

Jamie Lindemann Nelson, "How We Become Who We Are: Ashley, Carla, and the Rest of Us," *The Journal of Clinical Ethics* 28, no. 3 (Summer 2017): 197-203.

# How We Become Who We Are: Ashley, Carla, and the Rest of Us

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## ABSTRACT

Lisa Freitag and Joan Liaschenko's thoughtful and important article goes directly to the under-examined heart of Ashley's case, namely to what sustains her in a habitable and intelligible identity. Though quite sympathetic with their conclusion and line of argument, I try to trouble their proceedings a bit, largely by wondering how having a specific such identity, out of several that may be in-principle available, matters to someone with Ashley's cognitive scope. I do this not simply to be contrary, but because their article also seems to me to raise issues in the ethics of bioethics—in particular, what I call the dilemma of ethical endeavor: How ought one publicly pursue deeply important and complex issues, the very raising of which may offend interlocutors who indeed have grounds for resentment. Making a habit of second guessing oneself may be part of the answer.

## INTRODUCTION: DOING ETHICS— SOME MORAL COSTS AND CAUTIONS

Writing about ethical issues is a vexed enterprise in ways that we who work these vineyards seldom

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acknowledge explicitly. Consider, for example, the costs of failure. In other intellectual endeavors, the chief cost of failure would seem epistemic, theoretical—you might well bring it about that those attending to your work leave the exchange with new confusions and fewer true beliefs than they arrived with, should they be taken in by your plausible, persuasive, sincere, and yet fallacious reasoning. It's also possible that the very power of your sound reasoning might perversely encourage them to dig all the more into their own errors. Even if we believe both that the more reasonable and well-justified beliefs will out over time, and that all defensible methods must include public disputation, people who care about getting things right should care as well about the costs that may be incurred by their failure,

Yet if worries about failure in our efforts to get clear about the structure of the world deserve more attention than they generally get, the issues we face as moral thinkers are even more fraught. If we get things wrong in this domain, we not only degrade our own and possibly other people's sets of beliefs, but we lend our authority to bad behavior and may even court corrupting characters as well.

This is not something that I am charging Lisa Freitag and Joan Liaschenko with being in any particular danger of doing.<sup>1</sup> I rather think their thoughtful and sensitive return to the controversies surrounding the interventions that "Ashley" underwent over a decade ago elevates the preservation of Ash-

ley's identity to a central place in our deliberations, which is just where it ought to be. Further, in the end I accept their permissive conclusion, despite some worries about whether their use of identity can do quite all of the heavy lifting they think it does. I have had roughly this kind of view of the matter, for roughly their reasons, since first I learned about Ashley's situation a decade or so ago. Given that, it seems unlikely that my exposure to their article will erode my character further. Nor am I particularly worried in this respect about you, dear colleague. Readers of *JCE* are typically keen professionals who have a sense of their peril and can take steps to avoid it. No, what concerns and at the same time excites me about their piece is that, by topic, timing, and treatment, it foregrounds these under-considered issues in the ethics of bioethics, as it helps us to understand more fully just who Ashley is, and what is required for her to be so.

### Doing Bioethics in Fear and Trembling

Should conscientious bioethicists worry, not merely about the possibilities of inadvertently persuading people of conclusions that are erroneous—the costs of failure—but of causing unintended though foreseeable harms simply as a result of raising and pursuing certain issues in certain ways—the costs of endeavor?<sup>2</sup>

Imagine, if you can, that there has been a poor relationship between bioethics and another community of scholars whose work involves social groups who have been, variously and seriously, stigmatized, marginalized, and otherwise harmed. Imagine further that the disaffected community has reason to believe that the reasoning and pertinent conclusions of many bioethicists are marred by the same kinds of morally indefensible attitudes and practices that are at the bottom of this ill treatment generally—a particular source of resentment, as surely better might be expected of people who think about ethics for a living. Now, suppose still further that some bioethicists find a well-motivated and exciting new take on an old and betimes bitterly contentious issue whose re-awakening might, contrary to intent but predictably, deepen the divide between these groups, and cause some people significant distress.

Should we ever find ourselves facing such a situation, how, if at all, should it bear on what we write about, and how we write about it?

