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### *Family Story as Political Science: Reflections on Writing <i>Trapped in America's Safety Net</i>*

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Family Story as Political Science:  
Reflections on Writing *Trapped in America's Safety Net*<sup>1</sup>

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*Trapped in America's Safety Net* tells the story of my brother and sister-in-law as they attempt to navigate the incredibly complex world of social assistance, following a car accident that left my sister-in-law a quadriplegic. It is what anthropologists term an “intimate ethnography,” a work that explores the lives of family members while “finding ways of linking the individual stories to larger social processes” (Waterston and Rylko-Bauer 2006, 405). While in a companion piece in *The Forum* I examine the theoretical lessons for political science (Campbell 2015), here I discuss the challenges that intimate ethnography presents the researcher, “the methodological, emotional, and ethical issues attendant ” when one is writing about one’s own family (Waterston and Rylko-Bauer 2006, 405; see also Walley 2013).

Political science is an empirical discipline. But as my colleague Regina Bateson has pointed out, although the “word ‘empirical’ is commonly defined as ‘based on observation *or* experience,’ somehow the ‘experience’ side of things has disappeared from empirical political science.”<sup>2</sup> Having now *experienced* through close family members various programs I had studied for years, I can say that the lived reality taught me innumerable details and countless profound lessons that no technical analysis could ever reveal. For the first time I realized the real ramifications of many aspects of policy design that I had “known” about before but the

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<sup>2</sup> Personal communication.

implications of which I had never truly understood. I hope the book conveys to readers what I have learned in a compelling and powerful way.

Writing about this visceral experience as a political scientist, however, raised a number of empirical and normative issues. Bob Keohane warns that “we need to seek objectivity – a goal that is never realized but that we should strive for – because otherwise people with other preferences, or who do not know what our values are, will have no reason to take our findings seriously” (2009, 363). How could I write about my own family in a way that was true to their experience but also an “objective” report? How could I convey telling details without robbing my family of their privacy? How could I rein in my emotions to report their story, and did I pick and choose facts to protect them or to make them more sympathetic? How could I generalize from their experience to that of millions of social assistance recipients?

Here I consider these challenges in light of what other social scientists have said about the issues of close work with individual, sometimes vulnerable, research subjects. My hope is that I have achieved what anthropologist Christine Walley calls “a double consciousness,” a perspective that combines my viewpoint as the close relative of a family enmeshed in the problematic American safety net with the broader policy outlook of a political scientist (Walley 2013, 15). Witnessing my family’s struggles has been a searing experience – and a revelatory one, even if the resultant narrative is far from a standard research design.

### The Book’s Genesis

In March 2012, the Supreme Court heard oral arguments about the constitutionality of the Affordable Care Act’s provisions. An op-ed page editor from the *New York Times* who knew of my work in health policy had emailed me to see if I might write a piece about some aspect of the

ACA or the challenges to the law. Over the next few days Kimberly Morgan and I drafted a piece about the ACA in light of our *Delegated Welfare State* book (Morgan and Campbell 2011). In that volume we use a case study of Medicare to explore the common American practice of delegating social policy to non-state (and often for-profit) actors. By expanding health insurance coverage through private insurers, the ACA exemplifies such delegation, complete with its advantages and its many disadvantages, we argued. We dutifully sent in the piece.

Days later, however, I read a transcript of the oral arguments and was appalled by the tenor of the Justices' comments and questions. Yes, the broccoli exchange was inane, the justices asking whether the Obama administration's argument that everyone is inevitably in the health care market and should therefore have insurance is tantamount to requiring people to buy broccoli at the supermarket. But to my mind, the most egregious comment was Justice Antonin Scalia's assertion about young people: "They're going to buy insurance later. They're young and need the money now . . . When they think they have a substantial risk of incurring high medical bills, they'll buy insurance, like the rest of us."<sup>3</sup> That did it. I was furious. Just a few weeks earlier, my sister-in-law Marcella was in the car accident that rendered her a quadriplegic and turned her and my brother's lives upside down. She had tried to get health insurance and had been unable. Now she was relegated to a life on Medicaid (only later did I fully realize that what tethered her to Medicaid was not the need for health insurance but the need for personal care, for which Medicaid is the only source, public or private). At any rate, I thought Scalia's comments were woefully uninformed and divorced from reality. And so I fired off a second piece for the *Times*, which became the op-ed that ran in early April 2012. "I didn't expect this!" was the editor's response.

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<sup>3</sup> Supreme Court of the United States, *Department of Health and Human Services v. Florida*, oral arguments, March 27, 2012, p. 37. [http://www.supremecourt.gov/oral\\_arguments/argument\\_transcript/2011](http://www.supremecourt.gov/oral_arguments/argument_transcript/2011).

