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## Carried and held: Getting good at being helped

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# CARRIED AND HELD:

## GETTING GOOD AT BEING HELPED

PARK McARTHUR

*For the smallest social unit is not the single person but two people.*

—BERTOLT BRECHT

*Our bodies should always be better than the societies we currently have.*

—LAURA HENGHOLD

### Abstract

This personal essay uses the first-person voice to describe the author's experience as a dependent adult growing up in America after the Americans with Disabilities Act of 1990. The author's personal story is contextualized as a reality specific to her race, gender, class, and degenerative physical disability. Descriptions of the author's need for significant assistance serve as anchors for the essay's more open-ended questions concerning care on a massive scale for multiple generations of people. Such questions seek new social imaginaries that challenge Western social values of independence, individuated desires and activities, and an autonomous private life.

## **“I can safely say I never imagined I’d be doing this”**

I am getting ready for bed with my dad’s help and he speaks this statement quickly while breathing through his mouth. .... I sit in my wheelchair, taller than he stands bent in half, reaching for my feet. He lifts and guides my left and right legs into each corresponding hollow column of flannel pajama pant. I look down at his rounded back. He is fifty-four. I am twenty-six, his daughter. My feet stink. The oily funk of accumulated days smells strong.

My dad and I share this routine most weeknights. If I want to shower, my dad transfers me from wheelchair to shower chair as I pull my pants and underwear down. I lean my head onto his stomach for balance while he pulls my shirt over my head. We ask each other about the quality of our days. One of us makes a joke. I take my bra off. He gathers my clothes, positions the showerhead, and turns the lever to hot.

Clothed and cleaner, I drive my electric wheelchair parallel to my bed. My dad and I face each other, preparing for another lift. He steadies his stance and bends his knees. I scoot to the edge of my chair, placing my feet on the carpet floor. We look at each other, ready. Left hand under my armpit and right arm bent around my torso, he lifts and swings me from wheelchair to bed in one uninterrupted, experienced gesture that leverages my weight with his. I break the loop my arms make around his back to stabilize myself upright as the mattress accepts my body. My dad turns my pillow over, finding a smooth, impressionless surface. We strap molded plastic braces to my legs. He supports my weight and guides my head to the pillow. He straightens my hips by rounding my back. He pulls the covers over me. I reach for my bedside lamp and the book I am reading. He smiles a tired smile. My mom enters my bedroom and kisses me goodnight. They tell me they love me. I tell them I love them.

I began needing this kind of significant physical help at age nineteen. My younger sister Alex and I were diagnosed with an unknown kind of muscular dystrophy ten years earlier, and my family was given an estimated length of time in which to prepare for our necessary assistance on a sustainable scale. Changes to our life and family structure were made in deference to our anticipated needs: my mom resigned from her job as a physician’s assistant in women’s health and my dad took on the responsibility of making money and providing health insurance for all four of us. We exchanged our small farm for a custom-built, one-story house in the nearby suburbs. Privileges of class, race, and economic stability informed these difficult decisions.

Whereas my mom provided the majority of care and help during our adolescence, my sister and I now require both our parents' attention, particularly when all four of us are together for family vacations. Both parents must now make themselves available in the mornings to help us out of bed, during the day for meals and transportation, and at night in preparation for sleep. At times, one parent will help both my sister and me. Other times, we break into one-on-one pairings, working in collaborative teams of two, or, occasionally, two parents for one child. It is not so much a division, but a collaboration of labor that is undoubtedly tiring for my parents.

But this caring labor is also affirming. Because it resembles a hug, the lift that allows a caregiver to transfer my sister or me from one seat to another makes the caring aspects of assistance tangible—the lift literally looks like an expression of love. Working with and through the frustration that dependency can engender, each member of our family recognizes dependent adulthood not as an infantilizing throwback, but as an opening up of the possibilities found in demonstrative, quantifiable care. Our life together as a family of four—both parents caring for two adult children—requires a closeness that challenges social expectations of parent–child connections, physically, psychically, and emotionally. I credit my parents for the ways in which they've balanced unconditional care with respect for our growth and independence as young adults—a near impossible and precarious arrangement that allows for intimacy and distance at the same time. I acknowledge, too, their feelings of vulnerability when anticipating the kinds of support my sister and I will require as dependent adults—support my parents may or may not be able to provide physically or financially. I know that the challenges my sister and I face as dependent adults cause both my parents a great deal of grief and anxiety.