This is a question I raise but do not pretend to settle, although I'll have something more to say toward the close of this commentary. I will, however, try to illustrate my concern throughout by infusing my attention to Freitag and Liaschenko with a sort

of second-order self-suspicion, a sort of modesty that is focused not so much on the results of my thinking about Ashley with our authors, but on what is taken to be appropriate as a form of thought itself. This attitude is not a panacea, even when skillfully employed; still, I wish to recommend it to my fellow workers in this field. For even given the painstaking care in analysis and argument characteristic of bioethics, and our resultant confidence in the soundness of our conclusions, some issues justly trigger special worries about whether we can count on our characteristic ways of going on to detect all the reasons that bear on the issue, and reliably recognize and rectify our missteps.

Reasoning about Ashley ought to inspire just that kind of modesty—certainly for bioethicists like myself who are only starting to have experience of what living with even mild disability is like. Why, given what has long seemed to me to be a defensible justification to hand for Ashley's treatment, have so many esteemed colleagues, and particularly those who by experience, scholarship, or both, are alert to the circumstances faced by people with disabilities, seen the matter so differently?<sup>3</sup> Having already confessed my admiration for their article, sympathy for its approach, and approval of its conclusion, I shall try to think through Freitag and Liaschenko's work in ways that give a reasonably full run to countervailing concerns that emerge from disabilities-sensitive perspectives, as I understand them.

### HOLDING ASHLEY

As Freitag and Liaschenko note, the Ashley Treatment is often depicted as though it is a matter of subjecting a highly vulnerable person to surgical and hormonal treatment to benefit third parties—namely, to ease her caregivers' responsibilities, which will become increasingly challenging as she grows. Accordingly, one way of understanding the Ashley issue is to see it as a matter of what some moral theorists, with apologies to Samuel Scheffler, might call "parent-centered prerogatives."<sup>4</sup> These are considerations that purport to justify reducing the stringency of certain standing moral notions. For Scheffler, the relevant standing norm is utilitarian, but the prerogatives idea is more commodious than that. It could well modulate the force of, for example, doing no harm, putting patients' interests first, honoring patients' autonomy—those norms thought to be partially constitutive of the healthcare provider/care recipient relationship, in order to protect care-providers' interests. The incipient justification for Ashley's interventions here is that healthcare pro-

professionals were authorized by her parents, operating within the range of their parent-centered—or perhaps better, family-centered—prerogatives, as bolstered by a reasonable belief that Ashley herself would benefit from the procedure in medical ways.

In arguing for their permissive conclusion, Freitag and Liaschenko set aside such considerations of medical benefit and parental prerogatives, or perhaps, subsume them in considerations of the role of families in identity constitution and maintenance. I'm a bit dubious that this part of their strategy is altogether well advised. While it can be plausibly argued that none of these norms are either strictly observed nor strictly obligatory, unless pretty exhaustively further specified, neither are they mere pious pretense—whatever the appropriate range of parent-centered prerogatives, they can't be allowed to set countervailing patients' interests at zero. So the size of the risks to which Ashley has been subjected, the intensity and duration of discomfort or pain she suffered, are surely pertinent in determining whether what was done to her was defensible. As such, it is just slightly unsettling that Freitag and Liaschenko seem a bit insouciant about such matters, as when they write: "The medical risk/benefit ratio of the triple procedure has been much discussed elsewhere, and we feel the evidence is so far insufficient to either support or oppose the procedure on medical grounds." Their point, surely, is to remain agnostic about whether not having to, for example, experience menstrual distress or risk cancer in organs she will never use is worth whatever risks Ashley ran, or whatever pain she suffered; fair enough. Their stress is on the role of these interventions in securing Ashley a respect-worthy and coherent identity via these interventions. Yet might there not have been other habitable identities on offer for her, that did not require she undergo whatever her treatment cost her in terms of pain or risk?

This question puts the nature and value of what our authors see as Ashley's chief, nonmedical benefit on the table. Stunting Ashley's growth, preventing her sexual maturation, looks as though her parents, doctors, and nurses are making common cause with her disabling condition. They are mirroring its impact on Ashley's cognitive life with a similarly wide-ranging assault on her corporality, to steer her from one identity—a cognitively disabled adult—to another—a simulacrum of an infant—simply in order to make it easier for her parents to continue to care for her.

