



Autonomy on the horizon: comparing institutional approaches to disability and elder care

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Accepted: 27 January 2021/Published online: 15 February 2021

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Abstract

This article asks how people come to interpret themselves and others as autonomous given their multiple dependencies. We draw on a cross-case comparison of ethnographic studies with two populations for whom autonomy is both central and problematic: elderly patients in post-acute care, and young adults with disabilities in an independent living program. Analyzing the institutional efforts to make their clients “as independent as possible,” we find that staff members at each organization formulate autonomy as a temporal project through an ongoing calibration of open futures, ideal pasts, and situational competence. Constantly adjusting and fine-tuning where in time autonomy “really” is, workers arrange present dependence so that the contours of the future remain open for their clients. In other words, they make use of temporal markers to produce recognizable autonomous subjects whose dependencies are momentary. Theorizing this temporal project enables us to see more clearly how all of us engage in the constant business of “doing” autonomy, and to better understand the role of institutions in producing autonomous selves.

Keywords Agency · Aging · Autonomy · Disability · Independence · Temporality

Introduction

Autonomy is a central value in Western societies. It structures expectations of social identity, is inscribed in law and policy, and constitutes a goal or metric of success in myriad welfare programs and institutions. At the same time, critical analyses show that

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autonomy is impossible because actors are embedded in social worlds with multiple interdependencies (Korr et al. 2005). As feminist scholars claim, autonomy is a myth (Kittay 1999). And yet, it is a highly institutionalized ideal that orients action in everyday life. This paradox is the starting point for this article. Regardless of how we define the particular contents or meanings of autonomy, which philosophers and political theorists have long debated, we lack a sociological perspective of how autonomy is “done” (West and Zimmerman 1987). This perspective needs to account for how people bridge the disconnect between the reality of dependency and the interpretation of selves and others as autonomous. In other words: How do we build and maintain the fiction that people are autonomous subjects?

To answer this question, we draw on a cross-study comparison of two ethnographies in New York State with populations for whom autonomy is both central and problematic. One ethnography focuses on a post-acute care unit that works to recuperate elderly adults who are experiencing new forms of impairment and dependence. The other is an ethnography of disabled young adults who are “learning” autonomy at an independent living program. Both groups inhabit a liminal space between autonomy and dependency that allows us to observe the collective efforts to make these clients independent, which is the stated mission of both organizations.

Through an inductive approach that compares how the goal of autonomy structures work at each site, we set out to unpack the interactional and institutional production of autonomy. Our main argument is that an essential aspect of this production is the manipulation of temporality. We claim that “doing” autonomy is largely about dealing with time, which means that individuals constantly measure their momentary, present actions against their past and future selves, in order to claim a recognizable autonomous identity. We therefore take up a perspective grounded on sociological insights of temporality to theorize autonomy as a social process through which present actions are given meaning in relationship to an individual’s idealized past and imagined future (Mische 2009; Tavory and Eliasoph 2013). Where feminist theories argue that autonomy is constructed by obscuring dependence, we argue that it also requires actors to obscure or highlight potential past and future selves in order to construct an autonomous identity in the present.

We develop this argument by leveraging the difference between two contexts in which autonomy is a practical challenge. We focus on how staff members and participants at each site we studied talk about autonomy, how they define and measure it, and their struggle to reconcile its interdependent, albeit conflicting, dimensions, which we refer to as practical, institutional, and moral. *Practical autonomy* denotes capacity for present action, as it defines the capabilities most typically associated with independence, the ability to think and act on one’s own. *Institutional autonomy* is built into the bureaucratic requirements for assessment and reimbursement imposed on our programs by state and federal agencies. These standardized methods of giving care and measuring progress represent an effort to objectify future expectations of (in)dependence. Finally, *moral autonomy* denotes an individual’s motivation to be independent; in other words, it is not enough for clients to be capable of carrying out a task on their own: they must also desire a life that is continually progressing toward increased autonomy. Moral autonomy thus links immediate action and future goals to the person’s identity, establishing a continuity between them and the person’s past behavior.

In their everyday work, staff at both our field sites evaluate their clients' actions and practical capabilities against institutional benchmarks as well as interpretations of their clients' moral claims to autonomy. In this process, dependence is defined as momentary, and thus appropriate, as long as it can be situated within a long-term project of autonomy. At both sites, staff and clients co construct autonomy as a temporal project that motivates action towards an ever-moving, ultimately fictional, horizon that equates autonomous identity with the constant reformulation of goals. By framing autonomy in this way, staff signal that it can never be reached, but is most closely approximated when the institutional, practical, and moral dimensions of autonomy align so that the person is both capable of acting in line with cultural expectations and chooses to do so.

This perspective allows us to better understand how people interpret themselves and others as autonomous in the midst of their, sometimes, profound dependencies. More broadly, foregrounding and conceptualizing autonomy's temporal dimension illuminates how all of us engage in the constant business of "doing" autonomy. We conclude by discussing how our findings can be leveraged to better understand the role of institutions in producing autonomous selves.

Literature review

The problem of autonomy

Since the enlightenment, autonomy has been a central tenet of modernity (Cole 1983) which continues to exert a powerful hold on cultural and political imaginaries. Autonomy defines full, self-governing citizenship by denoting independent judgment, reason, and freewill—attributes typically recognized as signs of competent adulthood (Abrams 1998; Franklin-Hall 2013) and citizenship (Kymlicka and Norman 1994). Yet what it means to be autonomous has long been a key topic of contention across many academic disciplines and in public debate.

Primarily, philosophers and political theorists have run against the problem of how to reconcile individual autonomy with social relationships. Liberal definitions of autonomy classically emphasize self-directedness and freedom from being subject to the influence of others (Abrams 1998). Thus, autonomy as personal control and decision-making is often conflated with independence—i.e. the ability to *act* without help (Plath 2009).¹ This conflation particularly resonates in American culture, where notions of self-reliance, the self-made man, and freedom from government, are deeply rooted (Kymlicka and Norman 1994). Yet such a definition ignores the fact that people are embedded in social structures that shape their opportunities to learn and exercise autonomy (Anderson and Honneth 2005; Barclay 2000; Christman 2004; Friedman 2000; Stoljar 2011). With this in mind, feminist philosophers and carework scholars argue that independence is a "myth" (Kittay 1999) built upon racial, gendered, and classed markers that have historically rendered some individuals (women, people of

¹ In this article we remain attentive to the distinction between independence and autonomy, and note when it becomes problematic in our empirical observations, yet we also occasionally use the words interchangeably. At both programs people talked about "independence," never "autonomy." However, we identify nuance in the meaning given to independence and argue that autonomy is a larger, multidimensional concept that encompasses practical independence *and* the rational/moral basis for action.

color, or poor people) as less “autonomous” than others (Fraser and Gordon 1994). Denying that autonomy requires self-sufficiency, these scholars offer *interdependence* (Rivas 2011) and *relational autonomy* (Mackenzie and Stoljar 2000), concepts that define independence as a “two-way responsibility” that emerges in interaction (Ho 2008; Mol 2008; Reindal 1999).