In the meantime, I had flown to California again to be with my brother and sister-in-law. I ended up editing the piece from Marcella's room in the rehabilitation hospital, which was a surreal experience (accompanying her for imaging to try to learn why she suddenly couldn't speak, only to return to her room to find another set of editor's queries waiting). In early June I saw Larry Jacobs at a conference, and he suggested that I write a book about Dave and Marcella's experience for the series he edited at the University of Chicago Press. Political science editor John Tryneski was an enthusiastic supporter of the project from the beginning. Both urged me to include the policy information but to keep Dave and Marcella's story upfront, in the hopes that a narrative would have explanatory and persuasive power that a technical recitation of program details would lack.

### Hanging My Family out in Public

However, writing such a book poses myriad challenges, analytical, compositional – and ethical. I would be writing about my family in a highly detailed and personal way. How could I convey their story truthfully and compellingly without violating their privacy or inducing harm?

Among social scientists utilizing ethnography, participant observation, interviewing or other techniques that put them in direct contact with research subjects, potential harms are of paramount concern. Several have written thoughtfully on the ethical issues: the hurt that the researcher may impose with her questions; the coercion to participate that vulnerable individuals might feel; the social and economic ramifications for those individuals cooperating with an outsider. Reflecting on her research on political violence in rural Rwanda, Lee Ann Fujii has noted that a “seemingly innocuous question can touch on sensitive issues” (2012, 717). Even more concerning is the “power imbalance between researcher and researched” that may amount

to coercion (Fujii 2012, 718). Moreover, in such environments the very presence of the researcher could bring “shame, envy, or suspicion” to those interviewed (Fujii 2012, 718). And well beyond the coercion or social pressure that the researcher may introduce is the problem of physical harm. In her research on the civil war in El Salvador, Elizabeth Jean Wood chose not to publish certain data because it “may well be read by Salvadoran military officers” (Wood 2006, 382); similarly Charli Carpenter worried about revealing the experiences of the children of mass rape in war-torn regions (2012).

In contrast to researchers studying strangers, particularly those working with vulnerable populations such as child abuse victims or genocide survivors, I was less concerned about coercion or power imbalances with my subjects: Dave and Marcella willingly agreed first to the op-ed and later to the book project. However, I did worry about a number of other issues with which interviewers and ethnographers have struggled, in particular privacy and backlash. I did not want to share with the world details Dave and Marcella (or our families) wished to keep to themselves. Nor did I want my investigation to anger officials in a position to reduce Marcella’s benefits or otherwise make life difficult for her. Without these constraints, the book could have been an even more damning indictment of the American social policy system. But to protect Dave and Marcella I at times toned down my professional desire to reveal more. As June Price has written regarding her work on women reported for child abuse, ““my ‘own self’ warned me not to publish problematic data – to compromise the research rather than compromise the participant” (1996, 208; see also Carpenter 2012). Dave and Marcella are in these programs for the long haul, and so it was imperative that I not critique those with power over their benefits too much. My consolation is that the book is a pretty damning indictment as is.

## *Privacy*

My initial concern was with Dave and Marcella's privacy. When I wrote the *Times* op-ed, I referred to them simply as my brother and sister-in-law, still wary at that point of exposing their identities. In particular I was afraid to use their names lest crazies target them for hate mail. This was not an unfounded fear. Although most of the emails that I received in response to the *Times* piece were sympathetic, with many writers sharing their own families' insurance-related horror stories, several were pretty caustic. These missives typically asserted that Dave and Marcella should have sacrificed more to get health insurance, as the writers inevitably claimed that they had done themselves, or that Dave and Marcella had no business starting a family without permanent health insurance. As critical as they were, these emails were relatively polite: the writer had to look up my email address at MIT and then risk having their identity, or at least their email address, tied to their message. Far worse were the on-line comments on the *Times* op-ed, where writers used the cloak of anonymity to unload in excoriating terms. The last thing I wanted was for Dave and Marcella to be bombarded directly with such venom.

It turned out that my efforts to shield their names were moot; in an internet age, their identity was easily discovered. Within days of the op-ed coming out, the editor of our hometown newspaper, who had seen it referenced in economist Brad DeLong's blog, wrote me an email introducing himself and asking, "Unless I'm grievously mistaken, I immediately recognized that you were talking about Marcella, who suffered that terrible accident in February." Right? Right. With their names all over the local newspaper's online content, there was no point in trying to hide their identities. Sadly, some of the comments posted on the local newspaper articles were just as vicious as those appearing in the *Times*. Fortunately Dave was so busy tending to Marcella that he didn't have time to follow them.

