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## When Caring Is Just and Justice Is Caring: Justice and Mental Retardation

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*“Praise to you, Lord God, king of the universe, who varies the forms of thy creatures.” So begins an ancient Hebrew prayer which is to be recited upon encountering an individual with “deformities.”*

*Wolf Wolfensberger, The Principles of Normalization in Human Services*

*When speaking of a person labeled “profoundly mentally retarded” emphasize “profound.”*

*David Hingsburger, First Contact: Charting Inner Space*

### Interjecting Voice

**A**mong the various human forms alluded to in the Hebrew prayer, mental retardation appears to be one of the most difficult to celebrate.<sup>1</sup> It is the disability that other disabled persons do not want attributed to them. It is the disability for which prospective parents are most likely to use selective abortion (Wertz 2000). And it is the disability that prompted one of the most illustrious United States Supreme Court Justices to endorse forced sterilization, because

1. A word about the term *mental retardation*. In speaking of mental retardation, some speak of mental disabilities, or cognitive or intellectual disabilities, or developmental disabilities, or being mentally challenged. I reject the last term as condescending. Although only mental retardation captures precisely the population I address, I vary the terms with a sensitivity to their over- or underinclusiveness.

“three generations of imbeciles are enough.”<sup>2</sup> The mentally retarded have at times been objects of pity, compassion, or abuse by their caretakers and society at large. But they have rarely been seen as subjects, as citizens, as persons with equal entitlement to fulfillment.

Mental retardation comes to the public’s attention in sensational stories that expose appalling forms of abuse. We encountered the horror decades ago in *Look* magazine’s photo exposé “Christmas in Purgatory” and, more recently, in the heavily illustrated article in the *New York Times Magazine* showing conditions at Hidalgo in Guadalajara, Mexico, one of many “Global Willowbrooks” (Winerip 2000); or closer to home, in the *Washington Post*’s coverage of the unexplained and uninvestigated deaths of mentally retarded people living in the city-funded group homes of the nation’s capital (Vobejda 2000). And we gasp at the inhumanity of those entrusted with the care of extremely vulnerable people. We wonder: How can this happen? How is it that we allow this to occur?

Although we occasionally hear of these extreme cases of abuse, the victimization of severely intellectually disabled persons is more pervasive than these isolated examples suggest. Many individuals with mental retardation, especially when it is severe or profound or compounded by other disabilities, have been unaffected by the important strides made by other people with disabilities. Advocates of disability rights have insisted that the independence and productivity that are essential to being considered equal citizens in a liberal society are no less attainable for the disabled than for the nondisabled. They have argued that their impairments are only disabling in an environment that is hostile to their differences and that has been constructed to exclude them. Yet, the impairment of mental retardation is not easily addressed by physical changes in the environment. Although a significant number of mentally disabled persons have been moved out of large state institutions into smaller, community-based facilities or independent apartments and are employed in supportive environments, most will need to be financially supported or to subsist on very low salaries. Of all disabled people, the severely mentally retarded have least benefited from the inclusion fought for by the disability community (Ferguson 1994).

Perhaps this should not be surprising. The movement for the rights and inclusion of people with disabilities has followed a blueprint developed by persons of color, women, and gays and lesbians. All of these attempts by the marginalized to be recognized and fully enfranchised demanded that the practice of liberalism be

2. With this remark, Justice Oliver Wendell Holmes justified upholding the state’s right to determine that Carrie Bell, a “feeble-minded woman” residing in a state institution, should be sterilized (*Buck v. Bell*, 274 U.S. 208 [1927]).

consistent with its tenets of universal equality and freedom. All the formerly excluded have insisted on no longer being silenced, on having their voices heard. But for many with severe mental retardation, such a demand for voice appears futile. Even though other movements of inclusion have challenged the liberalism that they nonetheless invoked, the inclusion of people with mental retardation may well be liberalism's limit case, just as it is a limiting case for the demands of many in the disability community. Liberalism invokes a notion of political participation in which one makes one's voice heard. It depends on a conception of the person as independent, rational, and capable of self-sufficiency. And it holds to a conception of society as an association of such independent equals. Yet many with severe retardation cannot ever hope to be equal in these terms. Some, at least, may never be able to be independent or capable of participating in rational deliberation.

Those who speak do so in a language not recognized—and even demeaned—by those who speak in the language of the public sphere. Without a claim to cognitive parity, even those who can speak are not recognized as authors or agents in their own right. Those who cannot speak must depend on others to speak for them. Those who can speak find that their voice is given no authority. Perhaps there is no more disabling disablement.

To be heard, to be recognized, to have her needs and wants reckoned along with those of others, the mentally retarded individual requires an advocate—a role that has voice at its center. It is in the role of an advocate for my daughter, Sesha, that I enter into the field of “disability criticism.” I have wondered not only how and where I fit into this discourse; I have also considered how I interject my daughter into this critical discourse, into any public discourse. To do so, I must first tell the reader about her, for she cannot speak for herself.

