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Applied Ethics: A Misnomer for a Field?

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[slide 1] Perhaps because today is April Fools' Day, or perhaps because a Presidential Address is both an enormous honor and very intimidating, I decided to rush in and take this occasion to think seriously about the shape of the field in which I work.

I work in a field often called "applied ethics." It's a very young field—when I started graduate school, the field didn't have a name, John Rawls's *A Theory of Justice* was at the center of normative ethics (if normative ethics existed at all in the wake of non-cognitive assaults), and serious philosophers were just turning their attention to areas such as bioethics. The *Journal of Social Philosophy* and *Social Theory and Practice* both began in 1970 and *Philosophy and Public Affairs* published its first issue in 1971. The Society for Applied Philosophy was founded in 1982 and began publishing the *Journal of Applied Philosophy* in 1984. The Association for Practical and Professional Ethics is celebrating its 25th anniversary this year.

Sub- or related fields such as bioethics or environmental ethics are young too. A comprehensive organization for bioethics, the American Society for Bioethics and Humanities, began only in 1998 with the merger of three smaller organizations; the journal *Bioethics* began publishing in 1987 and volume one of *Environmental Ethics* appeared in 1979.

So with about 25 years to look back on, I'm going to advance several mild claims in this talk: that "applied ethics" is a misnomer, that it reflects a misguided approach to work in applied fields, and that we can do better.

More specifically, it suggests that there are theoretical paradigms or principles such as autonomy that are developed independently. [slide 2]

Theory development is one field—"ethics"—and theory application is another—"applied ethics" (or maybe "practical" –could it be opposed to "impractical"? –ethics?) The ethical principles are separate from the problems to which they apply. [slide 3]

These principles are then "applied" to real world circumstances in top-down fashion. [slide 4]

The enterprise is unidirectional; the ethical approaches do not learn from the problems to which they are applied and their context. [slide 5]

On this picture the theoretical paradigms pick out the problems to be addressed: decisions to withdraw or withhold treatment [slide 6], treatment of patients who lack decision making capacity [slide 7], experimentation with human subjects [slide 8], or protection of confidentiality [slide 9]. Other problems recede to the background, discussed as an afterthought if at all [slide 10].

This is very, very wrong. In the first part of my talk, I'm going to explain these ways in which it goes wrong in more detail. Then, I'll sketch out some ways in which, I hope, we can do better. To avoid suspense I'll tell you at the outset that I have a radical new name for the field: ethics.

1. So how do we go wrong?

1.1 Let me start with selecting problems in the field and the example of ethics and infectious disease.

A few years ago, four of us published *The Patient as Victim and Vector: Ethics and Infectious Disease.* (Battin et al. 2008) [slide 11] The original idea was the brainchild of my friend and colleague, Peggy Battin:

how, she asked, would bioethics have looked different if it had emerged

when infectious disease had been at the forefront of pressing problems rather

than being thought of as largely a phenomenon of the past?   Sometime in

the late 1970s, the US surgeon general had reportedly said "It is time to

close the book on infectious disease"—no one knows exactly when or where

this was said, or even if it was said, but it is widely quoted as reflecting

views of public health in the years just before the AIDS epidemic, the years

when bioethics was beginning to flourish as a field.

In *PVV*, as we called the book, we argued that infectious disease presents a

kind of naturalized Rawlsian thought experiment: we are all victims and

vectors to each other, interconnected in a web of actual and potential disease

transmission. At any given point, we do not know where we are in the web:

we could be sitting next to someone with multidrug resistant tuberculosis

[slide 12], staying with a friend who spent the weekend before hiking in a

remote area and was exposed to hantavirus [slide 13], or dragging ourselves

to class with the flu [slide 14]. So infectious disease reminds us that we are

all in this together. We need to rethink traditional issues such as informed

consent or confidentiality, asking people to consider the impact of their

decisions on others and informing them not only of the effects of their

decisions on themselves but also of the effects on others and potentially once again on themselves. And we need to think about new problems: planning for outbreaks, justice in primary care, forms of disease management that reduce overall transmission risks, and compensation for those in harm's way such as first responders.