Sociologists, too, have long grappled with the contradictions between autonomy and embeddedness. They have done so primarily by sidestepping autonomy as a sociological object of interest and shifting attention to *agency*, a concept that accounts for the capacity to act meaningfully within social systems. Echoing the feminist notion of interdependence, these theorists argue that agency is not a capacity “intrinsic to singular actors,” but an emergent practice that takes shape in systems of interaction (Mol 2008; Pickering 2002) which include people but also nonhuman structures, objects, and practices (Cetina 2009; Lupton and Seymour 2000; Scherer et al. 2005). Unlike theories of autonomy, these theories take for granted that agency is informed by social structure (Bourdieu 1997; Giddens 1984) and thus varies enormously across social worlds and throughout the life course (Hitlin and Johnson 2015; Sewell 1992, 2006).

Sociological attention to autonomy has also translated into critical scholarship on people who have lost their legal claims to autonomy, such as the unemployed, mentally ill, addicted, and incarcerated (Gong 2017; Haney 2010; Little 1999; Mason 2016; Seim 2017; Wacquant 2009). For these stigmatized populations, dependence is socially presumed to be a pathological choice (Brodwin 2013; Estroff 1981) and the various transitional institutions designed to deal with them (re-entry programs, welfare reforms, rehabilitation, etc.) impose regimes of independence in which self-reliance and self-discipline are restored (Haney 1996; McKim 2014). This research shows that autonomy is not an essential characteristic of human beings but a moral project to be cultivated. By showing how obligation to autonomy legitimates the authority of the state to discipline its subjects, it shifts attention from what autonomy *is* to what autonomy *does*.

In sum, sociological accounts of autonomy have either dismissed it in favor of kindred concepts, such as agency and interdependency, or reduced it to a disciplinary tool for neoliberal subject formation. This has resulted in two important oversights. First, sociologists have overlooked autonomy’s cultural and affective hegemony. It is not only the state apparatus that is invested in producing it, but also subjects themselves (Silva 2012, 2013). Second, and related, sociologists have ignored how these affective dispositions are socially produced and maintained. We argue, that rather than attempting to resolve the philosophical and moral contradictions of autonomy and embeddedness, we should investigate how these contradictions materialize in everyday life by asking how people reconcile the moral imperative of autonomy, and its many iterations in cultural and political objects, with the practical reality of dependency on others.

In this article, we examine the interactional production of autonomy by foregrounding the collective belief in this value and its institutionalized expectations. This inquiry allows us to consider *how* subjects engage in “lifework” to pursue the ideal of autonomy (Munson 2020). To ask this question, we turn to ethnomethodological approaches that highlight the practical work of accomplishing social norms. In their seminal article “Doing Gender,” West and Zimmerman (1987) argue that gender is not an individual characteristic nor a set of expectations that people internalize and stabilize through socialization, but instead, an ongoing achievement of interaction. We borrow

this approach to examine autonomy as a “category of practice” in which, like gender, isolated performances are rendered meaningful through their recognition by others. Our contribution is to argue that the way actors make sense of certain practices as indicative of autonomy is by situating them within a larger narrative of the past and future. In other words, we claim that an essential aspect of “doing” autonomy involves dealing with time. In what follows, we elaborate our theory by turning to the sociological analysis of temporality.

The temporal nature of autonomy

A growing body of literature highlights the centrality of temporality for how individuals attribute meaning to their actions and identities (Charmaz 1991; Ezzy 1998). Mische (2009) calls localized efforts to make sense of people and their actions *projects* to highlight the temporal process of planning and interpreting action. Drawing on phenomenological traditions, Mische argues that the meaning assigned to action is constructed according to an “imagined horizon” of possibilities and analyzed through “post-hoc accounting processes” (Suchman 2007; Suchman and Weber 2016). Perceptions of the future are a powerful force on agency, influencing life course trajectories and outcomes (Hitlin and Elder 2007).

While the temporality of action is an extremely subjective experience, individuals connect their subjective experiences of, and orientations to time, with socially shared enforced temporalities (Auyero 2012; Bourdieu 1997; Frye 2012) by juggling multiple timeframes, prescribed by “the various collectivities to which they belong” (Mische 2009:698). Institutions of all sorts—from schools to hospitals, workplaces and prisons—impose rhythms, timetables, and expected durations on their constituencies (Foucault 1995; Thompson 1967; Zerubavel 1979). As they calibrate their own sense of self in relation to social and institutional time, individuals experience disruption, anticipation, waiting, continuities, turning points (Altomonte 2016; Charmaz 1991; Flaherty 2002, 2010, 2013). In other words, the thresholds that mark the passage through the life course are institutionally structured and enforced *as well as* made of individual perceptions and aspirations to multiple possible futures (Johnson-Hanks 2002; Silva 2012).

Because personal and institutional expectations of time are often mismatched, scholars examine the various impacts of these misalignments as well as the practical work of sorting them out (Auyero 2012; Auyero and Swistun 2009a, b; Bourdieu 1990, 1997; Sharma 2014; Wajcman 2015). Tavory and Eliasoph (2013) identify three distinct modes of future coordination: moment-by-moment anticipation, following culturally scripted trajectories, and appealing to broader temporal landscapes. Given that these methods of coordination are loosely coupled, actors retain, and even manipulate, ambivalence as they calibrate their actions to future trajectories (Tavory 2009). For example, Frye (2012) argues that young women in Malawi draw on idealized futures as moral compasses to construct narratives about their present selves, even if these imagined futures do not match their present opportunities (see also Silva 2012). Similarly, Brown and Patrick (2018) show that women use egg freezing to uncouple the trajectory of finding a partner from the trajectory of having children.

This scholarship provides a framework for understanding autonomy as a temporal project, one in which a social identity is constructed by placing localized action in

relationship to the past and the future. As people seek to understand themselves and others as autonomous, they calibrate isolated practices of “autonomy knowledge” to cultural expectations about when people should be autonomous. Shared interpretations of these practices emerge from shared knowledge of the person’s past and common expectations for the future (Bourdieu 1997; Brown and Patrick 2018; Tavory 2009; Tavory and Eliasoph 2013).

In what follows, we draw on our empirical cases to show that autonomy is achieved by interpreting present actions with reference to imagined pasts and futures. Orientation to the past lies at the heart of the mission of *rehabilitation* in a post-acute care unit for the elderly, in which the project of autonomy consists of restoring past physical capacity.² In contrast, the mission of *habilitation* that drives our second empirical case, an independent living program for adults with disabilities, is largely informed by future anticipations of what autonomy will look like. This mission consists of habilitating, or to “make able,” which requires staff to leave the horizon of possible capabilities open. Ultimately, both cases illustrate how the elusive temporality of autonomy situates dependency in momentary, fleeting presents.

This temporal project is a critical way that people are made accountable and responsible for their own identities. Anthropologist Haim Hazan (2015) argues that in a postmodern world that elevates hybridity and fluidity, those who are perceived as having no possibilities for a malleable future (such as the very old, or the autistic) possess objectified identities and thus cannot be known as agents of their own lives. As a key aspect of modern selfhood, constructing autonomy is a reflexive process that presumes its subjects are changeable and constructible. And so, as we will argue, the open-ended temporal promise of autonomy’s project operates as evidence of individuals’ ability to evolve rather than being perceived as stagnant or “socially dead” (Hazan 2015).

