
Human Rights, Civil Rights: Prescribing Disability Discrimination Prevention in Packaging Essential Health Benefits

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Health Care Insurance, Health Care, and the Impact of Disability

Health care insurance schemes, whether private or public, are notoriously unaccommodating to individuals with disabilities. While most nonelderly nondisabled persons in the U.S. are insured through private sources, coverage sources for nonelderly persons with disabilities have traditionally been a mix of private and public coverage.¹ For all age groups, the employment-to-population ratio is much lower for persons with a disability than for those with no disability. Moreover, employed persons with a disability were more likely to be self-employed than those with no disability.² As a group, therefore, nonelderly people with disabilities have not been as well positioned as others to obtain private health care insurance because in the U.S., acquiring such coverage usually is employer based.

Private insurers have been wary of individuals with disabilities because, according to the U.S. Office of Disability, Aging and Long-Term Care Policy: “Health care expenditures are expected to be higher for the disabled than for the nondisabled, because of their higher utilization rates. However, the mean expense per event for all types of services available are also higher for the disabled than for the nondisabled.”³

Both within and beyond the U.S., public health care insurance programs are designed to include at least some individuals with disabilities on their rolls.⁴ But rarely, if ever, has the bare inclusion of disabled people in such a public health care scheme been accompanied by a mandate to be responsive to their disabilities in delineating the benefits to which participants are offered access.⁵ Some non-U.S. nations’ public health care rationing schemes have adopted prioritization systems that explicitly devalue some patients with disabilities by presuming that their impairments depress their quality of life.⁶

Once they are characterized as living less valuable lives than nondisabled people do, disabled individuals may readily be denied kinds and levels of care customarily allocated without demurral to nondisabled people, often on the ground that they cannot be made functional, or kinds and levels of care ordinarily not needed by nondisabled people, often on the ground that it is too costly to make them functional.⁷

In the U.S., some public health care programs have balked at offering to disabled individuals the kinds of adaptive items they need to be restored to equitably functional daily life. To illustrate, the Medicare man-

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ual for power wheelchairs indicates that they are not a covered benefit unless they are medically necessary for use inside the home, thus confining people with significant mobility limitations to their homes just because they can maneuver within the residence without powered mobility assistance.⁸ Funding for non-mobility-

When rights extend beyond protections from interference to the provision of goods such as health care or education, critics predictably invoke the specter of uncontrollable costs.¹² Soon after the advent of U.S. Medicare, Charles Fried¹³ argued that the right to health care should be understood not as an equal

We explore whether an appropriate basis for effectively banning such differential treatment as discrimination is an understanding — like that motivating the 2007 United Nations Convention on the Rights of People with Disabilities — that the highest attainable standard of health is a human right. Or is there an alternative understanding of the basis for protecting disabled people against inequities in access to health care services that would prove preferable?

disabled individuals to repair mobility-damaging conditions, such as surgery and casting for fractured hips and legs, and for some mobility-disabled individuals to compensate for mobility-damaging conditions, such as lower limb prostheses, do not carry the same restriction, which is imposed to lower costs by making wheelchair use as unpalatable as possible to those who can walk the few steps needed within a home. And U.S. private insurers often follow the public programs' lead in determining the benefits they will provide.⁹

The problems extend beyond insurance to health care offices and providers. A recent study indicated that a significant percentage of U.S. subspecialty physicians' offices remain inaccessible, although the Americans with Disabilities Act (ADA) has required accessibility for almost 25 years.¹⁰ In the U.K., a 2007 report called attention to mistreatment in the NHS of persons with learning disabilities. A report issued in 2013 indicated that the situation had not changed and that between 2010 and 2012, 42% of the deaths in this group of patients were premature and attributable to poor health care and discriminatory attitudes within the NHS.¹¹

In this article, we explore whether an appropriate basis for effectively banning such differential treatment as discrimination is an understanding — like that motivating the 2007 United Nations Convention on the Rights of People with Disabilities (CRPD) — that the highest attainable standard of health is a human right. Or is there an alternative understanding of the basis for protecting disabled people against inequities in access to health care services that would prove preferable?

right but as a right to a decent minimum because of its costs. In what follows, we begin by explaining why the understanding of health rights as human rights in the CRPD could be problematic for delineating a decent minimum that is equitable and inclusive for people with disabilities. We then develop an alternative, non-metaphysical account of rights construed not as human rights but as civil rights instantiated in ongoing social agreements. We conclude by applying this account to the right to health care under the U.S. Affordable Care Act (ACA).

Health Care under the Convention on the Rights of People with Disabilities

Coming into force in 2008, the CRPD is a human rights instrument meant to delineate universal freedoms and protections that all disabled people deserve. States parties to the CRPD commit to ensure that persons with disabilities are afforded full equality, including equal protection under the law. To date, 130 of the 155 signatory nations have ratified the CRPD; the U.S. is a signatory, but the Senate has yet to give the consent required for ratification.

Article 25 of the CRPD recognizes persons with disabilities as possessing a "right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability." Discrimination on the basis of disability in the provision of health insurance is prohibited. Further, health insurance must be made available to the disabled in a fair and reasonable manner. States parties are to prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. Disabled people are to be provided with the same range, quality, and stan-

dard of free or affordable health care and programs as provided to other persons, but also with health services they need specifically because of their disabilities. This latter provision entails that, due to disability, utilization of basic packages of essential services may be larger for some individuals than for others. It also entails that basic packages must be constructed so as not to exclude services essential for people with disabilities such as lower extremity prostheses or pharmaceuticals needed by patients with cystic fibrosis or multiple sclerosis. Health care professionals are to provide care of the same quality to persons with disabilities as to others; further, to apply health care services equitably to people with disabilities calls for their free and informed consent.