Alex and I grow weaker with age, which means we have become more physically dependent on other people as our emotional and mental lives seek self-determination and individuated identities. The care we require will continue to develop and change—a continual process of learning how to ask for, and how to receive, help. The care our parents provide us has grown to encompass friends, partners, teachers, employers, hired assistants, peers, and strangers. As dependent adults who can—and have been taught to—advocate for ourselves, we are in charge of creating networks of support that feel right to us and rightly provide for our daily needs. My sister and I were not born into a society that readily provides the care our dependent adulthoods require, but we are the beneficiaries of the entirety of our support system's working parts—some, accidents of birth, some

chosen gifts—all held together with great effort. Our current support systems have been carefully constructed out of family circumstance, ability, and solvency. And our lives will, no doubt, be different when any of these parts change.

My sister and I seek networks of support that do not compromise our—and our caregivers’—physical, mental, and emotional safety. Through the labor and commitment of friends, family, and paid help, it becomes more possible for Alex and me to work toward our lives’ ambitions—ambitions that must be recognized as historically situated. Only within the past half century have possibilities been imagined—let alone created—for women and people with disabilities to be political subjects with our own desires, agency, worth, and experience. Knowing that the system of support that makes my dependent life possible is currently seen as a privilege, not a collective human right, I ask: what will it take for all dependent people to get the care each of us needs? When envisioning radical care on a large scale, does the answer lie—with a sort of 1960s optimism—in expanding our definitions of the atomized family unit and of society? How can legislation acknowledge assistance as a national reality, honoring the fact that when full-time care is needed, it makes all the difference to receive care from someone you choose, or with the guidance of someone who has chosen a caregiver for you, with your best interest at heart?

The assistive equipment and accessible civic infrastructure that allow Alex and me to ride public transportation and shop at grocery stores do not (and will never) replace our reliance on people, day-in and day-out. To be sure, self-determined mobility and independence are gained or diminished depending on access to equipment and reliable medical care via private health insurance and class privilege. The resources available to Alex and me help us engage an American polity based hierarchically on constructs of mental and emotional reasoning, physical health and mobility—not forgetting race, class, national citizenship, sexuality, gender, and the intersections thereof. Care will always be needed to bridge the modern, standardized world human beings are expected to use, with the actual bodies and minds we receive. Care predates civil rights legislation benefiting people with disabilities, and it will outlast all biomedical advancement. Care is primary and it is primal. At this historical moment, care work continues to be gendered, classed, and delineated racially and colonially, with poor women of color providing the majority of un- or underpaid, unregulated, and unreturned labor to American care industries. Care, and the often precarious nature of its economic and interpersonal demands, is a fundamental concern for anyone working toward social justice and changes in social formations.<sup>1</sup>

In struggling to understand the realities of my physically dependent adulthood, I am necessarily limited to possibilities of imagination based on personal experience.<sup>2</sup> My relationship with dependency and external assistance is a decades-long project of how to take the need for significant assistance out of the realm of childhood and stretch it along the trajectory of adulthood. My physical autonomy peaked around age eleven. Only at that age was I most able to meet the world, physically, on its own terms. My adolescence and young adulthood required a restructuring of meanings given to *dependence* and *independence*. Namely, that independence is the goal and condition of living as an adult. Or that dependency is a barrier to independence.<sup>3</sup> More likely, these two conditions form a complementary shape-shifting whole—something like a coiled spring, a Slinky that stretches and compresses with the force of life's circumstances acting upon it. To play with the Slinky, to send it down the stairs is to see two flexible end stops endowed with self-cycling energy: tumbling down and changing places, one-over-the-other, indiscernible-head-over-indiscernible-heel, in limitless motion. Keeping the Slinky going requires not equivalence, neutrality, or perfect external conditions, but constant recalibration as variables change. Dependency acts as a reminder of something other than autonomous zones, embargoed relationships, and individuated desires. It provides a way of working that is neither colonial nor isolationist—but one that is far more difficult, far more complex. I believe that the forms of knowledge and experience gained from living with significant physical dependency and vulnerability have wider social significance.

Physical dependency places a person within a web of agency and vulnerability. Vulnerability, perhaps the most widely considered characteristic of dependency, makes the possibilities for abuse and neglect real. Acts of assistance carry with them great and deep powers when charged with tasks of helping to move another person's body, or helping to make another person's decisions. This invitation to influence another person's reality is a particular kind of colossus.

Vulnerability is also the reality of two or more people trying to coordinate their needs. Even assuming best intentions, regular, significant physical assistance can expose both parties to physical, psychological, mental, and emotional strife. Such needs—greater than either person—can isolate both people from each other. Vulnerability is an understanding that no exchange of power is reciprocally equivalent. A relationship based in physical dependence makes this inequivalence tangible, visible. I will never lift my caregivers as they lift me. Therefore, it is by some other gain (love, money, education, feelings of duty or humanity) that they provide me assistance, even—and especially—when they

do not prefer to. The reality—regular and commonplace—of receiving assistance when a caregiver would rather not provide it, is an uncomfortable kind of power to own. And it is a power I must reconcile with my own preference to not need their help, or to desire the attention of someone else.