How do I describe Sesha? In speaking not only about her, but for her, I have already begun by describing her in the negative—as one who cannot speak for herself. Yet this lack is a synecdoche for all that she is unable to do: feed herself, dress herself, toilet herself, walk, talk, read, write, draw, say Mama or Papa. I would have preferred to start by speaking of her capabilities: the hugs and kisses she can give, her boundless enjoyment of the sensuous feel of water, or her abiding and profound appreciation of music. When asked about my daughter, I want to tell people that she is a beautiful, loving, joyful young woman. But then I need to tell them what she cannot be, given her profound cognitive limitations, her cerebral palsy, and her seizure disorders. When people ask how old my daughter is I always hesitate, wondering whether to give her chronological age and speak of her as a lovely and intense thirty-year-old woman, or to speak of the indeter-

minate age that reflects her level of functioning and her total dependence. The positive set of responses is truer to who she is. Her limitations describe the face she shows to those who don't know her, but they also convey the ways she cannot make her own way in the world. Knowing her capabilities, one gets a glimpse into the richness of her life and the remarkable quality of her very being.

Nonetheless, the limitations shape her life and those of her family, so we all must address them if we are to make it possible for her beauty to flourish. Conversely, only by considering her in the fullness of her joys and capacities can we view her impairments in light of her life, her interests, her happiness—and not as projections of her “able” parents or of an able-biased society. An exclusive focus on her limitations would set her outside liberal definitions of personhood and citizenship that are fixated on intellect, independence, and productivity. These values throw into question her entitlement to the resources she needs for her full development and her flourishing.

### **Advocating for the Cared-for by Advocating for the Carer**

Foremost among her needs is the need for care. If she is to flourish, she needs good caring care—and lots of it. Care is a multifaceted term. It is a labor, an attitude, and a virtue. As labor, it is the work of maintaining ourselves and others when we are in a condition of need. It is most noticed in its absence, most needed when it can be least reciprocated. As an attitude, caring denotes a positive, affective bond and investment in another's well-being. The labor can be done without the appropriate attitude. Yet without the attitude of care, the open responsiveness to another that is so essential to understanding what another requires is not possible. That is, the labor unaccompanied by the attitude of care cannot be good care (see Kittay 1999).

Good caring is cultivated as a virtue by some who can provide it for intimates and strangers alike. More frequently it is elicited when we are in an affectionate relationship with another. But even here, consistency of care, maintaining care even when it is difficult and disadvantageous to us, requires the cultivation of the virtue. Care as a virtue is a disposition manifested in caring behavior (the labor and attitude), in which “a shift takes place from the interest in our life situation to the situation of the other, the one in need of care” (Gastmans, Dierckx de Castrelé, and Schotsmans 1998: 53).

Since my daughter requires constant and attentive care, and because such care (the labor) requires devoted and caring caregivers (the attitude), to advocate for my daughter without also advocating for those who are entrusted with her well-

being is at once unjust and uncaring toward the caregiver. It also fails to accomplish its original aim of assuring a good and fulfilling life for my daughter. This is so despite the fact that the interests of my daughter and those of her caregivers (whether me or others) are not always aligned, and that the interests of her paid caregivers are not infrequently at odds with those of her familial caregivers.

To give voice to one who cannot speak, whose very agency appears so attenuated, means to pay the utmost heed to what I have called elsewhere the “dependency relation”: the relation between one who gives care and one who is dependent upon caregivers for her most basic life functions (“the charge”), a dependency that, while always socially shaped, is grounded in the inevitable circumstances of the human animal (see Kittay 1999).<sup>3</sup>

As a worker (elsewhere I speak of the “dependency worker”), the caregiver is vulnerable to exploitation. But because of the special demands of caregiving and because of the traditional assignment of this work to women or servants, dependency workers are more subject to exploitation than most. When paid, dependency work is rarely well paid. When done by family members, it is, as a rule, unpaid. Paid dependency workers are frequently drawn from classes or groups who are themselves relatively powerless within the society at large and who occupy a social status lower than that of their charge. As a result, even though the charge may be totally dependent on the dependency worker for the satisfaction of fundamental needs, the dependency worker may be vulnerable to those whose interests it serves to have the charge cared for, as well as to the actions of her charge.

Conversely, given the dependency of the charge, or her physical or mental incapacity, the trust invested in the dependency worker not to abuse her power over the charge is enormous. The more stigmatized the condition that gives rise to the dependency and the more excluded and unvoiced the dependent is, the greater the opportunity and latitude for the dependency worker to violate that trust. It is conceivable that sheer coercion and policing could guarantee that a dependency worker charged with the care of a highly vulnerable person will not violate her trust and abuse her power over her charge. But the vigilance required makes such a means ineffectual in all but the most oppressive social conditions. More commonly, the emotional bond that forms between the caregiver and her charge secures the moral obligation to meet the needs of one who is vulnerable to your actions (Goodin 1985). The caregiver who has cultivated the virtue of care

3. Macintyre (1999) and Nussbaum (2000) tie our dependency to our continuity with other animals.

comes to view the interest of the charge as part of her own well-being. In the absence of some bonding or some attitudinal commitment, the care may be indifferent or even disastrously poor. Those who advocate for vulnerable persons must ask what conditions would encourage an attitude of care in the caregiver—all the while respecting the caregiver's own needs and desires.

