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**Caring for Persons with Intellectual and  
Developmental Disabilities**

**Ethical and Religious Perspectives**

Edited by Jos V. M. Welie

**Prayer Time with Tessa**

**Ethical Reflections about Paternalistic Decision Making on Behalf of  
Cognitively Impaired Persons**

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**Abstract**

Owing to the nature of their disability, paternalism is an inevitable reality in the daily lives of the intellectually disabled. Decision-making by others for their assumed best interests, but without their explicit consent, is usually beneficial and frequently justifiable. Unfortunately, the history of care for those with intellectual disabilities is replete with examples of misguided and often harmful paternalism excluding them from activities that are central to their ability to flourish. This paper analyzes under what conditions paternalism in the care of

adults with cognitive disabilities is justified, and is limited to instances in which such paternalism seeks to advance their spirituality.

Keywords: cognitive disability, developmental disability, ethics, intellectual disability, L'Arche, paternalism, spirituality

I decided to stay for dinner one night.<sup>1</sup> Dinner in the household is more of a traditional meal with everyone present. This included all of the core members (Derek, Marcus, Hank, Samuel, Rupert, and Tessa) and the live-in aides (Trent and Sarah) and me. The dinner was simple fare, plenty of it, and lively conversation around the table.

Tessa was at the end of the long table and had Sarah there to assist her. Tessa has the most severe case of Down syndrome in the community – she has the lowest verbal skills of the group and is difficult for an outsider to understand. Over time, the aides and other staff have learned to understand Tessa between her sparse verbalizations and her suggestive body language. Tessa seems to float in and out of our reality, drifting between participating in the group to looking off into space. Occasionally, she utters a series of short, loud sounds that are not words but have some individual meaning to her.

After dinner concluded it was nightly prayer time for the group. This prayer time was started by lighting a candle, followed by a formal opening prayer of thanks to God the Father by Trent, and then individual prayers by everyone at the table, initiated by Derek. Although he had been up to his usual antics throughout the meal, he focused very seriously and offered a solemn and humble prayer. All present took their turn, and all were quite reverent and whole-hearted; no one offered prayers in an insincere manner or from memorized forms.

Tessa's turn came at the end and I had been wondering how she would handle it, as she seemed to not be paying much attention during everyone else's prayers. When the candle was passed to Tessa, she did not seem to acknowledge that it was there, and Sarah had to get her attention several times.

Sarah took her arm: "Tessa, Tessa, it's time for nightly prayers, can you pray with us?"

Tessa focused on Sarah, smiled, and then looked away and left us again, uttering some clipped sounds.

Sarah tried again: "Tessa," she said, patting Tessa's arm, which she was still holding, "Tessa, Tessa, can you pray? Can you pray tonight, Tessa?"

Tessa looked back at Sarah, smiled, agreed verbally, and nodded a bit, but then drifted off again turning her gaze back toward the candle but not actually looking at it. She made some more noises.

Remaining patient, undeterred and smiling, Sarah gently persisted: "Tessa, Tessa, it is time to pray now. Tessa, you need to pray. Can you say a prayer, Tessa?"

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<sup>1</sup> This narrative summarizes the personal experience of co-author Paul Babcock, who observed this community while enrolled in his Practicum Course, leading to a Master of Science in Health Care Ethics degree program granted by Creighton University. Names have been changed for the protection of the individuals' privacy. The community is a group home operated by L'Arche, which is an organization that seeks to create a home environment for adults with developmental or intellectual disabilities, such as Down syndrome, so that they can live in a safe but semi-independent environment. L'Arche is a spiritually-oriented organization, co-founded by Jean Vanier. Although originally Catholic, as it has expanded throughout the world and encountered other faiths, L'Arche has learned to incorporate the local faith traditions, such as Hinduism and Islam, in the formation of its communities (<http://www.larcheusa.org>; Vanier 2005). L'Arche is distinctly different from many other adult living homes, in that it seeks to engage both the residents with disabilities and the staff members (or visitors) in "transformative relationships," where the intellectually disabled teach the "normal" about themselves through being assisted in coping with their weaknesses (Vanier 1992).

Tessa looked at her, focused, and finally understood. She abruptly turned her cross-eyed gaze to the candle directly before her, and very solemnly offered a whispered prayer, smiling all the while. Joy and love emanated from her with an almost visible glow as she offered her prayer. She then blew out the candle, which took a few attempts, and everyone clapped – the perfect ending to this beautiful time of prayer.