As we were writing *PVV*, we thought the explanation was that bioethics had developed at a time when problems of individual autonomy such as withdrawing or withholding high-tech life-sustaining treatment were at the fore. The field, we thought, simply not been exposed to infectious disease; bringing it to the center could force a paradigm shift. I now think this analysis is not sufficiently radical. Perhaps, instead, much early work in bioethics paid attention to problems such as withholding and withdrawing care because ethical concepts such as autonomy could readily be applied to them, not because the problems themselves stood out for attention. After all, HIV appeared on the scene almost immediately after the surgeon general supposedly closed the book. In 1979, although smallpox had been eradicated, polio cases numbered in the hundreds of thousands worldwide and the World Health Organization resolution to eradicate polio did not occur until 1988. [slide 15] In 1979, to the extent that malaria control was

effective it was the result of the use of pesticides such as DDT; the WHO

had decided that eradication was not a viable strategy and where treatment

was available it consisted primarily of fever management. (Snow et al. 2012)

The problems of infectious disease were all around: a lens of autonomy just

did not focus on them. [slide 16]

And even when HIV appeared on the scene, it was largely seen through

autonomy. Primary attention was paid to issues such as data confidentiality,

partner notification, demands for rapid access to therapy, and the wrongs of

quarantine. Other problems such as racial disparities in access to care and

support, the lack of an adequate public health infrastructure to treat sexually

transmitted diseases, homelessness, partner abuse, or punitive immigration

policies were largely off the ethical radar screen—albeit not entirely off the

legal radar screen (e.g. Rothenberg & Paskey 1995)—and their impact

remains today.

1.2 Top-down approaches are unidirectional. As such, they do not learn

from and are not reshaped by the people and contexts to which they apply.

Consider as one example the application of autonomy to people with

impaired decision-making capacities facing difficult medical choices. [slide

17] On a top-down model, the starting place is an idealization of autonomy: to be considered capable of making decisions on their own, individuals must have a basic understanding of their condition, treatment alternatives, and their likely outcomes. They must be able to understand and articulate their values and apply these values to the decision to be made. And they must be able to communicate their choices. If their choices do not reflect their values in at least some recognizable way, questions will be raised about their decision-making capacity. [slide 18] Health care providers will be advised either to seek a formal evaluation of capacity or to turn to surrogate decision-makers to act for the patient. To be sure, capabilities fluctuate and health care providers are reminded to manage patients to maximize their involvement in decision-making. Capabilities are also a matter of degree—some people will understand, reason, and communicate better than others—and so Buchanan and Brock (1990) and others have proposed to take this into account by adjusting the requisite level of capacity by the seriousness and irrevocability of the decision at hand. Decisions to withdraw or withhold life-sustaining treatment thus would require a more stringent standard for capacity than decisions to forego a knee replacement that might improve mobility. Value structures are complex as well; Agnieszka Jaworska (1999), for example, argues that people with dementia may still be

capable of originating critical interests if the objects of these interests are external to the person and they can still be fulfilled and if the person maintains some sense of what is good even without an overall narrative of his or her life.

These approaches to autonomy, I have argued with Anita Silvers, apply an unduly constrained picture of decision-making to people with intellectual disabilities. They all assume that individuals understand and articulate their values on their own, an assumption at best partially true for most of us. [slide 19] Even Jaworska's article—developed importantly on the basis of her experiences as a fellow at the National Institutes of Health—limits the participation of prosthetic decision-makers to helping people with dementia engage in means-end reasoning and implement their choices.

Consider by contrast to the approach to legal status developed in the United Nations Convention on the Rights of Persons with Disabilities (the "CRPD"). The CRPD, developed by a process that exemplifies the disability rights slogan "nothing about us without us," affirms inclusion as a basic principle. Article 12 of the CRPD reaffirms that people with disabilities have the right to recognition as full legal persons and must enjoy

legal capacity on an equal basis with others in all aspects of life. [slide 20]

Accordingly, states parties to the CRPD must take measures to provide

support for persons to exercise their legal capacity and appropriate and

effective safeguards to prevent abuse. Article 12 of the CRPD has

stimulated efforts in many jurisdictions to develop structures for supported

decision-making, decision-making in which persons with intellectual

disabilities work with another to develop, articulate, apply, and implement

their values. These efforts surely raise very difficult philosophical

questions: for example, what it is for values to be authentically those of the

individual and what exploitation is and how to protect against it.

Developing answers to these questions will also be informed by continuing

research in neuroscience. My point here is not that these questions are

simple, but that they are critical to understanding autonomy itself as an

evolving concept and cannot be addressed without interaction with people

with intellectual disabilities. How to do this is the philosophical task, not

how to instruct surrogate decision makers on substituted judgment or best

interests.