A good part of the burden Freitag and Liaschenko carry in their article is to challenge precisely this movement of thought. Here, they are far from insou-

ciant, but keen and resourceful. They enlist Hilde Lindemann's work on the role of social relationships in forming and sustaining individual identities, which includes a philosophical motivation for the common and crucial intuition that Ashley is one of us, a person, despite a permanent inability to conceive of herself in such terms.

### **What Personal Identities Are Made of**

Lindemann's interest is in personal identities as they involve how we understand ourselves and are understood by others, as contrasted with questions concerning how things of our sort persist over time and through change.<sup>5</sup> Much of the construction work is done not by us, but rather for us—we both piece ourselves together, and are pieced together by others. As Freitag and Liaschenko understand this process, its initial raw materials are typically provided chiefly by the results of the careful attention our bonded intimates pay to small and subtle hints and clues we provide as infants. Lindemann herself, however, emphasizes its social character—that identities are constructed out of "tissues of stories and story fragments,"<sup>6</sup> drawn largely from stock narrative plot lines available from one's culture.

The notion that personal identities are narrative in form is common enough—recall, as influential illustrations, Alastair MacIntyre's argument in *After Virtue* that, when it comes to making sense of people the kind of "deductive-nomological" explanations used in science are no improvement over ordinary, intensional explanations of human behavior that draw on the teleological structure of stories,<sup>7</sup> or Margaret Walker's argument in *Moral Understandings* that narrative provides the vehicle for expressing how persons relate to time.<sup>8</sup> While Lindemann accepts these views, her own reason for promoting a narrative perspective flows more from the content than the structure of a personal identity. Her argument for the narrative character of personal identities is itself narratively structured: throughout *Holding and Letting Go* she uses her gifts as a creative writer to tell compelling stories about both fictive and real people, that show how ubiquitous is the practice of drawing on culturally available narratives as we strive to make sense of other people, and of ourselves as well.

Lindemann also insists that there are limits imposed by this rough world on what can be achieved through our story telling: for example, for an effort to build a personal identity not to misfire, its target must have a human form, and have at least some form of subjective awareness. These constraints have been subject to some controversy even among those

broadly sympathetic with her overall view, although the effort to mark out some boundaries on what narrative can contribute to our form of life surely makes sense.

In broad terms, and acknowledging differences in emphasis, this is the conception that undergirds Freitag and Liaschenko's bid for how we should understand Ashley and what made her famous treatment defensible. She didn't go under the knife primarily to avoid periods and pregnancy, nor merely to make things easier for her parents, who denied her natural maturity because they were reluctant to accept the mounting challenges of caring for her as she grew into her own version of adulthood. Rather, her parents unflinchingly accepted the constraints that the world imposed on Ashley and creatively worked within them to sustain their daughter's identity within her intimate circle. The physical interventions made it much easier—perhaps even possible—for her to stay who she is, cherished by and enmeshed within her family. She can receive their loving care every day, conveyed through their tender touches. If the treatment is alleged to infantilize her, the reply is that no identity foreign or distasteful to her is being imposed—she can continue to be her family's sweet little pillow angel for the rest of her life.

That this isn't a fantastic and perhaps disturbing image is supported by Lindemann's account of how our personal identities in general require other people to sustain them, the practice that she has dubbed "holding" in personhood. In the poignant chapter from *Holding and Letting Go* that serves as a touchstone for Freitag and Liaschenko's position, Lindemann describes how the distinctive personhood of her own cognitively disabled sister was crafted by her family. She provides a lovely and affecting vignette about the six-year old Hilde deciding that Carla, clearly uncomfortably warm, needed her mother, and, ever so carefully, lifting her sister out of her crib, and carrying her down a flight of steps brought her to Mrs. Lindemann, who reacted with what might be called veiled consternation. In this glimpse into the Lindemann story, we get a sense of the interlinked attitudes and practices that marked Carla as one of the family.