Such equitable practice is to be accomplished explicitly by raising awareness of the human rights, dignity, autonomy, and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care. As with some of the other components of the CRPD, the conceptualization of human rights here mixes civil rights and social rights within a framework that accords these rights to all humans just on the basis of their being human.¹⁴ Thus, the CRPD pioneers aimed to bring the aspirations of people with disabilities for equality fully within the post-World War II movement to expand global recognition of human rights. The conceptual task is challenging, as the objective is to defend differential distributive treatment as equitable using ground that traditionally has rooted human rights in the presumption that persons essentially must be the same because all humans are persons and only humans are persons.

Human Exceptionalism as a Basis for Equitable Access to Health Care

The human rights frame initiated in European political discourse in the 16th century became fully endowed with philosophical justifications during the 17th and 18th centuries and thereafter has inspired a multitude of emancipatory enterprises and movements.¹⁵ In contrast to earlier accounts of the protections and privileges due humans from the state, which sorted humans into different classes and ranked the groups as to comparative worth, the traditional human rights position is that all humans equally are owed freedom from political or state-facilitated oppression.¹⁶ For the human rights tradition, or at least for its older branch, each human's obligation to respect and protect other humans derives from our all sharing the essential properties of human nature.¹⁷ Human rights are universal rights, belonging to everyone in virtue of their being human.¹⁸

This "human exceptionalism" approach argues that humans are distinguished from other animals in some singular objective way.¹⁹ Each human has a claim on recognition and respect from others because all alike seek opportunity to realize their uniquely human value in social interaction.²⁰ But human exceptionalism notoriously grants, as a corollary, permission to forgo acknowledging individuals who do not seem to manifest the essential human characteristic as bearers of rights. Thus, rights claims pertaining to biological individuals who might resemble humans in some — indeed, in many or even most — respects are open to being dismissed on ontological grounds by reference to their lacking a crucial human-making property.²¹ So might robots, however human their appearance and conduct, be denied rights; since Isaac Asimov's *I, Robot*,²² the matter of whether machines and animals have human liberty rights has been a central post-WWII science fiction theme.²³ And so have individuals with disabilities been denied the status of rights bearers.

Two different components of human nature have been invoked as the proper basis for acknowledging human rights. One kind of property is a broadly construed psychological or mental property. The other is a broadly construed biological or material property.²⁴

The argument for human rights based on distinctively human mental properties usually unfolds thus: a crucial cognitive or other kind of mental capacity is asserted to differentiate humans from other species. For example, Michael Tooley²⁵ argued that "[a]n organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity." A further step equates distinctively human psychological capacity with the capacity for rational conduct, and especially for formulating aims for action through self-reflection.²⁶ This singular characteristic that makes humans unique also is supposed to be the source of our fundamental value to ourselves and to each other. Each human therefore should respect the capacity of adult humans to execute the requisite kind of rational action, and to accept self-reflective responsibility for what has been done. But exercising our exceptional capacities requires being sufficiently self-governing, and free from social and political subordination, to self-determine the good for one's self.²⁷

Thus, from a mental difference that purportedly makes humans exceptional has been drawn a warrant for acknowledging and attributing human rights. Placing human rights on this basis, however, precludes the possibility that human rights can be universal in the requisite sense. Disabled people commonly have been perceived as failing to meet the standard of capacity

for self-reflective (and thereby responsible) action.²⁸ Consequently, individuals who are biologically human but are perceived as lacking the crucial level of cognitive capacity have been denied the usual freedom, and moral and legal protections, that human rights are expected to bestow. The metaphysical move of grounding rights in essential human properties thus has enabled exclusion from, rather than inclusion under, rights-bearers' protection.

There is, further, an infamous history of underestimating the capacities of individuals, based on their disabilities. For centuries, hearing-impaired people were mistakenly assessed as intellectually impaired, just because they did not speak what they thought.²⁹ The centuries of denying schooling to intellectually disabled people, as well as to people with other kinds of disabilities, and then condemning them as unable to learn because they lacked reading and writing skills other people acquired through schooling, also illustrate the effect of bias on accurate assessment of disabled people's capacity.³⁰ In general, non-verbal individuals, and other individuals whose disabilities impede communication, remain vulnerable to misjudgment of this kind. The impact of such bias against failing to display the species-definitive mental capacity set as the standard for being human is that biologically human individuals with disabilities have been regarded as not being really human or fully human persons with the same entitlements as other people.

This pretext has regularly motivated excluding disabled people from the ranks of rights bearers. As a result, in many legal systems individuals with disabilities have been bereft of legal standing and thereby deprived of equal protection from the law. Article 12 of the CRPD attempts a remedy, adjuring states parties to reaffirm the right of people with disabilities to be recognized as full persons and to enjoy legal capacity on an equal basis with others in all aspects of life. But the components of Article 12 that direct states parties to provide for effective safeguards to prevent abuse, coercion, exploitation, and arbitrary or excessive confinement, and of Article 13 that call for ensuring effective access to justice for persons with disabilities on an equal basis with others, indicate the enormous amount of justice system reform through which nations must go to achieve justice for all, including disabled people.