Nor is this a strong form of standpoint theory that would reject any

independent epistemological groundings or even accord persons with

intellectual disabilities special authority with respect to the truth about themselves. Rather, it is the recognition that knowledge production is interpersonal and social, not entirely individual. The interpretation, application, and understanding of principles such as respect for autonomy are no exception.

1.3 The "application" paradigm twists methodologies in the fields. It suggests that paramount methodological problems are the selection and justification of principles, not their development, articulation, understanding, and instantiation. To illustrate, I'll take two of the most famous articles from the first volume of *Philosophy & Public Affairs*: Judith Jarvis Thomson's (1971) "A Defense of Abortion" and Peter Singer's (1972) "Famine, Affluence, and Morality."

Thomson's famous violinist and his (yes, *his*) involuntary savior illustrate both the best and the worst of thought experiments. [slide 21] The experiment, which I expect is familiar to everyone, asks you to imagine the Society of Music Lovers kidnaps you and hooks you up to the violinist in order to save his life. You only need to stay hooked up for nine months. There is no alternative method for keeping the violinist alive: only you.

Then, Thomson asks, are you obligated to stay hooked up? Would it violate

the violinist's right for you to unhook yourself and return to your ordinary

life? Thomson's answer is "no"—and she thinks yours would be, too.

This thought experiment is the centerpiece of an article with the title "A

Defense of Abortion." It is deployed in an effort to show that abortion can

be defended even if we grant the assumption that the fetus has a right to life.

The experiment does show as a matter of abstract inference that it doesn't

follow from assuming that the violinist—or, by analogy, a fetus—has a right

to life that he has a right to the means of life. My students who oppose

abortion are happy to grant this, but claim that the circumstances of the

thought experiment are very different from the real world circumstances in

which pregnancies occur where people act voluntarily in various ways that

incur responsibilities.

Later in the article, Thomson considers some of these circumstances: when

a woman voluntarily "indulges" in intercourse knowing that pregnancy is a

risk, or when her best efforts at protection fail, or when she acts in ways that

are important to her well-being but that create a risk of rape. Thomson

sidesteps these cases, saying they don't show that all abortion is unjust

killing. But except at their most extreme, opponents of abortion don't claim that all abortion is unjust killing. Instead, they think that in many cases when people consider abortion, it is morally wrong.

So how does Thomson's thought experiment misfire? Her title suggests that it provides "a defense of abortion" against its critics. But it does not really provide a defense against the positions of many if not most abortion critics. Instead, the thought experiment is an analytic tool that distinguishes the abstract idea of a right from further specification of the content of the right, including whether it includes any claims against others.

Or take Peter Singer's (1972) "Famine, Affluence, and Morality." The impetus for Singer's article was the refugee crisis in East Bengal, in which he estimated that nine million people had been displaced by poverty, a cyclone, and civil war. (Coincidentally, estimates are that at least nine million Syrians are refugees today). In "Famine," Singer famously argued that how people react to such refugee situations cannot be justified and that our moral conceptual scheme needs to be altered along with our way of life. Here's Singer's argument, in a nutshell:

--suffering and death from lack of food, shelter, and medical care are bad [slide 22, 23]

--if it is in our power to prevent something bad from happening, without thereby sacrificing anything of comparable moral importance, we ought to do it (the prevention principle) [slide 24]

--we could prevent at least some of the refugee suffering without thereby sacrificing anything of comparable moral importance,

--therefore we ought to do what is in our power to prevent at least some of the refugee suffering.

Singer admits that the prevention principle takes no account of proximity or distance, and no account of whether someone is uniquely positioned to help—both factors that might be psychologically relevant but, he claims, not morally so.

This essay ushered in an entire field of global ethics. But it did so in a very peculiar way: in the absence of serious consideration of institutions or context. For Singer, the primary aspects of context to discuss are what others are doing or whether the aid will do any good. Government enters only as a foil, to whether private charitable aid will result in a reduction of

government aid. Other institutions, such as NGOs, are entirely absent. So is any discussion of the background of justice or injustice in the societies in question.

Indeed, both Thomson's and Singer's seminal articles have these features in common: neither takes relationships, social or political institutions from the family to the state, or background contexts of justice or injustice into account, in any significant way. There are of course many possible explanations for this: the time in which they wrote (the early 1970s) and their roots in liberal theory and individualism. But I would suggest another: both took principles of interest—in Thomson's case a view about rights and in Singer's a form of utilitarianism—and traced out their implications for the issue at hand. Thomson, for example, does not consider the context in which the abortions she was discussing take place and whether there is adequate social support for people with disabilities. And Singer never raises the issue of injustice within the societies under discussion, either England or East Bengal.