It's important to Lindemann, and to Freitag and Liaschenko, too, that the conferral of personhood on Carla and Ashley not be understood as a mere *façon de parler*. It is the real deal we are talking about here—which implies that a person's own contribution to who and what they are is not essential; this in turn raises questions about who has authority to narrate the identity of such people.

No challenges to the identity-constituting narratives enfolding Carla or Ashley could be expected to arise from their own point of view. Yet they well might from other, third-person perspectives. What prevents stories of the child as an oppressed victim, rather than a cherished daughter, from becoming the stuff of Ashley's identity, particularly if we accept Lindemann's stress on the socially available narrative matrix of our identities, rather than seeing our identities as formed from idiosyncratic details known to few other than one's intimates?

Lindemann's constraints of physical form and subjective content are not designed on their own to adjudicate contesting stories pressed from other third-person perspectives. Freitag and Liaschenko gently remonstrate with Lindemann about these constraints, suggesting in effect they are too strong, that she undercuts the power of her own insight.

Yet it isn't clear to me that, Freitag and Liaschenko fully appreciate the challenge constituted by other identity-constituting narratives that might be available to Ashley. Their stress on intimate particularities as the stuff of identity-constituting narratives suggests a way of answering the threat of the alternative identity on offer from relatively remote sources—the remote sources simply don't know as much about the bare bones of Ashley's narrative. Still, the significance to Ashley herself of those details is unclear, particularly if another narrative might allow her to sidestep significant surgery. There may be more direct ways to vindicate the importance of the family Ashley has, contrasted with others who may desire to claim her.<sup>9</sup>

Despite reservations about specific formulations, Freitag and Liaschenko seem to agree with Lindemann, that the possible identities that their intimates may construct on behalf of those unable to participate in the fashioning of their own identities are not malleable in any direction that may take a family's—or anyone else's—fancy. A good part of their point is that Ashley's surgical and hormonal treatments are not so much revisions of her identity as they are its confirmation; "infantilization" is a disrespectful mélange of practices and attitude as directed to those who are not infants. But infancy is not itself an abject condition, and an infant, cognitively, volitionally, and socially, is what Ashley is, and almost surely, what she ever shall be. Further, there is no reason to believe that any of this registers with her, at all. Where is the disrespect?

### Respect and Reasons

Ensuring that Ashley can continue as part of her family of origin strikes me as a very good thing. It

confirms her as a daughter, as a sister—statuses that are deeply human. It allows her progenitors to remain her parents, her mom and dad, carrying for her as moms and dads do for their most vulnerable children. It may increase the odds that she will experience care that is not merely competent, but exacting, for at least many years to come.

Yet there are those who are greatly troubled by the thought of Ashley remaining fixed in her pillow angel identity for decades yet to come, who see in her treatment another instance of nonconsensual power operating in the lives of people with disabilities for the primary benefit of others than themselves. If they think the goods of family life were substantially diminished or even silenced by what was done for it to continue, I'm not convinced that all the resources needed to reply effectively can be found in the way our authors deploy Lindemann's account of the narrative conditions of personal identity.

It can't, for example, be enough to point out that Ashley, while fully a person and therefore vulnerable to dignitary offenses, surely doesn't resent her treatment. Ashley has a strong moral claim to be well cared for. Yet the distinction between good care provided by the touch of her parents' loving hands, as opposed to good care provided via a competently used lift, while, as noted in the text, is extremely significant to Park McArthur, may not be salient to a person like Ashley at all. In addition to suffering from muscular dystrophy, McArthur is a visual artist and feminist aesthetician with graduate degrees, award-winning installations, and publications in significant intellectual journals to her credit.<sup>10</sup>

Further, while Donald Winnicott may well be spot-on in identifying parental touch as a crucial requisite for infants with developmental potential, the importance of parental touch must be differently understood for someone like Ashley, whose developmental path is so atypical.

If we are going to find a place from which to argue successfully about whose account ought prevail, we may need other aspects of Lindemann's thought to help us out. Chief among these, I suspect, will be some of the corollaries for families and for healthcare of her insistence on the deeply social character of selves: for example, her view that families typically play particularly crucial roles in forming and sustaining our identities, and her idea that family caregiving typically operates according to different and quite defensible moral norms, than those involved in the provision of professional healthcare. We may also need a good answer to a question that may not get an explicit reply in Lindemann's text.

