to prevent a serious childhood disease. As it happens, a vaccine she discovered proves effective, but she does not learn the good news about the clinical trials she had designed because she dies suddenly just before the news reaches her. Had the vaccine proven ineffective, her experience would have been exactly the same. Some would say that her accomplishment made her better off even though it did not affect her experience. Her life as a whole was more successful because it involved developing a vaccine that worked. Proponents of the Experience Requirement or Individual Requirement would have to disagree. They might acknowledge that her life was morally and instrumentally better than it would have been had the vaccine failed, but deny that it was better *for her*.

Consider another case that is hard to reconcile with the Experience and Individual Requirements. Someone believes herself to have a group of good friends, but, in fact, they despise her and badmouth her behind her back. Even if she never gets an inkling of their true feelings, it seems that her life goes worse for her than it would if she were enjoying genuine friendship. If effects on her experience or her body are necessary for something to go well or badly for her, this judgment is groundless.

We think that the solution to this problem is to deny the Experience and Individual Requirements and instead endorse a *Narrative Requirement*. The Narrative Requirement says that a state of affairs can affect one's well-being either by affecting her experiences and thereby her felt quality of life or, without affecting her experiences, by impacting *her life story*. An event that does not enter my experience can affect my interests only insofar as it would make sense for a story told about my life to include it. Thus, what I experience can make my life go better or worse, but so can other events, such as indignities involving my body that I would have cared greatly about, the success of people I love, the achievement of my major aims, and so forth. On the other hand, the success of the traveler's acquaintance is

¹⁴ Cf. Kagan, "The Limits of Well-Being," 181–182.

still ruled out by the narrative requirement – her business is not a part of the traveler’s life story. The Narrative Requirement captures the sense in which judgments about someone’s well-being must be about his life, not merely someone else’s, without being unduly restrictive concerning what counts as his life.¹⁵

We recognize that the Narrative Requirement, as just stated, is vague and requires interpretation. However, it successfully captures the cases that the Experience Requirement and the Individual Requirement cannot, while limiting the range of desires that count. Moreover, in cases in which it is hard to judge whether a particular unexperienced state of affairs affects someone’s well-being (e.g., the flourishing or languishing of a grandchild to whom one is not especially close), the Narrative Requirement leaves room for the plausible judgment that, if the state of affairs does affect one’s well-being, it does so *to a lesser extent* than factors that are unambiguously part of one’s life story.

The second challenge for any theory of well-being is *to show appropriate deference to an individual’s authority regarding what is good for them*. Our approach rests on the conviction that human beings, at least competent adults, are usually experts on what is good for them. When they make mistakes, those mistakes can generally be explained in virtue of getting the facts wrong (e.g., falsely believing that changing jobs will make them happy), reasoning erroneously (e.g., overestimating the importance of schmoozing in the quest for promotion), or acting out of weakness of will (e.g., having a drink after several sober months, against their own reflective judgment). When someone makes a mistaken judgment about whether something is good for her, it is very unusual to explain it on the grounds that she is mistaken about what is ultimately prudentially valuable for her. Competent adults generally know their own self-regarding priorities and have a sense of what they will find enjoyable, satisfying, and worthwhile that exceeds others’ predictions on the matter. When they are highly confident about the worthwhileness of their aims and what will make them happy, there is little basis for challenging their judgment.

Our claim here is not merely that it would generally be inappropriate, in practice, to second-guess a competent adult’s well-informed judgments about what would contribute to their well-being. We hold that no one has

¹⁵ There are close parallels here with narrative identity, one sense of the term “personal identity,” as discussed in Chapter 9. However, narrative identity as we construe it is essentially first-personal – that is, it concerns one’s *self*-conception. By contrast, the Narrative Requirement concerns a story about someone that could be told by that person or by others who know them well.

greater authority than an autonomous chooser regarding what *constitutes* their well-being. For example, if someone loves listening to opera and finds this activity rewarding, her response to opera makes it good for her to listen to it. If, however, she has exposed herself to a fair amount of opera – thereby becoming relevantly informed about what it has to offer – yet dislikes it and doesn't find it rewarding, then her response makes it the case that listening to opera is not intrinsically good for her.

These arguments notwithstanding, one might continue to disagree with our ascribing so much authority to a mature person regarding her own well-being. We doubt that we can win over everyone who is inclined to disagree with us on this point. We find, however, that ascribing such authority about one's own well-being to a mature adult is both fairly plausible on its face – more plausible than ascribing such authority to an external source such as natural law, a deity, or a rigid conception of human nature – and that this approach has plausible implications regarding individuals' well-being in particular cases, as we hope is evident in the sections that follow.

The third challenge to any account of well-being is related to the challenge just discussed: *being appropriately flexible with respect to differences among people*. It is clear that people have different passions, engage in different projects that they consider worthwhile, and generally enjoy very different activities. We think it implausible that there is any fine-grained ranking of these activities such that, for example, one person's development of her soccer skills is better than another's development of his cooking skills. Further, people have different aptitudes and characters. We find it plausible that most of them can nonetheless flourish. For example, it seems likely that what is good for an introvert and what is good for an extrovert differs. It also seems plausible that neither is intrinsically more fortunate in virtue of being an introvert or an extrovert; that is, both can flourish in the world as humans know it. We also believe, as discussed later in this chapter, that persons with substantial physical and mental disabilities are usually able to flourish if afforded appropriate support, even if their disabilities bar them from some activities (e.g., walking, reading) that many other people consider essential to their well-being.

8.5 Sketch of a Subjective Theory of Well-Being

The preceding sections presented a dialectic featuring competing accounts of prudential value and a set of challenges that any plausible account

should meet. Here we describe what we think is the most plausible theory of well-being: a subjective theory that combines aspects of hedonist and desire-satisfaction approaches.

We prefer a subjective theory for several reasons. First, as we have seen, objective theories have difficulty capturing the extent to which it seems that individuals have authority over what is in their interests, and difficulty in granting the flexibility regarding differences among individuals that seems plausible. Though it is possible to build such authority and flexibility into an objective theory, the more we do so, the less it seems that it is the objective goods listed in the theory that are guiding our judgments about well-being. For example, if our theory says that accomplishment is (for anyone) a component of well-being, then the theory can give us guidance but is not flexible enough. If it says that accomplishment is normally a component of well-being, but with exceptions for those, like Tushar, who do not seem to flourish through accomplishment, then the theory may be too indeterminate to be helpful and is so flexible that its status as an objective theory becomes questionable. Second, as we hope to show in sketching our theory, objective theories do not have obvious advantages in terms of better explaining at a fundamental level what well-being consists in or better capturing central intuitive judgments about cases.

