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### Independence, Dependence, and Intellectual Disability: From Cultural Origins to Useful Application

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## Independence, Dependence, and Intellectual Disability: From Cultural Origins to Useful Application

### Comments

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# *Independence, Dependence, and Intellectual Disability: From Cultural Origins to Useful Application*

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*American government educational policy and leading advocacy groups commonly espouse independence as a primary goal for young people with intellectual disabilities. An extensive philosophical literature of autonomy has focused mostly on analyses of cognition that achieve individual self-governance. But the loosely defined concept of independence used by disability policymakers and advocates provides a more malleable, social understanding that involves someone actively relying on the assistance of others. The purpose of this paper is to examine the cultural, historical origins of the notion of independence for disabled persons through an exploration of the biography of Ed Roberts, the father of the independent living movement, and the cultural context of Berkeley, California, in the 1960s and 1970s, where the movement began. The paper applies those cultural concepts to the life situations of persons with intellectual disabilities, asking how well independence serves as a useful goal for the group.*

## **Introduction**

Educators in liberal, Western societies generally assume that schooling should lead a growing young person to become economically and socially independent, able to effectively carry out the central cultural practices of employment, residential living, and recreation life under their own direction. Similarly, philosophers of education have often asserted the value of attaining personal autonomy: governing oneself, making the key decisions that give moral form and content to one's life, and exercising capacities of independent thought and action in social situations of possible influence or coercion (Brighouse 2006, 2009; Callan, 1997). The predominant Frankfurtian tradition in the philosophy of autonomy has charted this independence question within a relatively narrow range of human activity, focusing finely on the presence of context-neutral cognitive procedures that allow a person to reflect critically about how one ought to live (Christman, 1991; Frankfurt, 1971; Watson, 1975). This procedural hypothesis has been that an autonomous person exercises the intellectual capacities necessary to select and evaluate the values they wish to embrace and act upon. According to this tradition, education should prepare students by building the intellectual abilities required to reflect on considered convictions, weighing value options carefully and evenhandedly, resulting in uncoerced selections that are reasonable and consistent.

One might quickly conclude that students with significant intellectual disabilities lack the cognitive capacities necessary to engage in this kind of autonomous cognitive activity. Almost by definition, it would seem, persons with significant intellectual disabilities are naturally unqualified for the kinds of cognitive processing required for autonomy. Even the broader array of social practices often understood as indicative of independence – working a job, handling finances, maintaining a home,

managing a social life – would appear to be beyond the reach for many persons with significant intellectual disabilities.

Yet autonomy, or the rough practical synonym “independence,” is precisely what American special education and disability policy and the professional rehabilitation system seek for disabled persons, including those with intellectual disabilities. For example, the joint education policy statement of the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc embraces the four national goals of the federal Individuals with Disabilities Education Act (IDEA), “equality of opportunity, full participation, independent living, and economic self-sufficiency” (IDEA, 2019). Noting that two of the four goals chime themes of independence, this single policy brief gives quick evidence of how two leading national intellectual disability advocacy groups and the United States Department of Education champion independence as an educational policy objective.

Beginning with the Rehabilitation Act amendments of 1978, public disability policy in the United States changed dramatically due to the influence of the independent living movement. Initiated by Ed Roberts and a small group of disability activists in Berkeley, California, in the early 1970s, the movement involved the creation of independent living centres, grassroots disability advocacy, and service organizations relying on a de-professionalized, self-help model of assistance and empowerment. As the director of the first independent living centre, and while serving as state director of rehabilitation in the late 1970s, Roberts built a series of centres across California. He became the leading national and international spokesperson of the movement, fervently spreading a useful social theory of independent living, replacing traditional assumptions about the functional limitations and social isolation of disabled persons with radical visions of disabled citizens controlling decisions concerning their bodies and lives. The idea that adults with a variety of disabilities could live in the community while making the primary decisions regarding their residence, work, education, and social life, as well as care, gained credibility and popularity among both activists and rehabilitation professionals. As the epistemic control of the meaning of disability and the life possibilities available to disabled persons shifted from medical professionals to the disabled persons themselves, public policy came to adopt the concept of independence as central to a cultural understanding of citizenship and social participation for persons with physical, sensory, and intellectual disabilities.

In response to the procedural theory of autonomy, feminists and communitarians have countered with a relational philosophy of autonomy that recognizes the knowing subject not in atomistic isolation but as developed among, influenced by, and even constituted by social interactions, relationships, and systems of meaning (Christman, 1991; Mackenzie & Stoljar, 2000; Nedelsky, 1989; Ellis, 2001). Relational theories take into account the various ways in which humans are socially embedded, intimately related to other people, groups, and institutions; that they experience themselves and their values as part of ongoing narratives and long traditions, and that they are motivated by interests and reasons that can only be fully defined with reference to other people and things (Christman, 1991, p. 144).