Human rights are supposed to be universal, but the adduced essential human-making properties are not co-extensive with the class of individuals who in other circumstances are taken to be humans. Contrary to human rights programs' mandate to promote equality, this strategy does not escape sorting individuals, based on non-disability or disability, into classes of higher and lower status, with the former more socially

privileged and better protected than the latter. That affirmation of full legal standing to invoke rights has been so hard for disabled people to attain suggests the hazards of invoking a species-definitive psychological or mental capacity in validating human rights.

If special intellectual capacity is not the hallmark, perhaps the universality of human rights lies in the other familiar articulation of human exceptionalism, which is the claim that humans are all equally products of a special and singularly successful biological evolutionary process.³¹ The idea here is that humans are naturally constructed to be concerned about ourselves, and for those we believe to be our close biological kin as well. We biologically bond with kin to care for our offspring, and we naturally also ally with the smaller and larger circles of humans on whom our own welfare and our family's welfare depend.

Biological exceptionalism also lends itself to privileging some humans and marginalizing or excluding others. If kinship is supposed to be the basis of each human's duty to acknowledge human rights of others, some individuals will enjoy a more secure status than others, depending on how broadly their family resemblances reach. Far from being an expansive basis for human rights, biological exceptionalism seems to energize a kind of tribalism that might embrace close family members who happen to have disabilities, but by no means extends to most disabled people, who remain anonymous anomalous individuals distanced and treated as alien because of their disabilities. Another reason for concern about the power of inclusiveness offered by a "family ties" basis for universal human rights emerges from the muted or absent family responses to the disappearance of their disabled relatives during the Nazi euthanasia program years.³²

Sourcing a health care right in individuals' humanity, when this status is assigned on the basis of kinship bonds, also threatens to strain the health care system. In this circumstance, the most pressing and effectively presented claims for care will come from family advocates for whom the patient is supremely human and thereby deserving of the full array of care that medicine can offer. The troubled and sometimes ruinous process whereby families of disabled children are expected to advocate extensively so as to obtain special educational services should serve as a warning here. Better-educated families in more favorable economic condition have proven more successful than less fortunate ones in obtaining services, and individuals with disabilities bereft of favorable family support may have no one advocating for them at all.³³

Disparities of social status, which track appearance of functional deficit but do not take into account the adaptive functionality achievable with access to

effective services, can create unnecessary problems in assembling an essential health care benefits package. Bias that promotes normal appearance or conduct, or family resemblance, as important for preferable status and privilege, while anomalous function or presence has the opposite result, places a premium on providing medical procedures that aim at normality rather than adaptive functionality. Individuals are best situated to claim such rights when their appearances and conduct most resemble the species' paradigm, or else they look and act as their family or community group expects, but rights with warrants contingent on such family ties fall short of the universality to which human rights aspire.³⁴

Although some human rights theorists believe this human exceptionalist basis of rights affords dignity and therefore rights-bearer status without being defeasible

Collective Agreement as a Basis for Equitable Access to Health Care

To summarize so far, human exceptionalism is a traditional, and perhaps the prevailing, approach to grounding human rights, one with roots that predate the Enlightenment and one that remains strong today. But theories about an exceptional human psychological capacity for logical or reflective thinking, or an exceptional human biological capacity for personal attachment, both turn too easily into rationales for excluding at least some disabled humans from human rights protection by portraying them as so lacking in crucial, and exclusively human, dignity-conferring properties that they fail to qualify as rights-bearers.³⁷ And in regard to individuals whose disabilities do not debar them from the usual ontology of the human species or humankind, a traditional human rights

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due to disability,³⁵ there are both historical and logical reasons for being skeptical of this claim. To invoke uniquely human properties as the basis of human rights is to place a premium on the disabled's similarity or family resemblance to species-typical or normal humans. In the circumstances created by grounding policy in human exceptionalism, therefore, equitable essential health care packages ought to cover interventions meant to make patients seem more normal, whether or not they make the individual more functional.

In such circumstances, we should expect a human right to health care to be invoked in demands for health care interventions aimed at enabling the patient to appear less unusual or to seem normal. Health care packages thus would need to be designed with normality as the touchstone. Likely results could be, on the one hand, reluctance to cover services needed to attain functionality if supposed normality cannot be fully achieved, but, on the other hand, consumption of resources and courting of risks just to gain the appearance of or to approximate normality, even if reduced functionality results from such medical treatment.³⁶ So this recipe, called for by the standard for being treated as human that exceptionalism sets, appears to drive misguided, but also unnecessarily costly, health care interventions.

approach lacks theoretical resources to respond to those who are concerned that rights will become costly demands for services that are less about functionality than about the appearance of normality.

An alternative approach to rights rejects metaphysical beliefs about essential humanizing properties and instead understands rights as tools that both emerge from and enable the kinds of human interactions that shape our social environment. We humans are, individually as well as collectively, both creators of our own political and cultural values yet also creatures of the liberating or constricting political and cultural conditions we create. It follows that we humans possess individual and collective powers to narrow or expand who can be considered the parties included in such tacit cooperative agreements, as well as to regulate the repertoire of roles made available to facilitate different people's inclusion. As Rousseau observed, our frailty is a main characteristic that we humans have in common.³⁸ What approach to avoiding disability bias in delineation of essential health care benefits might be developed by invoking such non-metaphysical grounds for rights?