## Introduction

What we witness in the above narrative is a wonderful experience of Tessa praying. Yet she had to be guided and metaphorically dragged by the live-in aids to arrive at that moment. Tessa does not appear to actively resist their guidance. Thus we have no reason to believe that their guidance was exercised against Tessa's will. But we are left wondering whether Trent and Sarah, in their desire to involve Tessa in the group's nightly prayers, are making decisions for her that she would not have made on her own.

Coaching others to do things they may not have done on their own is an activity with which parents are very familiar. Indeed, parents are expected to do so and could be found guilty of neglect if they did not. The same is true of elementary and high school teachers who derive their responsibility and authority to do so by virtue of their acting *in loco parentis*. But college professors lack that authority, as do the parents of their college age children. The legal age of adulthood is technically the end of parental authority and responsibility. Generally, care givers make decisions on behalf of other adults because they are authorized to do so, but we still label such behavior as "paternalistic," which literally means acting in a "fatherly" manner. However, such paternalistic care-giving may not always be considered moral and legal. Even if the care rendered is objectively beneficial, some additional justification is necessary for such paternalistic care-giving to be considered morally sound.

The concept of paternalism is associated primarily with the world of health care and discussed mostly by bioethicists. Because of the dominance of the bioethical principle of respect for patient autonomy (about which more will be said below), paternalistic caring not only is in need of some additional justification besides its being beneficial to the patient involved; it has actually taken on a pejorative connotation and is assumed to be iniquitous except in very exceptional circumstances. To label an action as "paternalistic" in the eyes of many is virtually equivalent with considering it immoral.

As one of us has argued elsewhere (Welie), this pejorative understanding of paternalism in bioethics is quite dubious because of what it generally assumes about the nature of the therapeutic relationship: that health care providers are not able to know what is truly in the best interest of their patients. Hence, unless patients themselves indicate what care they want to receive, there is a real chance that those benevolent actions will turn out to be maleficent. In the annals of health care there is no shortage of examples of such harms being inflicted by overbearing, paternalistic physicians. And this is why paternalism is properly a topic of ethical reflection. But it does not follow logically that paternalism is *qualitate qua* morally suspect.

Indeed, even within today's anti-paternalistic paradigm, health care professionals continue to do many things to patients that are in the latter's presumed best interest and without those health care professionals ever having been authorized by their patients to do so, such as examining and monitoring patients, running tests, adjusting therapies, etc.

Ethicists may argue that these interventions are justified because of an implied consent by the patients involved.<sup>2</sup> But the simpler explanation, and surely the one that better matches real life practices, is that health care professionals simply take it for granted that they may and must do these beneficial things for and to their patients. These routine decisions do not cause any ethically challenging dilemmas and hence are not viewed as paternalistic.

The foregoing reflections about the field of health care for adult patients apply *a fortiori* to the area of care for adults with cognitive disabilities. Owing to the nature of their disability, the intellectually disabled will require some degree of assistance with many of the mundane tasks of life, and generally with important decisions as well. Paternalism, therefore, will always be an inevitable reality in the lives of the intellectually disabled, and indeed a beneficial reality in most instances. Unfortunately, the history of care for cognitively disabled persons is replete with examples of all kinds of harmful paternalism, including imprisonment, sterilization, experimentation, and euthanasia.

In this paper we seek to analyze under what conditions paternalism in the care of adult persons with cognitive disabilities is justified. Two such conditions can be readily discerned. First, in order to even qualify as a paternalistic intervention, the care must likely advance a significant interest of the person who is being coaxed to do something he or she might not have done otherwise. In this paper we are going to assume that spirituality falls in this category. We realize that this presumption is not without its critics (e.g., Smith). But the simple fact that the U.S. Constitution explicitly protects the right to freedom of religion seems to support our presumption. It can even be argued that spirituality is of greater significance than health, since the U.S. Constitution is completely silent about health and health care. We are also going to assume that cognitive disability does not render this right moot.

Second, since paternalism by definition always involves some degree of pressure, either without the compelled person's agreement (soft paternalism) or in opposition to her expressed wishes (hard paternalism), and since such pressure conflicts with the respect that we owe the other person's autonomy, a careful balancing is necessary. The benefit gained must outweigh the resulting harm to the patient's autonomy. When a disabled person is unable to sit still for a prolonged period of time in a dental chair, but treatment is urgently needed for an abscessed tooth, the benefit of receiving effective treatment will generally outweigh the paternalistic administration of sedatives. But does the benefit of active participation in communal prayer outweigh the paternalistic pressure needed to get somebody like Tessa to participate?