This approach, broadly speaking, appreciates not only that decision-making individuals operate in social contexts but “that there are no human beings in absence of relations with one another. We take our being in part from those relations” (Nedelsky, 1989, p. 9). Activities of agents choosing and acting in autonomous ways are more properly viewed as social achievements involving supportive and constitutive relational and cultural contexts that facilitate a person’s selections and commitments (Christman, 1991; Nedelsky, 1989; Ellis, 2001).

Unlike the work of the philosophers of autonomy, the growing acceptance of independent living as a general model of American citizenship for disabled persons did not rely on conceptual clarity. Independence has been an “ill-defined concept” (Bagenstos, 2009, p. 25), simultaneously influential and fuzzy. Prominent articulations of the concept have often been indirect, explained in terms of criticisms of the prior medical model approach to disability or the types of practical assistance provided by independent living centres (DeJong, 1979; Bagenstos, 2009). American democratic themes of personal self-reliance and individuality, while evident central planks of the construct, have been loosely

articulated. Present throughout is an ostensibly contradictory theme of interdependence, recasting individualism in a communal, relational way.

The development of independence as an on-the-ground, useful concept by Roberts and the disability rights activists is an example of how a sloppy, laypersons' relational philosophy of autonomy took shape and gained practical utility in a social movement. Leaders of the independent living movement smuggled in seemingly contrary elements to fashion an understanding of personal independence for disabled persons that includes strong motifs of interdependence and interpersonal relationship. As this paper will demonstrate, Roberts and his Berkeley disability rights colleagues drew from cultural strands of thought and practice that actively incorporated interdependence, regular reliance on the assistance of other persons, under the conceptual umbrella of individual independence.

The goal of the disability activists, chiming themes articulated by the relational autonomy philosophers, was not a well-reasoned, precisely argued construct but a useful way of thinking about individuality, disability, and community that created greater practical opportunities for disabled people to participate actively in the social spheres of mainstream society. What makes the activities and ideas of the independent living movement salient and powerful is the fact that it was built from the ground up, through the specific experiential crucibles lived by disabled persons.

Dewey (1938) has described human experiences as occurring in the social and biological interactions of persons and the particular contours of the lived environment. From the unfortunately common experiences of disabled persons living with social rejection and political blockages to participation, independent living movement leaders like Roberts carved rough-hewn concepts and allied social practices because they needed them, because they served an immediate purpose in the movement. It is suitable to view these developments as running parallel to the intellectual and practical work of first generation feminists.

This paper examines cultural meanings of independence as a messy, practice-based form of relational autonomy within the disability rights movement from the bottom up, employing a sociology of knowledge approach to the analysis of everyday concepts and language, as products and tools arising from social processes and organizational structures at specific moments in American history. It uses both macrosociology and microsociology of knowledge orientations, the former illuminating broad systems of thought formed and communicated across large social structures and the latter involving meaning occurring through interpersonal interactions and relationships (McCarthy, 1996; Stark, 1991).

Digging to the historical and cultural roots of society, this paper seeks to unearth the origins of notions of independence that came to fill the American disability policy and practice landscape. Where in the rich cultural terrain of individualism did Roberts and the Berkeley disability activists find available notions of personal independence that included social interdependence? How were these original concepts taken up and adapted by Roberts and the independent living movement activists? Finally, how are these notions of independence, crafted initially to fit persons with physical disabilities, adapted and aligned to the lives and goals of persons with intellectual disabilities? In the end, we need to question how well this practical vision of relational autonomy as carried out in the late twentieth century model of the independent disabled person aligns with the experiences and lives of people with intellectual disabilities.

The work of this paper is twofold. First, it will examine the cultural origins of the concept of independence as a value and life goal for persons with disabilities in the United States. This analysis will focus on the early roots of the concept in two overlapping social locations: the biography of Ed Roberts, the man widely acknowledged to be the father of the independent living movement, and in the Berkeley, California, disability community where Roberts was a leader in the early 1970s. Roberts and a few dozen disability activists, first at the University of California and then at the Center for Independent Living, built the concept from their own lived experiences and the cultural resources available to them.

In regard to Roberts' childhood biography, this analysis will examine prevailing themes of masculinity, independence, and interdependence in his childhood home life and developmental years

growing up in a second-generation railroad brotherhood family with a strong ethos of manhood and solidarity. How those masculine notions of independence informed the life of a teen boy paralyzed by the poliovirus will be central to the inquiry. Leaving his childhood home to attend university, Roberts spent the years 1962 to 1975 building up and leading what would become a vibrant, highly politicized Berkeley disability community. The examination of those years and that setting will focus on the profound influence of radical Berkeley, the hippy counterculture and the New Left, on the development of the independence concept. It will conclude with an exploration of the initial, ambitious outlines of a community services centre designed to support independent living for people with disabilities.