Before we outline our preferred theory, it will help to revise the idea that the basic components of happiness are pleasure and the absence of pain.¹⁶ Even if we understand “pleasure” and “pain” broadly to include all pleasant and unpleasant experiences, for various reasons – such as guilt, asceticism, or a desire to concentrate on something else – an individual might not welcome pleasure in certain contexts; and for various reasons – say, a desire to test one’s self-control – one might welcome pain in certain contexts.

We replace the terminology of pleasure and pain with that of enjoyment and suffering. *Enjoyment* is a positive response to a whole situation – to which we may bring our values and concerns – while *suffering* is, in parallel fashion, a negative response to a whole situation.¹⁷ Theoretical emphasis

¹⁶ This move is suggested in L. W. Sumner, “Welfare, Happiness, and Pleasure,” *Utilitas* 4 (1992): 199–223.

¹⁷ Here we might be using the terms “enjoyment” and “suffering” more broadly than they are generally used. For example, we mean to include under “enjoyment” even quiet states of contentment and under “suffering” even mild states of dissatisfaction. It is worth noting, in addition, that our approach can accommodate the plausible idea that a distinctive sort of painful experience – say, spending meaningful time with a dying loved one – can contribute to one’s well-being. Someone who values this activity, finding it meaningful, *prefers* it to any pleasant alternative that lacks the meaningful interaction. Here one has a desire, grounded in gritty reality, to engage

on enjoyment and suffering not only permits us to understand cases in which we disavow pleasure or welcome pain but also helps to illuminate the idea that there can be mental states that are much better than just the sensation of pleasure or much worse than the sensation of pain. For example, enjoying an hour shared with someone you love involves much more than just feeling good – it also involves valuing the experience and understanding it in the context of a long-standing relationship. It is also very plausible that what we find valuable about such moments is correspondingly greater than what we find valuable in a pleasant sensation. Thus, enjoyment and the absence of suffering are better candidates than pleasure and the absence of pain for the basic components of happiness.

With this revision, we are in a position to see that the good ideas behind traditional mental-statism and desire-satisfaction theories depend on and can reinforce one another. Critics of mental-state theories are right to point out that a life of good feeling that is not conditioned by contact with reality is not a fully flourishing life. For example, it matters that we actually have deep relationships rather than just believing we do. Relatedly, it matters that what we care about is also appropriately conditioned by reality – if we desire something only because of false beliefs or mistaken reasoning, then fulfilling that desire cannot be expected to promote our well-being.

We propose that *both* enjoyment and the satisfaction of (narrative-relevant) desires are prudentially good for an individual; suffering and the frustration of (narrative-relevant) desires are prudentially bad for an individual. Moreover, reality has an amplifying effect. Enjoyment is prudentially better when it responds to a state of affairs that actually obtains. Likewise, the fulfillment of desires is prudentially better when those desires are rational and informed. The two aspects of well-being are often united where there is felt satisfaction, which usually accompanies our getting what we want. *What unifies enjoyment and desire-satisfaction in a single coherent account of well-being is the fact that both reflect the lived, self-caring perspective of a conscious subject.* The truth in mental-statism is related to the fact that everyone cares about their quality of life, finding some experiences likable or agreeable and some experiences dislikable or disagreeable. The truth in desire-satisfaction theory is the fact that complex subjects can care about or value things, prudentially, beyond their felt quality of life. And the reason that we have to restrict the desires whose satisfaction is relevant

meaningfully with the dying loved one – and, as we are about to see, desire-satisfaction has a place in our theory of well-being.

to our well-being is that not all of our desires are about our own lives in the sense captured by the Narrative Requirement.

8.6 Convergence among Plausible Theories

While we have argued in favor of a specific subjective theory of well-being, it is worth noting that its verdicts for many questions in bioethics are likely to converge with those of other plausible theories. For example, earlier we described a plausible objective theory, whose list of goods included autonomous living, deep personal relationships, accomplishment, understanding, aesthetic enrichment, physical and mental functioning, and enjoyment. Such a list would be flexible, such that the well-being of different human beings would be promoted in different ways and to different degrees by the various goods. The flourishing of an intense, solitary intellectual might require more in the way of accomplishment and understanding than in the way of deep relationships; maybe lifelong partnership, for example, is not for them. These and similar observations cohere with the idea that autonomous living – steering by one's own lights – contributes to well-being. Yet for some individuals the burden of decision-making may generate so much distress that they have less of a stake in having a wide range of options than in other goods. Moreover, most of these objective goods are ordinarily tied to a subject's experience. For example, it is hard to imagine having a close friendship without the friendship affecting one's lived experience.

An objective theory with characteristics like this would converge with our subjective theory in many of its verdicts about what makes people's lives go well or badly. Some of the points of convergence that will prove most relevant to problems in bioethics are as follows.

- (1) *Enjoyment and suffering will be very important to an individual's well-being on any plausible theory.* In mental-statism, we have argued, they are basic prudential goods and bads. In a plausible objective view, they will count as intrinsically good and bad, respectively, but there are other basic goods than enjoyment and maybe other basic bads than suffering.
- (2) *There is a significant asymmetry between enjoyment and suffering.* Although all sentient beings, human and animal, are capable of experiencing pleasant sensations, many things that positively contribute to well-being – at least among human beings – require greater cognitive capacities than mere sentience. These include the ability to

engage in personal projects and, especially, to have meaningful relationships with other people.¹⁸ By contrast, how much one can suffer seems less dependent on one's cognitive capacities. While greater cognitive capacities can amplify the suffering caused by pain, we think that beings incapable of finding meaning or distinctive (nonhedonistic) value in certain kinds of experiences are capable of undergoing intense pain, discomfort, or distress – and that this can be terrible for them.¹⁹ This suggests that, for many nonhuman animals, persistent suffering in the animal's life virtually guarantees that it is not worth continuing. As we will see later, this asymmetry is also important in considering the quality of life of impaired infants.

- (3) *Many of the goods of life can only be had – or can be had to a greater extent – by someone with sufficient cognitive capabilities.* On our subjective theory this follows from the earlier analysis of enjoyment. While a barely sentient creature would be able to experience pleasurable sensations, it would be unable to enjoy the rich variety of experiences and states of affairs that human life can offer. On an objective theory, many of the things that are objectively good for someone to attain – including living autonomously, deep personal relationships, many accomplishments, and understanding – require significant cognitive capacities. Note, however, that this observation is not an endorsement of intellectual snobbery. No PhD is needed to act autonomously or have close and meaningful personal relationships; nor need we think that the value of understanding relativity theory is somehow better than the knowledge acquired by gardeners, musicians, electricians, and cooks.
- (4) *Mature individuals have considerable authority – when adequately informed – to determine what is in their own interests.* If someone is not misinformed about the empirical facts and is not making errors of reasoning, then we should be very hesitant to contradict her claims about what is good for her. This is clear on our subjective theory; it is a concession that we think an objective theory must make in order to be plausible. This thesis captures much of the spirit of liberal political

¹⁸ Compare Nancy Rhoden, "Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts," *Southern California Law Review* 58 (1985): 1283; and John Arras, "Toward an Ethic of Ambiguity," *Hastings Center Report* 14 (2) (1984): 25–33.

