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Parents of Adults with Diminished Self-Governance

Unique Responsibilities

JENNIFER DESANTE, DAVID DEGRAZIA, and MARION DANIS

Abstract: Most theories of parenthood assume, at least implicitly, that a child will grow up to be an independent, autonomous adult. However, some children with cognitive limitations or psychiatric illness are unable to do so. For this reason, these accounts do not accommodate the circumstances and responsibilities of parents of such adult children. Our article attempts to correct this deficiency. In particular, we describe some of the common characteristics and experiences of this population of parents and children, examine the unique aspects of their relationships, review several philosophical accounts of parental obligations, consider how these accounts might be extrapolated to semiautonomous adult children, and provide suggestions about parental obligations to promote autonomy and independence in adult children with cognitive limitations or psychiatric illness. In extending accounts of parental responsibilities to the case of semiautonomous adults, we find that the parental role includes the duty to continue to provide care—indefinitely if necessary—while cultivating autonomy and independence.

Keywords: parents; children; autonomy; decisionmaking capacity; independence; cognitive limitations; mental illness

Introduction

With advances in medicine, a growing number of children with complex medical needs are living into adulthood, including children with severe cognitive limitations or long-term mental illness. For many of these children,¹ their persistent medical conditions prevent their transition into independent and (more or less) autonomous adults.² This article focuses on those who are unable to live as self-sufficient, responsible adults because their cognitive or psychological state substantially limits their decisionmaking capacity and independence. For most of these adults, the additional burden of caring for them—at least as matters currently stand in the United States—falls to their parents (and this article addresses only those instances in which it is the parents who are their primary caretakers and supporters). Yet few philosophical theories of parental obligations emphasize parents' responsibility to cultivate their child's autonomy, which becomes apparent in

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cases in which such autonomy does not naturally materialize. Theories of parental obligation tend to assume, at least implicitly, that a child will grow up to be an independent, autonomous adult. They neglect cases in which this doesn't occur, creating a tension between the current philosophical framework and the reality that exists for these families. We therefore focus on cultivating the autonomy of adult offspring with cognitive and psychological illness. Families, caregivers, healthcare professionals, and these young adults themselves need a way to navigate relationships in which they continue to be significantly dependent on their parents. How can parents prepare these individuals to function in a society that expects adults to act as (more or less) autonomous, independent individuals? What is the appropriate parental relationship with these grown-up children, who are neither children in the sense of minors nor adults capable of the level of functioning and decisionmaking that we ordinarily expect of competent adults? *The overarching goal of this article is to explore and illuminate the moral responsibilities of parents to a set of children who have an ambiguous status as decisionmakers and/or responsible adults: adult offspring with cognitively and psychologically limiting conditions. Our thesis is that parents of these (adult) children have an obligation to cultivate their self-governance in order to promote their long-term flourishing.*³

Adults and children with special cognitive and psychological needs have claims on society that, in our judgment, are not adequately addressed.⁴ Our society, and in particular the state, should also provide more substantial assistance for caregivers. However, the nature and extent of society's obligation to these children and adults with diminished self-governance, and to their parents, lie outside the scope of this article. We focus on the obligations parents have to their children in the current societal context, which features inadequate societal support for this population.

We support the thesis stated previously—a parental obligation to foster self-governance in semiautonomous adult children—by demonstrating that it is a plausible extension of several leading accounts of the content of parental obligations, and by suggesting that, independently of any theory, it has considerable intuitive plausibility. Furthermore, we explore this topic because the development of children's autonomy and independence in this population is underappreciated in theories of parenthood, a fact that becomes apparent as more children with these cognitively and psychologically limiting conditions develop into dependent adults with diminished autonomy. In pursuing our overarching goal and developing the case for our thesis, we intend, specifically, to do the following: (1) characterize this special population through common features of their lives and through medically specified examples; (2) characterize the unique aspects of parent-child relationships in these cases; (3) examine several reasonable accounts of the content of parental obligations in order to see what guidance they may offer, even if only indirectly, regarding parental obligations toward the children in question; and (4) provide several original suggestions about the obligation to promote the partial self-governance of members of this population (while recognizing their limited capacity for self-governance). We argue that these parents, like all parents, have a responsibility to facilitate the development of the autonomy and independence of their offspring, despite the expectation that they will not reach the level of functioning that is characteristic of ordinary competent adults.