Tacit Agreement and Rights as Civil Rights

On a pragmatist view, what political morality requires is evolving and context-dependent. Humans live and interact in communities, developing, shaping, testing, and reshaping norms by which to live together. As Ruth Anna Putnam³⁹ points out, “Unlike other social animals, we are able to reflect on the ways in which we cooperate and on the effects of the manner of our association on ourselves and others.” As we have argued,⁴⁰ justice is constructed through building trust relationships that are inclusive of outliers. Thus, as we also have argued, justice should be understood always as a work in progress.⁴¹ We should not suppose, despite ideal justice theorizing pressing us to do so, that fully inclusive and therefore universal justice can be a *fait accompli*.

Rights claims are no exceptions. Political rights are the original core of the civil rights and international rights movements.⁴² Made within political institutions, both national and international,⁴³ their function is to press political institutions to recognize what is necessary for each of their members to lead flourishing lives within them, hence their acknowledgement of universal aspiration. Understood pragmatically, rights are instruments for expanding equality among different kinds of individuals who happen to be interacting with one another. Thus, their expression resists schemes that appoint some individuals as more deserving of flourishing than others. This expansive drive emerges from the nature of such rights, which is to protect individuals’ interactions by promoting respect equally for the integrity of all who have occasion to engage. As such, rights claims both reflect and challenge social arrangements. They both accept and question resource constraints, building on what exists in the continuing effort to create conditions under which all flourish because each can flourish. From a practical political organizing perspective, calls for civil rights engagement are familiar inspiration for such progressive pragmatic efforts.

Within this context, rights are claims on the social resources needed to meet basic interests that are critical to individuals’ interactive flourishing. For what have been termed “negative” rights — i.e., rights to non-interference — these are the institutions that protect physical security, freedom from torture and slavery, liberty of thought and expression, privacy, freedom of movement, and the like.⁴⁴ They are the political rights of assembly and participation.⁴⁵ For what have been termed “positive” rights — i.e., rights to specified resources — these are means by which to meet critical human needs: food, shelter, health care, education, employment, and the like.⁴⁶

Our contention here is that these rights should be understood in a pragmatist rather than a metaphysical framework, grounded explicitly in acknowledgement of people’s differences rather than rooted in claims about how humans essentially are the same. How rights are instantiated specifically in a given social context depends on the normative understandings in place at that time. These tacit understandings are not static, however; they are continually pressed to develop possibilities of flourishing for all.

Rights to health care can be understood purely as civil rights in this way. Existing assumptions and resources are the start. But their inclusiveness is subject to ongoing challenge in terms of whether they allow everyone equally to lead flourishing lives in accord with their conceptions of their good.⁴⁷ This may cost more for some than for others; the point is that each should have meaningful access to the benefits that health care can provide to them in the context in which they live. In what follows, we apply this approach — existing assumptions and resources tested against a meaningful access standard to health care in a manner that respects all — to the ACA and the cost pressures on it. Similar points could be made about cost pressures on the public health systems in place in most other advanced industrial countries.

ACA: Existing Assumptions

The ACA of 2010 was developed in a context in which approximately 45 million lawful U.S. residents were estimated to lack health insurance and many more had coverage inadequate to their needs. Those with insurance derived their coverage primarily from their employers, from the Medicaid federal-state partnership that provides coverage for the poor falling into designated categories, and from the Medicare program for the elderly and those with long-lasting disabilities. All of these programs were undergoing serious financial strain. Employer-provided insurance was contracting in the numbers of employers offering coverage, in the coverage provided, and in the extent to which costs were passed on to persons with insurance. The ACA aimed both to expand coverage and to stem the tidal wave of coverage reductions.

The ACA also sought to move beyond limitations in anti-discrimination. In the private market, the ADA Title I provided the only bulwark against disability discrimination in employer-provided insurance. Title I permits employer-provided plans to design benefits or charge rates based on underwriting judgments that are consistent with state law, so long as these are not a subterfuge for discrimination⁴⁸ — thus permitting significant differences in coverage and costs based on types of health needs. For plans purchased by individ-

uals on their own, ADA Title III, the public accommodations title, provided protection in accessing the offices in which insurance is sold but not the products available therein.⁴⁹ The ACA sets out to remedy these deficiencies in several ways. Large employers (with over 50 employees) must offer affordable coverage of a core set of benefits or pay penalties. Smaller employers and employees who do not have access to employer-provided coverage are to be able to purchase coverage through exchanges created in each state; plans sold through the exchanges must cover essential benefits.

Other anti-discrimination protections applied to public services, including Medicare and Medicaid. The Rehabilitation Act of 1973 provided that “[n]o otherwise qualified individual with a disability in the United States...shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.”⁵⁰ Subsequently, ADA Title II, the public services title, adopted the same language to cover public services,⁵¹ and the two statutes have been interpreted in tandem. In a critical 1985 decision under the Rehabilitation Act, the U.S. Supreme Court held that it is a denial of benefits to fail to provide individuals with meaningful access to the benefits in question.⁵²

Alexander v. Choate involved Tennessee’s decision to limit Medicaid’s inpatient hospital benefit to 14 days in any given year. Although it has been viewed as implying that financially motivated state Medicaid cutbacks are within the discretion of states and are not disability discrimination, this is not what the decision actually holds.⁵³ In the decision, the Court adopted the standard that persons with disabilities must have meaningful access to federally funded programs or to public services. However, the Court also held that the plaintiffs had not shown that Tennessee failed to meet this standard. Although the plaintiffs had shown that some patients had been discharged earlier than their physicians recommended or had not been able to receive certain types of care within the limit, they had not shown that these limits functioned to deny meaningful access to health care persons with disabilities in particular. The meaningful access standard has been used in a wide variety of subsequent decisions involving public services other than health care — but the misinterpretation that *Alexander v. Choate* gives states wide discretion in cutting health benefits remains. With this backdrop, limited effort has been devoted to developing an understanding of meaning-

ful access to health care for people with disabilities, along with everyone else.