I should emphasize that I am not attacking principles per se; particularism gets it wrong, too. I agree with the late John Arras (2013), writing on

"Theory and Bioethics" in the Stanford Encyclopedia: "But on the other hand, many who work in the area of bioethics, including many philosophers, are highly skeptical of the so-called "applied ethics" model of moral reasoning, in which exemplars of high theory (e.g., consequentialist utilitarianism, Kantian deontology, rights-based theories, natural law, etc.) are directly "applied" to practical problems. Indeed, most philosophically-inclined contributors to the bioethics literature have eschewed high moral theory in favor of various modes of moral reasoning falling on a spectrum between the strong particularism of various strains of casuistry or narrative ethics, on one end, and the mid-level norms of the enormously influential "principlism" of Beauchamp and Childress, on the other …." [slide 25]

2. So, much more importantly, how do we get it right?

In keeping with how I approach non-ideal theorizing, I don't think we have a complete answer to how theory and practice intertwine. Rather, I think we have strategies for doing ethics better. Here, I'm going to outline briefly an approach to non-ideal theory, and then deploy it illustratively in two contexts: first, reasonable accommodations and the recognition of individual differences and, second, aid in dying and the recognition of context.

2.1. Non-ideal theory. John Rawls famously introduced the distinction
between ideal theory and partial compliance theory in *A Theory of Justice.*
(1971) [slide 26] While theorizing about justice for ideal circumstances,
Rawls recognized that different approaches might be needed where either
natural or social circumstances were less than ideal. For my purposes here,
this attention to contexts is the most important point about non-ideal theory.
With respect to justice, for example, non-ideal theory treats issues such as
how progress can best be made toward justice, what injustices take
precedence to address, what strategies are likely to create new roadblocks to
overcoming injustice, or what are the obligations of individuals or
institutions when others continue to behave unjustly. (Cohen 2000; Miller
2011).

Rawls didn't see the need for non-ideal theory as a problem about ideals, but
as about whether real world circumstances were such that ideals could
reasonably be applied to them. Subsequently, discussions of non-ideal and
partial compliance theory have burgeoned. But these discussions, too,
largely see the problems as lying with existing circumstances, not with the
construction of ideals. [slide 27] For example, Zofia Stemplowska, in

"What's Ideal about Ideal Theory?" sees ideal theory as "theory that fails to issue recommendations for how to improve our society that are applicable for us here and now." She thinks theories that assume full compliance (and thus are inapplicable to present circumstances) can still be useful because they provide a standard against which to judge whether comparatively we are taking steps towards the ideal and to have a picture of what an ideal might look like.

Here, I side with Amartya Sen (2009, 2006), in emphasizing the importance of comparative rather than transcendental theories of justice. Sen argues that theories of justice need not take a complete or totalist form for many reasons, including information gaps, difficulties in judging among considerations that have a dimension of weight, or the need to make political room for areas of agreement among different points of view. A major driver of Sen's approach is his view about the limits of social choice and the ability of decision procedures to yield partial but incomplete agreement. My starting places are somewhat different. As I see justice, it is a matter of ongoing work at inclusion and flourishing: what next steps, at individual or social levels, will enable individuals in all their differences to do well at what matters to them? In my view, a picture of ideal justice might be so

abstract as to be vacuous, so fuzzy as to be unrecognizable [slide 28], or

perhaps even positively misleading. [slide 29] The same is true about

idealizations of autonomy [slide 30] In discussing how comparative justice

might work, Sen gives the example of the United States providing more

universal health insurance but remaining a society in many respects unjust. I

would develop this example by arguing that the US is a more just society if

it includes more people receiving funding for health care appropriate to their

conditions and choices, when others are already receiving similar care,

without having a complete picture of what a fully just health care system

would look like. Indeed, given developing technology, changing

understandings of the nature of disease, the ever-shifting world of disease

itself, and conflicting demands on social resources, we may not be able to

say what a fully just health care system would look like. Idealization might

tempt us to say: it would be a system in which everyone got the greatest

amount of needed health care possible under the circumstances. But this

idealization might be vacuous—what *is* this greatest amount?—or, more

disturbing, it might lead us into a situation (not so unrecognizably like the

problems we have today) wherein everyone might think that getting more

health care for themselves is a matter of urgent justice, when it might not be

comparatively more just at all. In her critical review of Sen, Frances Kamm

(2011) quite rightly observes that correcting one injustice—those left out of health care—might create others, as Oregon attempted to implement limits on some forms of care in order to expand its Medicaid program. [slide 31, 32] She is of course right—non-ideal theory is messy in this way—but it doesn't follow that we need an ideal of full inclusion to decide which is the preferable injustice. Rather, we need to keep challenging, evaluating and reevaluating the exclusionary effects of policy changes such as Oregon's rationing scheme.