Characterizing a Special Population

Semiautonomous Adults

In the following discussion, we focus on the closely related concepts of autonomy and independence, which together allow an adult to govern his or her own life.⁵ The concept of autonomy is especially important insofar as the grown-up children on whom we focus are characterized by only partial autonomy (in a sense to be explained) and, consequently, by significant dependence on their parents. It is worth emphasizing that when we speak of *full* autonomy, we do not mean perfect autonomy—which may be humanly impossible—but rather a level of autonomy that characterizes ordinary adults. The concept of autonomy is complex and branches into such specific concepts as those of the autonomous person, autonomous desires, and autonomous action.⁶ Most directly relevant to our discussion is the concept of autonomous *decisionmaking* (a type of action); competent adults, more or less by definition, have the capacity for autonomous decisionmaking. The present article assumes the following analysis of this concept: in order to make a decision—or choose—autonomously, one must be able to make the decision (1) intentionally; (2) with sufficient understanding regarding the decision and its implications; (3) sufficiently freely of internal constraints (e.g., compulsions or addiction) and external constraints (e.g., coercion by another person); and (4) in light of one's own values and priorities.^{7,8,9,10,11} Here developed skills in the relevant domain are important—for example, autonomous financial decisions require some knowledge of finances. One important implication of this conception—and one more in keeping than some analyses¹² with ordinary understandings of the concept—is that only someone who has values can be an *autonomous* chooser (as opposed to someone who simply chooses according to whatever desire is currently strongest). It is also noteworthy both that the specific capacities mentioned in the definition come in degrees and that some threshold level of these capacities—where we draw lines and distinguish between, say, competent and incompetent adults—is implicit. Our discussion stresses that many adults are, with respect to decisionmaking, “semiautonomous” and vary over time in their ability to act autonomously, though they are rarely fully autonomous.

Now, it is one thing to be able to make decisions more or less autonomously and another thing to be genuinely in charge of one's own life. Being in charge of one's own life—which we call *self-governance*—requires not only autonomous choice but also *independence*. Here we do not have in mind perfect independence from other people, an exaggerated notion that does not even apply to the most independent adults.¹³ Instead, we are defining independence as substantial or relative independence from other caretakers in everyday life, as exemplified by ordinary, high-functioning adults. Whereas an independent adult is in charge of her own life, is able to handle physical self-care, and can organize her life according to her own values and priorities, semiautonomous adult children cannot. Various aspects of self-governance—autonomous choosing and independent living—can be diminished by cognitive or psychological disability. The following cases and discussion demonstrate the importance of developing both the capacity for autonomous decisionmaking and the independence of these adults. In the discussion that follows, it should be borne in mind that we use the term “semiautonomous adults” to refer to adults who are only partially capable of self-governance—due to significant

deficits in decisionmaking capacity, in independence, or in both. (We declined to use the quite accurate term “semi-self-governing adults” only for esthetic reasons: too much hyphenation.) For the purposes of brevity we do not further specify the differential skill profiles of the individuals we are discussing. Suffice to say that these adults have varying levels of competence regarding reading ability, financial management, legal obligations, property management, welfare decisions, and more.

Specifying Examples within Our Population

Our population is defined by diminished self-governance and the need for persistent care into adulthood. This is a broad population, as there are a variety of conditions that can limit the development of one’s autonomy and independence.¹⁴ Common to all of these cases is the adult child’s limited decisionmaking capacity and/or independence and the need for persistent parental care due to a cognitive or psychological disability of childhood or young-adult onset.

To further clarify our population of interest, we identify two categories of case examples: adults with moderate cognitive disability and adults with severe mental illness. These cases involve deficits in self-governance in different ways and to different degrees. Adults with moderate cognitive disability have deficits in decisionmaking capacity and frequently rely on their parents to make decisions. Adults with mental illness have deficits in their psychological development or current function and decisionmaking capacity, causing them to be more dependent on their parents for guidance and emotional support, among other things.¹⁵

Many semiautonomous adults do not have deficits in just one area, and the two aforementioned categories often overlap. Indeed, diminished self-governance in one realm will often affect a person’s autonomy or independence in another realm. For example, an adult with diminished cognition that affects decisionmaking capacity also has diminished independence if he or she is unable to navigate the environment and has to rely on others for transportation. Although they feature different degrees and types of diminished autonomy and independence, semiautonomous, medically complicated adults are all dependent on their parents in some significant ways.

Examples of individuals in the first category are adults with mild or moderate mental retardation, trisomy 21, or autism.¹⁶ Although they often have ordinary physical mobility, their capacity for decisionmaking is significantly compromised, necessitating increased reliance on their parents.¹⁷ The cognitive limitations of these adults impede their ability to make decisions. They rely on their parents for guidance in both routine decisions, such as when to eat or what to wear, and major decisions, such as seeking medical care and applying for jobs.

The second category is exemplified by adults whose diminished self-governance is due to a severe mental illness such as schizophrenia, bipolar disorder, or severe and incapacitating substance abuse. One important feature of these and many other mental illnesses is that their symptoms may wax and wane. Severe mental illness can make it difficult for an adult to be substantially autonomous, even if the illness is only intermittently expressed. Often an adult with such intermittently expressed mental illness will regain much of his autonomy, but the relapsing and remitting course of mental illness can make it hazardous for parents to let their child live in an entirely self-governing way. Because of the variable nature of their disability, their parents may (depending on the details) reasonably believe that they should

maintain a relatively close eye on their child's decisionmaking and behavior, even during periods of high functioning. Adults with severe mental illness often rely on their parents for support in managing their medical care, assistance with independent life skills such as grocery shopping, and guidance in making life decisions.