Methods and data

This article compares data from two different ethnographic studies in New York State: one conducted at a post-acute care unit in a nonprofit skilled nursing facility, the other at an independent living program for adults with developmental disabilities. Both settings share a similar and explicit mission: to make their clients “independent.” In this sense, they constitute what Garfinkel (2002) referred to as “perspicuous settings:” organizational domains in which participants illuminate problems of central interest to social theory (Lynch 2007) by dealing with these issues as ordinary categories of practice rather than analytic concepts. In other words, the organizations we compare treat autonomy as a practical, everyday problem, which makes them ideal settings for studying how people attempt to translate an abstract notion into observable traits and outcomes.

However, both cases have important differences, as they operate under very dissimilar institutional constraints, including government regulations, criteria for

² The 1957 President’s Commission on Chronic Illness defined rehabilitation as “the restoration of the handicapped to the fullest physical, mental, social, vocational and economic usefulness of which they are capable.”

reimbursement from state and federal agencies, and market pressures. Here we describe the two settings in detail and how each author collected their data. We then explain our methods and rationale for combining and analyzing our cases through the comparative lens of how autonomy is produced at each site.

Oakville's post-acute care unit

Oakville is a nonprofit skilled nursing facility (SNF) located in New York City that houses approximately 300 long-term patients. It has a post-acute care or short-term unit with private and shared rooms for 44 patients. The majority of post-acute care patients are admitted after a hospital stay of at least 3 days, most commonly for orthopedic surgery, and remain on the unit for anywhere between one week and several months (typically two to four weeks), during which they receive physical and occupational therapy.

Post-acute care unit staff includes registered nurses, certified nursing assistants, social workers, a dietician, an activities coordinator, and off-site doctor and psychiatrist. Most rehabilitation patients are over 70 years old and many have been to Oakville before. Their racial, financial, and social backgrounds are heterogeneous and most patients pay for Oakville with a combination of Medicare, Medicaid, and private insurance.

Post-acute care is a transitional stage of elder care. After admission, Oakville staff design an interdisciplinary care and discharge plan which includes assessing the patient's physical condition, home situation, and insurance coverage. Social workers conduct cognitive and social evaluations and physical therapists evaluate the ability of incoming patients to conduct activities of daily living. Based on this initial evaluation they estimate how long a patient needs to be at Oakville and what their "goals" are. Patients then start physical and occupational therapy according to these goals. At weekly discharge planning meetings staff review every short-term patient to exchange updates about their progress and to project a discharge date. The aim is not to discharge patients fully recovered, since the majority of discharged patients continue to receive physical therapy, nursing services, or various kinds of assistance in their own homes.

Institutional constraints at Oakville Post-acute care is an increasingly important component of the elder care industry and is much more profitable than long-term care because it is largely financed through Medicare's Skilled Facility Benefit which reimburses SNFs up to \$700 per day using a prospective payment system (Medicaid reimburses \$280/day). These rates are based on the Minimum Data Set (MDS), a federally mandated patient assessment instrument for skilled nursing facilities. The MDS records patients' physical, psychological and psycho-social functioning. Staff from nursing, therapy, and social work collect this data upon admission and update it periodically. These updates provide a standardized measure of "quality of care" and provide patient "scores" that Medicare and Medicaid use to determine reimbursement rates. Thus, incoming Medicare patients who need more acute care bring in larger reimbursements than more stable, longer-term ones. These benefits have their limitations. Medicare provides coverage only up to 100 days per year per patient (including days at the hospital); after day 21 patients usually start paying a copay of \$165 per day. Payments to SNFs are progressively administered by HMOs, which can decline

payments or stop coverage with a 48-h notice if they decide that weekly notes provide insufficient documentation of progress to justify continuing services.

While post-acute care units, like hospitals, are under increasing pressure to discharge their patients as soon as possible, they are penalized for discharges that end in re-hospitalizations within 30 days, so they are mandated to execute safe discharges. Balancing fast and safe discharge was a main topic of weekly discharge planning meetings where staff were alerted to red flags or “barriers” that could impede timely discharge or prompt a stay at the facility’s long-term unit. Medicaid coordinators were thus also involved in care planning; if a patient is going to be long term they need to assess and obtain documentation to enroll them in nursing home Medicaid benefits. These bureaucratic mandates ultimately mean that the amount and pace of progress in rehabilitating patients is of paramount concern for the economic solvency of the organization.

Supported living at MTIC

Moving Toward Independence in the Community (MTIC) is a supported living community for adults 21 and older, with intellectual and developmental disabilities (IDD). The program is located in a small city in New York State where participants live on their own in apartments purchased by or co-signed with their parents. In contrast to Oakville, MTIC is designed as a lifelong service to provide support for independent living even after parental death.

The program screens applicants based on interviews with family members and trial engagement in program activities. While there are few strict guidelines, the program requires that participants live without 24-h supervision, manage their own medication, and be emotionally stable (free from significant mental health issues). Admission to the program is made on a case by case basis and a majority of those who choose to interview for the program are accepted. The few who are not are often encouraged to reapply after they have acquired more experience living alone.

Each participant at MTIC has a licensed social worker or mental health counselor with whom they meet weekly to discuss their lives and coordinate the support they receive. They are also assigned a Medicaid Service Coordinator (MSC) who works with them to apply for and manage public benefits (Medicaid, SSI/SSDI, food stamps, accessible transportation services, job support, etc.). Each participant receives at least four hours of direct support through Community Habilitation (ComHab) to learn life skills like cooking, cleaning, socialization, and travel. The care planning process is remarkably similar to Oakville’s with one exception: the goals that drive care at MTIC tend to focus on very long term social goals and less on physical ones.

While MTIC is a private program and is not certified by the NY State Office for People with Developmental Disabilities (OPWDD) roughly half of the 57 participants in the program are personally eligible for OPWDD services and Medicaid through the Home and Community Based Services (HCBS) waiver which allows states to use Medicaid funds to develop individualized community-based programs in lieu of institutional care. Some also receive income support through Social Security Disability (SSDI) and Supplemental Security Income (SSI). Those who are not OPWDD eligible are most often disqualified because their disability is not considered to significantly

impair daily life. Families pay privately for the program fee which ranges from \$10,000–15,000 per year. For eligible participants, ComHab (billed at \$35/h) and Medicaid Service Coordination (MSC) services are paid for by Medicaid. Participants without Medicaid pay privately for ComHab and MSC in addition to their annual program fee. Given the costs of the program, a majority of participants are from upper-middle to upper-class families. Those few families with lower incomes had support from wealthier family members and one participant had a trust fund from a medical malpractice settlement. At the time of data collection, all but one participant were white and 60% were male.