A central challenge for physically disabled people coming out of the shadows and joining mainstream society in the decades following the Second World War was securing effective forms of personal assistance that allowed them to function in the community – to work, to go to school, to be a community member – without being viewed as dependent and childlike. How can a person fulfill traditional American tropes of individuality, self-expression, and autonomy given a daily need for personal assistance from caregivers? What this first portion of the paper will clearly demonstrate is that Roberts and the early disability rights community of Berkeley were fortunate to draw from cultural understandings of independence as a form of social interdependence, as incorporating forms of interpersonal dependence. Relying in a variety of ways on the economic and social support of others has long been a present, if strategically deemphasized, cultural way of standing on one's own feet and making one's own way. Roberts and the Berkeley disability rights community drew from two strong strands of that interdependence-as-independence tradition in order to craft an ideal disability persona, a model of American disability life, that both values and supports the individual disabled person as an active community member.

The second purpose of this paper is to extend the analysis of independence that arose mainly in the experiences of activists who had physical disabilities, largely quadriplegics (like Roberts) and paraplegics, with some involvement of d/Deaf and blind contributors, to the lives of people with intellectual disabilities. By the late 1980s, Roberts was working closely with the Minnesota-based Partners in Policymaking (PIP) training program, teaching advocacy skills across the country to both disabled persons and parents of young people with intellectual disabilities, often supporting parents' efforts to secure inclusive schooling for their children (Zirpoli, et al., 1989; Governor's Planning Council on Developmental Disabilities, 1990; Partners in Policymaking, 1993). Without hesitation, Roberts applied the concept of independence to children and adults with intellectual disabilities. He viewed the concept and the practices of independent living centres as adaptable not only to persons with a wide variety of impairments but also, in his many years of international advocacy work, across the cultures of the world.

This second analytic goal is informed by the philosophers of relational autonomy and the analyses of disability and dependence supplied by Vorhaus (2005, 2006, 2007, 2017) and Kittay (2005, 2008, 2009, 2019). While concepts of relational autonomy introduce dimensions of social interdependence and interpersonal connection to questions of personal choice and self-governance, Vorhaus and Kittay each offer specific analyses of the kinds and degrees of dependency often experienced by persons with significant intellectual disabilities. Although Roberts and the leaders of the independent living movement struggled against social misunderstanding and oppression, they quickly convinced nondisabled university administrators and community leaders that they were articulate, thoughtful persons with unusual bodies. They benefitted from the cultural assumption that cognitive and verbal skill gives evidence of subjectivity and humanity. The challenge, as forwarded by Vorhaus and Kittay, is the common assumption that notions of personal autonomy do not apply to persons with intellectual disabilities due to their cognitive limitations.

## Masculine Independence in a Railroad Union Family

The Roberts were a railroad union worker family during the 1940s and 1950s when the running trades brotherhoods had a powerful impact on each member's family life, offering a guiding moral vision of proper gender roles and the structure and rituals of domestic activity. In a household brimming with manful spirit, Ed and his three brothers played sports from dawn to dusk with neighbourhood boys. His father, Verne, chain-smoked filterless Camels while wrenching on engines in the garage. The Roberts family was ideal soil for the cultivation of the railroad brotherhood ethos of the independent man (Roberts, M., 2018; Roberts, Z., 1995, 1996, 2018).

Ed's grandfather, Walter, worked through the 1920s and 1930s as a machinist for Southern Pacific Railroad, repairing steam locomotives at the Bayshore Roundhouse facility, a sprawling, whiskered maze of inboard and outboard tracks in San Francisco. Verne followed closely in his father's footsteps. Beginning in 1939, the year of Ed's birth, and continuing for twenty-five years, he was an electrician and crane operator, fixing locomotives and driving the sky-reaching cranes that hoisted enormous engines high above the yard (Roberts, M., 2018; Roberts, Z., 1995, 1996, 2018).

Two generations of family membership in the railroad workers unions, the influential railroad brotherhoods, inoculated the Roberts family with a strong values orientation that promoted specific understandings of "personal autonomy, economic independence, and manhood" (Taillon, 2001, p. 58). More than labour unions, the brotherhoods were fraternal organizations and mutual aid societies that offered members a tightly bonded, White male collective that prescribed a series of moral attitudes concerning personal behaviour, economics, relationships, and family life. The union was "an extended family where members had multiple obligations to one another" (Taillon, 2009, p. 40), an intimate social alliance of men supporting one another against numerous workingman's hazards. The brotherhood was a collective guarded against the domination of greedy corporations, the ever-present risk of workplace accidents in dangerous occupations, and the encroachment of immigrants and African Americans upon their jobs and livelihoods (Taillon, 2001, 2009).