Unique Aspects of Parent-Child Relationships with Semiautonomous Adult Children

Based on descriptive accounts, we have identified two distinctive features of parent-child relationships involving adult children we have characterized as semi-autonomous: enmeshed lives and shared decisionmaking.

Enmeshed Lives

Many grown-up children, in the normal course of events, despite no longer being minors, are dependent on their parents in a variety of ways: for housing, financial support, advice, babysitting, and so on. But in the majority of these parent-child relationships, physical, emotional, legal, and social boundaries develop as the child grows up and becomes an independent adult. Interactions between parents and young children that are considered socially acceptable (e.g., bathing or disciplining them) are ordinarily considered inappropriate when the child is an adult. But, rather than featuring the establishment of such boundaries, the lives of semiautonomous adults become intertwined with their parents' lives from the age when the child develops special healthcare needs.¹⁸ Adult offspring with long-standing cognitive limitations or psychiatric illnesses are more dependent on their parents and often remain in the dependent role as they grow and become adults.

For example, parents may continue to have an intimate physical relationship with their adult child who has cognitive limitations or psychiatric diagnoses. Parents may assist with showering, self-care, medical care, and/or life skills such as cooking and cleaning. Whereas most children in our society grow up and move out of their parents' home, adults with cognitive or psychological limitations often remain in their parents' home to live in close proximity or move back home with their parents (if they ever left home) and often lack clear physical boundaries in their relationship with their parents in contrast to common practices in the current prevalent Western culture.¹⁹

Adults with complex medical needs are often financially dependent on their parents, as they cannot always support themselves. (Of course, this is also often—even if less often—true of adult children who lack cognitive or psychological disabilities.) Those with cognitive limitations and mental illness often have difficulty obtaining well-paid employment with health insurance. Adults with mental illness, although they might have the potential for financial independence, may require their parents to provide financial stability, due to the unpredictable nature of their illness and the possibility of interruptions in their work life.

It is further worth noting that adults with diminished self-governance are often psychologically dependent on their parents. They may rely on their parents for emotional support more than adult children typically do, to fulfill the needs of intimate friendships. These adults rarely have partners or the close, personal relationships that other adults rely on for spiritual support, psychological guidance, and even social planning. In place of a spouse or best friend, they frequently turn to

their parents when they have a bad day, are bored, or experience disappointment. Their parents have to fill the psychological, social, and emotional role of close friendships and intimate relationships.

Finally, in some cases, the legal boundaries between parents and semiautonomous grown-up children are blurred when parents obtain legal decisionmaking control over their children. Parents of adults with moderate cognitive disabilities may obtain power of attorney in order to make legal, financial, and healthcare decisions on behalf of their child. Adults with mental illness can be placed in a legal guardianship under their parents. In both of these examples, the legal status of the child as an autonomous and independent adult decreases.

In sum, many parents of semiautonomous grown-up children are enmeshed in the daily lives and routines of their children. "Family members are stuck with each other," as one theory of family responsibility puts it.²⁰ Adults with diminished self-governance cannot live a life independent of their parents. Their dependence leads, in most cases, to a permanent intertwining of their lives with the lives of their parents.

Shared Decisionmaking

In the normal course of growing up, most children begin to develop a sense of self that is separate from their parents and may even rebel against their parents and, in the process, start making their own decisions in adolescence. Part of developing autonomy is learning from one's mistakes. Teenagers who stay up late and disobey rules learn from the consequences they face. Often these consequences come with a discussion between the parents and the child regarding how the child came to a decision. Such discussions are important opportunities. As Gillett conceptualizes it, a person should be actively supported in the exercise of relevant communication skills so that she can become a moral agent.²¹ But children with cognitive limitations or psychiatric illnesses may be more dependent on their parents and often not as forceful in pushing boundaries and declaring their emerging autonomy. Furthermore, many of these children face greater consequences from their actions. Experimenting with alcohol is more risky when the adolescent or young adult has a mental illness or is taking certain medications.

Because of their enmeshed lives and the need for shared decisionmaking, parents of semiautonomous adults generally play a more active role in supervising decisionmaking for their children. The level of parental involvement varies with the needs of the child. Parents of adults with a cognitive disability typically take on the role of a supervisor, often having permanent oversight of their child's decisions. Adults with severe mental illness require more intermittent supervision. If the adult is unable, at a particular time, to make decisions due to his or her mental illness, the parents can temporarily assume the role of primary decisionmaker for their child, just as they did when the child was young. As the adult child recovers his or her decisionmaking capacity, parents can return decisionmaking power to their child in a gradual and supervised fashion.

Several Accounts of the Content of Parental (or Family) Obligations

With this background, we examine several promising accounts of parenthood, parental responsibilities, and the role of the family in general with two goals in

mind: (1) to indicate that existing literature largely neglects the topic of parental responsibilities to semiautonomous adults and (2) to indicate that these accounts contain hints that lead fairly straightforwardly to our thesis.²² These accounts were not created to address the cases on which this article focuses, and they primarily focus on parental obligations to *young* children. In every instance, the account has to be extended to fit the unique parent-child relationships in which we are interested. Some of these theories prove capable of accommodating these unique relationships and illuminating parental obligations in these cases. We argue that plausible extensions of these accounts point in the direction of parental obligations to cultivate the autonomy of their semiautonomous adult children and to persist in caring for them over time.