One way to think about dependency's inherently vulnerable qualities is as a collaborative exchange of power. Vulnerability is also the power of receptivity and prompting. A heightened level of intuitive coordination and trust is needed. And I, as a dependent adult, must recognize my part in creating this trust. As a dependent adult who can communicate with her caregivers, I possess a particular authority: I am able to articulate how I want and need to be cared for. I can advocate for and speak on behalf of my physical vulnerability. And I have the privilege of working with people who honor and receive the knowledge and experience born out of this vulnerability.

For these reasons, I do not prefer a randomized selection of anonymous caretakers. I love loving the people who help me. The affection I feel for those who assist me is part of my dependency. These feelings of affection mean I take interest in their lives apart from assisting me—honoring each person's complex wholeness, the large parts of their lives that have nothing to do with me. In truth, I need to hear about and imagine the parts of their lives not beholden to me, so that my place in them makes sense. Our relationship is a negotiation of needs and ambitions; assisting me happens in between other events and situations. These realities help me to be a better dependent adult. They allow me to provide the person helping me with care and attention. And they place the uniqueness of our relationship based in physical dependence within a dynamism that is immanent and all its own.

My current support apparatus—strangers included—is a noisy, emotional, unpredictable composite. This system of support, this family of sorts, means I am one of the few dependent adults who receives the care I need, day-to-day, month-to-month, year-to-year. Because of such marked incongruence, I must end on the heels of questions asked earlier. How can workable, personalized systems take shape amid the current extremes familiar to us? Why are state-run institutions presented as the answer for families who cannot afford the extraordinary costs of hiring help or working fewer jobs when caring for dependent adults? American families do not live multigenerationally and we move away from family obligation, so what does homecare that prioritizes a dependent adult's personal choice look like? How can this preference for care in the private realm untie itself from the uncertainties and insecurity of private capital? And

how can we integrate personal choice with community support and government responsibility? How can our need for care bridge social responsibility with personal preference? In some cases, it means giving care and that care act specificity and attention—honing in on the meaning that care makes. In other cases, it's as complex as rethinking care at a massive scale as an urgent necessity, one that requires us to dignify the critical nature of caretaking. In all cases, it means accepting difficult truths: that self-sufficiency is never about oneself, but about ourselves, about us.

### Notes

1. Two of the many groups addressing care workers' exploitative employment realities are Domestic Workers United (DWU) and the National Domestic Workers Alliance (NDWA), formed in 2007 at the United States Social Forum. In 2010, NDWA helped to pass The Domestic Workers' Bill of Rights in New York State. One of NDWA's coalition campaigns is called Caring Across Generations, whose mission states, "across the country, individuals with disabilities, older adults and their loved ones face enormous challenges finding quality care. At the same time, care workers work under strenuous conditions, vulnerable to abuse and burn out."

2. For example, I am unfamiliar with the challenges experienced by people living with diverse neuro-functioning, communicative, and invisible disabilities. My body is visibly dependent, with details such as an electric wheelchair that signal my dependence. This dependence is informed by direct, nuanced, expressive communication and sensing. Furthermore, I do not know what it is like to wake up, one day, to a newly reconfigured mind or body.

3. Both terms have specific and contradictory resonances for people with disabilities. Much of Western disability rights-based discourse has centered on *freedom* and *independence* for people with disabilities who have been "taken care of" by medical institutions whose methods are abusive and carceral. The Independent Living Movement was born out of this history and aims to provide people with disabilities the resources to find jobs, housing, and personal care outside restrictive medical institutions. This emphasis on independence has since been complicated by disability activists who work to foreground the fact that no one is truly independent and that one's understanding of independence and dependence is influenced by one's living situation and culture. More recently, *interdependence* has been introduced as a term that challenges the dependent-independent binary, and has been a useful concept for both activists and theorists alike. Disability-justice activists have written and spoken widely about community-organizing practices that make interdependence a key component of solidarity—working with and for all members' access needs. The concept of interdependence is also a crucial part of feminist philosopher Martha Nussbaum's Capabilities Approach, which builds on and complicates John Rawls's theory of justice as an agreement between free and equal political subjects. In this essay, I use the terms *dependency* and *dependent adult* to emphasize my needs for long-term personal care that will accelerate significantly as I age. I use these terms to underscore and describe the



ways in which physical dependence is a fundamental part of my familial, professional, and intimate relationships. A different, yet related discussion of dependency as it applies to the U.S. welfare state, feminism, and political philosophy can be found in *The Subject of Care: Feminist Perspectives on Dependency*, edited by Eva Feder Kittay and Ellen K. Feder.

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