Growing nationally after the Civil War, the brotherhoods were "secretive, ritualized, and conservative societies of skilled railwaymen" that combined systems of social benefit, including health and life insurance, and widow's pensions, with a strong culture of moral teaching (Taillon, 2001, p. 55). Workplace and domestic family life were carefully cultivated and maintained under virtuous ideals of manhood. The railroad brotherhoods and attached women's auxiliaries (for workers' wives) proliferated a complex array of values and social practices that allowed the men to maintain a strong identity of masculinity and independence while fostering sanctioned forms of social interdependence in the union and within one's family. It was this American ethos of manly independence crafted with acceptable forms of social interdependence by the railroad brotherhood that guided two generations of the Roberts family and offered specific guidance to young Ed in his masculine development. Notably, these modes of interdependence actively devalued women and working men of colour.

The images of manhood proffered by the railroad brotherhood management and membership in the early to mid-1900s drew upon a rich cultural stock of working-class ideals and norms. Male identity was widely viewed according to an "ideology of separate spheres," a contrast between the harsh, rugged social spaces of the workplace and capitalist market versus the soft, caring domesticity of the family household (Taillon, 2009, p. 41; Rotundo, 1993). This binary recommended gendered activities and characters; fortified by male bonding, men struggled in the public realm of strength, brutality, and competition, while women were relegated to domestic homemaking and childrearing tasks enacting love, intimacy, and security. The activities and identities of the men, the cutthroat challenges and opportunities of significant achievement and merciless defeat, were understood as primary. Despite the man's reliance on his wife to attend to the children and maintain a functioning, attractive home, these forms of social interdependence were greatly submerged under the predominant image of the man as independent in his struggle and achievements in the public sphere.

The domestic sphere of womanhood, by comparison, was secondary, aesthetic, and nurturing, providing a sheltered environment for growing children and a quiet respite for the weary man at the end of the workday. The woman was viewed as economically and socially dependent, weaker than the rugged man who battled in the employment marketplace. Additionally, her intimate and caring connections, as well as her emotionality, characterized her as lacking the independent rigour and strength of her masculine spouse.

Among the numerous social identities and career pathways to fulfill the masculinity of a working class man in this era, sociologist Michael Kimmel offers two as primary: “The Heroic Artisan” and the “Self-Made Man” (Kimmel, 2012, p. 13). Both types can be seen in the life of Ed’s father, Verne, and the values of masculinity passed on to the four Roberts boys. While Kimmel describes these as two distinct types, he also notes that most men combined elements of each character in their life activities and roles. For our purposes, although this model undoubtedly seems oversimplified, it provides useful, historical insight into how American men fashioned masculine, independent identities focused on work and achievement.

The Heroic Artisan was “an honest toiler, unafraid of hard work, proud of his craftsmanship and self-reliance” (Kimmel, 2012, p. 13). He was a man whose calloused and skillful hands laboured carefully and strenuously to craft products of wood, steel, textiles, and stone. In the industrial society of the 1940s and 1950s, he was often a master of powerful and dangerous machinery, a tradesman devoted not to his corporate employer but to the value and valour of the demanding task itself, as well as the companionship of his male coworkers. The railroad brotherhood publications and communications carefully cultivated this portrait of the union workers, men of good character, an unquestioned work ethic, and unmatched vocational skill (Taillon, 2002, 2009).

The Self-Made Man derived “identity entirely from a man’s activities in the public spheres, measured by accumulated wealth and status,” by achieving economic stability for his family and career standing for himself (Kimmel, 2012, p. 13). In a savage public landscape of commerce and employment, the Self-Made Man built a masculine identity of competitive vigour, work-based victory, and economic independence. While this manly character suited rising capitalists, corporate executives, politicians, and other men of public status careers, it also took on a particular shape within the working-class culture of the railroad brotherhoods. White union men viewed themselves as worthy of a certain level of wages, and of a secure, comfortable but not luxurious standard of living for themselves and their family. To be self-made, in this brotherhood context, was to achieve an economic threshold shared by one’s union compatriots, rising above lesser men and conforming to the lifestyle standards of one’s closely bonded male coworkers. Verne Roberts, for example, was repeatedly offered a promotion to railyard foreman, but he turned the job down in order to remain one of the working men, a social position of solidarity and an economic position of stability without excess (Roberts, M., 2018; Roberts, Z., 1995, 1996, 2018).