Stewardship

Stewardship is an account of parental responsibilities defended by Michael Austin.²³ He believes that parents should make all decisions regarding their child as if they were the child's stewards and plan to transfer responsibility for the child to him or her when he or she grows up and becomes an autonomous adult. Furthermore, Austin argues that parents have an obligation to help their children *develop into* autonomous adults,²⁴ so the parents can transfer stewardship to the adult child successfully.

Stewardship theory can be extended to some of the instances of parent-child relationships we have described. Many parents of children with cognitive limitations or psychiatric illnesses essentially continue as stewards or guardians as their children become adults. Given the numerous healthcare decisions they often face, they naturally take on the role of an advocate or surrogate decision-maker. However, this can lead to an overly paternalistic view of the role of these parents. The idea of stewardship concentrates our attention on the parent's role as a guardian, deemphasizing a parent's obligation to cultivate a child's autonomy, support a child's physical and mental growth, and prepare a child for a fulfilling existence. To his credit, though, Austin's account is not limited in this way: he acknowledges that parents have an obligation to help their child develop into an autonomous adult and recognizes that this process is a gradual transition.²⁵ But he does not mention the possibility of children developing even partial agency as they get older. We believe much more might be said about a child's need to *practice and develop* his or her burgeoning agency.

In addition, and to make a general point, we suggest that parents' responsibilities include an obligation to ensure that there is always someone who functions as a steward to their adult child. Most often this will be the adult child herself. But in cases in which the adult child proves unable to take over stewardship of her own life, it is the parent's responsibility to ensure that someone reliable, like a spouse or a sibling, will function as a steward. In some cases the adult child can select someone to serve as a steward, as in the case of Jenny Hatch.²⁶ This selection—similar to the process of selecting a healthcare decisionmaker—might be an important way that the adult child can use his or her developing autonomy. However, if no one else is available, the parents are obligated to continue or resume their stewardship of their child, albeit in a manner that is consistent with the child's emerging values.

What we suggest here largely matches the permanent role that parents of semi-autonomous adults in our society typically assume. Unlike most parent-child relationships, these relationships never undergo a (nearly) complete transfer of autonomy and independence to the child. Instead, the parents monitor the progress and development of their child and modulate the extent of their child's independence and responsibility for decisionmaking depending on her development and the details of her condition and circumstances. But, crucially, we understand such stewardship to involve actively cultivating the child's self-governance as much as possible in the hope that the adult child will become her own steward. Parents should allow their children to take partial responsibility for themselves in a safe environment so as to cultivate their autonomy and independent life skills.

The Lindemann Nelsons on the Role of the Family in Medicine

In *The Patient in the Family*, Hilde and James Lindemann Nelson provide an account of family relationships as they intersect with healthcare.²⁷ We focus on two of their "stars to steer by" when examining family relationships.²⁸ First, "family members aren't replaceable." Parents will always have unique responsibilities, as parents, to their children, such as providing a loving and nurturing relationship. Second, "family members are stuck with each other." Family relationships are rarely terminated, and parents are always somewhat responsible for their children. Crucially, parental obligations do not simply disappear when a child becomes an adult, even a substantially autonomous adult. With a few amendments, the Nelsons' theory seems fairly realistic and plausible when applied to semiautonomous grown-ups. Importantly, the authors emphasize the permanent nature of the parent-child relationship and the lifelong commitment of parenthood.

Open Future

In his classic paper "A Child's Right to an Open Future," Joel Feinberg argues that when making decisions for their children, parents should not unduly constrain their children's future options as adults—for example, by heavy-handedly ushering them down a single career path.²⁹ According to Feinberg, parents have an obligation to keep their children's future opportunities as open as possible and to treat their children in a way that allows them to develop into independent, autonomous adults who will find their own path. This theory is applicable in many parent-child relationships, including some of the aforementioned instances (e.g., some cases of adults with severe mental illness). Even when extended to children who necessarily have a limited future—for example, children with moderate cognitive disability—Feinberg's thesis makes the valid, even obvious, point that parents should not constrain their children's future opportunities unnecessarily. On the other hand, the idea of a child's right to an open future—we might say "a future as open as possible, given the child's capacities"—is only a starting point. The best chance that children with cognitive limitations or psychiatric illnesses have for an open future is if their parents actively cultivate their child's future options, not just refrain from constraining them. Accordingly, a child's right to "a future as open as possible" entails more than a prohibition on parents from limiting their child's education. It also entails, for example, an obligation to try to arrange special education for a child with significant learning disabilities, an obligation to try to get

braces for a child with a club foot, and an obligation to try to get appropriate therapy for a child with mental illness. Importantly, the individuals on whom our article focuses—semiautonomous adults with cognitive limitations or psychiatric illnesses—continue to have a right to an open future *as adults*, just as the associated parental obligations continue indefinitely.