Because good caregiving is inherently other directed, the agency of the good caregiver is not easily accommodated by the picture of the agent under liberalism, the rationally self-interested actor. Because the severely and profoundly mentally retarded are so dependent on the caregiver to exhibit other-directed behavior, the relationship between the two falls outside of conventional understandings of relationships between equals within liberalism.

The advocate for the severely retarded person needs to look beyond liberalism, while still respecting the values of autonomy and liberty propounded by liberal theory. She must seek conditions that are just to the caregiver as well as conducive to good care and justice for the charge. To advocate for caregivers is to insist that significant resources be set aside to pay for the services of caregivers, to provide them with the same benefits as other workers, to invest in training and the building of skills that will enable those who give care to help their charges develop all their capabilities.

But why, a skeptic may ask, should we invest such resources (presumably public resources if they are to benefit all affected individuals) for the sake of a population that will never be able to reciprocate, whose material contributions will never match the outlay? We can demand such reciprocity from the subject of traditional theories of liberal justice, but it makes little sense in the case of persons whose mental capabilities are very seriously limited. Charity or benevolence may motivate us to contribute to the care of such people, but is there any case to be made for the injustice of doing otherwise? Simply allowing those who cannot care for themselves to go unfed and unattended seems indecent. But do we have any duty to provide for their flourishing? We need therefore to ask what is due to the retarded, why it is due to them, and what is due to those who care for persons as dependent and vulnerable as my daughter and others like her.

### **The Tradition of Personhood**

William Wordsworth, speaking of his poem "The Idiot Boy," wrote of the "loathing and disgust" evoked by a person with mental retardation, and remarked that this is the consequence of a "want of comprehensiveness of thinking and feeling," a "false delicacy" (De Selincort 1935: 295–96). Perhaps there will be a time when

we can rid people of the “false delicacy” and broaden the measure of thinking and feeling to embrace a capacious concept of personhood. But it was not so in Wordsworth’s time, and it is not so now and here. Beauty may charm and physical prowess may awe, but intellect rules supreme.

The intellect not only provides access to power and material goods. From Aristotle to Rawls, it is by virtue of our intellect, our powers of rational deliberation, that humans acquire a unique moral status as well. For Aristotle, the possession of the deliberative faculty and ability to act from rational deliberation was the *sine qua non* for citizenship, an ability he attributed only to free men, not women and not slaves. The ascendancy of humans’ rational capacities as the defining mark not only of citizenship but of personhood itself is illustrated by John Locke’s definition of a person as “a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places” (1987: 1.27.11). Persons, in turn, become the bearers of rights, the only signers of the social contract, the only actors in our morality plays, the only players to whom the rules of justice pertain, and so, the only ones for whom citizenship and justice are defined.

Kant understood the dignity of humans to derive from their ability to assume duty through a law they themselves author. The capacity that elevates humans to the status of moral agents, he thought, is the rationality by which we judge if we can universalize maxims we choose for our own actions. Rational agency, he maintained, not our mere species membership, gives us the dignity of moral beings. Because we are capable of autonomy, of rationally determining what our duty is, we are due the respect of an end-in-itself, of an inhabitant of the kingdom of ends.

Kant’s is a tradition that has endured; it finds especially influential expression today in the theory of justice advanced by John Rawls. Let us linger for a moment on Rawls, for his is the reigning theory of liberalism. Rawls understands justice to be due to those who enter with others into an association based on fair terms of cooperation. Those who are fully cooperating throughout their lives are the free and equal citizens of the well-ordered society. It is they who partake of both the benefits and burdens of social cooperation. Two moral powers, maintains Rawls, can be attributed to citizens who are both rational in recognizing and pursuing their own conception of the good (the first moral power) and reasonable in recognizing the fairness of others also pursuing their own ends (the second moral power). It is the business of a just society to provide its citizens with the means to express these moral powers, that is, to pursue the good life as they see it and to allow others to pursue the good life as they see it. With Rawls’s theory of justice,

free and equal agents in a fair procedure deliberate and choose the principles by which “primary goods” (the goods we require whatever our conception of the good is) are distributed through the basic institutions of society (Rawls 1980: 526). These goods presume and are determined by a conception of the person as possessing two moral powers, that is, as being both reasonable and rational.

Where in this moral universe—and in a social/political world so represented—is there room for those whose rational, reasonable, and reasoning capacities are impaired, perhaps severely? A conception of the primary goods is not tailored to their lives. It is not clear that their moral powers are adequately captured in this picture of moral life, or that this conception of the moral powers is adequate to provide them with the protection, care, and resources they require to flourish (see Kittay 1999). Can moral citizenship be granted to those lacking such powers, powers presumed in the citizen who is “fully functioning throughout a life?” (Rawls 1980: 546). What moral status does my daughter then have? If she has no place at the table of equal deliberators, of free and equal moral agents, of free and equal citizens, does justice apply to her?<sup>4</sup>