The ACA was aimed to stem the receding tide of private health insurance by providing access for individuals and small businesses to affordable coverage of essential benefits. It also was meant to expand coverage of public programs to everyone below 138% of poverty. The objective was to provide a minimum national floor of health care for everyone. What this means in regard to providing disabled people with the opportunity to obtain equitable health care will need to be informed by a conceptualization of meaningful access on equal terms for all.

ACA as a Civil Right: Meaningful Access on Equal Terms for All

The ACA has been promoted to disabled people as a cure for the disadvantage they typically have had to endure in both seeking and utilizing health care coverage. Healthcare.gov,⁵⁴ a federal website managed by the Department of Health and Human Services, tells disabled people:

If you’re living with a disability, private health insurance may be hard to come by. Even if you can afford to buy it, it probably doesn’t cover all of your needs. Worrying about where to get coverage and the cost of your care is the last thing you want to do. The Affordable Care Act is expanding your options for health insurance and making them more affordable.

Much of the website’s text describing options, however, focuses on elimination of pre-existing condition requirements, provision of preventive care to avoid disabling conditions (presumably to reduce the size of the group the message needs to reach), and proscription in some cases of a cap on lifetime benefits. Absent is reassurance of what actual benefits may be, other than abstract reference to mandating an essential benefits package covering a very generally specified collection of services.

Moreover, dire predictions about cost pressures sound a continuing drumbeat. There seems to be general agreement that health care costs have to be brought down, but also that more people must be served. In this regard, it will be attractive to suppose that the least costly approach is to tailor services to the needs of typical patients, even though doing so may make health care more expensive or unavailable for atypical ones. Such thinking cannot help but invite imposing disparately disadvantageous burdens of cost for health care and access to health care on individuals with disabilities. For these reasons, whether the

ACA improves health for disabled people by improving their access to health care will to a great extent be decided by how essential benefits are defined.

In principle, the ACA alters the U.S. health care picture by opening the opportunity to be insured for health care to everyone alike. In doing so, however, the ACA also opens questions about how to avoid disability-based discrimination in providing for the potential health services needs of individuals who vary dramatically in their health states, and especially of individuals who may incur higher expenses for one or more reasons relating to their disabilities. We highlight several areas of particular concern here, showing how the understanding of rights as civil rights applies to them: defining essential benefits for coverage sold through exchanges, making possible changes in the Medicaid program, and permitting plans to charge more for individuals who do not meet specified wellness targets.

The services that constitute essential health benefits for insurance plans offered through exchanges fall into ten categories. Some of these — such as mental health services, rehabilitative and habilitative services and devices, and chronic disease management — are of special importance to people with disabilities. The degree to which each disabled person in the U.S. can be functional and independent will be affected by how austere, or generous, the minimal provision of services in these categories will have to be. The character of the minimum will constrain not only those disabled people who have the barest permissible coverage for such services, but also more affluent disabled individuals who can afford to purchase higher end coverage and to make supplementary non-reimbursed purchases of equipment and treatments as well.

For example, the quality of rehabilitation services and assistive equipment that is available for purchase is constrained by what insurance will pay, even for private purchasers, because insurance programs constitute the largest market. What is covered by “rehabilitative and habilitative” services may make an enormous difference in regard to access by people with disabilities. If rehabilitative services do not include services needed to maintain function, but only include services that increase function — as is the case for many plans, including Medicare, today, patients with incurable disabling conditions may find their access to the repertoire of physical, psychological, and occupational therapeutic services to be greatly inferior to that of patients for whom normal functioning can be restored. Further, for other services, such as hospitalization and maternity services, disabled people often may need more extensive or different services than nondisabled people typically do. Emphasizing the

expense of services — e.g., the U.S. decision to impose a tax on so-called “Cadillac” high premium plans — puts the question exactly backwards by construal in terms of what can be fitted within cost constraints.⁵⁵ Indeed, one recent analysis indicates that taxing based on premium costs, rather than examining how variations in such matters as salaries or regional differences in utilization affect plan costs, risks reducing needed services.⁵⁶ Rather, the question should be what is required for functioning on equal terms and how this can best be achieved.

The original idea of ACA was that the essential benefits required of plans sold through exchanges would be uniform nationally. That way, people would not find themselves consigned to limits by the arbitrary accident of geography. However, beyond the categories required in the statute, the idea of uniform essential benefits has proved difficult to apply. Instead, benchmark plans have been selected for each state, reflecting the type of coverage available in that location. The result is considerable flexibility in what essential benefits might require, especially for items such as durable medical equipment or home health care that may be especially important to people with disabilities.⁵⁷ If available plans fall short in providing meaningful access to groups of people such as those with mobility impairments, however, they will be subject to challenge under the civil rights view we have developed above.