David Archard and Mianna Lotz both expand on the open future framework, emphasizing the requirement that the future adult develop autonomy. Archard states that “the end of any good upbringing should be to bring to adulthood someone with the greatest degree of autonomy.”³⁰ Lotz analyzes Feinberg’s argument, as well as Claudia Mill’s response,³¹ concluding that the right to an open future is not merely a child’s negative right to not have his or her future interfered with or unduly constricted but a positive right that brings about certain parental obligations (consistent with the point we made about doing what is needed to help the child fulfil his or her potential): “Specifically—but tentatively—I want to suggest that the child’s right to an open future imposes a duty on parents *to seek, with their capacity, to provide adequate conditions for a child’s emerging autonomy.*”³² Lotz recognizes the parental duty to assist in their child’s development of autonomy but stops short of arguing for their active role in cultivating a child’s autonomy. Moreover, we wish to emphasize the need to continue to cultivate a child’s autonomy when that child is a semiautonomous adult with cognitive limitations or psychiatric illness.

Cultivation of Autonomy

John Bigelow et al. identify the development of a child’s autonomy as a moral requirement for an adequate parent-child relationship.³³ The authors note that when most children grow up, “the end result of the process should be autonomy for the new adult.”³⁴ However, they do not discuss *how* children are to develop this autonomy.³⁵ Like Feinberg and Lotz, they do not emphasize the obligation parents have to *actively cultivate* their child’s autonomy. Amy Mullin expands on this requirement, arguing that “parents need to encourage [children] to develop skills, acquire knowledge, care stably about some goals, and develop self-control.”^{36,37} She contends that parents have an obligation to develop nascent autonomy in their children and that “dependence on others need not be a barrier.”³⁸ John Eekelaar similarly states that “the *purpose . . .* is to bring a child to the threshold of adulthood with the maximum opportunities to form and pursue life-goals which reflect as closely as possible an autonomous choice.”^{39,40} Although these authors appreciate that parents have a duty to develop autonomy in their children, they do not provide specific guidance for developing autonomy in children who may be anticipated to have increased dependence into their adult years. We would argue that adults with significant cognitive limitations and psychiatric illnesses should be included in this discussion as well. They need to be actively supported in their cultivation of autonomy.

Actively Cultivating Self-Governance in This Special Population

Parents have many obligations to their children, including an obligation to develop their child’s self-governance. In extending these accounts of the content of parental responsibilities to the case of semiautonomous adults, we find that the parental

role includes the duty to continue to provide care—indefinitely if necessary—while cultivating autonomy and independence, insofar as possible, in order to enlarge their future possibilities and thereby promote their flourishing. The obligation to cultivate self-governance and to supplement it when full self-governance is not achievable is often overlooked and is even more important when the child faces significant limitations. No child's future, of course, is completely open; everyone faces limitations of some kind, whether medical, social, mental, or otherwise. But parents have the job of empowering their children to overcome their limitations to the extent possible and to (accurately) see their future as offering choices. For children with cognitive limitations or psychiatric illness, this can be a hard task. These individuals, both while they are growing up and once they are young adults, confront significant impediments, both real and perceived.⁴¹ Moreover, although the stages of childhood development of moral reasoning and judgment have been well studied, these stages have been less well delineated for the population under discussion here. Because there are no set "stages" of development for these adults, there are no clear guidelines by which their parents can judge their moral development. Therefore it is harder to judge exactly how paternalistic parents should be in helping their children create and pursue options for their future. Parents must be particularly careful in areas in which the child's life choices may not accord with their values. Depending on the nature of the cognitive limitations or psychiatric illness, there are specific ways that parents can develop their child's autonomy and independence.

First, even if a child will never develop full self-governance, due to a cognitive disability, for example, parents should provide their child with opportunities to function as a partially independent adult. This can include enrolling such children in vocational school so they will be employable as an adult or teaching them life skills so they learn to care for themselves. It may mean assisting them with volunteer opportunities or certain self-defining hobbies, such as Special Olympics, to provide them with a sense of identity or self-worth. Throughout this process, the parents can monitor the development of their child. As these adults become more independent and autonomous, some of the responsibility for the child will shift from the parent to the child, and the nature of the parent-child relationship will change.

The second method parents can employ is a partially paternalistic approach to facilitate decisionmaking. Parents can guide their children through the decision-making process with encouragement, persuasion, and bargaining. Parents can talk with the child, help him or her weigh the costs and benefits of a decision, evaluate the alternative options, discuss possible outcomes, and prioritize the personal values that bear on a decision. Due to the adult child's cognitive and/or psychological limitations, parents may have to be fairly actively involved in cultivating their child's decisionmaking capacity and in supporting particular acts of decisionmaking. Now, some may feel that active parental involvement in supervising decisionmaking contradicts a disability rights approach. To the extent that parents' involvement runs counter to their children's immediate preferences (e.g., if the grown-up children don't want to deal with a particular decision that needs to be made) or encourages them in the direction of a particular decision that the parents think best, the parents' involvement does involve a measure of paternalism. But the partially paternalistic approach is a method to help these children develop their skills as autonomous decisionmakers. Sometimes measured paternalism can

help foster the longer-term prospect for self-governance, which is in line with the disability rights approach.