If traditional theories in the Western moral and political tradition are correct in their exclusion, then we have to wonder: When the heart cries “Injustice” upon encountering pictures of the mentally retarded tied to their beds, where one attendant cares for over one hundred entirely dependent residents (as in the “asylum” in Guadalajara), is this merely a misunderstanding of the term *justice*? When we read Nancy Scheper-Hughes’s (1992) vivid and sympathetic account of the abject lives of sugarcane workers of northeastern Brazil, of the numbed misery of the mothers who allow their weak (and doubtless impaired) infants to “return to Jesus” by failing to feed them, and believe that unjust circumstances compel these mothers to participate in a moral wrong (albeit one for which they are not the prime culprits)—are we merely foisting sentimental middle-class values on those who cannot afford them? And is there any ground for the accusation that the United States—the wealthiest nation in the history of the world—is unjust for not providing appropriate resources to families who lack means to properly care for their developmentally disabled child? Wealthy parents might, of course, choose to lavish care on their “deviant” family members, just as those with resources can lavishly spend on the many things for which there is no public support. Similarly, a family who has resources to care for a child with Down syn-

4. Rawls, in fact, does not seem to think that the individual who is permanently impaired in such a way that he or she cannot fully participate in social cooperation throughout a life is not a citizen. See my discussion of this point in Kittay 1999: 105 n. 178.



drome might refuse prenatal testing and selective abortion. But should any family expect public support for such a child when an abortion would have been an inexpensive way to prevent such a birth? Are there any claims from justice to extend public provision for families to lighten the extra demands of raising a child with cognitive deficits so severe that no education or habilitation will turn that child into a future taxpayer?

In the above discussion, we began thinking of the individual with intellectual disabilities, but we soon find ourselves including the family of which she is a part and her caregivers in our consideration. Earlier I spoke of caregivers as if they were different from the family and directed us to the vulnerability of the paid caregiver. But all caregivers, familial or paid, become derivatively dependent when they turn their time, attention, and concerns to a dependent other. And the greater the dependency of their charge, the greater their derivative dependency. Elsewhere I argue that not only are dependents effectively left out of the social contract, but dependency workers are implicitly excluded as well (Kittay 1999). Even as they advocate for their charge or other dependent kin, their own voice and the needs that arise from their role as caregivers come to be eclipsed. I asked above whether assistance to those who are dependent because of their permanent mental incapacity should expect support at the expense of the public. The same question could be asked of those who provide their care—even though the latter are surely capable of the full functioning that Rawls (1972, 1992) speaks of as requisite to membership in the community of equals. We can ask whether parents or kin who assume the role of caregiver should have claims on the larger society to support them in their efforts to provide care. If, for all the effort and care in raising a child with disabilities into adulthood, there is no payback (conventionally understood) to the society at large, can we still insist that there be a state interest in helping families with the additional burdens of caring for a developmentally disabled child? Is there a state interest in assuring families that their vulnerable child will be well cared for when the family is no longer able or willing to do so?

### **The Construction of Disability, the ADA, and Mental Retardation**

The enactment of the 1990 Americans with Disabilities Act (ADA) is an affirmation of the citizenship and the justice due to all disabled persons. That act, however, does not try to establish the ground for affirming the personhood or citizenship of disabled Americans. It assumes it. Its point is to make discrimination based on disability illegal. Modeled on other antidiscrimination legislation, its

approach is largely a negative one, stipulating that obstacles not be placed in the way of an individual's opportunity to participate in the social cooperation constitutive of citizenship.

As Anita Silvers (1998) argues, in the case of disability, a purely negative right not to be interfered with actually mandates positive action, such as the building of ramps and the modification of toilet facilities. Such positive action is largely compensatory, since the physiosocial environment might have been built so as not to exclude persons with differing abilities. Silvers makes the case that this approach supports the social model of disability rather than the medical model. The medical model locates the source of disability in the individual: the individual is defective and needs fixing; the social model locates the source of the disability in the social situation: the social situation requires fixing, not the individual. The supposition, endorsed by Silvers and adopted in some of the language of the ADA itself, is that once the barriers to full participation are removed, the disabled will be able to be as productive, self-sustaining, and independent as the abled.

The focus on physical disabilities has given much plausibility to the arguments of the disability community that disadvantage, and the disability that results from a physiological impairment, is itself a consequence of an environment built to accommodate certain capacities but not others. Such an analysis of disability is especially applicable to physical disabilities, but may have some limited applicability to persons with a mild retardation as well. As a number of disability theorists and advocates have argued, it is only a consequence of our technologically advanced environment that we need to have skills that depend on very developed and trained cognitive capacities, skills beyond the capacities of mildly retarded persons. In an agrarian community, the mental abilities of a mildly retarded person may be quite sufficient to allow such an individual to live a reasonably independent and productive existence—a life that is viewed as normal. Even if this is true of very mildly retarded adults, there is no accommodation that transforms as severe a case of retardation as that of my daughter, Sesha, into a condition that is not profoundly disabling. The cognitive impairments of the severely and profoundly retarded are not merely contingently disabling. Unlike many disabilities, hers are not simply social constructions. Someone such as my daughter could not survive, much less thrive, without constant and vigilant attention, without someone performing for her nearly all the tasks of daily living, as well as providing for her—and her caregiver—the material resources required for her existence and flourishing.