Even though the railroad brotherhoods actively fostered many forms of interdependence under a flag of working-class manliness, they drew a line at disability. When Ed Roberts contracted polio in 1953, the predominant orientation of the railroad brotherhood to his manhood and independence was clear. Over the many decades, as the brotherhoods developed helpful systems of economic and social assistance for union members who became incapacitated or lost limbs through workplace accidents, “able-bodied trainmen had come to view their disabled brothers with pity and suspicion” (Williams-Searle, 2001, p. 180). Men with disabilities were a threat to the belief that “independence (consisted of) control over one’s body, one’s household, one’s workplace, and one’s financial well-being” (ibid., p. 181). Failures of bodily control and loss of employment resulted in a morally fallen man, who due to diminution of strength and skill surrendered the “superior moral virtue” of the able-bodied man (ibid., p. 181). Men with physical disabilities were generally viewed as “less than men” (ibid., p. 181), greatly because of their dependency on others for economic support and personal assistance.

The views of the railroad brotherhood were not unusual in America during the decades following the Second World War. Over 600,000 American soldiers returned from the war with long-term mental

and physical disabilities. Additionally, the polio epidemic between 1944 and 1955 infected over 360,000 Americans, often resulting in some degree of bodily paralysis (Wilson, 2005). The main social anxieties that these disabled men experienced involved fears of lifelong economic dependence due to unemployment and the stigmatized “dependent, infantile state” of receiving personal assistance with feeding, bathing, and bladder and bowel care (Linker and Laemmli, 2015, p. 133).

Men who acquired physical impairments were viewed as once being whole, morally and bodily, as strong and capable workers who could prove their worth in the rugged activities of working class male occupations. An accident or disease was an act of unfortunate fate that sadly stripped the man of his vitality, competence, and masculine value.

A man with an intellectual disability, in this scheme, never qualified as capable and virtuous in the first place. A woman with an intellectual disability was incapable of arising to the feminine status and the feminine virtues, as limited as they were, of domesticity and childbirth. She was not expected to marry and raise children. A person with an intellectual disability was seen as a perpetual child, ineligible for successful fulfillment of masculine or feminine adult roles.

When Ed Roberts came home from the rehabilitation unit of San Francisco Children’s Hospital in 1955, his sixteen-year-old body, paralyzed from the neck down by polio, emaciated due to loss of muscle mass, did not fit the masculine norm of a worker’s body in terms of function or appearance. Although the railroad union ethos of the Roberts household involved a range of acceptable types of personal support and assistance, a web of familial and fraternal support that allowed men to be “independent” economically, vocationally, and socially, it would take Roberts’ own initiative and the creative support of the Berkeley disability community to push the boundaries of independent living to include disabled men and women previously understood to be ineligible for such a life. He enrolled at the University of California in 1962, participated in the Free Speech Movement of 1964, and started the Rolling Quads, a disabled student activist group, in 1969. The meaning of independence would change in these tumultuous years as much as America would.

## Hippy Counterculture and the New Left

“There wasn’t a square inch of the University of California at Berkeley that was not political, that was not seething with the potential of being political.” (Grimes, 2000, 24)

Roberts and the members of the Rolling Quads brought their lives and the concerns of people with disabilities to the University of California at a propitious moment, when the cultural stagnation of the 1950s was bursting open, social and political norms were under assault, and anyone breathing the Berkeley air experienced the chaotic electricity of cultural change. San Francisco Digger and founder of the Red House commune Peter Coyote (1998, p. 41) observed that the furious coalescence of the civil rights movement, antiwar protests, and widespread discontent among the youth, with the stultifying social norms of their parent’s generation, made “society appear suddenly permeable and open to both self-investigation and change.” Weather Underground leader Bill Ayers (2001, p. 73) similarly observed the cultural landscape to be “no longer immutable, no longer finished or fixed.”

The University of California and the Berkeley community were ground zero for radical activity. Yippie Jerry Rubin’s description of how an average University of California student experienced the cultural and political turmoil aptly captures the experiences of the disabled students: “Dig the straight student who came out of a Los Angeles suburb to get an education at Berkeley. Heading for his dormitory or apartment after a hard day at school, he passed down Telegraph Avenue: like walking through the revolution on the way home” (Rubin, 1970, p. 24).

The revolution surrounded Roberts and the dozen or so students with physical disabilities, engulfing them in the insurgent pulse of life in Berkeley. Roberts and Herb Willmore were repeatedly trapped inside immovable crowds as throngs of protesters flocked across campus or Telegraph Avenue

to outrun the blue jumpsuited Alameda County police (Willsmore, 2000). Cathy Caulfield and Roberts out-wheeled clouds of tear gas as they rolled from class back to their residence (Roberts, Z., 1995). Jim Donald (1998) kept a gas mask attached to his wheelchair like a Seattle resident carrying an umbrella. When he didn't move his chair quickly enough to escape a police sweep of the campus, an officer smacked him on the back of the head with a baton. Protesters forced the police back and escorted him to safety.