### **Why Being Held in Your Identity Matters—Even When it Doesn't Matter to You**

In addition to crediting the good faith and reasonableness of her parents' belief that the treatment will make life easier and safer in the long run for Ashley, we ought to consider that the importance to Ashley's parents of the particular style of loving caregiving they provide to their daughter is worthy of our respect, even if it may not be experientially significant to Ashley herself. Considering the impact of caregiving on caregivers, and allowing treatment decisions to be influenced by it is not a common understanding of the moral defaults in healthcare. But Ashley's primary caregivers are not healthcare professionals. They are her family, and there is surely something to be said for allowing them to make determinations that will allow the family and its members, not only to endure, but to flourish, with Ashley at its heart. Given the role of this particular family in providing loving care to their daughter while maintaining her in a respect-worthy identity, their claim to represent her interests in seeking medicine's help in continuing to provide such care deserves sympathetic attention.

Yet if we allow the tethers between Ashley's experiential good and justifying surgical and medical interventions to loosen, it seems that we may need to allow other considerations than those concerning her family to have a look in, too. In emphasizing how identities are formed out of fragments of "stock plots," rather than idiosyncratic details, Lindemann is supported by the idea that our intelligibility to ourselves and to others is more readily secured if at least a good deal of the semantic resources used for the job are widely familiar. At least in principle, however, this must be a reciprocal process—we find in the general library of narrative themes the resources to understand who we are, and we then work in our own distinctive elements, a few of which may sometimes become both sufficiently distinctive and sufficiently celebrated—or excoriated—to attract the attention of others and win a place for themselves in the storehouse of stories.

One of the distinguishing features of Ashley's story is that it introduces new and unsettling elements to a common story, a new variation on themes available to disabled people: a surgically shaped pillow angel, whose body is medically adjusted not in response to her own most deeply felt yearnings for a coherent identity, but to suit the desires of others. Particularly given the tragic history of nondisabled people making free with the bodies of people with disabilities, resistance to the spread of this narrative seems not only reasonable, but required.

This is just where I want to return explicitly to the theme of the ethics of bioethics in general, and to the ethics of endeavors in particular. It's been a decade and more since Ashley underwent her treatment; is it really a good idea to return to it now, when nothing seems practically pressing about the case or any offshoots, and when dredging it up again may cause more people with disabilities to feel again unheard and hurt, and more disabilities scholars to feel yet further alienated by mainstream bioethics? There surely needs to be a reason for running such risks, that goes beyond the opportunity to insert a bright new idea into the literature.

But here's just where I think Freitag and Liaschenko have made a substantial and worthy contribution by drawing the connections between Ashley, Carla, and Lindemann's work. Lindemann provides a way of thinking about personhood and personal identity that allows Ashley and Carla, and so many others like them, to count robustly and univocally as persons, despite lacking the kinds of complex subjectivities that allow them to understand and have views about their situations—considerations that are criterial for personhood in so many philosophical theories. In Lindemann's more naturalized account, the work of identity formation and maintenance as it involves people with profound cognitive disability is no more the heteronymous imposition of an alien will in their lives than it is in anyone's; rather, it seems part of the work that's necessary to bring it about that one might speak with sense about Ashley and Carla's having the kind of dignity that makes these concerns pertinent at all.

I don't wish to deny that growth attenuation and sterilization are, at first face, very disquieting, as is the notion of a person living on for decades, yet always held in her earliest identity. Yet one of the lessons that mainstream bioethics, and mainstream society in general can learn, if we will but be taught, from the witness of people with disabilities and the work of disabilities studies scholars, is that the human form is express and admirable in many different incarnations. It might be useful, in my view, for work such as is attempted by Freitag and Liaschenko to note and feature such affinities with the views expressed by those involved in the disability community, as they attempt to reawaken debate on such a deeply fraught matter.