Another aspect of a partially paternalistic approach is for parents to allow their children to make decisions in supervised situations before giving them more freedom in other environments. Tamar Schapiro correctly ascertains that autonomy develops in different areas of decisionmaking and activity at varied trajectories: "We should be willing to allow children to make rules for themselves where they are capable of doing so. Since autonomy starts out as sovereignty over limited domains of discretion, children should have the opportunity to make decisions in limited ways wherever possible."⁴² Schapiro's guidance for parents of young children is similar to Gillett's advice for those working with adults with mental illness.⁴³ Parents of adults with diminished self-governance should employ an analogous strategy: first allowing their child the autonomy to make minor decisions, such as what to wear and when to eat, before permitting them to make major decisions like scheduling physician appointments and taking medications. Children with cognitive limitations or psychiatric illness can first demonstrate their decisionmaking skills in environments with fewer consequences before practicing decisionmaking in other environments. For instance, a child with trisomy 21 should first demonstrate his ability to make his own schedule on a weekend, when there are fewer things on the to-do list, before he is permitted to set his own schedule on a weekday. Adults with diminished self-governance require more support, guidance, and safety nets than other adults, who are more adept at developing their autonomy by learning from their mistakes.⁴⁴

Partially paternalistic decisionmaking is similar to a process labeled "supported decisionmaking," by which adults with intellectual disability who are unable to make decisions autonomously "receive the help they need and want to understand the situations and choices they face, so they can make life decisions for themselves, without the need for undue or overbroad guardianship."⁴⁵ The concept was developed from the United Nations Convention on the Rights of Persons with Disabilities with the goal of replacing the protectionist relationship of legal guardianship. This approach empowers intellectually disabled adults to make decisions for themselves, albeit in a supported environment.

In some cases, adults with conditions that tend to diminish self-governance manage to achieve substantial self-governance for extended periods of time. However, even in these cases, parents remain significantly responsible for their adult children. Adults with severe mental illness often have episodes of illness in which they temporarily lose the ability to function as self-governing adults. During this time, their parents typically assume certain responsibilities with the hope that the child will eventually regain his or her independence and decisionmaking ability. They may take over financial matters, household chores, and even medical decisions. But they should do so in a way that respects the adult's nascent self-governance. As the semiautonomous adult recovers, the parents should provide their child with chances to develop, stretch, and practice his or her self-governance, by gradually transferring stewardship back to the adult child. It is the job of a parent to help their children grow in these ways, thereby opening up their future opportunities. Indeed, the children's best chance for an open future requires that their parents support and supervise them when they fall short of their baseline of autonomy and are dependent on their parents.

At the same time, the future possibilities of an adult with severe mental illness may be further opened up in another way. While at his baseline of relatively high functioning, the mentally ill adult may forge an agreement with his parents about how to handle situations in which he relapses into a state of severely compromised functioning and incompetence. For example, an adult with schizophrenia who sometimes stops taking his antipsychotic medications and consequently decompensates might agree, while functioning at his best, that in this situation he is to be driven to his favorite hospital for either emergency admission or voluntary admission to the psychiatric unit in which he has previously received good care. This agreement aligns the patient's highest-functioning, more autonomous "self" with his parents' judgment by creating what amounts to an advance directive. Like Ulysses, who asked that his shipmates tie him to the mast when they approached the sirens on shore so that he would not be seduced by their call, the present individual sensibly prioritizes his autonomous decisions over his nonautonomous desires (e.g., to avoid treatment, to go to the sirens), thereby reducing conflict with his parents and serving his own longer-term interests as understood through his baseline values and priorities.⁴⁶ This is another way in which a type of paternalism—limiting the liberty of someone whose autonomy is substantially compromised—can be respectful of a person's long-term autonomy.

We recognize that some may object to the additional obligation to develop a child's self-governance—perhaps especially when the child is of adult years—as this obligation further burdens parents who are saddled with responsibility for medications, treatments, educational programs, psychological therapies, and the like. In addition, the duty to promote self-governance will often conflict in the acute setting with other parental responsibilities. Parents may feel torn between their obligation to foster their child's independence and their duty to ensure that the child gets his or her medication. They may be conflicted between their role as a protective steward and their obligation to cultivate autonomous decisionmaking in a supported environment. However, actively cultivating their child's self-governance will allow the child to begin making autonomous decisions and will reduce the extent to which the child's life is entangled with those of his or her parents.

Conclusion

The parent-child relationship is unique in many facets when the child is a semiautonomous adult. Typical boundaries do not exist; lives are intertwined, decisions are made jointly, and parents must proactively work to develop their child's independence and decisionmaking capacity, thereby expanding the child's future possibilities. But although these relationships are unique in the active role the parents take in developing their child's capacity for self-governance, the development of autonomy and independence is surely, as noted earlier, a universal norm of parenting. All parents have an obligation to cultivate of their child's self-governance to ensure that their child has a reasonably broad array of opportunities in his or her future and a fulfilling life. With adults who remain only semiautonomous, however, this parental project is one that continues indefinitely.