Here we need to add a caveat: ethical questions only arise when the coaxing is such that it makes another person do what the latter does not (seem to) want to do and would likely not have done on her own account. We readily grant that Tessa is not a paradigmatic example of paternalistically coaxing a cognitively disabled person into adopting a particular spirituality. One could reasonably surmise that Tessa likes to pray but occasionally needs a

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<sup>2</sup> Such consent is thought to be implied by an explicit and more encompassing consent given earlier. For example, it can be argued that by coming to the office of a physician, the patients' consent to be interviewed and examined by the physician is implied.

little nudging. Then again, spirituality is not like an artificial heart that can be implanted in a single dramatic surgery; it is implanted through a series of small engagements like the one described above. Taken together, many small instances of coaxing Tessa into prayer could be viewed as proselytizing, which would raise serious ethical questions.

If we grant that spirituality is an important benefit to most people, including cognitively disabled persons, and if we furthermore grant that precisely their being cognitively disabled often makes it more difficult to discern what care actions undermine the respect of their autonomy that we owe them, the question now before us is whether and under what conditions the kind of paternalistic pressure exerted by the live-in aids to get Tessa to participate in a spiritual practice can be ethically justified. Since the ethical dilemma of paternalism is evoked by the autonomy of the persons involved allegedly being placed at risk by such paternalism, we begin by revisiting the autonomy of persons with cognitive disabilities. We then reexamine the benefit allegedly advanced, that is, their engagement in spirituality. In the third section we try to outline the specific conditions that must be met to justify paternalism.

Before we embark on our analysis, we need to acknowledge that our examination is limited by the monotheistic perspective on spirituality that we adopt here. Our first reason for doing so is, quite simply, that our own experience and expertise are limited to this perspective. Second, we are interested in those forms of spirituality that are communally practiced as opposed to, for example, solitary meditation or privately adopted belief systems. We are painfully aware that the disabled have been both protected and vilified by monotheistic religions throughout the ages (Harris 2006). However, contemporary monotheism has become relatively consistent in protecting those with disabilities (Harris 2006; PBS). Although some religious leaders still exercise their paternalistic power to keep “the deaf and the dumb” out of their faith community, our ethical reflections are focused on the question whether and when *inclusionary* paternalism is justifiable (Harris 2006).

### Autonomy Revisited

Particularly in Western societies, where individual choice and the exercise of personal liberty are cherished political and moral principles, any restriction of a person’s autonomy is generally considered a severe harm. All forms of directing another person, even if truly for her own good, are considered morally suspect. Indeed, the mere possibility that somebody’s autonomy can end up being restricted leads to the label “paternalism,” as in “soft paternalism.” Much has been written about the topic of autonomy, which we will not even attempt to summarize here. However, in view of the specific issue we are discussing in this paper, two aspects of this debate about personal autonomy merit closer attention: power and rational choice.

It is, unfortunately, often likely that those with the power to compel will abuse their right to compel not to benefit those they are supposed to lead or govern, but rather to advance their own interests. Power is enticing, as it was even for Christ himself such that he had to chase away the devil and his temptations. This concern about abuse is what led political philosophers such as John Locke (1632-1704) and John Stuart Mill (1806-1873) to insist that governmental structures should not be based on a paternalistic relationship in which the ruler, like any father, can be expected to benevolently lead his subjects in return

for trusting submission. Rather, each person's individual freedom is the cornerstone of any morally sound political system and it is the consent of the governed, and only their consent, that can justify governmental power. Following Mill, Peter de Marneffe argues, "that our interests in individuality will be inadequately protected unless the government observes a general principle of antipaternalism because paternalistic policies stifle individuality" (86-87). The relative success of representative democracies to maintain peace and justice supports this line of reasoning. But it is far less clear that this antipaternalistic principle carries as much weight outside the political domain and specifically in narrower relationships of care.

For example, the cornerstone of the relationship between health care professional and patient is not consent, but trust. Health care providers do, of course, have to obtain consent from patients before initiating a treatment, but that consent is only a final check to ensure that the patient is indeed willing and ready to undergo the treatment plan developed in close cooperation between provider and patient. It is even justifiable for a health professional to presume consent when it is not physically possible to obtain an explicit consent from the patient (as in emergency room situations), or to rely on the consent of a family member (when the patient is not competent to provide consent).