We might say, however, that in the case of developmental disabilities, espe-

cially severe ones, though the disability itself is not socially constructed, the view that mental retardation is a “problem” rather than a possible outcome of human physiology *is*. Those who have developmental disabilities require more supports than those without these impairments. However, they also provide different and rich opportunities for relationships and experiencing new ways of seeing the world (see Cushing and Lewis n.d., Bogdan and Taylor 1992, and Hingsburger 2000). Constructed only as a problem, Sesha and other developmentally disabled persons appear to have no claim to the aids and supports that they need to live and live well. According to some theories she is not a citizen of this or any country.<sup>5</sup> Must she and those who share her disabilities then be consigned to live off the scraps of a gratuitous and uncertain generosity?

### **An Alternative Conception of Personhood**

In a recent essay, I contrast the lives of those shattered by inappropriate institutions and social neglect with that of Sesha. I evoke a morning in my kitchen when Sesha, accompanied by her caregiver, is having breakfast, and I sneak in to give her a kiss:

Sesha, as always, is delighted to see me. Anxious to give me one of her distinctive kisses she tries to grab my hair to pull me to her mouth. Yet at the same time my kisses tickle her and make her giggle too hard to concentrate on dropping the jam-covered toast before going after my hair. I negotiate, as best as I can, the sticky toast, the hair-pulling and the raspberry jam-covered mouth. In this charming dance, Sesha and I experience some of our most joyful moments—laughing, ducking, grabbing, kissing. (Kittay 2000b)

They are “small” pleasures, to be sure, but pleasures that provide so much of life’s meaning and worth that they permit the deep sorrows of Sesha’s limitations to recede into a distant place in the mind; they are small joys, but are so profound that they even make me question that very sorrow. It is a pleasure both Sesha and I would have been denied if we could not share our lives together.

Because we as a family have been able to keep Sesha in our home and community, those who have made contact with her and have learned to see her as we who love her do have gained new perspectives on what it means to be a person. Seeing Sesha in her interactions with those who care for—and about—her

5. See Sachs 1999 for a report on the hurdles put in the way of persons with mental retardation and other mental disabilities by changes in the immigration law that took effect in 1994.

reveals that being a person has little to do with rationality and everything to do with *relationships*—to our world and to those in it.

If personhood is limited to those who possess certain intellectual capacities and to those who are productive, then my daughter would not be a person. But my daughter is a person. She is, after all, my daughter. How can she be anything but a person? If traditional conceptions of personhood are not capacious enough to include Sesha and those who share her impairments, we need a new definition. I propose that being a person means having the capacity to be in certain relationships with other persons, to sustain contact with other persons, to shape one's own world and the world of others, and to have a life that another person can conceive of as an imaginative possibility for him- or herself (see Diamond 1991). It is a definition that brings our relationships (real and imaginative) with others to the center of any conception of personhood. We do not become a person without the engagement of other persons—their care, as well as their recognition of the uniqueness and the connectedness of our human agency,<sup>6</sup> and the distinctiveness of our particularly human relations to others and of the world we fashion.<sup>7</sup>

The shaping of one's own world is a gift that each individual possesses and that some make more use of than others. Sesha, in spite of all her limitations, makes ample use of this gift. To be with Sesha is to enter her orbit, to gain a glimpse of the world as she constructs it. Even those who are still more limited than Sesha have this capacity. It requires an openness to experience it. In one who can scarcely move a muscle, a glint in the eye at a strain of familiar music establishes personhood. A slight upturn of the lip in a profoundly and multiply disabled individual when a favorite caregiver comes along, or a look of joy in response to the scent of a perfume—all these establish personhood. We know that there is a person before us when we see, as David Hingsburger (2000: 24) says, that there is "someone home"; that the seemingly vacuous look is not vacant at all; that an individual's inability to articulate a "language" as publicly defined does not indicate a lack of anything to say. To fail to recognize that capacity is to deny an individual's personhood. When we do so, we cut ourselves off from those who enlarge our relational possibilities, and we lessen ourselves as persons.

Keeping Sesha at home would not have been possible without an extensive and costly support system. Without these neither Sesha, nor her family, nor those

6. See Becker 2000 for an account of the good of agency and the ADA.

7. I take species membership to be central to our understanding of personhood, as does Diamond (1991). The kiss I share with another human is distinctively human. I argue that to reduce what makes us persons to a set of defined characteristics is a mistake. See Kittay 2000a.

who have come to know her would have come to realize the person she is. Her very personhood would have been denied; ours would have been diminished. But this sort of care is not cost effective; it cannot be supported by a minimal budget grudgingly set aside for the mentally disabled. The costs can never be recuperated by Sesha's future earnings, and whatever costs might be saved are saved at the expense of those of us who undertake her care.

The view that community placement has as its goal the independence and productivity of the disabled operates with a concept of personhood quite different from the one I invoke here. It is one that depends on "rationality" and on the ability to partake in reciprocal cooperative arrangements. This independence and productivity can be justified as ultimately cost effective because it turns persons who are dependent on others for support into self-supporting individuals. Cost-effectiveness then becomes part and parcel of the rationale for court decisions based on the ADA. So when it is not cost effective to promote "independence" and "productivity"—if it would be more costly to promote these than to continue state support—then a way of life that is more self-determining, even when it is desired by the individual and recommended by state-appointed professionals, can be scrapped.