My further concern in writing the book was in naming my nephew. While Dave and Marcella consented to have their names and personal details disclosed, my nephew was a minor, and a non-verbal one at that. Perhaps later in life he would not want these personal details about his family revealed. Thus in early drafts of the book I referred to him only as “the baby.” But Dave and Marcella soon agreed to use his name. It was all over the local newspaper and internet anyway; anyone looking up Dave and Marcella’s names would immediately see Logan’s. A relative who is an academic historian argued, “It’s his story too. He should be able to be identified, to own it.” Then I remembered the experience of reading Anthony Lukas’s account of the Boston desegregation busing episode, *Common Ground*, in college (Lukas 1985). Among the families profiled were the Divers, who had chosen to engage in “urban homesteading” rather than join the white flight out of the city. The text mentioned a colleague of Colin Divers’ in the Mayor’s office who had bought a house in an affluent suburb and who, while committed to the desegregation cause and to improving the city, resisted the Mayor’s hints to move back, saying that “he would never subject his family to the rigors of city life” (172). I instantly recognized the name: his daughter was my college classmate. He was protecting *her*. But while I recognized her name, it was no big deal. I felt no animosity toward her for her parents’ decision. Moreover, *Common Ground* was a best-selling, Pulitzer-prize winning book with a wide readership. I know we political scientists like to believe that we are important, but in reality, my book will sell a few thousand copies. In twenty years, when Logan is an adult, no one – no college admissions officer, no future employer – is going to remember that he was in this book, unless he chooses to reveal it (if they do an internet search for his name, those old newspaper articles about his family are going to come up anyway). If I were an incendiary, best-selling memoirist like Mary Karr, I might worry about revealing the identity of my relatives. Short of that, I’m not too concerned.



Indeed, Marcella and Dave were themselves my guide on privacy. As I was writing, I gauged the degree to which they wanted to reveal details in their reactions to my questions and in their sharing with the local media and on Marcella's medical fundraising page. I figured that anything they said in the newspaper or online was fair game. Nor did the reviewers or editor push me to include material that the family didn't want used. In the end, Dave and Marcella read the manuscript; there was nothing they asked me to remove. Perhaps that is because I self-censored a bit, in two ways: I did not include material that I thought would incite backlash from program officials. Nor, as I discuss later, did I air certain family tensions, which, although telling of the strains we all experienced, would have been gratuitous to include and unhelpful to family comity in the long run. Because the thing about spinal cord injuries is that you're in it for the long run.

### *Backlash*

In many ways, what concerned me more than privacy was backlash. If I complained too much about the nature of these programs, or worse, about the way in which Marcella and Dave have been treated, would program officials be offended and take action against them? I so feared making Dave and Marcella worse off.

Researchers have long struggled with the tensions around revealing too much. Jane Mansbridge felt by the mid-1980s that she could write about the fight for the Equal Rights Amendment without hurting the movement only because by then it was so politically dead (Mansbridge 1986). But I was writing about people currently and indefinitely enmeshed in a system from which they could experience harm. And while I didn't have to worry about what a military junta might do to them, I did worry about social workers. As Joe Soss and co-authors

have illustrated so vividly in their research on the cash welfare programs AFDC and TANF (Soss 1999; Soss, Fording, and Schram 2011), case workers in means-tested programs have great control over benefits and tremendous latitude in deciding who gets what. If they were to get angry and stop authorizing the extra catheters Marcella needs each month, or indefinitely neglect her other needs (a new wheelchair, a new mattress topper), it would be a disaster.

To prevent backlash, I did not attend Dave and Marcella's meetings with social workers; I did not want to elicit the ire of caseworkers by appearing to monitor them. In the text I do not name or blame individual social workers. Unlike Joe Soss's interviewees, who are anonymous and can criticize their caseworkers without repercussion (1999), Dave and Marcella are obviously identified and in a repeat game with her social workers. In addition, I have avoided doing a book event in our hometown, even though it might draw quite a crowd and sell a lot of books (apologies to the Press!). I didn't want to stir the wrath of social workers and others upon whom Marcella is dependent. In general I have tried to practice a kind of "mindful ethics," to be "aware of interviewees' personal, family and everyday life experience" and to "recognize potentially harmful situations and consequences" that the researcher might otherwise take for granted (González-López 2011, 450). I chose not to reveal information or expose the shortcomings of named individuals that might harm Dave and Marcella even if it would have been helpful to my argument. The tradeoff is that to get a complete picture of these programs' operations, it is necessary to read my book in conjunction with work like that of Soss and his co-authors, who do expose the shortcomings of individual program officials.