¹⁹ Although only cognitively sophisticated beings can experience the suffering that is sometimes involved in deep shame or a sense of personal failure, we see no reason to think that these psychologically complex states involve *more intense* suffering than, say, a fox feels with a leg caught in a trap.

philosophy, and we embrace it wholeheartedly. It is also of paramount importance in bioethics. The mature individual's capacity to determine her own best interests is one pillar of the doctrine of informed consent (the other pillar being respect for autonomy rights). It is also important in establishing that the self-regarding priorities and values of a mature individual play a significant role in determining whether her death, in a given set of circumstances, is harmful to her (as discussed in Chapter 4).

- (5) *Subjective and objective theories will agree on many of the specific activities and states of affairs that are generally conducive to people's well-being.* These likely include autonomous living, deep personal relationships, accomplishment, understanding, aesthetic enrichment, good physical and mental functioning, and enjoyments.²⁰ Subjective and objective theories disagree on the status of these goods. For subjective theories, the value of these goods is instrumental but, with the exception of enjoyment, not intrinsic, whereas objective theorists assert the intrinsic value of such goods. Despite this theoretical disagreement, there is convergence on the prudential value – whether instrumental or intrinsic – of these goods. This point of agreement suggests conditions that both theories will agree tend to make people's lives go better. They include liberty and the protection of autonomy rights, freedom of association, education and fair equality of opportunity in the workplace, a minimum economic provision (food, clothing, shelter, etc.), access to health care, and opportunities for recreation and relaxation.

Having completed our theoretical exploration of well-being or prudential value, we turn to three significant areas of practical concern in which prudential value theory proves important.

8.7 Disability in Relation to Well-Being

Both in the academic world and in broader society the nature of disability and its relationship to human well-being or flourishing is hotly contested. Until recently, disabilities had been almost universally assumed to be objective defects in the physical or mental functioning of individuals. Disability advocates have challenged this simple picture. They deny that

²⁰ We propose this list as plausible for human persons, not necessarily for other types of sentient beings. We doubt, for example, that the absence of deep personal relationships amounts to a loss – the absence of a relevant good – for an animal that is solitary by nature.

people with disabilities generally lead lives as bad as people without disabilities suppose and assert that insofar as their lives go worse this is substantially a result of contingent, unjust social conditions.²¹ Their challenge raises the questions of what disabilities are and how bad they are for those who possess them. The answers to these questions have implications for how resources should be allocated to benefit people with disabilities, to what extent choosing or allowing disabilities for one's children should be allowed, and, more generally, how to think about disability in relation to human flourishing.

Turn first to the question of how bad disabilities are for the people who possess them. Even the way we have posed the question reveals the common assumption that physical disabilities, such as paraplegia and blindness, are prudentially *bad*. Yet many people with disabilities, even major ones, deny being frustrated with them. Indeed, some state that they are happy to be living a life characterized by their disability and that their experience with it has added something valuable to their lives.²² If disabilities are inherently disadvantaging, what are we to make of these positive self-reports?

One response is to say that these reports result from *self-deception* and *adaptation*, which can distort people's self-assessments of well-being. People deceive themselves when they permit themselves to believe something despite compelling evidence to the contrary. A disabled person may persuade herself that she is faring as well as she would without the disability, but, it may be argued, such a self-assessment is unreliable. In cases where individuals *lose* functioning as a result of illness or accident, adaptation is common: after an initial period of frustration and a sense of loss, the individual adjusts to his new situation and reports growing satisfaction with his life. Such cases may involve a *lowering of expectations* so that one comes to have desires (say, to watch the ocean waves) that are easier to satisfy than earlier desires (say, to surf or swim in the ocean).

Data on the quality of life of people with disabilities reveal diverging evaluations by people who have them and by people who do not. For the most part people overestimate the negative effects that disability or chronic illness will have on their lives. Their misapprehensions appear to result

²¹ In this section we use both the "people-first" terminology of "person with a disability" and the term "disabled person," which is argued to highlight the extent to which the disability experienced by people with physical or cognitive differences results from the way that the social environment has been set up.

²² See Elizabeth Barnes, "Disability, Minority, and Difference," *Journal of Applied Philosophy* 26 (2009): 337–355, especially 341–342.

from excessive focus on the disability's specific effects on their life (e.g., how having a colostomy will affect their ability to go out in a bathing suit, but not about the many activities that would not expose their colostomy bag) and from underestimating their ability to adapt to changed circumstances.²³ However, data also suggest that at least some *acquired* disabilities have long-lasting impacts on subjective well-being.²⁴ Even though people with acquired disabilities generally report faring better than would be predicted by people without disabilities, on average they report lower well-being than they had before acquiring the disability.²⁵

In the light of these phenomena, how should we evaluate the well-being of people with disabilities? For an objective theorist, someone's well-being must take into account not only the extent to which an individual meets their own present standards but also how those standards relate to the objective goods of human life. Accordingly, the objective theorist will maintain that major disabilities, such as blindness, deafness, paraplegia, and substantial cognitive impairment, are inherently disadvantaging and inimical to well-being. On our subjective theory of well-being, however, these conclusions do not follow. Well-being consists in reality-based enjoyment and the fulfillment of informed desires. The presence of disabilities may or may not, in individual cases, reduce well-being by these measures. We do not think that people with disabilities will, in general, be worse at identifying whether they are flourishing according to these criteria than people without disabilities. Moreover, the people living with the disabilities are clearly best placed to judge what living with them is really like.

Now, it is *possible* that people with disabilities who rate their quality of life highly are routinely self-deceived. But without good evidence in favor of this claim it seems as though we would be assuming that someone is self-deceived simply because we have assumed already that they must be worse off. Here, as elsewhere, barring evidence to the contrary, we accept that mature individuals are generally good authorities regarding their own well-being.

²³ Peter Ubel et al., "Mismagining the Unimaginable: The Disability Paradox and Health Care Decision Making," *Health Psychology* 24 (4S) (2005): S57.