As the daily turmoil of the political struggle on the streets and campus literally captured the disabled students, the cultural themes, issues, and norms of the hippy counterculture influenced how they thought about themselves as individuals and the community they lived in. Moreover, the ethical and practical sensibilities of the hippy counterculture, including the New Left political movement, were of practical interest to the disabled students. The widespread alienation experienced and expressed by the insurgent youth closely mirrored their own feelings of rejection and outrage as disabled persons largely excluded and disrespected by society. "To be young and American," sociologist Todd Gitlin (2001, p. 285) wrote of the counterculture, "is to have been betrayed ... to be enraged." That experience and feeling rang true for the disabled students.

Shared experiences of isolation and devaluation, of languishing without purpose or apparent future in hospitals and nursing homes, provided a common foundation for solidarity among the disabled students. They knew the experience of being written off and warehoused during their adolescent years when families and communities celebrated the potential and possibilities of their nondisabled counterparts. Berkeley and the university burst into their lives as a sudden, unexpected opportunity to escape dead-end existences in hospitals, institutions, and nursing homes. The disabled students of Berkeley and the alienated youth of America were both, in Gitlin's (2001, p. 286) words, "staking out room to breathe in an alien land."

Similarly appealing to the burgeoning disability community in Berkeley was the countercultural emphasis on the development of an individual consciousness, an aesthetic of self that effectively stripped away the norms, normative assumptions, and social practices learned in childhood. If the larger patriarchal and capitalist culture was toxic, dominating, and inauthentic, then the practical challenge of the counterculture was the pursuit of practical strategies to expand and raise one's consciousness, "unraveling the lessons learned from birth – the very socialization process – so that the individual could see how the system operated to mold one's self, and in doing so, envision alternatives" (Michaels, 2002, p. 42).

Changing one's perception, tuning one's mind and spirituality to one's authentic identity, required cleansing away the social programming that had built a hyper-competitive, greedy, and violent culture. "The goal is each-man-his-own-revolution," explained Rubin (1970, p. 126). Sedimented among the many political hierarchies of American society – the systems that oppressed African Americans, women, Native Americans, Mexican Americans, and the poor – was the consistency of insult and discouragement communicated to people with disabilities. The countercultural mantra of expanding one's own consciousness in order to comprehend and, more importantly, replace the common conventions of political oppression neatly suited the disabled students. They looked to these new perceptions as an opportunity to remake the social meaning and value of disability by hitching their visions and hopes to a rehabilitated notion of personal independence. Perhaps the social achievement of independence traditionally dominated by White men could become available to persons from a number of political minority groups, including disabled citizens.

What this awakened individual should do, according to the hippy counterculture of Berkeley, as well as the New Left politics, is steer their own life on a path that is authentic, true to one's self. Coyote (1998, p. 142) wrote, "We don't mourn for a man who lived life as he chose."

Reanimating the romantic individualist traditions of Thoreau and Whitman, Tom Hayden and the leaders of the Students for a Democratic Society (SDS) envisioned people throwing off the hyper-conformity and constraint of the dominant culture to make effectual and creative contributions to the direction and shape of their own lives. "Men have unrealized potential for self-cultivation, self-

direction, self-understanding, and creativity” (Students for Democratic Society, 1962, para. 14). The citizen, armed with capacities of learning and growth, is the prime author of their own self and their own experiential road.

Central to the self is authenticity – living in a truthful relation to the self under construction, directly counteracting the corruption of the business marketplace and political arena with an individual goodness. The notion of fidelity to self arose not from theory or social dictate but from the depths of one’s own experience in the world. As Ayers (2001, p. 76) proclaimed, “what counted was experience and more experience.” Or as Rorabaugh (2016, p. 12) explains of the counterculture, “When they found a society filled with hypocrisy, consumer gluttony, status seeking, and power politics, they fled to create space to live a life true to the self.” That fidelity required a critical rejection of oppressive cultural mores as well as formal ideologies in favour of allegiance to the lived experiment of the free process of human activity. Ken Kesey declared to his Merry Pranksters, “no theology, no philosophy ... The experience – that was the word!” (Wolfe, 1968, p. 126).

The Berkeley culture at the end of the sixties greatly rejected traditional notions of expertise based in social standing as well as the normative roles and behaviour recommended by the dominant culture. What it offered in response was a bottom-up, experience-driven, creative approach to the personal construction of individual identity – a reclaimed romanticism of the self that open up possibilities for disabled persons to assert dominion over their own identities and lives while also relying extensively on the government and other persons for funding, accommodations, and daily bodily care.

### Interdependence and Community

It isn’t surprising that the efforts of the Berkeley disability community, beginning with the Rolling Quads on campus in 1969 and expanding across the city with the Center for Independent Living in 1972, did not focus on clearly defining independence or independent living for someone with a disability. Motivated by a shared understanding of the kinds of isolated, inactive, doldrum lives many of them had experienced prior to entering the university – and that still awaited them if their radical experiment with independent living failed – Roberts and his friends worked fastidiously on developing a new type of community that supported disabled persons seeking the many versions of American individualism.