In truth, the limitations of individual caseworkers are only part of the story. One enormous problem is the Byzantine system itself. There are a hundred ways to be eligible for Medi-Cal alone, layered on over the last 50 years, not to mention the complexities of its

interaction with other means-tested programs. Thanks to the University of Chicago Press, I got the best possible access to top Medi-Cal officials, and even they could not answer our questions: Why was my nephew kicked off Medi-Cal at one point? What is the most money my brother can earn without rendering Marcella ineligible for insurance? Of the scores of programs within Medi-Cal, which maximizes their financial security while maintaining Marcella's access to the supports she needs? Those at the top of the program were unfailingly polite, forthcoming, generous with their time, and clearly dedicated to the program and its clientele. But the fact that even they didn't know the answers was truly shocking. Those phone calls were the most disturbing episodes in writing the book.

Other failures are the fault not of social workers or program officials, but of legislators. Why does Medi-Cal continue to have some of the lowest reimbursement levels in the nation? It's been 50 years since the program was implemented under Governor Ronald Reagan, who placed it in a new agency staffed with his cronies rather than the Department of Social Welfare, which he didn't trust (Sparer 1996). Is path dependence really that strong? Why hasn't the asset limit been adjusted in 25 years? Or the "family maintenance need level" – the income program recipients are allowed to live on? The state might pride itself on progressive innovations in many areas, but it's not immune to the cowardly fiscal tactic of policy drift (Hacker 2004). One might hope some of these things would change in Jerry Brown's California, but the truth is that even in a blue state there is little electoral incentive to update programs to meet the poorest constituents' needs.

*Special treatment?*

My colleague Gina Bateson wondered whether, in contrast to harms, Dave and Marcella would now get special treatment that other beneficiaries without a political scientist sibling wouldn't get. Would their now-public needs get addressed, like shoppers who finally get action from recalcitrant companies after they appeal to a consumer advocate columnist who publicizes and pursues their case? As Lee Ann Fujii has noted, sometimes researchers can be viewed as "a valuable patron" capable of bringing benefits to marginalized communities (Fujii 2012, 719). Would I unethically be securing benefits for Dave and Marcella that others don't get?

If only! Any illusions that I would be able to sweep in and solve their problems with my special access evaporated when I actually spoke with the top Medi-Cal officials. My phone calls were greeted with a shrug, not a campaign to put things right. Marcella wasn't put in the optimal Medi-Cal program (we can't even figure out what that is). Nor has equipment that she requested, like a reclining wheelchair, materialized. *Nada*. My stepmother's colleague tells us that we may be able to get the local state assemblyman to sponsor a very specific piece of legislation that could put Marcella into the optimal Medi-Cal program by fiat. But we have to determine what that is – probably the California Working Disabled program – and even so, we can't do it now; if her and Dave's income were to rise because of CWD allowances, they would lose their childcare subsidy and be no better off. So perhaps we'll try that in two years when Logan begins kindergarten. In the meantime, they're ensnared by the interactions among means-tested programs, and no phone call from me is going to change that.

To the degree that Dave and Marcella have received any special treatment it was certainly not because of me, but because of our late father. Although he passed away six years before the accident, he was a bigger cheese in my home town – the hospital's chief medical officer – than I will ever be in the larger policy world. As a result, Marcella enjoyed some small benefits from

those who remembered our Dad – like getting the ICU room with the best view of Mount Shasta – and some large ones – like the air ambulance ride the hospital donated to deliver her to the rehabilitation facility quickly and comfortably, and avoid the freeway, which terrified her. As for “unethical” benefits that I have delivered? In my dreams.

### Personal Experience as Academic Project

In addition to worrying about what the publication of the book might do to my family is a second set of concerns about the nature of its content. First, I faced what I’ll call the cognitive challenge of writing the book. How did I balance getting in close to enumerate the details of their situation while also pulling back to discuss the general situation of means-tested programs? How did I choose which facts of their story to reveal and which to withhold? Second was the emotional challenge of writing the book. To prevent the book from devolving into a diatribe I had to tone down my fury, my very frequent thoughts of *What the hell kind of country do we live in anyway?* I also had to deal with the guilt of our very different situations and my inability to do more for Dave and Marcella. Finally, there was the analytical challenge of writing an intimate ethnography about American social policy. How representative are Dave and Marcella’s experiences? What do we learn from their situation that we would not learn from a standard academic research design? Conversely, what would a traditional analysis reveal that a single case study cannot?