Of course, I have not the slightest wish to discourage the pursuit or the publication of deeply thoughtful and creative research—quite the contrary. Yet everyone tempted to weigh in ought to do so in the awareness that, among its other effects, their work may help shape such variations on the stock

plots that allow us to envisage and enact new forms of identity; whether the Ashley Treatment was or was not justified may, at day's end, be influenced by which understandings of identity in general, and of her identity in particular, get the most uptake. In their public performances, bioethicists and disabilities scholars may do more than argue for one or another such conception—they may help bring about what they warn against, replenishing the stock of stories with the story of Ashley: either a cautionary story of parental indolence, that marred the natural character of a child's body, or a laudatory story of parental creativity that sustains a child's identity while it expands our sense of the ways the human form can have beauty and dignity. Who Ashley ultimately is may remain an open question—something else she shares with many of the rest of us.

#### CODA: HOLDING CARLA

I conclude with a short memory of a walk I once took through an autumn graveyard in St. Peters, Minnesota, roughly 30 years ago. I was with the woman who would become the author of *Holding and Letting Go*, and we were looking for the resting place of her sister. Memory is an odd thing; I remember how poignant that walk felt, and, almost incredibly, I am pretty sure I remember what I was wearing. What I can't quite remember is whether we ever found Carla; if pressed, I'd have to say that I don't think we did. Not that it really matters; it was in the looking that we continued to affirm who Carla was, and to hold her in that identity, despite her then being 35 years gone, and no more able to understand what we were about than she was when her six-year old sister gently scooped her from her crib, and so carefully carried her down the steep stairs to their mother.<sup>11</sup>

#### NOTES

1. L. Freitag and J. Liaschenko, "Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability," in this issue of *JCE*, 28, no. 3 (Fall 2017).

2. I'm aware that my handling of the ethical problem involved in failing at and even attempting ethical argument is couched in a cognitivist idiom, but it seems to me that the same issues arise for any noncognitivist meta-ethics that accommodates the notion that some ethical positions are more satisfactory than others, and that ethical reasoning can be worthwhile, as a means of sorting sheep from goats. I further assume that the vast majority of bioethicists accept meta-ethical views that are so accommodating. Translation from my idiom to your favorite non-

cognitivist jargon should be straightforward.

3. I have particularly in mind here many of the writers cited in Freitag and Liaschenko, note 8, in particular: Adrienne Asch, Sara Goering, and Eva Kittay, from whose work I have learned a good deal, though not, I expect, as much as any of these scholars think I ought to have.

4. See Samuel Scheffler, *The Rejection of Consequentialism: A Philosophical Investigation of the Considerations Underlying Rival Moral Conceptions*, 2nd ed. (New York: Oxford University Press, 1994).

5. To use a distinction introduced into the literature by Marya Schechtman, Lindemann offers an answer to the *characterization* question, as opposed to the *reidentification* question. See M. Schechtman, *The Constitution of Selves* (Ithaca, N.Y.: Cornell University Press, 2007).

6. H. Lindemann, *Holding and Letting Go: The Social Practice of Personal Identities* (New York: Oxford University Press, 2014).

7. A. MacIntyre, *After Virtue: A Study in Moral Theory*, 3rd ed. (Notre Dame, Ind.: University of Notre Dame Press, 2007).

8. M.U. Walker, *Moral Understandings: A Feminist Study in Ethics*, 2nd ed. (New York: Oxford University Press, 2007).

9. At a meeting at the Hastings Center on prenatal screening held in the mid-nineties, I well remember the passion with which a disabilities studies scholar, herself a woman with disabilities spoke of aborting fetuses as a result of finding them to have anomalies that would give rise to disabilities. "These are *our* children," she said.

10. "Park McArthur," [https://en.wikipedia.org/wiki/Park\\_McArthur](https://en.wikipedia.org/wiki/Park_McArthur).

11. This article is a contribution to the work of the Project on Responsibilities in Change/The International Research Consortium on the Ethics of Families in Health and Social Care ([www.familyethics.net](http://www.familyethics.net)) funded by the Netherlands Organization for Scientific Research (NWO). Many of its themes are discussed in more depth in my contribution to *Social Lives, Personal Identities: Essays in Honor of Hilde Lindemann*, currently in preparation.