Scopious, without precision, tapping broadly into longstanding American traditions of self-reliance and economic self-sufficiency, as well as newer counterculture models of self that valued expression, reflection, and experiential experimentation, they viewed themselves as widening the range of opportunities for disabled persons to live acceptable and valued forms of individuality. They understood themselves as the disability strand of a broad social experiment whereby the historical Whiteness and maleness requirements for independence exploded to allow new spaces for women, people of colour, and the LGBT community. As a practical matter, the goal was to develop a supportive disability community, organized and unified around the social hub of a disability-led organization, that provided for the kinds of interdependence, of social connection and assistance, that made individuality possible for disabled persons.

The earliest articulations of the goal of independent living were developed by a group of the disabled University of California students in a fall 1969 group problems course, Sociology 198, entitled “Problems of the severely disabled as they relate to the transition between institutional care and independence.” The instructor was John Hessler, a graduate student, and a quadriplegic resident of Cowell Hospital. Eleven disabled students enrolled, and the weekly class meetings were held in Cowell (Sociology 198, 1969c).

The course title itself posited “institutional care” as including the Cowell Hospital campus residence where the physically disabled students lived on campus, and “independence” as a mode of living in the community after university. The course goals repeated this contrast between “attending

school” and “attempting to become independent.” It is clear from the syllabus itself that the students were using the course as a launching pad to research and plan for their lives in the community after graduation (Sociology 198, 1969c).

What would that independent life consist of? And what kinds of interdependence would facilitate a successful independence? These questions drove the research and discussion activities of the course. The course syllabus stated the overall group goal of developing “a proposal for a halfway house,” indicating that the imagination of the students at semester’s start for how they might live in the community was limited to an institutional model that segregated disabled people (Sociology 198, 1969c).

The halfway house idea was discarded quickly by the group. By early October, the students had redefined the overall course aim as “to identify and contact the disabled population in Berkeley with the idea of giving them the chance to take an active part in creating a community services center.” Involving disabled members of the surrounding community was viewed as necessary so that the new centre would reflect “what their needs are and what services they would like to have provided” (Sociology 198, 1969b). Efforts focused on creating a discussion both with existing disability groups such as the Easter Seals and those with disabilities whom the students recognized might be difficult to locate, given the tendency of disabled people to remain hidden from public life. They decide to create a directory of local agencies and organizations that provided any kind of service or assistance to people with disabilities.

By mid-October, the Sociology 198 students had named their proposed community services centre the “Center for Independent Living,” the actual title that the organization would take when it was founded three years later (Sociology 198, 1969b). The group projects included developing a questionnaire to administer to local disabled persons to discover their service needs, reaching out to local television and radio stations to publicize their work, and creating a list of possible sources of funding.

Rather than worrying about a precise definition or conceptualization of independence, the students worked under the unspoken assumption that all persons who live in the community, who occupy relatively typical social roles in work, education, family, and community life, rely on other persons to provide numerous forms of assistance. Independence is the result of a series of effective activities of interdependence. The difference between the disabled students and other members of society was primarily the forms that assistance took, the shape and content of the dependencies. A “community services centre” was needed because only disabled persons truly understood how to create the specific types of social interdependence, including solidarity with other disabled persons, required for a person living with a disability to live well in American society.

## **Independence through Dependence**

“Our experience shows that even the most severely and profoundly disabled individual can be independent – they may need all kinds of help – but that they can be in control of their lives” (Roberts, E., 1977, p. iii).

This essay has presented the historical roots of the development of the concept of independence in the 1970s disability rights community, drawing from Ed Roberts’ childhood in a railroad brotherhood family and the Berkeley hippy counterculture. These narratives display prominent conceptual strands of the development of a ground-level, flexible, and useful notion of relational autonomy in the disability activist community. Independence was viewed as a social and political achievement requiring supportive interpersonal relationships and organizational structures. The history of the independence concept also demonstrates the politics of gender, race, and disability in those relationships and structures. The movement for disabled Americans to gain independence relied on the creation of

political strategies to elevate disabled people, a traditionally oppressed group, to new levels of equality and participation in society.

An argument can be made that the independence construct built by activists with mobility impairments does not apply well to persons with significant intellectual disabilities. Perhaps persons with intellectual disabilities do not have the cognitive capacity to achieve the rationality necessary for an autonomy that locates decision-making processes in the individual (Carey, 2009).