Institutional constraints at MTIC Unlike the financial arrangements at Oakville, reimbursement considerations are not a strong constraining force at MTIC where only half of the participants are eligible for Medicaid. Even those participants who do qualify for Medicaid-reimbursed ComHab services do not often use all of their funded hours because they either don't have time during the week to fit them in around social and work commitments or because Medicaid has overestimated how much direct support participants need and want.

While the financial constraints of Medicaid do not exert a strong influence on the amount or type of care provided to participants, the ethical stipulations of state funding do. Only half of the participants qualify for Medicaid, but MTIC follows Medicaid's documentation and reporting protocols for all participants in the program, to facilitate efficient and consistent care. Like they do at Oakville, reporting requirements orient the program to consider progress toward explicit goals as a central justification of care. In instances where a participant stalls or fails to make progress over an extended period of time, staff remove that activity from the care plan, not because of financial or time constraints, but because progress toward goals is the ethical frame laid out by Medicaid and the Office for People with Developmental Disabilities (OPWDD). In addition, the expectation that participants will consent to care and make agentic decisions about their lifestyle is mandated by OPWDD's Justice Center which defines coercion by careworkers as an offense that must be reported to as abuse. Consistent with this framework, staff are trained to emphasize their clients' desires and motivations through all of the support they offer.

Data collection

We conducted separate ethnographies and interviews at these two sites. Altomonte conducted 15 months of participant observation at Oakville between July 2016 and April 2018 by spending between two and five hours on site, two to four days a week. She attended weekly staff discharge planning meetings, as well as daily meetings between staff, patients and family members to discuss care and discharge plans. She also shadowed social workers and physical therapists in their initial evaluations of incoming patients, delivered meals to residents, and conducted observations in both common areas and on the physical therapy unit. Over twelve months she also conducted periodic ethnographic observations and interviews with 10 elderly patients after they were discharged to their homes or to long-term care. This ethnography was

complemented with 32 interviews: 16 with staff members at Oakville, 12 with elderly patients, and four interviews with patients' primary family caregivers.

At MTIC, Munson conducted 18 months of ethnographic research during which she observed 30 staff meetings, 20 Medicaid Individualized Service Plan (ISP) meetings, and 109 meetings with adult participants and staff. In addition to these formal observation periods, she attended over 50 activities ranging from trivia night at a local bar, a knitting class which she taught, a newspaper club, internships, classes and a weekend trip to Williamsburg, Virginia. Most of these observations centered on the interactions between program participants and staff members. This ethnography was complemented by 38 interviews with parents and siblings.

We used similar data collection techniques, taking notes profusely during our observations, which we later expanded into long form narratives. We both wrote periodic memos on emerging themes, and we inductively coded data using Atlas.ti and NVivo according to these themes and others that emerged during the analytical process. The similarities in our methodology and analytic techniques yielded remarkable similar products: several hundred pages of field notes, captured primarily from the standpoint of staff, detailing the daily work of (re)habilitation.

Combining and comparing data

The idea for this article emerged as we realized that, despite differences in financing, structure, and clientele, the organizations we studied were tasked with a shared cultural value (Vaughan 2016:318): making their clients "as independent as possible." Our separate observations of the way independence permeated staff's interventions and interactions with clients prompted us to ask a common question: How did these organizations incorporate the abstract notion of autonomy into their everyday work?

We started our analysis by "pooling" (West and Oldfather 2016) our interpreted findings: memos and fieldnotes we had each previously coded around broad categories of independence and autonomy. By reading and commenting on each other's data we identified three new categories of autonomy present at both field sites: cognitive, physical, and moral/motivational. We populated a table with these categories and the field notes that underpinned them. Through another round of closely reading and comparing field notes we identified critical tensions among these different types of autonomy, which we discussed in the light of our main question: Through what social process is autonomy produced?

This iterative exercise allowed us to gain a deeper understanding of both the commonalities and differences between our cases, especially the distinct institutional constraints that shaped interventions at each site. Our comparative analysis led us to further refine our categorization of how autonomy was being used at both sites into three dimensions: institutional, practical (which encompasses the cognitive and physical), and moral. Interrogating how the contradictions among these dimensions were reconciled, we saw that staff tended to situate autonomy "elsewhere" in time: whether in an open future or an ideal past. This observation yielded the main contribution of this paper, which is how time allows actors to manipulate a fuzzy boundary between dependence and autonomy.

While our methods and their common missions make our organizations comparable, the significant differences between their populations yield important insight into how

autonomy is constructed and managed. Both groups benefited from the legacy of deinstitutionalization in the 1970s which has prioritized community living for long-term care. Each program operates against the backdrop of their total-institutional foils, the group home (Levinson 2010) and nursing home (Diamond 2009): institutions that symbolize silenced identities (Hazan 2015), homogenized care, abuse, and separation from the community. To counter the abuses of the total institution, the deinstitutionalization movement valorized self-determination and independence (Bagnall and Eyal 2016) and challenged the paternal and objectifying language of “care” (Fine and Glendinning 2005). This notion eventually infused gerontology perspectives and led to perceptions that maintaining independence in old age requires distance from nursing homes (Altomonte 2020; Burr et al. 2005; Plath 2009). Through this movement autonomy became a moral imperative inscribed in culture and legislation for both the elderly and adults with disabilities. However, the stigma of being cared for differs for each group. Impairment and dependency have been historically regarded as a relatively “normal” (though increasingly undesirable) part of growing old, but an “abnormal” part of being young or middle-aged (Putnam 2007). The result is that direct intervention is more appropriate for the elderly than it is for people with disabilities where greater tensions remain between the need for care and the right to agency and autonomy.

Operating in the shadow of this legacy, MTIC is an “entry” point into independent adulthood for a population whose autonomy is contested by the state and society in general. Oakville, on the other hand, serves a population of elderly people whose medical conditions and impairments bring new forms of dependency into view; post-acute care constitutes a space of transition out of independent adulthood and into new forms of assistance. Thus, the end goals of each program differ: at Oakville it is discharge from post-acute care into home care services; MTIC’s goal is to enable independent living skills while providing lifetime support for participants. As noted above, Oakville services are largely funded through public programs (Medicare and Medicaid), while MTIC is primarily funded through private pay.

In the following sections we describe the three dimensions of autonomy we identified as common to both cases. While we present them here as “ideal types,” it is important to note that in practice these dimensions are constantly entangled with each other. We then discuss the tensions that emerge between them and develop how, in managing these tensions, staff make use of temporal markers to produce recognizable autonomous subjects whose dependencies are momentary.

Findings

Staff at Oakville and MTIC treat autonomy in three different ways. The first, which we call *practical autonomy*, refers to capacity for present, every day action. At Oakville this most often means that a person can physically move on their own. At MTIC, physical autonomy is less well-defined, in part because most participants in the program do not have physical impairments that obviously inhibit daily function. Instead, the notion of practical autonomy is best summed up by MTIC’s goal that participants be “as independent as possible,” possibility being limited by the cognitive limitations of participants. At both programs, then, *practical autonomy* also refers to the cognitive capacity to make decisions without coercion or undue influence from others.