In genuine relationships of care, trust is a more important ethical principle than respect of each other's autonomy. While granting the need for further empirical evidence, it seems a safe presumption that unlike politicians, those who dedicate themselves to guiding people with developmental or intellectual disabilities do not crave power, and, while not immune, are less prone to succumb to the temptations of power. Likewise, the motive for someone seeking guardianship of a cognitively disabled person generally is concern for that person's welfare. But even benevolent individuals can succumb to the temptations of power. Abject abuses in the not too distant past such as the forced sterilizations and compulsory euthanasia of the "feeble-minded," supposedly for their own good and for the good of society, demonstrate the ease with which such guardianship can descend.

Conversely, it is clear that cognitively disabled persons are dependent, to varying extents, on the help of their caregivers. Some may require help for daily tasks like getting dressed or bathing; others may only need help in the proper administration of a medication; still others need help in managing financial resources. Not only would it be foolish to deny this relationship of dependence, it would also be a disservice to those involved in this relationship. Indeed, all of us rely on the assistance of others almost every day in some form or another. It is interdependence that is the backbone of any family or community, as well as of society itself. Interdependence is not the contrary of independence, nor does it restrict independence. Rather, human beings are by their very nature social beings who can only flourish within interdependent relationships. This is what L'Arche is actually trying to accomplish, to allow those with intellectual disabilities to flourish through meaningful relationships built on trust.

Sometimes, our interdependence involves coaxing or even some measure of compulsion from others. Parents compel their children to dress warmly before going out in the snow; teachers compel pupils to study hard; employers compel their employees to take on more demanding tasks; police officers compel drivers to slow down and wear a seat belt; health authorities compel the public to be vaccinated. We can try to justify all of this compulsion by

pointing to the representative political systems we have put in place, which allow us to argue that our freedom is not really restricted by all this compulsion since we freely consented to being so compelled. But this theoretical justification does not adequately reflect the reality that all of us routinely submit ourselves to multiple forms of guidance, coaxing, and occasionally even compulsion. We surmise that most of us accept this reality not because of the sophisticated democratic structure we have put in place, but quite simply because we *trust* the people who guide and coax and compel us.

The second critical note that must be made about the contemporary emphasis on the ethical principle of respect for individual autonomy concerns the highly intellectual and indeed rationalist nature of autonomy. Both in the secular and in the religiously informed literature on this topic, it is generally presumed that autonomy proper or genuine self-determination equals considered choice, which in turn presupposes the capacity for rational deliberation and freely willed action.

Several times, we have already mentioned the phenomenon of patient consent, which is the single most important operationalization of the modern bioethical principle of respect for patient autonomy. Prior to any medical intervention, a health care professional must provide the patient with detailed information about the latter's diagnosis, prognosis and treatment options, and then obtain an explicit consent from the patient. Furthermore, the patient's consent is valid only if the patient is competent to consent. Competence, in turn, presumes the capacity to understand information, retain it, consider it, and then derive decisions from it. If patients are unable to engage in any part of this intellectual process, they are deemed incompetent, that is, unable to behave in an autonomous manner; instead, another intellectually more capable person will be enlisted to make health care decisions on behalf of the patient.

This emphasis on rational deliberation and decision making is tempered only by the fact that patients must be assumed competent unless proven not to be so, which results in a rather low threshold for patient decision making competency: as long as patients agree with their doctors' recommendations, nobody will question their competence. But now the question arises why this kind of abidance by common and expected patterns of behavior and ready submission to the expertise and benevolence of men and women in white coats is indicative of genuinely autonomous, let alone authentic, behavior on the part of patients. Conversely, for the category of persons whose life as a whole defies a neat fit in established patterns of behavior, it would seem counterintuitive that genuine respect of their self-determination is conditional on their concordance with the established rationality of the health care system and its providers.

We are not here advocating a wholesale rejection of rational decision-making. We are, however, calling attention to the rather narrow, overly rationalistic understanding of autonomy that prevails in contemporary bioethics, both secular and Christian. This understanding can easily lead to an under-appreciation of other modes of exercising autonomy that are not reason-oriented and that persons with cognitive disabilities utilize. For example, James C. Harris (2010), a physician specialist and expert in the field of the intellectually disabled, makes the case that these persons rely much more on empathy than on rational deliberation. Whereas nondisabled persons may use both reason and empathy,

the cognitively disabled tend to overcompensate with empathy for their diminished reasoning capacity. Harris provides the example of a runner in the Special Olympics, who, although winning, went back to help a competitor who had fallen down. For them, empathy is a more important source of moral knowledge than reasoning because doing the right thing is *felt* more than *thought*.