²⁴ Richard Lucas, "Long-Term Disability Is Associated with Lasting Changes in Subjective Well-Being: Evidence from Two Nationally Representative Longitudinal Studies," *Journal of Personality and Social Psychology* 92 (2007): 717.

²⁵ Here we generalize over disabilities, even though the extent to which people adapt varies greatly depending on the type of disability. For example, people tend not to adapt psychologically very much to chronic pain, degenerative diseases, or schizophrenia. Psychological adaptation to stable, physical disabilities is much greater.

The phenomenon of adaptation following the acquisition of a disability is also not as problematic on our subjective theory as it might be for an objective theorist. Take the person who was once a keen swimmer but is now too physically frail to enter the ocean. Perhaps, to compensate, she takes up painting seascapes instead. Over time, she comes to enjoy painting the ocean as much as she once enjoyed swimming in it and comes to have desires related to watercolors and views, rather than exercising in the water. Provided that her enjoyment and desires are not based on mistaken beliefs or errors of reasoning, her new pastime may contribute just as much to her well-being as did her old one.

We have argued that there are good reasons to trust the evaluations of people with disabilities regarding how well their lives are going. Frequently, those evaluations rate the quality of life with a disability higher than it would be rated by someone without the disability. Nevertheless, as already noted, most people who acquire a major disability experience some enduring reduction in their subjective well-being. Perhaps, in addition, those who have *lifelong* disabilities typically, or on average, experience a lower level of well-being than those lacking such conditions. If in fact there is, typically, some disadvantage associated with disability, or at least major disabilities, what is the basis of this disadvantage? Answering this question requires us to ask what disability is.

According to the *medical model of disability*, a disability is a relatively long-lasting, biologically based condition of an individual that significantly impairs functioning in one or more ways. According to this mainstream conception, it is the person's condition itself that causes problematic functioning. Being blind, for example, is a disability because it excludes one from the important function of seeing. The *social model of disability*, by contrast, claims that disability involves a limitation or loss of opportunities to participate in valued activities or forms of community due to social or institutional barriers. According to this *disability-as-difference thesis*, so-called disabilities are really only differences in functioning from those considered normal.²⁶ From this perspective, such "disabilities" as dyslexia, deafness, blindness, and paraplegia are not *inherently* disadvantageous any more than being non-Caucasian is inherently disadvantageous. Disadvantages stem from the context in which the relevant conditions

²⁶ See, e.g., Union of the Physically Impaired against Segregation, *Fundamental Principles of Disability* (London: UPIAS, 1976); and Ron Amundson, "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," in David Wasserman, Jerome Bickenbach, and Robert Wachbroit (eds.), *Quality of Life and Human Difference* (Cambridge: Cambridge University Press, 2005), 101–124.

exist, contexts that often feature substantial discrimination and lack of consideration on the part of the “nondisabled” majority. In other words, any disadvantages that accompany the “disability” are contingent, rather than being necessary consequences of an objectively bad condition.

The case for the disability-as-difference thesis may proceed as follows. Whether a given condition is disabling depends on the context, environment, and existing social arrangements. Unless one wants to become a pilot, color-blindness is mostly ignored and not considered a disability. But if the green and red lights of traffic lights were placed in varying configurations so that color-blind people could not distinguish them, these people’s ability to drive safely would be significantly impaired and they would be disabled in that regard. Dyslexia is regarded as a significant disability only where reading is expected. Before reading became part of human culture, the same condition was probably not noticed, much less considered a handicap. Deafness is considered a disability by a hearing majority that uses spoken language, but it is really only a difference – one that might not be disadvantageous in certain environments. If everyone signed instead of spoke, and texted rather than called by telephone, deafness might not seem to be a disability to the hearing majority. Indeed, if our world were filled with loud, varying noises that consistently distracted hearing individuals, hearing might count as a disability.²⁷

Acceptance of the social model of disability would have significant implications. First, if disabilities are disadvantageous only because of the way the human environment has been arranged – that is, in a way that is convenient for nondisabled people without taking into account non-“normal” ways of living – then there will be a strong case in favor of removing or compensating for these disadvantages. If society makes disabled people worse off, then society has a strong obligation to correct this injustice. Second, the social model implies that people with disabilities are not people in need of “fixing.” Rather than expending resources on medical interventions to remove or prevent disabilities, we should be finding ways to change the environment so that people with disabilities are able to flourish.

We find the social model to offer a helpful corrective to the naïve simplicity of the medical model: it is true that there are many socially determined ways in which people with disabilities are disadvantaged because they do not function in the same way as the majority of people.

²⁷ Cf. Robert Sparrow, “Defending Deaf Culture: The Case of Cochlear Implants,” *Journal of Political Philosophy* 13 (2005): 135–152, at 138.

Examples include buildings that can be accessed only by stairs, important documents written in small print and unavailable in braille, and public lectures without signers. However, we think the social model exaggerates insofar as it claims that all disabilities are nothing more than social constructions.

We favor a more moderate *interactive model*, which construes disability as a product of the interaction between biological dysfunctions of an individual's body or mind – often called *impairments* – and the social and physical environment in which the individual lives.²⁸ Take a disability like blindness. Irrespective of society's choices, blindness is a physical trait that prevents normal functioning of a sort – namely, vision – that is deeply important to creatures like us. It is hard to imagine an environment in which humans would flourish but seeing would not tend to be beneficial to them. Inability to see is therefore an objective impairment in human beings, who normally see. Another example is clinical depression that is caused by an individual's natural brain chemistry (as opposed to being a response to particular events or circumstances). Depression, by its nature, causes suffering and makes enjoyment more difficult, so depression is inherently disadvantageous. To generalize, many severe disabilities prevent or impair functions that are – from the perspective of real human beings – undeniably important. These impairments, by their very nature, tend to interfere with opportunities for human well-being in the environments in which human beings live.

It is important to be clear about what does and does not follow from this interactive account of disability. It implies that at least some disabilities generally reduce the well-being of people who have them. For these disabilities, therefore, there are sometimes good reasons to develop and provide treatments for them rather than focus only on changing social and environmental factors. It also supports a presumption against permitting prospective parents to choose to create children with those disabilities when there are alternatives.²⁹

On the other hand, the interactive account does not abandon the insights of the social model, which should serve as helpful correctives to common ways of thinking about disabilities. First, we understand disabilities as involving an interaction between two factors: (1) a biological

²⁸ For a helpful discussion of these models, see Wasserman et al., *Quality of Life and Human Differences*, 12–13. For a critique of the distinction between disability and impairment that is central to the interactive model, see Elizabeth Barnes, "Against Impairment: Replies to Aas, Howard, and Francis," *Philosophical Studies* 175 (2018): 1151–1162.