Moral autonomy refers to an individual's desire and motivation to be independent. At both programs motivation is tightly wound with the practice of goal-setting. At Oakville for example, patients are assessed on the "initiative" they demonstrate to engage in their recuperation. Similarly goals serve as the basis for staff action at MTIC; if Sally "would like to learn independent meal planning", staff will "train Sally to read a recipe and write a shopping list." By organizing their work around client goals, staff at both Oakville and MTIC make their work contingent on the willingness of the subjects of care to engage their interventions. The essence of moral autonomy is that it is not enough for clients to be independent, they must also desire a life that is continually progressing to increased independence. In contrast to *practical autonomy*, *moral autonomy* is subjective and cannot really be measured and defined against objective standards like the ability to walk, cook, or count money; the nature of these actions are subject to the interpretations of others. An individual's practical autonomy, the things they do, must be seen as subject to the desires and motivations of the self (Foucault 1982, 1995; Rose 1992).

These dimensions of independence are objectified in the documents, policies, and procedures that govern work at the two organizations we studied. Documentation is an essential requirement in any organization, especially those regulated by state and federal agencies and that receive payments from programs such as Medicaid and Medicare. While others have written about the ways in which the requirements of documentation for insurance purposes turn the work of caring into discrete, reimbursable tasks (Rodriquez 2014), our concern here is to note how the documents and records staff at Oakville and MTIC were required to keep, update, and submit, reflect the desire of the welfare state to see a specific kind of autonomy in the clients they serve. We call this dimension *institutional autonomy* to denote an idealized state of independence that is built into bureaucratic structures. Most visibly, practices of documentation reflect the temporal expectations of the state that define successful care as progress toward a continually evolving future autonomy. Patient goals, care plans, and discharge forms impose this vision of autonomy as an organizing principle at both organizations. In other words, when organizations assess independence using these benchmarks, they make autonomy "objective" so that actions and expectations can be measured against it.

The bureaucracy of independence: Autonomy as an institutional goal

Oakville

At Oakville, the principle of autonomy is built into the regulations of skilled nursing facilities dictated by CMS (Centers for Medicare & Medicaid Services) that promote person-centered practices and patient choice. The law mandates "resident dignity, autonomy, and quality of life" and demands skilled nursing facilities to "ensure that all individuals have the opportunity to learn about home- and community-based services and to receive long term care in the least restrictive setting possible" (Centers for Medicare and Medicaid Services 2017). This requirement permeates the stated mission of Oakville, which is "to restore our residents' independence and help them return to community living" after a hospitalization. In other words, the

organization provides care that aims at bringing clients back to a previous level of autonomy so that they can continue to live in their homes, which constitutes an ideal future of independent old age.

How do staff assess performance in this institutional goal? As mentioned, all evaluations of patients are conducted using the MDS survey instrument. The MDS tool serves to standardize and assess patients' autonomy along three main categories: cognitive, physical (which together constitute our *practical autonomy*), and motivational (which we conceptualize as *moral autonomy*). First, the MDS determines the cognitive status of incoming patients. Besides questions that aim at evaluating a person's memory and ability to recall basic information, the MDS records "the resident's actual performance in making everyday decisions about the tasks or activities of daily living." These cognitive capabilities are weighed against the extent to which a "resident's decisions [are] consistent and reasonable (reflecting lifestyle, culture, values)". At Oakville, staff most commonly use the term "Alert and oriented" to signal that a patient is cognitively capable according to these guidelines. While "alert and oriented" adjudicates autonomy in the present tense, it does so with reference to the past. Patients are deemed capacitated as long as their decision-making and demeanor reflects their perceived *past* "lifestyle, culture, and values." When this capacity is called into question, a psychiatric capacity consult is requested.

The MDS tool is also used to assess and document physical autonomy through the category of "self-performance," a measurement which ranges from "total dependence", to "high-functioning", and "independent." Physical therapists and nurses record the number of feet a person can walk, the number of steps they can climb, their ability to transfer between bed, wheelchair, and standing, and other activities of daily living like eating, dressing, and wound care. The MDS tool therefore translates the abstract notion of autonomy into standardized and comparable categories which become key indicators to evaluate the amount of post-acute care services patients should receive. For instance, in one discharge planning meeting staff reviewed a patient who was projected to be discharged within one month. "But that date may be moved forward, she's walking 100 feet so that's too much time," pointed out a physical therapist. Regardless of other factors that might impede this patient's return to her home, as her practical autonomy becomes measurable it provides a key rationale for discharge.

As mentioned, if staff cannot offer documented proof that rehab is improving patients' physical autonomy, insurance will decline payments. Documentation of physical independence therefore makes the temporal expectations of autonomy quite visible. If patients' progress is too slow or even imperceptible, physical therapists can hardly justify continuing services because Medicare and HMOs will only reimburse these services when they are needed and beneficial for patients' recovery. In other words, a patient who is not expected to gain independence from rehabilitation has no justification to receive it. If patients progress too quickly, however, insurance companies will also no longer justify keeping them in post-acute care and demand their discharge to lower levels of care.

Finally, through the MDS patients are assessed on their "initiative," or moral autonomy, which at Oakville primarily means that they wish to engage the work of rehabilitation with the ultimate goal of leaving the facility. Patients are expected to take an active part in stating their goals and priorities. One day in a care planning meeting between staff and a 90-year-old patient named Cora, a social worker asks her if she has

stairs in her apartment. Cora says she has eight steps at the stoop and a large step at the door. Julie, the social worker, tells her the tentative discharge date is August 8th (ten days from today) but subject to change if therapy asks for extra time. Cora replies she thought it was the 15th. Yes, says Julie, “but therapy changed it based on your progress and their goals.” “But what about MY goals,” complains Cora. “If I feel that I need more time [practicing climbing] steps, that’s what I need, they are my nemesis because that’s where I fell. I would want that option.” Julie concedes: absolutely, don’t worry about that date because it can always be pushed back.

Although staff referred to Cora and her daughter as “annoying,” they ultimately valued that this patient could articulate her wishes clearly because it aligned with their expectation of patients to be speaking subjects (Livne 2019; Mol 2008). In determining and modifying discharge dates, staff considered a resident’s “motivation to improve” as a key indicator of their future ability to live independently. This moral imperative to work and plan towards returning home, and the notion of progress implied in the documentation of patients’ rehabilitation, both complicate the orientation to the past described earlier. Oakville patients are required to move toward the future by using the past as a benchmark. As we develop below, this requires staff and patients to coordinate action by simultaneously referring to imagined pasts and future selves.

MTIC

Similar to Oakville, the procedures for documenting and providing care at MTIC reflect bureaucratic principles of autonomy as they are built into federal law, especially the Home and Community Based Services (HCBS) waiver system. The HCBS waiver requires programs to develop care plans, in consultation with the individual, that document an individual’s care needs and provide “appropriate supports” which provide adequate safeguards without delivering care that is unnecessary or impinges on an individual’s rights. Medicaid requires these plans to be reviewed annually and revised to reflect the individual’s shifting care needs. As mentioned, while only half of the participants are eligible for Medicaid, MTIC uses the documentation and reporting standards of OPWDD (Office for People with Developmental Disabilities) to structure the program as a whole.