2.2. Individual differences and accommodations. Since enactment of the Americans with Disabilities Act in 1990, and the Rehabilitation Act before it in 1973, US law has developed an extensive jurisprudence of reasonable accommodations. The ADA employment provision states that it is discrimination to fail to make "reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability who is an applicant or employee, unless such covered entity can demonstrate that the accommodation would impose an undue hardship on the operation of the business of such covered entity." (42 U.S.C. § 12112(a)(5)) [slide 33] Critics of the ADA claim that the reasonable accommodation requirement is not a civil right, but a special privilege that benefits people

with disabilities at the expense of other employees and imposes significant and unjustifiable costs on employers more generally. Assessing this claim requires attention to individual differences and their significance.

Many factors affect workplace design: history, convenience, social conventions, efficiency, costs, and inertia, among others. Often, these factors are unrelated to the goals of jobs, skills needed to perform them, or modes of performance. Working in a room that is accessible only by climbing stairs [slide 34], wearing robes, sitting for long periods of time, or being elevated on a high bench is not relevant to judging, for example. [slide 35] Nor does impartiality require that oral arguments take exactly one hour without breaks, that case materials be filed in a format that is in practice inaccessible to people with visual impairments, or that Communication Access Realtime Translation (CART) be the only technology provided for people with hearing impairments in court—as a common portrayal of justice reminds. [slide 36] Changes in longstanding practices may be inconvenient or expensive, but this is a different question than whether actual or potential employees are capable of performing essential job functions. There may of course be disputes about what are essential job functions or whether alternative modes of performance are effective. But as Anita Silvers and I

and coauthors argued in "Accommodating Every Body," accommodations are reasonable when they enable work-capable people to perform jobs successfully. (Stein, Silvers, Areheart & Francis 2014) Their costliness is a further question; if workplaces have been designed in ways that make it easier for typical people to perform, it may be fairer to share redesign costs socially rather than letting them fall on particular employers. But the alternative—maintaining the workplace status quo as the presumptively acceptable state of affairs—would continue to effectively exclude otherwise capable individuals and should thus not be taken as the position against which all changes must be evaluated.

Compare this jurisprudence of accommodation against another policy area where accommodation has taken a major role: religious beliefs. The connection between non-discrimination and accommodation first made its way into US civil rights law in the Civil Rights Act of 1964, which defined religion for anti-discrimination purposes as including "all aspects of religious observance and practice, as well as belief, unless an employer demonstrates that he is unable to reasonably accommodate to an employee's or prospective employee's religious observance or practice without undue hardship on the conduct of the employer's business." (42 U.S.C. § 2000e(j))

[slide 37] The primary understanding of this accommodation requirement was that employers should be flexible about scheduling, shift assignments, or dress requirements that might interfere with individuals' practice of their religions. Here, as later with disability accommodation, the goal was shaping the workplace to allow capable individuals with different religious commitments to perform their jobs successfully. More recently, employers have claimed accommodation rights with respect to obligations to provide contraceptive coverage under the Affordable Care Act—claims that may impede rather than recognizing difference. Their argument is that filing a form to claim a religious exemption violates their free exercise of religion under statutory and constitutional law. The 10th Circuit Court of Appeals determined that this notice requirement did not unduly burden religious liberty because the employers are not required to provide coverage or bear any costs with respect to coverage, are not penalized for failing to provide coverage, and are not themselves required to do anything with respect to coverage other than giving notice. In other words, all the employer needs to do is to self-affirm that its religious beliefs prohibit the coverage—hardly a requirement with the effect of excluding people with religious beliefs opposed to contraception. By comparison, employees who do not share their employers' beliefs and who wish to use contraception will be excluded from

an important benefit available to others if they do not receive this health benefit from other sources. [slide 38]

2.2. Now consider aid in dying and the importance of context. Legalization of aid-in-dying in the United States is a continuing goal of defenders of patient autonomy. At present, aid in dying (but not physician-administered dying) is legally permitted in Vermont, Montana, California, Oregon, and Washington. Active campaigns for legalization are under way in more than 20 other states, including Colorado, Massachusetts, and New York. The primary argument for aid-in-dying is patient autonomy; in the words of Compassion & Choices: "Everyone who believes in end-of-life options owes a debt of gratitude to Brittany Maynard . . .Compassion & Choices is honored to join with Brittany's family to continue her campaign to make aid in dying available to every American, no matter where they live." (C&C 2016) [slide 39]