²⁹ This presumption will be challenged in some "nonidentity" cases (see Chapter 10).

impairment of a function that is valued – either in contingent social circumstances (e.g., reading) or in all realistically imaginable human circumstances (e.g., seeing) – and (2) a social context, which importantly includes attitudes toward individuals with the impairment in question and any accommodations for it. In light of the second, social factor, we suggest that prejudicial attitudes toward individuals with disabilities must be identified and countered and that accommodations should be creative and extensive. These responses will help to increase opportunities and respect for individuals with disabilities, with likely improvements to their well-being.

Second, a particular disability need not prove disadvantageous for a particular individual even if it is disadvantageous for most people who have the disability.³⁰ Maybe it is true, for example, that blind people experience more frustration and suffering, *on average*, than sighted people for reasons connected to their blindness. However, if a particular blind person is just as happy with his life as the average sighted person is with her life, then there is no reason to judge his well-being to be lower due to blindness. Moreover, if it is true that blind – or deaf or paraplegic – people tend to be less happy than their “nondisabled” peers, that is due in significant measure to social arrangements, institutions, and attitudes of bias and condescension that could improve. So, even if some group of persons with disabilities is less well-off *today*, that may be a contingent fact rather than a necessary consequence of their disability.³¹

8.8 Making Decisions for Impaired Newborns

Some infants are born with such severe medical complications that it may be questioned whether continued life is in their interest. In the cases in which this question is most pressing, the complications entail not simply disabilities but the prospect of substantial, enduring suffering. In such cases, parents and health care providers may have to decide whether to initiate life-extending treatments, including the artificial administration of nutrition and hydration. As discussed in Chapter 5, where someone cannot make decisions for themselves and has no advance directive, as is the case with all newborns, medical treatment decisions should be guided

³⁰ Depression and chronic pain seem to be exceptions due to their directly negative impact on well-being.

³¹ This point is advanced in David Wasserman, “Philosophical Issues in the Definition and Social Response to Disability,” in Gary Albrecht, Katherine Seelman, and Michael Bury (eds.), *Handbook of Disability Studies* (London: Sage, 2001), 230.

by the reasonable subject standard. According to this standard, the proxy decision-maker for the child – normally a parent or parents – ought to decide on the child's behalf as the child would decide if they were a rational agent acting prudently within the constraints of morality.

The discussion in Chapter 5 noted that the reasonable subject standard differs from the best-interests standard, in part, by explicitly taking into account the interests of other parties who are affected by the proxy decision-maker's choice. In the case of a decision about whether to treat a newborn with an incurable, serious condition, two additional sets of interests are likely to be relevant. First, there are the interests of the parents, who will be responsible for looking after the child (assuming they do not give the child up for adoption). For children with severe disabilities this might entail a lifetime of caregiving. Also relevant are the interests of other members of society – especially others with serious medical needs – who are less likely to get needed treatment if the newborn is treated. All health care systems have limited resources: expending substantial resources on a newborn with a serious condition means fewer resources for others. For example, the baby might be occupying a space in a neonatal ICU that could be given to another very sick newborn with better prospects.

Although, as some of the examples that follow illustrate, we think that it can be legitimate for parents to give these other interests weight, we urge caution about when they should be allowed to do so. Very young children are completely dependent on others and unable to advocate for themselves. If parents are granted excessive discretion to refuse beneficial treatment, there is a danger that the newborn's interests will end up being inappropriately sacrificed. (Decisions about the rationing of care, where multiple parties would benefit from the scarce resources being distributed, should not be made by the parents of one of those parties, in any case.) We therefore recommend that parents not be permitted to refuse treatment for a neonate who is reasonably expected to benefit from it – except in cases in which benefit to the child is likely to be modest and the burden to the child's family is expected to be enormous. Where the child will *not* benefit from treatment, however, the interests of family and of the broader health care system provide strong reasons to withhold treatment.

This discussion indicates that in order to help parents make good decisions about the treatment of their severely sick newborn children, it is vital to assess whether a child is expected to live a life worth living if treated. In what follows, we consider a variety of incurable neonatal impairments. In each case, we ask whether it is in the interests of the infants to survive or to be given just palliative care to mitigate any

suffering. Where their survival depends on medical treatment, the question is whether it is in their interests to receive such treatment. In cases in which no medical treatment is required for survival, the question is whether it is in their interest to receive food and water.³² (We do not engage here with the additional issue of whether and when it would be permissible to actively terminate the life of a suffering infant, rather than allow the infant to die by not intervening. For discussion of the additional issues involved in euthanasia, see Chapter 4.) In several cases the expected net benefits to the child of treatment are either questionable or relatively low. We therefore consider, in addition, whether burdens to the caregivers might make it permissible to decline treatment.

Earlier we identified an asymmetry between enjoyment and suffering. Many factors that enhance well-being require greater cognitive capacities than mere sentience. These include the abilities to think of oneself as an enduring agent, to form plans and pursue them, and to have meaningful relationships with others. By contrast, how much one can suffer seems less dependent on one's cognitive capacities. Thus, we think that *very severe* cognitive disabilities can reduce an individual's capacity to benefit while still allowing them to experience substantial suffering. Where there is expected to be considerable suffering, then, this suffering is more likely to outweigh the benefits of continued life than it would in the case of an individual who is less cognitively disabled, since the latter individual is more likely to find sources of meaning and value that compensate for suffering.³³

Anencephaly is a condition that results when the head side of the fetal neural tube fails to close, resulting in the absence of major portions of the brain, skull, and scalp. Infants with this disorder lack cerebral hemispheres, which neuroscientists generally agree are necessary for consciousness.³⁴ Anencephalic infants, however, are often born with a functioning brain stem, permitting certain reflexes such as spontaneous breathing and

³² Our characterization of these medical conditions has benefited from three medical websites (all accessed September 28, 2020): National Institute of Neurological Disorders and Stroke, "All Disorders" (www.ninds.nih.gov/disorders/disorder_index.htm), US National Library of Medicine, "MedlinePlus: Medical Encyclopedia" (www.nlm.nih.gov/medlineplus/encyclopedia.html), and Genetics Home Reference, "Health Conditions" (<http://ghr.nlm.nih.gov/BrowseConditions>).

³³ Dominic Wilkinson, "Is It in the Best Interests of an Intellectually Disabled Infant to Die?," *Journal of Medical Ethics* 32 (2006): 454–459.