“(S)elf-sufficiency is always a lie,” Kittay (2019, p. 161) retorts concisely. She counters by claiming that the assumption that rationality is foundational to both personhood and autonomy is a misunderstanding of the basic empirical realities about how humans actually live, creating an artificially abstract subject in isolation from the social connections that life involves and requires: “[W]hat it is to be human is not a bundle of capacities. It’s a way that you are, a way you are in the world, a way you are with one another” (ibid., p. 621). An examination of autonomy as an empirical human achievement necessarily appreciates how “independent and dependent states generally co-exist within persons,” how dependence is often a necessary aspect of achieving independence (Vorhaus, 2007, p. 29). Emotional, social, and bodily supports, occurring in a wide variety of cultural practices, including interpersonal interactions of family life and workplace or school, supply the conditions that make actions of self-governance for persons with and without intellectual disabilities possible. Autonomous behaviour often depends on the beneficial supports of numerous forms of social dependency (Donaldson and Kymlicka 2011; MacIntyre, 1999).

What often differs for persons with significant intellectual disabilities, in comparison with nondisabled persons, are the kinds of dependency and the social interactions and relationships required to fulfill those needs (Kittay, 2005, 2019; Vorhaus, 2006, 2007, 2017). These dependency interactions frequently involve the person receiving intensive forms of assistance – for example, feeding, toileting, and hygiene – reserved typically for young children, infants, or hospital patients. In the case of persons with intellectual disabilities who, due to cognitive or communicative limitations, contribute little to their own self-care and life management, the existence of dependency relationships may result in their being framed as passive service recipients, depersonalized bodies needing basic bodily care.

While acknowledging these common differences, Vorhaus (2006, 2007, 2017) and Kittay (2005, 2019) contend that philosophers have made two errors in thinking about the dependencies of persons with significant intellectual disabilities. First, there is a general tendency to underestimate the personal competencies and abilities of disabled persons because of the kinds and degrees of dependency. Vorhaus (2007) argues that a bodily or behavioural feature of a person is often interpreted as an indication of personal inabilities wholly unrelated. Roberts exploited this error repeatedly in his speeches, interpreting correctly that when people see a quadriplegic who depends on other persons for basic acts of daily feeding and bathing, they casually assume he is unable to think in complex ways, take effective actions in his life, and lead a national social movement.

Second, philosophers have often assumed that the interpersonal relations between a disabled person and their caregivers deliver human value and benefits in only one direction. They fail to notice the interpersonal reciprocity in action, including the love and support supplied by the disabled person to the caregiver. Family members, friends, and paid attendants often develop deep connections with persons with significant intellectual disabilities, cultivating loving bonds filled with emotional reliance on the disabled person. Nondisabled people count on the love and giving of people with intellectual disabilities to bring joy and meaning to their lives (Kittay, 2005, 2009, 2019; Vorhaus, 2007, 2017).

These two common errors oversimplify and misconstrue social relationships and interactions of dependency in the lives of persons with intellectual disabilities in ways that diminish our awareness of the meaningful and substantive ways that these persons can contribute to social processes of self-governance. Kittay, Vorhaus, and Roberts alert us to the many overlooked ways that persons with significant intellectual disabilities can make valuable contributions to community. More specifically, they can participate meaningfully in the interactions and communications of shared decision-making about what matters most in their own lives. The combination of personal capacities and the proper

array of social support can render the activities of interdependent – combined independence and dependence – planning and decision-making possible. For example, inclusive educators have used the MAPS (Making Action Plans) and PATH (Planning Alternative Tomorrows with Hope) processes – carefully delineated procedures of educational planning that foster the central contributions of the person with the intellectual disability within a social context of relational support involving family and professionals. MAPS and PATH honour both the capacities of persons with significant cognitive disabilities and the powerful interpersonal relationships of loved ones to reach planning activities and outcomes that reflect both the person and the social nature of personal commitments and choices (Forest & Pearpoint, 1992; Pearpoint, Forest, O’Brien, 1993).

If, as the relational autonomy philosophers maintain, and the independent living movement displays, personal independence often occurs through processes of social interaction, arrangement, and support, then our philosophical inquiry should investigate the social arrangements, structures, and processes of relational interdependence that support people making authentic personal commitments and choices. A philosophy of relational autonomy should attend to the numerous ways that activities of social dependence allow a person with a significant intellectual disability to play a central role in the primary decisions regarding their life. These decisions concern not only where they live, who they live with, and what they do with their time, but also the shape and content of the forms of assistance received – how they are helped by others. Further, it encompasses the shape of meaningful interpersonal relationships that provide for opportunities for mutual support and affection for both participants. These foci are admittedly messy and practical, fully accepting the assertion in relational autonomy that a person’s decisions involve substantial input and influence from other people. These foci are also risky, admitting the possibility that coercive influence might overwhelm the voice and intentions of the disabled participant. The upside potential, as the independent living movement leaders discovered, is meaningful participation for persons with disabilities in not only vital life decisions but also the richest avenues of family and community life.

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