*Deciding what to report*

A main challenge in writing the book was deciding what kinds of personal details to include to maintain verisimilitude without airing too much dirty family laundry. It's a balance that many scholars working closely with interview subjects must strike. In her work on reproductive politics, which included interviews with pro-life and pro-choice activists, Laura Woliver chose not to report "personal animosities between group members or untoward behavior by activists." Doing so could "hamper [her] access," as activists "travel in small worlds" and can let each other know of poor experiences with a researcher (2002, 677). This decision presented tradeoffs: interpersonal conflict is an important detail, telling of the fragility of a group; but exposing it can harm both the researcher's access and the group itself. To prevent such interviewer contamination, Woliver decided not to "name people who hate each other, or who feel that someone is hogging the spotlight or using the group for his or her political career or personal agenda" (2002, 677). In order to convey the tensions, however, she did choose to write about group factions as a way to "mask the conflict and discuss it in another way" (2002, 677).

If anything, families are even smaller worlds, and the ramifications of revealing internal tensions even higher. I was careful not to let research for the book undermine my relationships with various family members. And in truth, our relatives displayed remarkable patience and tolerance toward each other and the unbearable situations in which they found themselves: our mother and Marcella's mother living together for three months in a tiny apartment adjacent to the Bay Area rehabilitation hospital, miles from home, with nothing to do but visit Marcella, watch Logan, and try to help Dave; our mother, Dave, and Logan living for another year after that in the home of our stepmother, a woman who had become accustomed to her own routines in the six years since our father's death, only to see them blown apart by these unanticipated long-term houseguests. Given the tight quarters and the potential frictions of daily life, the fact that all of

these disparate personalities got along reasonably well was nothing short of remarkable. Having a very cute baby to bond over helped tremendously.

But there were also individuals within and across the families who didn't get along. Some relatives were heroes in the beginning, only to slink away later. Countless times tempers flared, and tears were shed. As my aunt said, if I were a playwright, I would have produced quite a different project. But in writing a piece of social science, albeit a narrative-driven one, I didn't think it necessary to report all the human foibles. I was particularly sensitive to the fact that as someone who parachuted in periodically from 3000 miles away, I was hardly in a position to judge those doing the truly hard work day in and day out.

That said, some of the interpersonal strife was driven by the nature of public policy, which relies so heavily on families and puts them in untenable situations.<sup>4</sup> Indeed, as Dave and Marcella's story has continued to play out, there are new developments that I find problematic, decisions that relatives have made given the incentives the current state of social policy supplies. After returning to Redding from the rehabilitation hospital, Marcella lived with her parents for nearly two years, while friends and family renovated Dave and Marcella's house. During that time her mother and several other relatives performed Marcella's personal care (and were paid to do so at least in part, as the In Home Support Services program in California allows the stipulated number of paid care hours to go either to personal care assistants or to family members). When Dave, Marcella, and Logan moved back into their home in April 2014, after the book was in press, her sister Melissa declared that she would become Marcella's primary caregiver once the school year was over. Melissa was an elementary school teacher with four children under age 10. She explained that although the state's personal care wage was lower

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<sup>4</sup>Untenable is Jennifer Hochschild's word. Personal communication.

than her teacher salary – just \$9.30 per hour – after paying for daycare for her younger two, and after-school care for the older two, she was no better off continuing to teach. By becoming Marcella’s caregiver, she would be able to spend more time both with Marcella and with her children, and financially it was a wash.

My social policy alarm bells went off when I heard about this arrangement. I recognize the myriad incentives pointing this direction: the fact that family members *can* be paid to give care; that childcare is so very expensive; that teacher salaries are so low. But, but, but. In the short term, perhaps Melissa’s financial situation is a wash. But in the long term she has undermined her financial security. She gave up her California state teacher’s pension. She will now have a much lower Social Security benefit in retirement as well, because of her new, lower earnings. The arrangement clips Marcella’s wings also. How is she supposed to go back to school when her caretaker is saddled with little kids? I suppose these limitations are temporary – both Marcella and Melissa will have freer schedules once Logan and his little cousins are school age. But Marcella would have a freer schedule now, because Logan is in subsidized day care until mid-afternoon each day. But she’s essentially stuck at home because her caretaker is. Again, I’m hardly in a position to judge. Clearly the advantages of having her sister as a caregiver outweigh the drawbacks in Marcella’s mind, at least for now.