³⁴ Some neuroscientists, however, reject this view, holding that some form of consciousness is, or might be, possible for individuals lacking a cerebrum (see especially Bjorn Merker, "Consciousness without a Cerebral Cortex: A Challenge for Neuroscience and Medicine," *Behavioral and Brain Sciences* 30 [2007]: 63–81). Our discussion assumes that anencephaly precludes conscious experience or at least any sort of conscious experience that would enable a life worth continuing.

responses to sound or touch. Neurologists generally agree that such reflexive behaviors are not indications of pain or other conscious experiences, so that the capacity for sentience and higher mental life are permanently precluded. The life expectancy of such infants, even with life support, is not more than a few days or weeks – although a few cases of survival for more than a year have occurred.

How should we understand the interests of anencephalic infants? In our view, such infants have no interests at all because they are permanently bereft of consciousness. They cannot suffer any more than they can experience enjoyment. They cannot be harmed or benefited – at least in the usual senses of these terms that pertain to well-being. Being kept alive is therefore neither in their interests nor contrary to them. This entails that there is no morally important reason to provide life-supporting medical treatment (except perhaps to give parents a little time to come to terms with their child's condition). Given that there are weighty reasons against expending scarce medical resources on individuals who receive no benefit from them, the morally best decision for parents and clinicians is not to treat these infants.

Tay-Sachs disease is a genetic disorder in which infants, after apparently normal development for several months, begin a relentless physical and mental decline.³⁵ Afflicted individuals become blind, deaf, and unable to swallow. Muscles atrophy, leading to paralysis. Neurological symptoms include seizures and the onset of dementia. Children with Tay-Sachs may need a feeding tube. Most die by age four from recurring lung infections. Treatment is solely aimed at relieving symptoms, such as by using medication to prevent seizures and relax muscles.

Overall, we think that infants who live out their lives with Tay-Sachs do not experience enough good to outweigh the bad in their lives. Unlike normally developing children who are increasingly able to interact with their environment and the people around them, these infants become less and less able to access such goods. Moreover, there is clearly a great deal of suffering that accompanies the relentless decline in nervous system functioning.

However, because of the delay before symptoms of Tay-Sachs appear, the question of whether and how to treat newborns with the condition is challenging. The first months of life will not be bad for the infant, which suggests that it would be in her interests to live through those at least. It is

³⁵ A rare form of Tay-Sachs occurs in patients in their twenties or early thirties. We discuss only the more common, juvenile condition.

only because she is destined to suffer so much later that dying immediately after birth would be preferable. How much she will suffer later depends on both how effective symptomatic management will be and what options are available for assisting the death of young children. An additional complicating factor is the interests of the child's parents. It is not just that providing care for a medically complicated child is more burdensome than caring for other children – this might be true but primarily argues in favor of giving such parents much greater support. It is also the awful experience for the parent of raising and loving a child who is destined to die so young and in such a terrible manner. One could scarcely blame a parent who wanted to avoid such a fate.

Given the amount of suffering for the child and parents involved in seeing Tay-Sachs disease through its natural course, we think that the option of ending the child's life at birth should be available. Depending on one's views on the correct policy regarding euthanasia, this might entail interventions to end the newborn's life directly or the withholding of nutrition and hydration and providing comfort care. Moreover, if there will be no further opportunity to end the child's life when she has declined to the point that the suffering outweighs other prudential goods, it would be better to choose death as a newborn than wait until the child is three or four and suffers respiratory arrest.

Lesch–Nyhan syndrome (LNS) is an inherited disorder involving overproduction of uric acid. Symptoms include severe gout, poor muscle control, and developmental delay. Few children with this disease learn to walk and many have severe difficulty with speech. Beginning in the second year, compulsive self-mutilating behaviors emerge, such as lip- and finger-biting and head banging. Symptoms also include severe kidney dysfunction and neurological symptoms such as grimacing and writhing that are similar to those found in persons with Huntington's disease. Individuals with LNS usually die of renal failure in their first or second decade of life, though some survive well into adulthood.

LNS is clearly associated with a great deal of suffering. The physical symptoms are painful. The inability to walk and communication difficulties present serious impediments to many of the activities that make human lives go well. The self-mutilating behaviors are injurious to health, interfere still further with the patient being able to do as they want, and are highly aversive experiences – LNS patients do not welcome these behaviors but view them as alien. No one would deny that this is a tragic condition.

Is LNS so bad that it is better to die than to live with it? Despite some uncertainty on this matter, we think it probably is not. Three considerations are crucial to drawing this conclusion.

First, LNS is frequently described as involving substantial intellectual disability and consequently lower prospects for flourishing.³⁶ However, the data on cognitive impairment that seem to support this picture might reflect the challenges of administering standardized tests to this patient population, who have communication difficulties, tend to recalcitrant behavior, and cannot be schooled in standard ways. A survey of caregivers of forty-two LNS patients concluded that:

Only 1 boy appears to have any significant generalized cognitive impairment. The patients' memory for both recent and past events is excellent, their emotional life has a normal range of reactions and is appropriate; they have good concentration, are capable of abstract reasoning, have good self-awareness, and are highly social.³⁷

A later study suggested a picture lying somewhere between the claim of pervasive intellectual disability and the alternative just quoted: "intellectual levels ranged from moderate mental retardation to low average intelligence, with some common patterns of strength and weakness."³⁸ Based on these findings, and despite some empirical uncertainty about LNS in relation to cognitive disability, it seems reasonable to assume that in general people with LNS are capable of enjoying many things, including meaningful personal relationships.

A second crucial consideration in our thinking about this condition is that the self-mutilating behaviors that evoke such consternation in commentators on LNS can be managed to a substantial extent. At its simplest this management involves the use of restraints. It should be emphasized that people with LNS welcome receiving these restraints when they feel an urge to self-harm coming on.

Third, given that people with LNS frequently reach a point at which they can have reasonable understanding of their condition, we should respect their own views about whether their lives are worth living. We do not know of any studies that asked people with LNS so directly about their views on their lives, but suicidal behavior does not seem to be common. That suggests that people with LNS generally want to continue their lives, and we doubt there are compelling reasons to second-guess their apparent judgments that their lives are worth continuing.

³⁶ See, e.g., Wilkinson, "Is It in the Best Interests of an Intellectually Disabled Infant to Die?," 456.

³⁷ Lowell Anderson, Monique Ernst, and Susan Davis, "Cognitive Abilities of Patients with Lesch-Nyhan Disease," *Journal of Autism and Developmental Disorders* 22 (1992): 189–203, at 189.

³⁸ See Wendy Matthews, Anita Solan, and Gabor Barabas, "Cognitive Functioning in Lesch-Nyhan Syndrome," *Developmental Medicine and Child Neurology* 37 (1995): 715–722.