Disabled persons have fought hard for the right to live independently, to have access to work that suits their talents and temperaments, to be included among the "productive" and contributing members of society. They have insisted on their dignity, a dignity that refuses to be an object of pity and charity. They have argued that modifications and accommodations they may require to function independently and be productive should be classed with other antidiscrimination legislation, not glossed as exceptionalism or "special needs." And they have argued that treating disabled people as full citizens will ultimately reduce costs to the wider society, costs incurred by limiting the disabled to a debilitating dependency. Claims for inclusion, full dignity, and citizenship ought to apply in the case of a person with the sorts of dependencies, disabilities, and capabilities of Sesha as well as those who can be independent and productive. Is there a way to reconcile the needs of someone as inevitably dependent as Sesha with the concerns and analyses of those who have argued that both disability and the apparent dependency of disabled people are socially constructed?

Perhaps a way of including the severely intellectually impaired person and bestowing the dignity of citizenship is to interpret what it means to live independently, to be employed, and to be productive, in very broad terms. So, for example, if Sesha, in her adulthood, were to live in an apartment or group home with around-the-clock attendants, we would call this "independent living." If she can

be made to partake in one tiny step in an assembly line production, and she is given some material compensation, we would call this “working” and being “productive”—whether or not this activity has any meaning for her.<sup>8</sup> To so stretch these concepts both empties them of meaning and undermines the possibility that dignity is compatible with life-long dependency. It means that when a disabled person requires attendants to help her dress, assist her mobility, or monitor a medical disability–related condition in order to be “independent,” we mask a genuine dependency.

But who in any complex society is not dependent on others, for the production of our food, for our mobility, for a multitude of tasks that make it possible for each of us to function in our work and daily living? Many of these dependencies are hidden, as when we fail to think about our dependence on those who grow our food. Other dependencies are hypervisible, such as the dependence that results from certain disabilities or the dependence on state support of poor, single mothers who cannot simultaneously be employed (at minimum wage) and care for young or disabled children. But dependence that goes unacknowledged is still not independence.

Independence, except in some particular actions and functions, is a fiction, regardless of our abilities or disabilities, and the pernicious effects of this fiction are encouraged when we hide the ways in which our needs are met in relations of dependencies. On the other hand, this fiction turns those whose dependence cannot be masked into pariahs, or makes them objects of disdain or pity. It causes us to refuse assistance when it is needed. It encourages us either to deny that assistance to others when they require it or to be givers of care because we fear having to receive care ourselves. In acknowledging dependency we respect the fact that as individuals our dependency relations are constitutive of who we are and that, as a society, we are inextricably dependent on one another. I suggest that it is preferable to refuse the contractarian basis for the distribution of benefits and burdens (that only those who assume their share of society’s burdens are due a fair share of the benefits) and with it the myth of independence and an overemphasis on rationality. In acknowledging dependency we can borrow from what is best in Marx: that benefits and burdens are to be assigned by need and capability, respectively (cf. Nussbaum 2000).

Behind the ADA and the prohibition of discrimination is the deeper concept that physical or mental impairments should not result in lives devoid of the satisfactions for which we all yearn and which make life worth living. The satisfaction

8. These are all interpretations that I have, in fact, heard applied to very severely retarded adults.

of those yearnings may take forms that are distinctive, but the disabled person—even when profoundly mentally retarded—is as entitled to them as the nondisabled. The principle that the disabled are as entitled as the nondisabled should not be held hostage to a notion that a disabled person must become “productive” or live “independently” if “suitably assisted,” or that it is less costly to place an individual in a community rather than an institution.

### **Supporting the Caregiver—Justly**

The appalling conditions found in the global Willowbrooks, of which the psychiatric hospital in Mexico is only one example, are part of the history we thought we left behind when we moved large numbers of institutional residents into group homes. But the mistreatment, which largely had been attributed to the systemic inadequacies of what Goffman (1961) had called “total institutions,” has resurfaced in group homes. The headline in the *Washington Post* announcing the criminal conduct of those who run many of the group homes in Washington, D.C., and the callousness and indifference of some of the staff, testify to the persistent nature of the problem of good care for the mentally retarded. And this case is only one among many (see Ohlemacher 2000, Tully 1999, and Boo 1999).

In “a society which defines and confines all meaning and worth in terms of production, profit, and pervasive greed,” writes James Trent in his history of mental retardation, the intellectually disabled will be exploited (1994: 277). In such a society, their caretakers will also be exploited and will have the opportunity to become victimizers as well as victims. The change from institution to group home can help, but the form of the residence will not alter the poor care its residents receive if the caregivers are as abject as their charges. In such a society, care will be minimal, and callous caretakers will be inevitable.

**Family Dependency Work** The home may not always be “a haven in a heartless world,” but for the very vulnerable, connections with family members are often the only shield against the slings and arrows of an uncaring society. Family members are often, but not only (and not always), those whose ties are biological or legal, but are those “who by birth, adoption, marriage, or declared commitment share a deep personal connection and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need” (Levine 1990).