Other risks are persistent limits in Medicaid, the U.S. safety net program providing health insurance for eligible categories of people in poverty. U.S. states are not required to have Medicaid; before the ACA, all states participated in the program but many offered only the minimum requirements for pregnant women, children, the elderly, people in certain categories of disability, and others who were made eligible by falling into specified categories. Excluded were many adults, including people with disabilities not falling into the specified categories or over the maximum limits on income and assets but unable to purchase insurance through the private market. A goal of the ACA was expanding Medicaid to cover these people at least up to those with incomes of 138% of poverty. The U.S. Supreme Court, however, determined that this required expansion trammled on the role of states in the federalist system. Many states are balking at expanding Medicaid coverage, thus leaving people in those groups still without likely access to health insurance. Moreover, a few states are trying to bargain with the federal government to let them use Medicaid program money to buy exchange coverage; states such as Ohio and Florida have sought additional concessions that they will not need to cover services included in

Medicaid if the services are not included in the state benchmark plan. The federal government has resisted these bargaining efforts, making it likely that these states will join the states not expanding Medicaid. In all of these states, many individuals in poverty or near-poverty, some with disabilities, will not have access to health care at all except on a charity or emergency basis, thus perforce, not having meaningful access to these benefits. Even those with Medicaid may not have

of the disability category and thus signaled intent to provide protection against disability-based discrimination in a fairly broad way, there is little indication of how this approach would play out in the complex context of disparate impact of disability on health insurance premiums. Especially difficult will be determination of whether different treatment was on the basis of disability or for other non-discriminatory reasons. Therefore, it will be critical to pro-

We have argued that the understanding of health care as a human right, as found in the CRPD, fails to provide the theoretical machinery for responding to the pressing challenges of health care costs. These challenges are real and potentially devastating. We develop instead an account of health care as a civil right. What this right requires is dependent on the context and resources of the time, so long as all have meaningful access to the benefits provided.

meaningful access to health benefits on the terms of others in society, given likely cutbacks imposed to save money. For example, Louisiana has announced cuts in hospice services and psychiatric care for Medicaid patients.⁵⁸

Also of concern are premium variations for persons not meeting specified wellness targets. Coverage sold through exchanges must not exclude pre-existing conditions and premiums must be community rated. However, there may be significant variations in premiums for failure to reach wellness targets. There are exceptions for people whose physicians certify they cannot meet targets or meeting the target would not be medically advised.

How this permission to increase premiums for individuals who fail to meet targets will be applied to people with disabilities is unclear.⁵⁹ The ACA prohibits discrimination based on health status.⁶⁰ However, the ACA also makes it clear that the premium difference is not discrimination based on health status. It is not unheard of to place responsibility for having physical or mental deficits, or for failing to overcome these, on the disabled. It may be difficult to prevent insurance companies, whose interests lie with deflecting responsibility onto the insured, from delineating as straitened a space as law and public sentiment will allow for unavoidable absence of wellness.

The prospect here is for a replay of the avalanche, encountered during the first two decades of the ADA, of successful defenses against charges of disability discrimination based on narrowing the definition of disability. Even though Congress subsequently amended the ADA to block excessive constriction

vide that exceptions for those whose disabilities prevent them from participating in standard wellness programs be readily available without reproducing the familiar adversarial processes required by other programs for persons to prove disability. Otherwise, on this basis as well, implementation of the ACA will violate the civil right to health care as understood in this discussion.

Conclusion

The promise of health care as a right has all too often proved hollow for people with disabilities. In this article, we have argued that the understanding of health care as a human right, as found in the CRPD, fails to provide the theoretical machinery for responding to the pressing challenges of health care costs. These challenges are real and potentially devastating. We develop instead an account of health care as a civil right. What this right requires is dependent on the context and resources of the time, so long as all have meaningful access to the benefits provided. The ACA includes some provisions that may prove antithetical to this nondiscrimination standard.

In the circumstances created by grounding policy in human exceptionalism, the conclusion to be drawn is that equitable essential health care packages ought to cover interventions meant to make individuals seem more normal, whether or not they make the patient more functional. To invoke uniquely human properties as the basis of human rights is to place a premium on the disabled's similarity to species-typical or normal humans. Instead, the driving rights-based challenge to existing arrangements with respect to health care

should be the extent to which these arrangements provide each on equal terms with the health care needed to lead flourishing lives.