At the same time, the interests of parental caregivers are also morally important. Parents might find the prospect of raising a child with this syndrome, even with optimal support, overwhelmingly burdensome, especially considering the significant chance of losing the child in their first decade or two. Such a judgment would be understandable and might justify a decision to bring about the death of an infant diagnosed with LNS (unless there is a realistic prospect of transferring the child to adoptive parents who are well prepared to assume the burdens of care). Moreover, if parents made such a decision, any harm that death would entail for the infant would be significantly discounted due to his very weak psychological connections over time (see Chapter 4's discussion of our "gradualist" account of the harm of death). If, however, such an infant grows into a person, with the associated rights against harm and much stronger psychological connections to his future self, this would cease to be a permissible option for the parents to choose.

Juvenile Batten disease, an inherited disorder of the nervous system, is another condition that features a postinfancy onset. Indeed, its onset is sufficiently late that afflicted children are likely to be aware of their profound loss of capacities. Symptoms usually appear around age five or six, with vision problems or seizures. Vision loss advances rapidly, eventually resulting in blindness. After the initial symptoms appear, children with this disease experience developmental regression – losing previously acquired skills such as the ability to speak in complete sentences and motor skills such as the ability to walk or sit. They also develop bodily stiffness and slow movements. Affected children may have epilepsy, heart problems, mood disorders, and behavioral problems. Most people with juvenile Batten disease live into their twenties.

Given the relatively late onset of juvenile Batten disease, afflicted individuals typically have a significant segment of healthy childhood. After symptoms begin to appear, cognitive and physical decline is relentless and, with some aspects of health such as vision, rapid. What makes this disease especially devastating is that its victims experience life as ordinary-functioning, healthy children before undergoing the loss of their powers and health. The decline occurs late enough in childhood for the children to be aware of their deterioration. And most endure their condition for many years.

As with LNS, however, the tragic nature of the disease should not lead us to the conclusion that it is better to die at birth than to live a life with juvenile Batten disease. Even during the child's decline, most of the time their life will be worth living. After all, even if we judge blindness or the

inability to walk to be bad for someone, these conditions are entirely compatible with a life worth living. Likewise, with most mood disorders and other cognitive problems that people with juvenile Batten disease experience; very rarely would we judge that someone's depression is so bad that their life is not worth continuing. In considering these matters, those of us who are relatively healthy might assume that life with this condition is intolerable – because it is so much worse than our status quo – but fail to grasp that those who have this condition may regard living with it as preferable to not living at all.

At the same time, like LNS, juvenile Batten might be a condition in which burdens to caregivers are so great as to justify a parental prerogative not to preserve the life of an infant with this condition – despite the likelihood that the child would have several years of worthwhile life. We have in mind not only the burdens of providing direct care to an afflicted child as their symptoms become more severe, but also the emotional burden of losing a child in late childhood or adolescence. We find it reasonable that these costs to caregivers overturn the usual presumption that, if a child is likely to have a life worth living (even if it is a short life), the only reasonable option is to try to preserve that life. As with LNS, however, we note the possibility that the availability of capable adoptive parents might undermine any such prerogative of the biological parents.

The final condition we will consider is *Down syndrome* (or Trisomy 21), a condition caused by an extra chromosome 21. Individuals with Down syndrome have below average cognitive ability. About half of affected children are born with a heart defect and sometimes there are digestive abnormalities, such as blockage of the intestine. Individuals with Down syndrome also have an increased risk of gastroesophageal reflux (a backflow of stomach acids), celiac disease, hypothyroidism, and hearing and vision problems.

The severity of cognitive impairment and most of the physical problems that sometimes accompany the former are difficult, if not impossible, to forecast after an infant with Down syndrome has been born. Nevertheless, children, adolescents, and adults with Down syndrome – at least when supported appropriately – generally appear to have happy lives with significant personal relationships and often continual employment as adults. They are often among the highest-functioning of cognitively disabled persons.

Even if it is obvious that a diagnosis of Down does not justify overturning the ordinary presumption that survival is in a newborn's interests, what about Down plus a significant physical dysfunction? Suppose a baby

with Down syndrome is born with an immediately detectable heart defect or intestinal blockage. Normally, these anomalies can be easily corrected by surgery, so their presence along with the cognitive impairment of Down provides no serious reason to question the usual presumption in favor of preserving neonatal life. In several high-profile US cases in the 1970s and early 1980s, parents and medical personnel reasoned differently, allowing infants with Down syndrome who had life-threatening but surgically correctable defects to die from nontreatment. These decisions were seriously wrong.

8.9 Irreversibly Unconscious Patients

The previous section included a discussion of anencephalic infants, whose condition (neurologists generally assume) makes them permanently incapable of conscious experience. There are several other conditions – besides the temporary periods of dreamless sleep that we regularly undergo – that render an individual temporarily or permanently unconscious. *Coma* is a state in which one appears to be asleep and, except for spontaneous breathing, may appear to casual observation to be dead. Usually, within a few weeks, a comatose patient (1) awakens into consciousness, (2) dies in virtue of meeting legal criteria for *brain death* (in which all significant brain functions, including those necessary for spontaneous breathing, are irretrievably lost), or (3) enters a so-called *vegetative state*. In vegetative states, there is an absence of responsiveness and awareness due to overwhelming cerebral dysfunction but sufficient function in the brainstem to permit sleep-wake cycles – and therefore a sort of unconscious “wakefulness” – as well as a host of reflexes including yawning, swallowing, and eye tracking. The apparent wakefulness and reflex movements of vegetative patients sometimes induce observers to believe that the patients have some subjective awareness or consciousness. However, the absence of cerebral function appears to preclude this possibility. Matters are complicated by the fact that it is sometimes difficult to distinguish vegetative states from *minimally conscious states*, which patients can enter when they partially recover from vegetative states or comas. In minimally conscious states, patients have some conscious experience but are still too neurologically compromised to produce unambiguously purposeful or conscious behaviors.

The term *persistent vegetative state* (PVS) is a source of some confusion. According to standard medical usage in the United States and many other countries, a diagnosis of PVS – based on various neurological and other tests – indicates that due to extensive and apparently irreversible brain

damage, a patient is highly unlikely ever to regain consciousness. Informal guidelines permit making this diagnosis once a patient has been in a vegetative state for four weeks with no indications of recovery. Occasionally, such diagnoses prove incorrect when a patient emerges from the vegetative state into consciousness.