Dennis Heaphy sees it another way. One of the disability activists I interviewed for the book, and a quadriplegic himself, he dislikes state policies that allow family members to be paid caregivers. The wage is so low that the whole family gets dragged down into poverty, he says. It’s bad enough that the disabled person has below-poverty SSI benefits; now you’ve sucked other family members into the below-living-wage workforce as well. And he worries about the possibly uneven quality of family caregiving and the toll that personal dynamics can take. If a



professional caregiver were chronically late or delivered poor quality care, you would fire them. But you can't fire your mother.<sup>5</sup>

Due to the many shortcomings of public policy, family is the most important resource Dave and Marcella have. It would have been unconscionable for me to report every conflict or individual weakness. As Laura Woliver has said, "It is up to the judgment of the interviewer to know when these conflicts are a serious part of the story and when they are just part of the complexities of people's personalities and relationships and not important politically" (2002, 677). No doubt some of the interpersonal conflicts were important and were indeed driven by the public policy environment. But just as Jane Mansbridge didn't want to undermine the ERA movement by reporting on it, neither did I want to abase our extended family by airing gratuitous details. Some of these may have been policy relevant, and if I reported them fully, Dave and Marcella's story would have been even more damning, as I mentioned. But I was determined not to undermine their support network for the sake of the book.

Another aspect of deciding what to include concerned my portrayal of Dave and Marcella. As political scientists have repeatedly shown, attitudes toward social policies and their recipients are influenced profoundly by notions of deservingness and blame (Cook and Barrett 1992; Schneider and Ingram 1993). Those perceived as responsible for their own poverty, such as poor adults, are shunted into the degrading and stingy social assistance side of the American welfare state. Those managing to gain assistance from gate-keeper caseworkers are subject to monitoring and must constantly re-apply for their meager assistance (Soss, Fording and Schram 2011).

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<sup>5</sup> Personal interview, May 17, 2013.

Given my sensitivity to these dynamics, I would often ask myself as I wrote: Am I being an honest reporter? Am I cherry-picking the facts to make Dave and Marcella seem more sympathetic and blameless? Interviews – and their interpretation – can never be completely objective (Carpenter 2012). Would a journalist's or a stranger's account be the same?

I was fortunate to get an outside reality check. A few months after the accident and the op-ed, an editor from *Glamour* magazine contacted me. In addition to fashion and lifestyle articles, *Glamour* runs pieces of serious journalism, and the editor thought the paralysis and hardship of a young woman the age of the magazine's readership would make for a compelling story. She dispatched Libby Copeland, a journalist with impressive credentials (*Washington Post*, *Wall Street Journal*, *Slate*) to do the story. She traveled to Redding and interviewed Dave, Marcella, and others. Her story matched mine in tone and content (Copeland 2013). Phew.

While others may disagree, to my mind, Dave and Marcella are pretty blameless for their situation. Yes, I had a pang when they told me they were pregnant with only temporary health insurance. But health insurance is not the problem – it's the lack of long-term care provision from any source other than Medicaid. Some might say that family members should just provide care for free. Others might say you should pay for such care yourself. But it's so extraordinarily expensive that no one short of a one percenter could afford it.

Nonetheless, it's been quite revealing to give talks about the book in various settings. I have spoken to academic departments, student audiences, university staff, think tanks, teaching-hospital grand rounds, and community groups. It has been fascinating to watch reactions and see when and how the issues of deservingness and blame come up. The mostly liberal academic audiences generally view Dave and Marcella as the blameless victims of a seriously flawed system. More interesting are community presentations. The audiences are with me while I

discuss Dave and Marcella, but as soon as I turn to other means-tested programs and illustrate how much benefits and eligibility for welfare, Medicaid, state EITC's and other programs vary by state, I can see the veil of blame come down over their eyes, and the hostile questions begin. "So, can illegal immigrants get Medicaid?" (Well, no, they are legally barred from Medicaid benefits, as are legal immigrants for five years). "Asset tests are a good idea because you wouldn't want lottery winners getting welfare, right?" (Ah, lottery winners – the contemporary version of Reagan's welfare queens). That's why I try to emphasize in the book and especially in person that because of the shortcomings of American social protections, most of us are one car accident, one aneurysm, one divorce away from the same fate.

### *Dealing with emotions*

I have felt a variety of emotions while doing political science research and writing: excitement, frustration, impatience, doubt. But never fury. Never guilt.

The fury threatened at times to get me – and Dave and Marcella – in trouble. It's probably a good thing that I didn't attend their case worker meetings; for those in a vulnerable position, fury is the wrong emotion. Where caseworkers serve as gatekeepers, it's best to "just take whatever is dished out," as one of Joe Soss's AFDC interviewees said (1999, 366). When I learned that Marcella's nursing program wouldn't readmit her as a student – even though there are many nursing tasks that she could carry out as a quadriplegic (patient education; telephone triage; administration; and so on) – I was, in a word, furious. Surely the program's decision was a violation of the Americans with Disabilities Act. And better yet, I had just met someone at a disability-related conference whose wife works for the ADA enforcement arm of the U.S. Department of Justice. "Excellent!" I thought. "We'll bring DOJ down on their \_\_\_."