References

- M. Alder, "The Disabled: Their Health Care and Health Insurance," U.S. Department of Health and Human Services, 1990, available at <<http://aspe.hhs.gov/daltcp/reports/disabled.htm>> (last visited October 7, 2013).
- U.S. Bureau of Labor Statistics, "Persons with a Disability: Labor Force Characteristics Summary," 2012, available at <<http://www.bls.gov/news.release/disabl.nr0.htm>> (last visited October 7, 2013).
- See Alder, *supra* note 1.
- Id.*
- World Health Organization, "Fact Sheet No 352: Disability and Health," 2012, available at <<http://www.who.int/mediacentre/factsheets/fs352/en/>> (last visited October 8, 2013).
- A. Williams, "Response: QUALYing the Value of Life," *Journal of Medical Ethics* 13, no. 3 (1987): 123; R. Amundson, s.v. "Health Resource Rationing," in G. Albrecht, ed., *Encyclopedia of Disability* (Thousand Oaks, CA: Sage Publications, 2006): 841-845. Important differences may be elided in how this argument is made. One view is metaphysical: that people with disabilities are different in kind from others whose lives are of greater value. Another view is normative: that because they are different in kind (or perhaps for some other reason), they have different moral status and so whatever value their lives have will count less than the lives of the non-disabled. Still another view is empirical: that because of their disability, their lives will feature experiences of lesser value, so even if they count equally the same benefit will be worth more for a person without the disability. An illustration of this last view is the claim that blind people, because they cannot experience visual perceptions, live less rich lives and therefore benefit less from life-saving cancer treatment than do sighted people. An illustration of the metaphysical view is that blind people are different in kind from sighted people, and an illustration of the normative view is that they are therefore of lesser moral status.
- A. Silvers, "Predicting Genetic Disability While Commodifying Health," in J. Bickenbach, R. Wachbroit, and D. Wasserman, eds., *Quality of Life and Human Difference* (Cambridge: Cambridge University Press, 2005): 43-66.
- "For Medicare to cover a power wheelchair or scooter, the physician must state that the patient needs it due to a medical condition from which the individual suffers. Medicare won't cover a power wheelchair or scooter that is only needed for the individual to go outside the home." Centers for Medicare & Medicaid Services, "Medicare Coverage of Durable Medical Equipment & Other Devices," at 5, available at <<http://www.medicare.gov/Publications/Pubs/pdf/11045.pdf>> (last visited October 8, 2013).
- For example, Blue Cross and Blue Shield of Montana considers a power wheelchair not medically necessary if it is needed for ambulation outside of the home. Consequently, an individual who can walk from his bed to the bathroom, but not the additional distance to the corner grocery store or the doctor's office two blocks away would not qualify for a mobility scooter that enabled him to obtain food and medical care. Medical Codes, "Wheelchairs and Wheelchair Accessories," available at <<https://www.bcbst.com/MedReview/Policies/Wheelchair-sandAccessories/v101.aspx>> (last visited October 8, 2013).
- T. Lagu et al., "Access to Subspecialty Care for Patients with Mobility Impairment: A Survey," *Archives of Internal Medicine* 158, no. 6 (2013): 441-446. See also W. Peace, William, "New York Times Misses the Point Yet Again: Inaccessible Doctor Offices," 2013, available at <<http://badcripple.blogspot.com/2013/05/normal-0-false-false-false-en-us-ja-x.html>> (last visited October 8, 2013); E. Pendo, "Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access," *St. Louis University Journal of Health Law and Policy* 2, no. 1 (2008): 15-56.
- P. Heslop et al., *Confidential Inquiry into Premature Deaths of People with Learning Disabilities: Final Report*, 2013, available at <<http://www.bristol.ac.uk/cipold/fullfinalreport.pdf>> (last visited October 8, 2013).
- T. Machan, "The Perils of Positive Rights: Positive Rights Conflict Most with Our Basic Negative Rights to Life, Liberty and Property," *The Freeman*, April 1, 2001, available at <http://www.fee.org/the_freeman/detail/the-perils-of-positive-rights#axzz2i7mQP92> (last visited October 22, 2013).
- C. Fried, "Equality and Rights in Medical Care," *Hastings Center Report* 6, no. 1 (1976): 29-34.
- T. Degener, "A Human Rights Model for Disability," in M. Stein and M. Langford, eds., *Disability Social Rights* (Cambridge University Press, forthcoming 2014).
- H. Hannum, "The Concept of Human Rights," in *International Human Rights: Problems of Law, Policy, and Practice* (New York: Aspen Publishers, 2006): at 31-33.
- Id.*
- A. Fagan, s.v. "Human Rights," in J. Fieser and B. Dowden, eds., 2005, *Internet Encyclopedia of Philosophy*, available at <<http://www.iep.utm.edu/hum-rts/>> (last visited October 8, 2013).
- Id.* (Fagan); for further discussion, see also J. Finnis, *Natural Law and Natural Rights* (Oxford: Clarendon Press, 1980) and H. Shue, *Basic Rights: Subsistence, Affluence, and U.S. Foreign Policy* (Princeton: Princeton University Press, 1980).
- Cynthia Townley, "Animals and Humans: Grounds for Separation?" *Journal of Social Philosophy* 41, no. 4 (2010): 512-526. For a discussion of human exceptionalism in regard to cognitive disability, see J. McMahan and E. Kittay, "Cognitive Disability, Cognitive Enhancement & Moral Status," Q&A Session at "Conference on Cognitive Disability: Its Challenge to Moral Philosophy," Stony Brook University, New York, available at <https://podcast.ic.sunysb.edu/blojsom_resources/meta/phicdc/36-KITTAY%3AMcMAHAN_Q%26A.mp4> (last visited October 22, 2013).
- M. Liao, "The Basis of Human Moral Status," *Journal of Moral Philosophy* 7, no. 2 (2010): 159-179.
- A. Silvers, "Moral Status: What a Bad Idea! Why Discard It? What Replaces It?" *Journal of Intellectual Disability Research* 56, no. 11 (2012): 1014-1025.
- I. Asimov, *I, Robot* (New York: Gnome Publishing, 1950).
- I. Asimov and R. Silverberg, *The Child of Time* (London: Gollancz, 1991).
- See Silvers, *supra* 21.
- M. Tooley, "Abortion and Infanticide," *Philosophy & Public Affairs* 2, no. 1 (1972): 37-65.
- D. Wasserman, A. Asch, J. Blustein, and D. Putnam, s.v. "Cognitive Disability and Moral Status," in E. N. Zalta, ed., *The Stanford Encyclopedia of Philosophy*, summer 2013 ed., <<http://plato.stanford.edu/archives/sum2013/entries/cognitive-disability/>> (last visited October 9, 2013).
- A. Silvers and L. P. Francis, "Thinking about the Good: Reconfiguring Metaphysics (or Not) for People with Cognitive Disabilities," *Metaphilosophy* 40, nos. 3-4 (2009) - reprinted in E. Feder Kittay and L. Carlson, eds., *Cognitive Disability and Its Challenge to Moral Philosophy* (New York: Wiley-Blackwell, 2010).
- A. Silvers, "Embracing Freedom for Disability: The Hardest Thing To Do," Keynote Address for Menschen Recht Inklusion: International Symposium on the Implementation of the Convention on the Rights of People with Disabilities into Practice, Evangelische Fachhochschule RWL, Bochum, Germany, June 6-8, 2013, available at <http://www.efh-bochum.de/brk/pdf/doku/Silvers_Human_Rights_engl.doc> (last visited on October 22, 2013).
- J. Berke, "Deaf, Not Retarded: When Misdiagnoses Are Made, Everyone Pays," About.com, 2010, available at <http://deafness.about.com/cs/featurearticles/a/retarded_2.htm> (last visited October 9, 2013).