In the United States as well as in most other nations, state support for families who want to keep their family member home is far too limited and tends to be

means-tested, providing relief only for families who are below a certain income. As one researcher states, “when programs are limited in scope and size, returning a person with disabilities to the community may be a euphemism for returning the child to the mother” (Nemzoff 1992: 20). Affluent as well as poor families find themselves overwhelmed with medical and caretaking responsibilities. The Kelso family, the father a CEO and the mother an activist for disabled people, made the front page of newspapers across the country when they abandoned their multiply disabled and medically fragile young son in a hospital during the Christmas holidays, when relief caregivers were in very short supply (Jacobs 1999).<sup>9</sup>

Given the circumstances families face, it is hardly a wonder that when families decide to place their child in residential care, there is an estrangement—an estrangement that comes with the relief of a burden too heavy to bear.<sup>10</sup> In group homes within the community there is a better likelihood that the protective connections will be retained, but not for individuals whose families have already lost touch. When families disappear from the scene, there are few who provide the oversight to assure that residents are not neglected or abused. The weight of the burden that causes the estrangement is less a function of the impairment per se than of the larger society’s failure to help the family in its efforts to care for its disabled relative.

Although familial caregivers are as capable of neglect and abuse as strangers paid to care,<sup>11</sup> affective bonds that normally form between family members offer important defenses against the harmful behavior, especially when supports are available to ease hardships. It would seem that expenditures that aided mothers, fathers, grandmothers, and other family members who do the dependency work or continue to assume dependency responsibilities even when their relative is in residential care would be especially well spent.

**Paid Dependency Workers** If unpaid familial caregivers need assistance in maintaining their relationship to their mentally disabled family member and keeping ties alive for the long haul, caregivers who do their work for pay need support in

9. Manning 2000 places the Kelso case into the context of others raising children with serious medical and mental disabilities.

10. Reported in discussion with the director of the Sullivan County Diagnostic Center in Sullivan County, New York.

11. See Bonner and Rimer 2000 for a report on Johnny Paul Penry, a retarded man and convicted rapist and murderer in Texas, who suffered abuse at the hands of his mother.



forming the bonds in the first place. Earlier I argued that abusive behavior by those who are charged with providing care is facilitated not only by the social devaluation of persons with mental disabilities, but also by the devaluation of the caregivers themselves. If we want to remove the prejudice and lack of understanding that blights the lives of people with mental retardation, we can begin by treating their caregivers as if their work mattered (because it does) and as if they mattered (because they do). To do this we need to provide caregivers with conditions that allow them to do their work well and receive just compensation. They need appropriate training, the opportunity to grow in their work, a voice in the care of their charges, compensation that matches the intensity of their labor, and encouragement in their sympathetic and empathic responses to their charges (see Bogdan and Taylor 1992).

I have argued elsewhere that when thinking about the care of dependents, we cannot employ the usual model of reciprocal cooperation, of the equal sharing of benefits and burdens (Kittay 1999). Those who are dependent (at least when, and to what extent, they are) cannot reciprocate the care that they receive. In our dependence, we cannot pay back our caregivers and compensate them for their labor. Another must do so. I have called this form of reciprocation *doulia*, after the doula, the contemporary postpartum caregiver who cares for the mother so that the mother can care for her new infant. I have called for a public conception of *doulia*, by which the larger society supports those who care for the “inevitably dependent” (dependent because of age, infirmity, or severe disability). I conceive of this as a principle of justice, in fact, a principle of justice that embraces those excluded by the contractual model of reciprocation. We need a principle of *doulia* for a caring that is justly compensated, and a justice that is caring.

### **Just Caring and Caring Justice**

At the beginning of this article, I proposed that advocating for severely and profoundly mentally retarded persons required simultaneously advocating for their caregivers; that such a project was not only just and caring, but was the only way to advocate effectively for the initial group. I have maintained that liberal conceptions of justice have excluded both those with severe developmental disabilities and those who are their caregivers. With a principle of *doulia*, we have seen how we can reconfigure justice so that the labor of caregiving is counted and rewarded as part of a broader idea of reciprocal social cooperation. Such an idea reflects the view that any society, and surely any decent society, has the care of dependents as one of its central functions.

With one stroke, dependents—be they small children or incapacitated adults, be the impairments physical or mental—become an integral part of any social organization. To presume that they stand outside of justice, that they are not entitled, that—for reasons of their impairments and dependence—they lack rights, seems odd indeed if the point and purpose of such principles (if not the sole one) is a social order that secures the ability to care for dependents.

Inevitable dependencies, the dependencies of our early years, old age, disability, and illness, however, have been privatized, so that we have come to discount them and the integral part of social life they in fact constitute. Doing so permits us to avoid our collective responsibility to maintain dependents. We forget the extent to which we need social organization to assure that should we become dependent, we will have the assistance we need, and to assure that should we have to care for dependents, we ourselves will not come to bear the full burden and become unable to meet our own needs. Not all of us will remain in a state of dependency as profound as that of my daughter. But any of us could become so—an illness or an accident could make us so. From the vantage point of our socially constructed independence, we might think, “Oh, but should that happen, I would rather be dead.” From the vantage point of my daughter, that is wasteful of what life has to offer, a failure to appreciate the gifts of being.

Within the reigning liberal understanding of justice, we must continue to think of those with severe or profound cognitive disabilities as exceptional, as those who can never be citizens, whom we will care for out of compassion (or pity?), and who have no rights associated with their needs. If we meet their needs, it is out of a gratuitous kindness, a kindness they have no right to demand. As “exceptions” then, those with profound developmental and cognitive impairments are vulnerable to the vicissitudes, indignities, and stigma of being passive recipients of charity.