Empathy is necessarily relational (unlike intellectual knowing). It always involves another person, not merely some object that is seen or an idea that is understood. Not surprisingly then, throughout the literature on persons with cognitive disabilities, the importance of relationships appears and reappears as a defining characteristic. This suggests that genuine respect for persons with developmental or intellectual disabilities cannot be realized primarily, let alone adequately, by fostering their independence, privacy, and other aspects of individual freedom. Rather, their capacity to relate and their embeddedness within a close-knit community must be respected, protected, and nurtured. Consequently, paternalistic interventions towards those with developmental and intellectual disabilities are ethically most precarious not when and because they restrict the autonomy of the individuals affected, but when and because they endanger relationality and embeddedness. We will return to this observation in a later section.

### Spiritual Interests

As mentioned earlier, paternalism proper presumes that the coaxed behavior will benefit the person who is so coaxed. But how exactly is spirituality beneficial to the intellectually impaired? Do developmentally or intellectually disabled persons have needs that are best met through spiritual engagement such as active participation in communal prayer?

Those who tend to answer the latter question negatively commonly use one of two justifications to exclude these persons from religious services: (1) they are disruptive and distracting to others, and (2) they do not understand what is going on anyway (PBS; Smedes; Swinton). The first objection fails because it is based on the interests of *other* worshippers who do not want to be bothered by the allegedly noisome disabled, rather than on an assessment of the needs of the disabled worshippers *themselves*. We suggest that the need for perfect quietude of some abled persons does not outweigh the spiritual needs of the disabled, particularly since the former can easily create other modes of worship such as meditation.

The second objection ultimately fails as well but is more sophisticated. We acknowledged earlier that religious leaders have in the past, and occasionally still, exclude persons with developmental or intellectual disabilities from communal spiritual practices because it is assumed that benefit from these practices is conditional on a rational understanding of the nature and purpose of such practices. For example, in order to participate in holy communion within the Catholic Church, the Code of Canon Law requires that person to have attained “the use of reason” and “understand the mystery of Christ.”<sup>3</sup>

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<sup>3</sup> *Code of Canon Law*, 914: “It is for the pastor to exercise vigilance so that children who have not attained *the use of reason* or whom he judges are not sufficiently disposed do not approach holy communion” (emphasis added). *Code of Canon Law*, 913 §1: “The administration of the Most Holy Eucharist to children requires that they have sufficient knowledge and careful preparation so that they understand the mystery of Christ according to their

But a careful reading of the Code also makes clear that the decisive criterion is not whether the person has a solid theological understanding, but rather, whether the person is “able to receive the body of Christ with faith and devotion” (canon 913, §1), or – if even that is not attainable – at least is able to “distinguish the body of Christ from ordinary food and receive communion reverently” (canon 913, §2).<sup>4</sup> In other words, the recipient must be able to recognize the transcendent nature of the practice of Holy Communion and react accordingly. That is, the person must be capable of spiritual engagement. This would suggest that use of reason catalyzes spirituality but is not a necessary condition.

If spirituality is, at its core, a dialogue with God, it would be utterly anthropocentric to assume that God is only able to dialogue with his creation in an intellectual mode. Indeed, if we provide options for the developmentally and intellectually disabled members of the human family to enter into a dialogue with God and we are willing to carefully observe, we will readily notice that they are quite able to pray and worship, are engaged and enjoying it, and are understanding in an emotional/relational manner that supports their dialogue with God (PBS; Smedes; Swinton). Allowing someone with Down syndrome to “conduct” the choir in front of the congregation harms no one and meaningfully engages that person in the religious service (personal observation by Babcock). Most importantly, passionate conducting may constitute a greater form of glory to God and be more pleasing to him than what is done by the real conductor, particularly if the latter is doing so simply for the sake of being paid to do so.

Rejecting the aforementioned two objections does not yet establish affirmatively that developmentally or intellectually disabled persons do indeed have needs that are best met through spiritual engagements. More specifically, we have yet to establish that the alleged spiritual needs of these persons are so important that a certain degree of paternalism to achieve their realization may be justifiable. Furthermore, as discussions on paternalism in health care have already made clear, for paternalistic coaxing to be justifiable, these needs must present themselves as vulnerabilities to be redressed rather than as pathways to flourishing. Thus, it may be justifiable to pressure a leukemia patient who is disillusioned by

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capacity and are able to receive the body of Christ with faith and devotion.” Note that canon 913, while insisting on “sufficient knowledge,” appears to make the level of “understanding” to be attained conditional on the specific “capacity” of the child, thus enabling considerable flexibility.