For the purposes of our discussion, we will introduce a technical term: *irreversibly unconscious state* (IUS). We will use this term to refer to any medical state about which competent neurologists would judge that recovery of consciousness is, for all practical purposes, impossible. Thus, IUS includes, along with anencephaly, PVS or coma where expert opinion states that there is no realistic possibility of the patient's regaining consciousness.³⁹

Family and medical personnel must decide whether to terminate life support for IUS patients. According to the commonly accepted hierarchy of medical decision-making standards, in cases in which informed consent is impossible, proxy decision-makers should follow a valid advance directive if one exists and applies to the case at hand. If not, they should attempt to apply the substituted judgment standard by determining on the basis of available evidence what the patient would have wanted in the present medical circumstance. If there is insufficient evidence to support a substituted judgment, then caregivers should apply the best-interests standard.

In Chapter 5, we argued for several modifications to this hierarchy. First, filling out an advance directive or appointing a surrogate decision-maker constitutes an exercise of someone's autonomy. There are good reasons to respect those decisions. Deciding on someone's behalf using a substituted judgment standard, however, does not involve the patient exercising their autonomy at all. Insofar as the substituted judgment standard is warranted, it is because what people would want is often a good guide to what is in their interests. This follows directly from our theory of well-being. Second, the best-interests standard does not capture all the considerations that are relevant to deciding on someone else's

³⁹ In this discussion we assume that the legal standards for the determination of death remain as they are today. Accordingly, we assume that an individual who is irreversibly unconscious yet maintains cardiopulmonary function or at least some brain function is alive. In Chapter 9 we argue that the higher-brain standard of death – according to which one who has irreversibly lost the capacity for consciousness is dead – is as reasonable as the cardiopulmonary and whole-brain standards. We do not infer from this that changing current laws is necessarily optimal; an alternative is to retain current laws and liberalize certain practices traditionally associated with a determination of death such as vital organ procurement and unilateral discontinuation of life support.

behalf, since sometimes the interests of others are morally relevant. Instead, where someone has not given instructions on how they should be treated, a proxy decision-maker should adopt a reasonable subject standard and ask: What would be in the patient's interests within the constraints of morality?

What can our theory of well-being tell us about an IUS patient's interests? IUS patients cannot have experiences, either now or in the future. This has led theorists who accept the Experience Requirement to judge that an IUS patient has no interests, in which case there is no reason to maintain them on life support.⁴⁰ As Allen Buchanan and Dan Brock put it, "the best interest principle does not apply to beings who have no capacity for consciousness and whose good can never matter to them."⁴¹

We rejected the Experience Requirement in favor of a theory that includes the satisfaction of informed, narrative-relevant desires as one aspect of well-being. Because people often have desires regarding what will happen to them in a state of irreversible unconsciousness, and these desires might be important enough for their satisfaction or frustration to affect their life stories, this suggests that IUS patients sometimes have interests.⁴² In some cases, then, remaining on life support is either in the interests of or contrary to the interests of an IUS patient. How should a proxy decision-maker then decide what to do?

To begin, note that the extent to which a patient's interests can be affected by her treatment while in an IUS is very limited. The patient cannot suffer, nor can she enjoy anything. Moreover, because the majority of people's desires are intimately linked to experiences that they could have, none of these desires can be fulfilled or frustrated by what happens to her when permanently unconscious.

⁴⁰ Here we set aside the possibility of justified continuation of life support for a limited time in order to give loved ones an opportunity to say goodbye to the patient while the patient is alive.

⁴¹ "Deciding for Others: Competency," *Milbank Quarterly* 64 (supp. 2) (1986): 67–80, at 73.

⁴² Some commentators thought this was true of Nancy Cruzan, the American PVS patient whose parents fought for removing her feeding tube, arguing that some of Cruzan's prior statements expressed a desire not to live in PVS. In response to this case, the US Supreme Court recognized for the first time a right to refuse unwanted medical treatment while also judging that the state of Missouri (where Cruzan resided) did not violate her constitutional rights by applying a "clear and convincing" standard of evidence for determining what she would have wanted. See United States Supreme Court, *Cruzan v. Director, Missouri Department of Health*, in *United States [Supreme Court] Reports* 497, 1990: 261–357. For a commentary that rejects the "clear and convincing" standard as overly strict, see John Arras, "Beyond *Cruzan*: Individual Rights, Family Autonomy, and the Persistent Vegetative State," *Journal of the American Geriatric Society* 39 (1991): 1018–1024.

Nevertheless, it is useful to consider desires someone may have that could be relevant to her treatment while in an IUS. These are most likely to be desires relating to her body, to specific interventions that might be used on her, and to other people. Regarding her body, she might be concerned about the “indignities” involved in continued care, such as emaciation, highly contorted postures, permanent incontinence, and compromised privacy. These concerns are amplified for patients for whom resuscitation will be attempted if they experience cardiac arrest. Such resuscitation can be quite violent. On the other hand, she might care about the continued biological life of her body and want it to be prolonged as long as possible. Someone might care about specific medical interventions – for example, she might not want cardiopulmonary resuscitation, artificial respiration, and other “aggressive” life support, but still want artificial nutrition and hydration as well as antibiotics as needed. Regarding other people, one might think that such a patient can continue deep personal relationships, but such relationships would be so one-sided – with the patient completely unaware of them – that we cannot plausibly ascribe much of a contribution to the patient’s well-being on the basis of such relationships. She might still care a great deal about the well-being of the people close to her; for example, she might want them not to see her waste away or be burdened by medical decision-making, or she might want them at her bedside.

After weighing up whether continuing on life support is in the IUS patient’s interests, a decision must be made about what to do. If there is reason to think that maintaining life-support measures would be contrary to the patient’s interests, then the decision is straightforward: these measures should be discontinued. If there is no evidence to suggest that she would have wanted to remain on life support, we think it is also best to remove her from it. For most people, there are likely to be desires that will be thwarted either way. A judgment about whether remaining on life support is in someone’s interests is therefore very difficult to make. But there are also additional reasons for taking her off life support relating to the opportunity costs of using scarce medical resources. Where we are unsure either way about the patient’s interests, these additional reasons should be sufficient to provide a verdict about what to do. In this regard, it is worth recalling how restricted the possible interests are that can be affected in an IUS. It does not take as much to outweigh them as it would to outweigh the interests of someone who was expected to regain consciousness.

If, on the other hand, there is good evidence that a patient in an IUS would prefer to remain alive, then this provides a consideration in favor of

maintaining her on life support. In this case the question of how to proceed is much more challenging. In most cases, we think the presumption should be to withdraw life-support measures from irreversibly unconscious patients. The factual basis of this prerogative is concerns about resource allocation and the reasonable assumption that better use can be made of a health care institution's resources and personnel. The moral basis of this presumption becomes apparent when we remember the proviso of the reasonable subject standard, which calls for making medical decisions as the patient would make if acting prudently *within the constraints of morality*. In this context, the constraints of morality include responsible use of health care resources.