Care needs are assessed with the Developmental Disabilities Profile (DDP-2), a form that must be completed by everyone served by OPWDD funded residential and day programs. The form must be completed within 30 days of entering a new program, whenever “a significant change occurs to an individual’s characteristics,” and at least every two years “to update a person’s capabilities.” The DDP-2 collects a variety of information, including characteristics of the person’s disability, level of intellectual functioning, medication use, presence of psychiatric diagnoses, and the frequency of use for clinical services. Behavioral issues (physical assault, self-injury, verbal abuse, and emotional outbursts) are measured on a scale that measures frequency of behavior ranging from “not this year” to “daily.” Self-care and daily living skills are also measured on a scale from total support, assistance [requires lots of hands-on help], supervision [requires mainly verbal prompts], to “independent.”

Drawing on the data collected in the DDP-2, OPWDD assigns an ISPM (Individual Services Plan Model) score that reflects a person’s behavioral and direct support needs

and provides the basis for an individualized determination of the least restrictive environment. This involves calibrating the level of support to the capabilities of the individual but also ensuring that the care setting adequately provides for their needs, including the cognitive ability of the person to direct their own care (self-direction, non-24 h settings, etc). While HCBS waivers provide funding for many types of services (rehabilitation, respite care, personal health services, etc.), MTIC's support falls under *habilitation*, or "services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings."

Reflecting the HCBS requirement that habilitation services improve a client's independent living skills, care plans explicitly link the actions of staff members to the self-motivation of participants to pursue autonomy (see Table 1). Care plans are organized around "Valued Outcomes," which always begin "[the participant] would like to" and define a vague future state in which the individual will be more independent. The vagaries of valued outcomes, "Dana would like to learn independent meal planning," are translated as discrete and measurable goals, "to make a grocery list." The caregiving actions of staff, notably, come last and borrow the language established in a participant's goals, "Staff will train Dana to make a grocery list." Staff actions reflect their supporting role in a participant's autonomy. Staff will "support", "train," "model," or "role play," but they never do anything directly for participants.

Translating valued outcomes as goals communicates the temporal project of care at MTIC, that autonomy is something that will be achieved in the future. By breaking valued outcomes down into measurable goals, the terms of progress and success in this project are made explicit. As individual goals are met, they are removed from care plans or revised to reflect a participant's new capabilities. When a participant stops progressing toward a goal, either because they don't want to or because they have reached some physical limit, staff members remove the goal saying, "if they will never do this, it can't be a goal." Ongoing areas where a participant needs support but will not progress toward further independence are placed in a separate section of the care plan

Table 1 Excerpt from a care plan at MTIC

Valued Outcome #1: Dana would like to learn independent meal planning	
Allowable Service:	Training in general household management
Goal/Activity A:	To make a grocery list
Objective:	Make purchases at the grocery store that are based on an established grocery list
Staff Action:	Staff will train Dana to make a grocery list based on meals she will make throughout the week
Frequency:	Weekly

Accessibility Caption: The figure lists the billable service, goal, objective and staff action for a single valued outcome, "Dana would like to learn independent meal planning"

called “safeguards” and they are not addressed in the active work of *habilitation*.³ While MTIC does not have formal discharge goals like Oakville, individual goals are “discharged” by removing them from care plans altogether. Goals can be discharged because the participant has achieved the goal and because they have stopped progressing. In addition some participants “graduate” to half-time care or stop ComHab altogether, as we come back to later.

Together, the documentation procedures in use at MTIC and Oakville communicate a temporal construction that views autonomy as something in the future, and charts the progress made toward that goal. However, at both sites (explicitly at Oakville, implicitly at MTIC) such progress is necessarily measured against past ideas of autonomy for each participant. While the practical and moral dimensions of autonomy are objectified in the tools we have described here (which we call *institutional autonomy*), they become entangled in practice. Local interpretations of *practical*, *moral*, and *institutional* autonomy conflict and compete with each other but when they do, they make productive sites to explore the temporal contours and negotiations of autonomy. We turn now to these tensions.

Situating autonomy’s horizon: Ideal pasts and open futures

While staff at Oakville and MTIC draw on the institutional indicators described above to assess clients, in practice making their clients “independent” requires situated knowledge and interpretations of behavior. A key aspect of this work involves defining whether clients’ shortcomings result from lack of practical capacity or lack of motivation. By negotiating this tension, staff seek to distinguish whether a person *cannot* or *will not* engage the interventions they design to improve autonomy. In identifying the distinction between what a client can’t and won’t do, staff identify an individual’s *autonomy horizon*, or projected future autonomy, in order to develop a care plan that realistically reflects their expectations and goals for each client. Staff at both organizations use past behavior and the possibility for future action as focal points to organize their work with their clients.

Here, important differences emerge between the temporal projects of enhancing autonomy at Oakville and MTIC. At MTIC, the question of who clients *could be* if afforded the opportunity to flourish looms large and demands that the future (the horizon of autonomy) be kept open. At Oakville, the yardstick of autonomy depends on who the clients *were*. Situating the goal of autonomy means to build consistency with elderly patients’ previous identities.

Autonomy oriented toward past selves At Oakville, as mentioned, the mission of rehabilitation essentially means to restore individuals’ capacities to the fullest extent possible. This requires staff to establish *which* point in patients’ past they should use as a benchmark to situate the goal of autonomy. One crucial way in which they did this was by distinguishing what an elderly patient physically could not do from what they simply refused to work on. By identifying what a patient can’t do, staff defined the

³ It should be noted that this reluctance to care is not universal for adults with intellectual disability, but is specific to programs like MTIC that do not provide residential home-health or personal care services and thus don’t need to account for more traditional caregiving tasks like bathing, feeding, medication management, etc.

content of their rehabilitation project: the physical inability to walk or climb stairs can either be improved through rehabilitation or ruled out as a goal because of circumstances beyond the individual's control (i.e. new physical limitations). Identifying things a patient *won't* do indicates a more serious problem: that patients will not participate in the rehabilitative project because they lack motivation or interest. While lack of motivation and physical capacity are both practical barriers for the organizational mission of discharging patients home, lack of motivation also prompts a morally charged judgment of character, that the patient doesn't *desire* independence, *won't* work toward it, and therefore cannot be interpreted as having moral autonomy. As others have pointed out, in the neoliberal "structure of feeling" (Sharma and Tygstrup 2015), lack of ambition to improve oneself constitutes the highest wrong (Haney 2010; McKim 2014; Munson 2020; Soss et al. 2011).

The line between can't and won't, however, could be fuzzy. At a weekly discharge planning meeting staff discussed Ms. B, who had just been admitted. "Is there any motivation?," asked Ruth, the MDS coordinator. "She does nothing," said Vivian, the head of the physical therapy department. "We had this issue with her last time she was here," said Julie, the social worker: "she needs a lot of motivation... this is how she is, she needs someone to be firm with her." Julie says the daughter gets her to do stuff. "But based on her pattern she'll be here a long time," insists Ruth. "Let's see how she does next week," says Julie. The next week, at the same meeting, the patient's lack of motivation came up again. Vivian reported that Ms. B "has 7 steps at home and she's not doing them," mobilizing institutional indicators of autonomy to suggest that discharging her would be a problem. "I didn't expect her to, she wasn't doing them last time!," says Julie. "I know her. I think we got her to [walk] 50 feet last time, if we can get her there the daughter can take her home," she adds.