<sup>4</sup> *Code of Canon Law*, 913 §2: “The Most Holy Eucharist, however, can be administered to children in danger of death if they can distinguish the body of Christ from ordinary food and receive communion reverently.” Although this paragraph pertains to dying children only, the United States Catholic Conference of Bishops in its 1995 *Guidelines for the Celebration of the Sacraments with Persons with Disabilities* actually uses this lower level of intellectual capacity as the benchmark in case of persons with developmental or intellectual disabilities: “It is important to note, however, that the criterion for reception of holy communion is the same for persons with developmental and mental disabilities as for all persons, namely, that the person be able to distinguish the Body of Christ from ordinary food, even if this recognition is evidenced through manner, gesture, or reverential silence rather than verbally. Pastors are encouraged to consult with parents, those who take the place of parents, diocesan personnel involved with disability issues, psychologists, religious educators, and other experts in making their judgment. If it is determined that a parishioner who is disabled is not ready to receive the sacrament, great care is to be taken in explaining the reasons for this decision. Cases of doubt should be resolved in favor of the right of the baptized person to receive the sacrament. The existence of a disability is not considered in and of itself as disqualifying a person from receiving the Eucharist” (§20).

the slowness of the progress achieved into undergoing yet another round of chemotherapy, but not to pressure a healthy adult to undergo in vitro fertilization or cosmetic surgery.

Several works on spirituality regarding the intellectually disabled advise utilizing the Tartaglia framework as an evaluative tool for diagnosing their spiritual needs (Prins; Gaventa; Harris 2006). Tartaglia's framework, originally developed for the spiritual needs of HIV patients (although applicable to anyone), is organized around four main categories of vulnerability or woundedness: fear, alienation, guilt, and despair. For example, a spiritual diagnosis of alienation, which can be diagnosed by observing feelings of rejection and habits of estrangement, indicates an underlying existential/spiritual question of "Do I belong?" (Landau-Stanton et al.; Harris 2006). Jean Vanier comparably claims,

I have discovered that even though a person may have severe brain damage that is not the source of his or her greatest pain. The greatest pain is rejection, the feeling that nobody really wants you "like that." The feeling that you are seen as ugly, dirty, a burden, of no value (1992: 13).

In addition to being one of four primary forms of woundedness, alienation can also become the cause of any of the other three. Given that empathy and relationships compensate for diminished reasoning capacity in persons with cognitive disabilities, a sense of not belonging is one of the psychologically most destructive actions that they can experience. Inclusion in the spiritual community hence is of great importance to a population that is suffering from rejection because inclusion ameliorates profoundly felt pain; and pain often motivates people to engage in bad and disruptive behaviors (Vanier 2005). For this population in this context, respecting "the other" demands inclusion: "Alienation is rectified through social acceptance, through communion, and embracement, and the experience of being loved and included as a member of the community" (Harris 2006: 342).

Whereas the intellectually disabled benefit from inclusion in a spiritual community by healing the emotional toxicity of rejection, there is an additional beneficial aspect worthy of examination. Based on his experience with the intellectually impaired, Swinton concludes that love of God and love of neighbor are not separate commands but are inextricably connected:

[W]e can see that for the profoundly handicapped individual, awareness of the transcendent love of God is mediated through, and experienced in, temporal love, offered in loving relationships. It is therefore in the quality of our relationships, as opposed to the quantity of our intellect, that the image is restored. Consequently, all human persons can be seen to have spiritual potential. For the profoundly cognitively disabled person . . . The absence of a certain level of cognitive capability does not exclude a person from the experiential spirituality made manifest in loving relationships (24-25).

If Swinton is correct, then it is by experiencing spirituality in communal practice, through direct contact and loving relationships with others, that the intellectually disabled come to personally experience God's love and, in turn, are enabled to love God. Granted, the same can be said for anyone spiritually adrift; these observations are not unique to the

cognitively disabled. However, given their marginalization and alienation as a group in our society, we find the above insights to be critical to understanding their spiritual needs.

### **Paternalism**

The forgoing reflections, though admittedly in need of further research and more refined analysis, suggest that spiritual engagement yields important benefits for cognitively disabled people. Whether they do for any specific individual has to be determined in each individual instance. But that kind of prudential, case-based assessment is not any different than the assessment made by a clinician who is trying to assess whether her particular patient will likely benefit from treatment X, which is known to be beneficial to most similarly diseased patients, but maybe not to this patient. The benefits thus assessed have to then be balanced against the harm of compulsion.