Not so fast, said Marcella. Not so fast, said Mark Schlesinger of Yale, when I related the story to him a few months later. Taking on a disabled student is an expensive challenge for any university, especially one strapped for resources to begin with. As Marcella said, if she really wants to work with these people, she can't start by suing them.

Okay, okay. I cooled off. But it's harder making the guilt go away. I unearthed many pieces of information that have helped Dave and Marcella, from policy provisions I was able to suss out from my research, to recommendations for programs and equipment from other disabled people I interviewed. One of the many difficulties they face is the lack of a disability community in their rural location, and certainly not one composed of young mothers like Marcella. Sure, she and Dave could jump on the internet – which they did do to research their wheelchair van. But next to money, time is their most precious commodity. Dave wears every hat in the household and is incredibly busy. It takes Marcella an entire morning just to get ready for the day, and then Logan comes home at 2 pm. I have more opportunity to uncover information than they do, and it's satisfying that I can at least do them that service.

On the other hand, I feel incredibly guilty about two things in particular. First, I'm not on the ground. Living across the country limits what I can do for them (it's one reason that I *haven't* attended their caseworker meetings, for example). And sometimes other people are better than I am at certain tasks. When Marcella's sister and sister-in-law divided up all the programs to look into after the accident, I could help them assemble the list, but they were the ones who became Marcella's legal proxies, as I was in town too infrequently. And in some ways they were better suited to do so because members of their own families had applied for Social Security Disability, unemployment, and other programs. They knew where the offices were and what the bureaucratic procedures would be – better than me, the coddled professor with my

cocoon of private benefits and 30,000-foot level of knowledge as a social policy scholar. Indeed, in their street smarts and grit Marcella's relatives reminded me of Joe Soss's welfare interviewees, who had figured out how to navigate the system and who "expressed far more doubts about [his] ability to understand it, as a nonparticipant, than about their own" (1999, 375).

Second, even though the information I found helped Dave and Marcella, at times writing the book felt incredibly self-indulgent, particularly in contrast to the daily struggles they encounter. It was important to get their story out, for people to realize the shortcomings of existing social provision. I'm highly gratified that Justice Ginsburg cited the op-ed in her concurring opinion on the ACA case; as Dave says, the ACA doesn't help them much, but at least their tragedy has helped others in some small way. Hopefully the book can spark further policy debate (the New America Foundation is using it as fodder in their fight to eliminate asset tests for means-tested programs, for example).

But at other times, I felt some whiplash writing the book. As it happened, I was on fellowship at the Radcliffe Institute during the academic year after the accident, which greatly facilitated my research and writing. In a clash-of-worlds moment, I got the phone call that I had been awarded the fellowship when I was in the hospital cafeteria line with Dave, days after the accident. And back in Cambridge, between trips to California, I often felt guilty working in my well-appointed, climate-controlled office at one ridiculously posh institution while on leave from another. And now that the book is finished, I get to fly to Washington, DC and appear on think tank panels (on the shuttle! With leather seats! And free booze!) while my brother tries to figure out for the umpteenth time why his 45-year-old vehicle won't start or how he's regularly going to get Marcella down to UC Davis, where her rehab doctor has now moved, a three-hour drive away. My life is so easy, and theirs so hard. And all the research in the world is only going to

improve their lot in incremental ways. I try to assuage my guilt by putting the proceeds from the book into a trust for Logan. If Medi-Cal rules essentially force his parents to disinherit him from birth, at least I can help him in this modest way.

### *Generalizability and deep truths*

“If a picture is worth a thousand words, a good story is worth many columns of statistics.” So wrote the editors of the “Narrative Matters” section of *Health Affairs*, which has published dozens of insightful, often searing stories of health policy encounters since its inception in 1999 (Mullan et al. 2006, xiii). While the bulk of the journal’s content remains empirical analyses of health policy, the narratives are often the most “clicked-on” pieces. But far beyond their sheer popularity, the narratives make deeper contributions. As physician and author Abraham Verghese noted, in such stories “the writer captures a unique and personal experience that in its uniqueness is also archetypal” (Verghese 2006, x).