30. N. Murdick, B. Garton, and T. Lee Crabtree, *Special Education Law*, 2nd ed. (San Francisco, CA: Pearson Education, 2006).
31. E. F. Kittay, "At the Margins of Moral Personhood," *Ethics* 116, no. 1 (2005): 100-131.
32. C. Koall, "Historian Götz Aly: Victims of Nazi Euthanasia 'Have Been Forgotten,'" *Spiegel Online International*, April 25, 2013, available at <<http://www.spiegel.de/international/germany/historian-goetz-aly-on-nazi-euthanasia-program-and-inclusion-debate-a-896209.html>> (last visited October 9, 2013).
33. M. Kelman and L. Gillian, *Jumping the Queue: An Inquiry into the Legal Treatment of Students with Learning Disabilities* (Cambridge: Harvard University Press, 1998).
34. See Silvers, *supra* note 28.
35. See Degener, *supra* note 14.
36. E. Parens, ed., *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (Baltimore: Johns Hopkins University Press, 2006).
37. See Silvers, *supra* note 28.
38. B. S. Turner, "Outline of the Theory of Human Rights," *Sociology* 27, no. 3 (1993): 489-512, at 501-507.
39. R. A. Putnam, "Neither a Beast nor a God," *Social Theory and Practice* 26, no. 2 (2000): 177-200.
40. A. Silvers and L. P. Francis, "Justice through Trust: Disability and the 'Outlier' Problem in Social Contract Theory," *Ethics* 116, no. 1 (2005): 40-77.
41. *Id.*
42. P. Sieghart, *The Lawful Rights of Mankind: An Introduction to the International Legal Code of Human Rights* (Oxford: Oxford University Press, 1985).
43. F. Carreira da Silva, "Outline of a Social Theory of Rights: A Neo-pragmatist Approach," *European Journal of Social Theory*, forthcoming 2013.
44. Universal Declaration of Human Rights, at Arts. 3-19, available at <<http://www.un.org/en/documents/udhr/>> (last visited October 9, 2013).
45. *Id.*, at Arts. 20, 21.
46. *Id.*, at Arts. 22-27.
47. We have argued elsewhere that even people who are not articulate are able to formulate conceptions of their good that require respect from others (see Silvers and Francis, *supra* note 27; see L. P. Francis and A. Silvers, "Liberalism and Independently Scripted Accounts of the Good: Meeting the Challenge of Dependent Agency," *Social Theory and Practice* (2007): 311-334).
48. *People with Disabilities and the Affordable Care Act*, 42 U.S.C. § 12201(c) (2013), available at <<http://www.healthcare.gov/law/information-for-you/people-with-disabilities.html>> (last visited October 9, 2013).
49. For example, *Weyer v. Twentieth Century Fox Film Corp.*, 198 F.3d 1104, 1115 (9th Cir. 2000). Courts have interpreted the statutory language – place of business – literally.
50. 29 U.S.C. § 794 (2013).
51. 42 U.S.C. § 12132 (2013).
52. *Alexander v. Choate*, 469 U.S. 287 (1985).
53. L. P. Francis and A. Silvers, "Debilitating *Alexander v. Choate*: 'Meaningful Access' to Health Care for People with Disabilities," *Fordham Urban Law Journal* 35, no. 3 (2008): 437-477.
54. Healthcare.gov website, available at <www.healthcare.gov> (last visited October 9, 2013).
55. R. Abelson, "Bearing Down on Health Costs," *New York Times*, May 27, 2013, at B1, available at <http://www.nytimes.com/2013/05/28/business/cadillac-tax-health-insurance.html?pagewanted=all&_r=4&> (last visited October 9, 2013).
56. J. Gabel et al., "Taxing Cadillac Plans may Produce Chevy Results," *Health Affairs* 29, no. 1 (2010): 174-181.
57. CMS, Center for Consumer Information & Insurance Oversight, "Additional Information on Proposed State Essential Health Benefits Benchmark Plans," available at <<http://www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html>> (last visited October 9, 2013).
58. J. Adelson, "Louisiana Cuts Health Care, Medicaid and Hospice Programs to Rebalance Budget," available at <http://www.nola.com/politics/index.ssf/2012/12/louisiana_cuts_health_care_med.html> (last visited October 9, 2013). Medicaid Watch has a list of planned state cuts (and a few expansions, to be fair) as of April 30, 2013, available at <http://www.adapadvocacyassociation.org/pdf/Medicaid_Watch.pdf> (last visited October 9, 2013).
59. R. C. Rabin, "Could Health Overhaul Incentive Hurt Some?" *New York Times*, April 12, 2010, available at <<http://www.nytimes.com/2010/04/13/health/13land.html>> (last visited October 9, 2013). For a criticism of such "fat taxes," see R. L. Rausch, "Health Cover(age)ing: The Weight of Health Insurance Fat Taxes," *Nebraska Law Review* 90, no. 4 (2012): 201-251.
60. PPACA § 2705(a)(1).

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