In the above sections, we have already specified several conditions that must be met for this balance to tip in favor of the former. First, the person exerting paternalistic power over another adult must intend to do so for the benefit of the other and not to foster his or her own interests. Second, the person subjected to paternalism must likely benefit significantly from the paternalistic intervention. Third, the pressure exerted, while exceeding mere nudging, does not amount to a level of coercion that supersedes the benefits gained. And a fourth condition, which we have not so far made explicit but that is quite evident, is that the benefit sought cannot be readily achieved without exerting such pressure.

In order to develop a more refined set of criteria, we can next distinguish between *positive* paternalism and *negative* paternalism (Kleinig). Here, the qualifiers “positive” and “negative” do not express a value judgment. Rather, if the paternalism is “positive,” it means that the subordinate person is made to behave in a way that the compelling authority figure believes is beneficial for the subordinate. In contrast, “negative” paternalism occurs when the subordinate person is kept from doing what he or she might otherwise choose to do because the authority figure believes the subordinate’s best interests would otherwise be harmed (Kleinig). The example of Tessa’s being coaxed to engage in prayer is an example of positive paternalism. By contrast, if a person with Down syndrome likes to mow the lawn but left to himself would do little else, and a care-taker were to limit this person to mowing the lawn weekly instead of daily, that could qualify as negative paternalism.<sup>5</sup>

Although both forms of paternalism by definition entail a restriction of the freedom of the compelled person, it can be argued that the restriction is less severe in negative paternalism. If a person is kept only from undertaking an action and all alternative courses of actions are still available, that person thus retains extensive freedom toward the future. On the other hand, if a person is compelled to do a specific action and all alternative options are prohibited, then that person no longer has any choice about the future.

Within the category of positive paternalistic actions, one can further distinguish between soft and hard paternalism. In soft paternalism, we do things to another person or have another person do things, without knowing whether that person wants to be so engaged. In

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<sup>5</sup> Co-author Paul Babcock observed that this is actually the case with Derek, who would mow the lawn every day if the mower were not locked up.

contrast, if we act against the known wishes of the other person, our actions qualify as hard paternalism. In the category of negative paternalistic actions, this distinction cannot be made since it always involves keeping a person from doing what that person evidently wants to do and hence is always hard.

How shall these three forms of paternalism be ranked in terms of their ethical risk? Negative paternalism and hard positive paternalism both involve overriding a person's known wishes, but the latter is ethically more risky than the former because of the aforementioned closure of alternatives. It is also clear that hard positive paternalism is ethically more risky than soft positive paternalism, because the subordinate person's expressed wishes are overridden. But it is not nearly as clear whether soft positive paternalism is more risky than negative paternalism. Soft positive paternalism involves closing down all other options; but since the compelled person has not yet formed a clear will in the matter, there is an even chance that the compelled person comes to actually will what that person was compelled to do. It would seem that this is what happened in the case of Tessa. When it was her turn to pray, the focus of her attention was elsewhere. It took some coaxing by the caregivers to have her address the task at hand. But when she refocused her attention and complied, she did not resist praying, and wholeheartedly engaged in the prayer in a way that glorified God.

In Tessa's example, the compulsion applied, though positive, was only minimal and the outcome turned out to be genuinely beneficial for Tessa herself. But the scenario would become much more complicated if we were to add the following hypothetical detail: What if Tessa was not Catholic, but had been raised in a strict Calvinist tradition in which the use of candles in prayer was prohibited? If we keep all other case details exactly the same, would this new piece of information force us to re-label the actions of her counselors as *hard* paternalism? Would their actions amount to what Childress has considered one of the most dangerous forms of paternalism: imposing unfamiliar values on the person that are substituted for the person's own values?

Apart from the question whether Tessa's parents (or legal guardians) knew of the religious communal practices adopted by the L'Arche home and, if so, why they had nevertheless elected to entrust their daughter to this particular care facility, the paternalism seems to deny the possibility and indeed the right of Tessa to shape her own life and embrace a mode of spiritual engagement, even if her parents believed candles should not be used in such a prayer service.

Furthermore, we have to remain mindful of our earlier conclusion that spiritual engagement for this population proceeds less along rational and intellectual lines and more along empathic and relational lines. To insist on abidance by, let alone rational acceptance of, specific doctrinal correctness, unduly restricts other modes of being with God. Since people with intellectual and developmental disabilities tend to rely more heavily on empathy and relationships with others in their choices, inclusion in a spiritual community may actually help them clarify their own values. In this sense, paternalistically coaxing them to actively participate in communal spirituality may actually bolster their autonomy rather than frustrate it. In contrast, insisting that they achieve such value clarification in a strictly independent and individualist manner may very well undermine their self-determination.