Ms. B is categorized as a patient who cannot accomplish the benchmarks of autonomy set for her because she lacks motivation. In this assessment, staff's previous interactions with her play a large role — assertions like "I know her," "this is how she is," point to moral evaluations based on a past image of Ms. B as a patient who has already been at Oakville. When Julie claims she "didn't expect her to [do steps], she wasn't doing them last time," she expresses certainty that Ms. B's present behavior is consistent with that past identity. However, implicit in these judgments is a prior image of Ms. B as an elderly individual who, at some point, *was* able to carry out the physical tasks she now *won't* do. Staff orient their temporal project of autonomy to two imagined past selves: the person who was at Oakville last time and wouldn't do anything either, and the imagined self who presumably could, and wanted to, walk before her first hospitalization.

In other words, to coordinate action, staff must agree not only on a shared future (Tavory and Eliasoph 2013), but an idealized past. Devising an appropriate intervention to discharge Ms. B. requires a shared imagined past against which to make sense of the patient. Once Ms. B exhibits a pattern of refusal of autonomy, staff take it as evidence that they can no longer push her to work and recalibrate the horizon of autonomy to reflect their dwindling expectations for her progress.

Autonomy oriented to an open-ended future The tension between "can't" and "won't" in adults with developmental disabilities consists of disentangling motivation and *cognitive* ability. This distinction was more problematic for MTIC staff than Oakville's

in part because of the stigma attached to impairment for people with disabilities. One day at an MTIC staff meeting, Elizabeth asks, “Can we talk about Allen?” Elizabeth has been having a hard time balancing between the expectations of Allen’s mother, which Elizabeth thinks are too high, and Allen’s willingness to engage with the program. She reports that Allen infrequently attends activities and refuses to work with his ComHab. Allen’s mother makes frequent suggestions to Elizabeth about ways to “push” him to be more social. “I keep telling his mom... ‘I can’t force him to do any of these things’. He doesn’t want help. He is just here to hang out with his friends.”

Staff’s interpretation of Allen’s behavior illustrates both the moral and practical realities of independence. Allen is painted as a problematic participant because he doesn’t want to work on anything, “he is just here to hang out with his friends.” This moral judgment entails practical consequences since staff define their role in participants’ lives as offering a specific type of care that is mobilized by participants’ willingness to engage. Without Allen’s participation, Elizabeth “doesn’t know what to do,” because she has nothing to define her work against. His mom’s emphasis on Allen needing to be “pushed” runs counter to the larger project of autonomy which requires him to be self-motivated. Elizabeth restates this in the meeting, “We aren’t in the business of pushing.” Nancy, the program director, agrees, “we can’t drag him out of his apartment.” The entire project of defining expectations for Allen’s autonomy horizon is thus complicated by his apparent lack of moral autonomy.

At the same time that she struggles against Allen’s lack of motivation, Elizabeth confronts what may be a cognitive limitation for him. Recently Allen told Elizabeth that he was frustrated with his brain and inability to communicate like he wants. He really would like to be an actor and aspires to the witty speech he sees in his favorite TV show, *Family Guy*. At the request of his mother, Elizabeth offered him some local activities that would enable him to practice his language skills. In doing so, she tried to explain the difference between improving vocabulary and being capable of the grand speech that Allen aspires to, a conversation which caused him to “totally shut down.”

For the most part, staff at MTIC are reluctant to accept that there are things a person can’t do, because it limits the imagined possibilities for autonomy in the future. What should be noted here is the nuance in how Elizabeth describes what Allen *can’t* do. When she alludes to the limit of Allen’s capacities by saying she doesn’t think her proposals can afford him the “grand speech” he aspires to, she suggests what she believes to be a realistic goal, improving Allen’s vocabulary. When Allen takes offense to Elizabeth’s suggestion that there is a physical or cognitive barrier to his goal, he shines a light on a fundamental transgression of the goals of the program, foreclosing the open-ended project of autonomy. Elizabeth turns this back on to him by highlighting his continued reluctance to engage even those activities that reflect his desires.

In this sense, staff at MTIC are also (albeit implicitly) making sense of clients’ behaviors and possible futures by referring to past identities. Yet rather than looking for evidence of consistency with past selves like workers at Oakville do, MTIC workers look for signs that young adults are willing to change with respect to undesirable past dependencies. Thus, while interpreting his incapacity as something Allen “won’t” do passes moral judgment on Allen’s lack of motivation, it also leaves the horizon of autonomy more open — he *could* improve if he *wanted* to.

At both organizations, interpreting clients as lacking motivation rather than ability also helps staff negotiate the inevitable conflict between institutional assessment and

clients' own ideas about their capacities. One of the first questions Oakville staff ask incoming patients is, "whether the plan is to return home." In a staff meeting with social workers, Lina, an MDS coordinator, explained that this question was essential and its answer should code the residents' "stated expectation" *regardless* of the nursing home's assessment, otherwise they would incur in a violation of civil rights. Frank, the social work director, asked, "what about a resident with dementia that wants to go home — are we violating their civil rights if we want to protect them?" Lina said "yeah, this is regardless of what we think." Similarly, at MTIC staff are insistent on distinguishing a participant's own goals from those of their parents; reminding participants of their own desire for *future* autonomy was often employed as a strategy for convincing them to act independently in the present. Consistent with the deinstitutionalized landscape in which populations are governed through the freedom of choice (Gong 2019; Rose 1999), appealing to people's past and future autonomous identities is a useful tool staff use to intervene when patients assert their right to refuse care.

Situational competence: Learning when to be (in)dependent

The primary organizational goal of both Oakville and MTIC is to make clients "as independent as possible." The phrase orients staff to a flexible future that leaves the possibilities for independence open while simultaneously implying that there *are* limitations to it. Working out these contours is a matter of situating present forms of dependence and need within the larger context of past and future autonomy. In the previous section, we explored how staff interpret actions by assessing their client's practical and moral autonomy. Here we explore another area of tension, between what clients can and should(n't) do, which reveals that the production of autonomy requires demonstration of what we call "situational competence." At its most basic, this means that it is necessary in some cases and, especially, at *some times* to be dependent, in order to enable the larger project of autonomy.

At Oakville, such calibration is framed by rehab workers in terms of achieving both practical autonomy and safety, i.e. sitting, standing, and walking in the way least likely to cause injury. Situational competence is defined in explicit relationship to new physical dangers posed to elderly clients by their aging bodies. This is conveyed by Oakville staff's constant insistence that patients use technologies of support such as grabbers or canes, and techniques for safety such as reaching back to the chair armrests before sitting down. While the goal of rehabilitation is to return clients to an earlier state of physical activity, they are trained to do so in ways that account for their new physical limitations.