Various frameworks have been developed to describe and guide a parent's relationship with and obligations to his or her child, but few emphasize a parent's obligation to actively cultivate the child's independence and autonomy in order to provide cognitively limited or psychiatrically ill children with an open future and

the greatest prospect for flourishing. These individuals deserve to live lives that are not entirely captured and constrained by their disability or illness. A parent's responsibility to promote his or her child's autonomy and independence, and to continue care as necessary when the child is an adult, is essential to the child's prospects for having a fulfilling life.

Notes

1. For the purpose of brevity, we refer to adult offspring as "children," in the relational sense, not as a reflection of age.
2. There is an extensive literature on the nature of disability, featuring a competition among various models. For an excellent introduction to the issue, see Wasserman D. Philosophical issues in the definition and social response to disability. In: Albrecht G, Seelman K, Bury M, eds. *Handbook of Disability Studies*. London: Sage; 2001. Because our argument does not assume a particular model, we do not need to adjudicate the debate over the nature of disability.
3. Caring for a child with special healthcare needs can be an overwhelming task, and we do not mean to burden already overwhelmed parents with what might seem to be yet an additional burden. Although our recommendations are framed as parental obligations, they can potentially help to alleviate the caregiving responsibilities that parents face: to the extent that children develop autonomy and independence, this growth will benefit not only them but also their parents. We acknowledge that this potential is not present for all the adult offspring we are discussing.
4. Anita Silvers and Leslie Francis Pickering argue for including adults with cognitive disability in theories of justice, providing foundations for a societal obligation to provide for them (Silvers A, Francis LP. Thinking about the good: Refiguring liberal metaphysics (or not) for people with cognitive disabilities. *Metaphilosophy* 2009;40:475–98).
5. In a similar vein, Grant Gillett discusses "the ability to act or enact one's own story" (Gillett G. How do I learn to be me again? Autonomy, life skills, and identity. In: Radoilska L. *Autonomy and Mental Disorder*. New York: Oxford; 2012: 233–51.)
6. There are various definitions of "autonomy," for both medical and social contexts, as well as various critiques of mainstream thinking about autonomy. With no pretense of adequately defending our definition, we submit that it is largely compatible with leading conceptions. See also notes 7–11.
7. This analysis shares with that of Beauchamp and Childress (Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 7th ed. New York: Oxford University Press; 2013, at 104–5) the conditions of intentionality, understanding, and freedom from controlling influences.
8. This analysis shares with the partial analysis presented by DeGrazia, Mappes, and Brand-Ballard (DeGrazia D, Mappes TA, Brand-Ballard J. Introduction. In: DeGrazia D, Mappes TA, Brand-Ballard J. *Biomedical Ethics*. 7th ed. New York: McGraw-Hill; 2011:41–44) the distinction between external and internal controlling influences or constraints, while adding the fourth condition mentioning the subject's priorities and values.
9. Cf DeGrazia D. *Human Identity and Bioethics*. Cambridge: Cambridge University Press; 2005, at 95–106.
10. Cf Dworkin G. Acting freely. *Nous* 1970;4:367–83.
11. Cf Frankfurt H. Freedom of the will and the concept of a person. *Journal of Philosophy* 1971;68:5–20.
12. See, e.g., note 7, Beauchamp, Childress 2013.
13. Perfect independence would be an individual's ability to be entirely self-reliant and never require assistance from another individual. As every autonomous, independent adult requires some form of assistance at some point, whether from a mechanic when his car breaks down or from a babysitter when she has a work dinner, perfect independence is not the standard we use in defining independence.
14. We recognize that not every adult who carries one of these diagnoses will be an adult with diminished self-governance. These examples are meant to be neither comprehensive nor defining of our population. We aim merely to identify concrete examples of groups of individuals whose members are frequently adults with limited self-governance.
15. In this connection, Gillett explores the interactive process by which adults with mental illness develop their "discursive abilities" through learning interactions with close associates (see note 5, Gillett 2012).