Just how the availability of aid in dying enhances autonomy is not fully specified, however, and context matters here. Aid in dying does add an option not otherwise available, but the mere addition of an option is insufficient for advancing autonomy; whether autonomy is enhanced

depends on what choices are made effectively available and the importance of these choices to the individuals who make them. Clearly, people who seek aid in dying over other alternatives want it very strongly indeed—but the strength of a desire is also insufficient to show that the availability of means to its fulfillment enhances autonomy. There are reasons beyond intensity of desire to think that the option is an important one: it furthers experiential interests in being free from pain and other forms of distress and in not anticipating pain or distress, and what Dworkin called critical interests in living out ones last days on ones own terms and in being remembered as one was before the final days of illness took their toll. In the words of Atul Gawande, quoted on the Compassion & Choices (2016a) website: "Spending one's final days in an ICU because of terminal illness is for most people a kind of failure. You rely on a ventilator, your every organ shutting down, your mind teetering on delirium and permanently beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said goodbye or 'It's O.K.' or 'I'm sorry' or 'I love you.'" [slide 40] Contemporary forms of palliative sedation—coupled with the surety that this will be readily available when needed—can largely obviate the need for aid in dying to address experiential interests. It is unclear how aid in dying will do better than planned sedation in enabling

meaningful closure with others. No matter how available or well managed, however, palliative sedation will not address the critical interests that remain: the ability to choose how one dies and how loved ones remember last days. Context can help with this, too—with support, comfortable surroundings, a kind of pre-death lying in state—but it cannot address these interests fully. What this leaves is the question of how important the choice of the manner of the last few days really is. Simplistic arguments from autonomy fail to capture these nuances.

Another aspect of the context is advanced by disability activists opposed to aid in dying. These critics are concerned that some people will choose aid in dying because of subtle or not-so-subtle forms of coercion—a concern not borne out by the data on individuals actually opting for aid in dying, who tend disproportionately to be desirous of control over their lives. (Ganzini, Goy & Dobscha 2009) Critics also contend that legalization of aid in dying expresses or reflects erroneous views about the quality of life of people with disabilities; this, too, fails to recognize that aid in dying is being defended only as a matter of choice, not as a matter of what would be in the best interests of people who are terminally ill or what their quality of life might be. A better contextual argument advanced by its opponents is that aid in

dying is problematic in circumstances in which people lack adequate access to pain management or support for care at home or other supportive services such as vocational rehabilitation. The Netherlands, the initial jurisdiction adopting voluntary euthanasia, has universal health care paid for by subsidized and income-related premiums. The Exceptional Medical Expenses Act covers additional costs for long-term chronic illness with the fundamental goal of helping people to live at home for as long as possible. Care includes nursing care, personal care, domestic help, and sheltered accommodation. (Alzheimer Europe 2016) In comparison, the US offers far less. All of the states in which aid in dying is currently legal have expanded Medicaid (one, Montana, is using a demonstration waiver as an alternative to traditional Medicaid), but there are now eight states with pending aid in dying bills that have not expanded Medicaid. (C&C 2016, statereform 2016) [slide 41] In the states with aid in dying, the average rate of people under 65 without insurance in 2014 was 10.4% (with a range of 7% in Vermont to 15% in Montana). In the states with aid in dying bills that have not expanded Medicaid, the comparable numbers were 12.9%, with a high of 18% and a low of 10%. (KFF 2016) As for home health, California covers unlimited amounts for both the categorically and the medically needy and Washington covers two visits a day for these groups. Other states offer more

limited benefits, often for smaller numbers of people. These are essential services for people to be able to live in their communities.

My point here is not that we must always choose access to health care over aid in dying, or even that we have to choose between the two. Rather, it is that if we understand the contexts in which these policies are defended we can see what each actually might do with respect to autonomy. We can, that is, see more specifically both how aid in dying might expand autonomy and why people with disabilities might think that advocacy for Medicaid or home health is far more important.

Conclusion

You may have guessed that I'm a pragmatist, methodologically. To that, I plead guilty; I think ethics could learn a great deal from the pragmatist tradition. And one of the most important things it could learn is to object to artificial separations between "ethics" and its "application." [slide 42]

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