However, it may be that calling for charity and benevolence is sufficient for protecting this portion of the disabled population from neglect and abuse, that it is unnecessary to overhaul long-standing treatments of justice because they exclude the retarded. Can’t we argue from benevolence and charity that the mentally retarded should not be neglected and abused? Indeed, to invoke “the stigma of being passive recipients of charity” and to speak, as I did earlier, of generosity as uncertain and gratuitous may be prejudicing the case and may be mere rhetoric. Is charity really inadequate? Why insist on a full-blown notion of personhood or citizenship to cover those whom so many have so long viewed as falling short, as inappropriate subjects for justice?

Let us concede, for the sake of argument, that the severely retarded do not

have claims to citizenship and may not even be persons. Still, they should not be harmed, because doing so diminishes those in the larger society who would do the harm or allow the harm. Just as cruelty to animals may be immoral not because of what it does to the animal, but because of what it does to those who inflict the cruelty, so we should not be cruel to the mentally retarded. Is this not sufficient to protect the severely retarded from neglect and abuse?

If such thinking is the basis for providing aid, the aid will, of necessity, be a low priority in any public distribution of resources. It will tend to be minimal, except in cases in which individual acts of generosity surface. But if such support is minimal, those who do the dependency work for this population will, as is now the case, be only minimally rewarded for their labors. The respect they gain for their work will be similarly minimal. The low pay and lack of respect will encourage the conditions that breed the neglect and abuse that calls for charity and benevolence were intended to counter.

For nonhuman animals it may be sufficient to invoke the principle that harm inflicted on them is wrong because of what it does to those who do the injury. Nonhuman animals can fend for themselves, if they are not harmed or interfered with by humans. But the fate of human beings who are impaired is intimately tied in with other humans—especially those who provide care. Not being harmed is only part of what we require when we are dependent, and the lack of care—the full-blown sort, not the labor mechanically carried out—is equivalent to harm. How the care is bestowed makes all the difference between the potential for harm and spirit-sustaining aid.

Care is a costly morality: costly in the personal and emotional resources it demands and in the time it consumes (time that cannot be devoted to investing in a career or advancing oneself materially). When care is not adequately supported, either the cost of care is borne by the caregiver alone or the charge fails to receive adequate care—or both suffer. If the retarded person should be treated with charity and benevolence because she should not be harmed, then she must be treated with an enlarged concept of justice—a justice large enough to embrace her and her (familial and nonfamilial) caregivers—that gives a right to care and support for care. Only then can the most vulnerable of disabled people hope to be safe and able to develop and flourish as persons in a just and caring society.

To stigmatize dependency, ignore its frequency, and valorize only a particular segment of human possibility is to shirk our collective responsibility to take care of one another and to ensure that we are well taken care of by someone for whom our well-being matters deeply. Looking at justice through a lens of social constructionism that only sees dependence as constructed and fails to see indepen-

dence as still more constructed will only reinstate prejudices against disability. This time the prejudice falls most heavily on the shoulders of the severely and profoundly mentally retarded, who are the most vulnerable and whose enormous dependencies cannot be nullified by environmental modifications. But we exclude them from justice at a cost. That cost is the denial of the dependent animals we are. It is a condition no amount of rationality can alter.

Although care seems to have less in common with rights and justice than with virtues and benevolence, the virtue and kind hand of care requires a just setting in which to blossom. In a context of condescending pity (toward the mentally impaired dependent) and exploitative demands (toward the dependency worker), the inequality between dependent and dependency worker too easily fosters domination rather than caring. In a society ruled by the conceptions of liberalism, where rights are “trump cards,” charity and benevolence can never replace the guarantees of human dignity that entitlements of justice provide. In the end, this may be the great achievement of liberalism. It is one that we cannot forgo, no matter how much we challenge liberalism in our hope for a more progressive, a more inclusive, and a more caring political vision than it now provides. Justice that is caring begins with an acknowledgment of our dependency and seeks to organize society so that our well-being is not inversely related to our need for care or to care; such justice makes caring itself a mode of just action.

### **Coda—An Acknowledgment**

For my daughter, dependence of the most profound sort will be part of her normal existence. But such dependence does not preclude a certain form of mutual dependence. I depend on her as well. Sesha and her well-being are essential to my own. Her smile chases away the trivial distractions of the day. Her embrace grounds me in what is important and precious. Watching her grow and develop skills and take pride in her accomplishments nurtures me as much as my own work. In another place I’ve written: “It’s perhaps self-delusional to say that I am as dependent on her as she is on me, but perhaps not. Others could take care of her and even love her—in fact, I must think that she will continue to thrive with or without me. But without her, I would wither” (Kittay 2000b). Writing that passage, acknowledging that I was even more dependent on her than she on me was itself a moment of discovery.

Although my daughter can never be “productive” or pay back to society anything of material value, still her contributions are great. Her sweetness radiates and enriches the lives of everyone she touches, those who allow themselves to be

touched by her. Without her abundant and exuberant love, the world would be a more dismal place. I am only beginning to fill volumes with what I have learned from her.

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