The downside of the story is that we don’t learn certain things that would be revealed by a standard research design.<sup>6</sup> I cannot describe how the social policy experience of people of different races, ages, and gender differs from that of Marcella. We know that if she were older and more likely to have been a “worker” in the social insurance sense, that she would have qualified for Social Security Disability Insurance and Medicare rather than the means-tested Supplemental Security Income and Medicaid programs (although as a quadriplegic, she still would have had to rely on Medicaid for long-term supports and services). Would her experience have been different if she were a man? Perhaps being a young mom won her some sympathy from the rehab hospital deciding whether to take on another costly Medicaid patient, for

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<sup>6</sup> Many thanks to Fotini Christia for raising this set of issues.

example. Would her experience have been worse if she were African-American? Lots of social science evidence suggests that that is likely (Gilens 1999; Soss, Fording, and Schram 2011).

Other researchers engaging in auto-ethnography have explicitly sought to generalize from their own experience. Sandy Maisel, in his personal account of running for Congress, sought generalizability by surveying other such candidates and reporting the results alongside the anecdotes from his campaign (1982). I tried to convey a sense of the larger social policy picture by blending Dave and Marcella's story with program statistics, discussing the number of Americans who have low incomes or no health insurance, or who sit on wait lists for housing assistance, or who remain in poverty even after accounting for their means-tested benefits. I also tried to show how individuals in other situations would fare – how completely a socially insured or a privately insured worker would be covered if disabled, or how people like Dave and Marcella would fare in other states with different arrays of means-tested benefits.

Although individual narratives may have their limits in terms of generalizability, they succeed in revealing details and conveying realities with a scope, precision, and level of detail that standard academic analyses simply cannot match. As anthropologist Christine Walley wrote in her book, *Exit Zero*, which examines the demise of the American steel industry through the lens of her own steelworker family, she found the academic literature on class and deindustrialization divorced from her family's experience. "The more theoretically sophisticated a text seemed to be about class, the more inaccessible and distant it sometimes felt from the working-class lives it was intended to describe" (2013, 12).<sup>7</sup>

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<sup>77</sup> In addition, in disciplines such as political science, there are strong incentives to excise the personal. Reflecting on her research on the children of mass rape, international relations scholar Charli Carpenter discusses removing references to her own status as a mother from the book version of her dissertation.

Empirical program analyses are invaluable and necessary, but my experience writing this book suggests two important shortcomings. First, such analyses tend to examine one program at a time, whereas many lower income individuals are enrolled in multiple programs. It's precisely the *interaction* of these programs that creates so many problems for recipients who hope to better themselves. In its 2011 budget, the Obama administration proposed raising the asset limit for federal means-tested programs such as food stamps and SSI to \$10,000. That's wonderful news, except that for the many recipients also enrolled in state-run programs with lower asset limits, the higher cap is moot. The usual single-program research approach is blind to such an effect. Second, most academic treatments do not analyze programs from the recipient point of view. Lost in such analyses, therefore, is the way in which program rules shape and distort recipients' lives. As a colleague who studies state politics and policy recently told me, "Until I read your book I thought that of course the government would want to have asset tests. You wouldn't want people with resources using these public programs, so asset tests are a perfectly reasonable way of achieving that goal. But now I realize their drawbacks."

In the end, we need both kinds of work – the personal stories and the academic analyses. Together they illustrate the shortcomings of social policy provision and can point the way to solutions. My hope is that the power and immediacy of Dave and Marcella's story can have a broader reach than our scholarly efforts typically do. As one colleague teaching a comparative welfare state class wrote, "At the beginning of the course, more than half of my students said they took this course because they 'don't believe in welfare' and want to understand why it is still around." After reading the book, many "called it an 'eye-opener.'" The book clearly helped to clear up misconceptions about the generosity of welfare benefits and the ease with which people



can avail of them, but I think it was also important that the students could better relate to the people who are in need of welfare and better comprehend the issues they are facing.”

### Conclusion

The empirical parts of the book were “easy” to write – I just did a mental download of the social policy courses I’ve taught for years. I had to do a lot of research into the details of specific programs’ and specific states’ parameters, unearthing information that was sometimes difficult to obtain. But those are things I know how to do. Much harder was determining what to reveal and confronting the emotional challenges of writing about close family. Inevitably I left out some telling but sensitive details and pulled my punches to minimize the harm my account might cause. Such tradeoffs no doubt tempered the story somewhat.

But I believe in the end that the tradeoffs were worth it. Dave and Marcella have benefited from information that I was able to uncover. And I can hope that this book will help inspire debate about the designs of our social policies and provide ammunition for those advocating for change. As I have told many colleagues, I am very sorry to have been in the position to write this book, but I am glad that I did it.

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