16. We note that children with autism may or may not experience cognitive impairment. The Child Mind Institute provides helpful clarifications regarding these conditions: Child Mind Institute. *FAQs about Autism*; 2004; <http://www.childmind.org/en/autism-faqs/>. (last accessed 28 Sept 2015).
17. In contrast, adults with severe cognitive disabilities—such as individuals with hypoxic ischemic encephalopathy, an in utero neurologic insult, hydrocephalus, or a severe intraventricular hemorrhage—are substantially nonautonomous, lacking any significant decisionmaking capacity. Though it is important to recognize the dignity of these adults, such substantially cognitively disabled individuals are not the focus of our discussion on cultivating autonomy.
18. For a fuller description of this enmeshment when the child is young, see Bowyer L. The ethical grounds for the best interest of the child. *Cambridge Quarterly of Healthcare Ethics* 2016;25(1):63–9.
19. Some adults with diminished self-governance move into group homes or other housing arrangements where they are dependent not on their parents but on other caregivers. Though their relationship with their parents will be different under these circumstances, their reliance on others and their need for their parents to actively cultivate their self-governance are unlikely to change.
20. Nelson HL, Nelson JL. *The Patient in the Family*. New York: Routledge; 1995, at 74.
21. See note 5, Gillett 2012.
22. We have focused our discussion on theories of parenthood that describe the content of a parent's obligations to his or her child, ignoring theories such as the causal theory and volunteerism, which aim to clarify who has parental obligations to a child and from what basis these obligations arise. This discussion is not intended to be either a complete survey of theories of parenthood or a thorough discussion of their supporting arguments and implications. It is intended, rather, to ground the discussion that follows.
23. Austin MW. *Conceptions of Parenthood*. Farnham, England: Ashgate; 2007.
24. See note 23, Austin 2007, at 113.
25. See note 23, Austin 2007, at 111.
26. Vargas T. Woman with Down syndrome prevails over parents in guardianship case. *Washington Post* 2013 Aug 2; available at https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html (last accessed 31 Aug 2015). A lengthy description of the Jenny Hatch case is not feasible here, but the case exemplifies the conflict that can arise between a parent's obligation to protect his or her child and his or her duty to cultivate the child's autonomy and independence. Jenny Hatch was a young woman with Down syndrome who successfully petitioned the court, with the help of her employers and friends, to overturn her parents' legal guardianship. Her parents opposed the court ruling because they felt that guardianship and the structured environment of a group home were in Jenny's best interest.
27. Although the Nelsons focus on family relationships in general, much of what they say is particularly applicable to the parent-child relationship with a semiautonomous adult child. The Nelsons focus on family relationships in which one member has a significant interaction with the healthcare system—and the impact this has on the rest of the family.
28. See note 20, Nelson, Nelson 1995, at 74. The next two quotations come from the same page.
29. Feinberg J. The child's right to an open future. In: Aiken W, LaFollette H, eds. *Whose Child? Children's Rights, Parental Authority, and State Power*. Totowa, NJ: Littlefield Adams; 1980:124–53.
30. Archard D. Children, adults, best interests and rights. *Medical Law International* 2013;13:55–74, at 69.
31. Mills C. The child's right to an open future? *Journal of Social Philosophy* 2003;34:499–509.
32. Feinberg Lotz M., Mills, and the child's right to an open future. *Journal of Social Philosophy* 2006;37:537–51, at 546.
33. Bigelow J, Campbell J, Dodds SM, Pargetter R, Prior EW, Young R. Parental autonomy. *Journal of Applied Philosophy* 1988;5:183–95.
34. See note 33, Bigelow et al., at 192.
35. To their credit, Bigelow et al. recognize that the process of developing autonomy sometimes fails and that, in these cases, parents continue to have responsibilities. However, they give no advice as to what parents can do to encourage autonomy in their children when it does not develop naturally.
36. Mullin A. Children, paternalism and the development of autonomy. *Ethical Theory and Moral Practice* 2014;17:413–26, at 415.
37. See also note 5, Gillett 2012.
38. See note 36, Mullin 2014, at 417.
39. Eekelaar J. The interests of the child and the child's wishes: The role of dynamic self-determinism. *International Journal of Law and the Family* 1994;8:42–61, at 53.

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40. This topic also appears in healthcare ethics. Guy Widdershoven and Tineke Abma argue for an active role for healthcare providers in ensuring their patients' autonomous decisions. They feel that autonomy requires "support from others who may help the person to find out what is right for him through dialogue and deliberation" (Widdershoven G, Abma TA. *Autonomy, dialogue, and practical rationality*. In Radoilska L, ed. *Autonomy and Mental Disorder*. New York: Oxford University Press; 2012:217–32).
41. Children with special healthcare needs often feel more limited in their future prospects than their medical condition entails. Such children are often treated as medically fragile—sometimes rightly and sometimes out of habit. Children may internalize this portrayal and view their future as more limited than it is.
42. Schapiro T. What is a child? *Ethics* 1999;109:715–38, at 736.
43. See note 5, Gillett 2012.
44. The partially paternalistic approach to decisionmaking is similar to a liberal political theory that appeals to "the shared construction of the good." Representing this theoretical perspective, Silvers and Francis (see note 4, Silvers, Francis 2009) argue that a "trustee" can assist in developing a conception of the good for a severely cognitively disabled person. Insofar as developing one's own values and priorities is part of developing autonomy, we find the authors' thesis to be in line with our approach.
45. Supported decision-making: An agenda for action—February 2014 (document produced for Best Practices in Supported Decision-Making, a symposium organized by Quality Trust for Individuals with Disabilities, the Council on Quality and Leadership, and the Burton Blatt Institute); 2014 Feb; available at http://bbi.syr.edu/news_events/news/2014/02/Supported%20Decision%20Making-2014.pdf. (last accessed March 2015).
46. For an interesting discussion, see Radoilska L. *Autonomy and Ulysses arrangements*. In: Radoilska L, ed. *Autonomy and Mental Disorder*. New York: Oxford University Press; 2012:252–80.