This analysis would change yet again if Tessa had not finally zoomed in on the candle and energetically engaged in prayer, if she had pushed the candle away and tried to get up from the table or otherwise expressed her displeasure with the situation. Any further cajoling by the caregivers could have been a form of hard instead of soft paternalism, and might no longer have been justified.<sup>6</sup> Likewise, if the caregivers had kept her from voicing the kind of prayer Tessa herself wished to voice, whether a traditional Catholic prayer, a Calvinist prayer, or a Buddhist meditation, such negative paternalism would not have been justifiable.

## Conclusion

Kittay and Bérubé both argue that we should not set predetermined limits to the capacities of cognitively disabled persons because we do not know what they are really capable of achieving. Proclaiming what someone cannot do may be a self-fulfilling prophecy, if it prohibits the person from even making the attempt. Over the last century, those with cognitive disability have made tremendous social gains. Capabilities that were once thought to be beyond them, such as music appreciation, ethical reasoning, art, or acting, have all been proven to be activities in which some developmentally or intellectually disabled persons have been able to excel (Bérubé). It would therefore be foolish to presume that people with developmental or intellectual disabilities cannot participate to some meaningful degree in spiritual practices.

Given that spiritual engagements can be experienced as very meaningful and beneficial, there is no *a priori* reason to presume these goods would not be available to persons with developmental or intellectual disabilities who engage in comparable spiritual practices. Each person's particular mode of being spiritually engaged, whether the person is disabled or not, is unique. Furthermore, to assume that God is only able to relate to God's sons and daughters in an intellectual, rationalist manner, suggests that God is seriously disabled and far from almighty.<sup>7</sup>

Moreover, spiritual practices that are communal in their operationalization are particularly beneficial to a group of people with disabilities. Rejection from society, or even from family, is one of their most commonly experienced pains. Inclusion in a faith community offers relief of their frequent and profound sense of alienation. Inclusion in a faith community helps them clarify their own values and nurtures their personhood; it provides further opportunities for loving relationships with others and ultimately leads them to experience the love of God.

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<sup>6</sup> More precisely, the caregivers would not have been able to justify their cajoling toward spiritual benefits that they presumed Tessa was going to derive from prayer engagement. They may, however, still have been able to justify their compulsion by arguing that non-exclusive participation in group activities is very important for the cohesion of the community, as is true of any "family." The relative weight of such additional factors is not considered here.

<sup>7</sup> As Christians, we are not commanded to have faith in God because we must see the truth in a syllogism or logical proof; rather we are exhorted to "Love the Lord your God with all your heart, with all your soul, and all your mind" (Matthew 22:37). The movement in the Gospels to "loving God" is one of emotion to will to reason and not the other way around. A heart and soul inflamed by love of God, but lacking reasoning capacity is surely more pleasing to God than the agnostic rationalist that assents to God's existence as a sort of cosmic clockmaker but lacks the "love" that faith requires.

However, that leaves unanswered whether it is justifiable to include these individuals in religious practices when doing so requires some degree of paternalistic coaxing. Paternalism has become a morally suspect practice, not only in the political domain but also in care practices such as health care, elder care, education, and care for developmentally or intellectually disabled persons. Certainly, each person, irrespective of his or her particular (dis)abilities, deserves to be respected as a unique person or, in Judeo-Christian language, a child of God created in God's image. Theologically speaking, we are born with free will as a gift from our loving Creator; to subordinate the free will of others and to compel them to act against their will is to thwart God's intention for God's highest creation. In an ethically just society each person's unique self must be respected, providing him or her with maximal opportunities for individualized growth and self-determination.

We have argued in this article that a wholesale rejection of paternalism in the care of developmentally or intellectually disabled persons cannot be morally justified. This is not only true in more obvious areas such as financial management or medical decision-making, but also in the area of spirituality. Paradoxically, paternalistic inclusion in communal spiritual practices may actually foster personal growth and individual self-determination for people with developmental or intellectual disabilities. For a community of intellectually and developmentally disabled persons, empathy and relationality, rather than rationality and autonomy, are primary modes of perceiving the world and their place within it. The joy and love that emanated from Tessa as she prayed appear to indicate that Sarah's paternalism was beneficial to Tessa. She experienced acceptance and love, precisely as she is, by being included in the nightly practice of her faith community, a place at a table where all are welcome.

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