Situational competence extends beyond immediate physical dangers like sitting without the appropriate support, it also requires that clients moderate their motivation to be independent by cultivating a disposition to life in which they assess when to act alone and when to ask for help. For example, when Mrs. W woke up in the middle of the night to use the bathroom without asking for assistance she was scolded by her son and Oakville staff members, "you have to ring the bell if you want to go to the bathroom and someone will assist you." She "tries to be very independent, which I

guess is a good thing,” her son points out, but the fact that Mrs. W uses blood thinners makes a fall especially dangerous. While her eagerness to walk unassisted could potentially be lauded as proof of appropriate motivation, here it is only evidence that she “tries to be independent” without an appropriate judgment of her safety.

Internalizing situational competence is thus a matter of translating institutional (generalized) benchmarks for progress back into specific contexts. For example, while working with elderly patient Camille one day Liz, her occupational therapist, steps away to work with another client, giving Camille a chance to rest between her standing practice. While Liz is still away helping another client, Camille stands on her own and exclaims “Yes, I can do it by myself.” Just then Liz returns. “Did you see me?” Camille asks. “Yes, that was very good but don’t do it without me! I am trying to get you to a complete stand. And I need you to be safe.” Then she places Camille’s legs on the wheelchair’s leg rests and takes her to do arm exercises, pulling a cord with a weight using both arms. “Give me 75, take your time.” While the stated goal of her work with Camille is that she will stand unassisted, Liz urges Camille to work toward this goal slowly, standing autonomously only when it is safe to do so.

Autonomous subjects are therefore expected to calibrate their orientations toward the immediate *and* distant future (Tavory and Eliasoph 2013). These messages are in tension with the dimension of institutional autonomy that suggests elderly people can and should return to a previous level of physical autonomy. When they communicate situational competence, staff reveal the impossibility of that goal and highlight the importance of establishing new limits to autonomy. Clients who internalize these fine-grained nuances are “responsibly (in)dependent,” cognizant of their moral obligations to both improve and accept new configurations of dependence.

At MTIC situational competence is less concerned with physical safety and instead requires participants to accept their cognitive dependence on others.⁴ “Good” participants are those that both challenge the boundaries of independence *and* acknowledge the need for help along the way. For example, when Tyler joined the program Elizabeth, his program specialist, reported to the rest of the staff that he was adjusting well, “this is not a forever thing for Tyler. It’s just something to get him going.” Collectively, the rest of the staff recounted his capabilities and eagerness to gain new skills. Marilyn, another program specialist, surmised that Tyler is good at independent living because he doesn’t have the kinds of anxiety issues that might limit his independence. Elizabeth chimes in again adding, “it’s not been his experience that to accept help is bad.” She recounts his proactive work to contact the disability office at his college before classes and to ask Elizabeth for help reviewing his monthly budget. For staff, Tyler has struck a balance between doing things on his own, reaching out for support, and embracing his independence apart from his parents. Tyler is not afraid to ask for help and easily incorporates dependence into his personal work toward future autonomy.

Brendan, on the other hand, hadn’t fully internalized the situational competence of autonomy when he defended his habit of taking long walks along a secluded riverside bike path. For Brendan, these walks signalled his growing independence in pursuing a personal fitness goal. For his staff and parents, these walks were dangerous in the

⁴ We argue that these impairments (physical and cognitive) are comparable for the sake of our argument, because they constitute the content of disability and areas of intervention at our respective sites.

sweltering summer heat and put him at risk of assault. Brendan had a history of being harrassed on the street by strangers and had become aggressive toward them in the past. Kara, Brendan's social worker, suggested that Brendan join MTIC's recently formed walking group which would both keep him safe and allow him to socialize. Brendan objected: "They don't go as far as I do." As the group laughed nervously at Brendan's persistence, his parents imposed a rare "rule" to limit his desire to walk alone, "Okay, no more wandering past the county center unless you are with a group. You can do two laps if you want. That is a rule Brendan, do you understand?" Brendan continued his defense, citing his growing interest in nature photography. His parents repeated their rule, couching it in a qualification, "If you want to walk that far, go with friends. Use this as an opportunity to share your interests with someone who would enjoy them."

While his parents' "rule" established timely limits to Brendan's desire for exercise, they also defined appropriate circumstances for these walks. Brendan can go with friends, a setting which would incorporate multiple goals, exercise and socialization.

In short, the work of staff consists of properly situating the person in relation to their horizon line of autonomy by acknowledging dependence in specific ways that will not compromise but enable the larger project of independence. Participants' future autonomy is contingent on staff and participants knowing how, and when, to accurately calibrate the motivation to work toward autonomy and the current need for dependence.

Defining success: Moving the autonomy horizon forward

We have pointed out that an essential paradox cuts across the missions and labors of MTIC and Oakville: Staff, and presumably clients, know that attaining "real" independence is not possible. Ultimately, both the elderly and adults with disabilities are, like the rest of us, embedded in multiple forms of dependency. The question, as suggested above, is figuring out *which* types of dependency are acceptable *when*. Here, we elaborate on this idea further by discussing what constitutes success at each organization. How do staff know when the project of constituting autonomous subjects is completed?

At Oakville, the simple answer is: when patients are discharged home. "Going back home" is the primary goal of the post-acute care organization, overwhelmingly stated by staff and patients in their multiple encounters. Small celebrations and heartfelt good-byes took place when patients were discharged. One day, three patients were leaving all at once. Amanda, a physical therapist, was pushing one patient out of the dining room in her wheelchair, yelling "This is one of my successes! I fully take credit!" Another woman whom everyone seems to like is also leaving now. An aide helps her get up to walk with a walker, "one last time!", says Julie the social worker, who is standing by. "I've never seen you walk! This is so exciting!" When this patient starts to move toward the elevator to leave the unit everyone hugs her. Julie warns her, half jokingly, that she doesn't want to see her back in her beds.

Discharge was especially celebrated when the patient in question was in dire shape upon admission and had made progress against all odds. At one meeting, staff discussed Mrs. M, who was trying to walk 30 ft. "If she can do a flight [of stairs] I can get her home," says Julie. "She's my miracle child." "After all those falls!" says Beatrice, the head nurse. Another time staff also referred to another patient as "a

miracle!” when the rehab director gave updates on how much she was walking. “You guys are awesome,” said a staff member, referring to therapists.

Underneath this shared sense of success, however, there is complexity. Almost all patients are discharged with various forms of support: wheelchairs, walkers, canes, hospital beds at home, toilet seats, and home care services, to name a few. One discharge Julie was particularly happy about was a woman who had been at Oakville twice already, the last time for several weeks. Julie said she was finally leaving because she got coverage for 24 h of home care, “no one ever gets that!” Julie celebrated her exit from Oakville as a success precisely *because* she had been able to secure full-time support that enabled her practical autonomy.

From the point of view of Oakville, the project of restoring autonomy is completed upon discharge because patients are “independent enough” to go home, thus aligning the practical, moral, and institutional demands of autonomy. No matter how much dependency patients carry with them upon leaving, discharge is the milestone that marks the beginning of an open future of autonomy for the elderly. Staff communicated that a world of possibilities awaited outside of institutional care. This was especially the case when patients were considered not old enough to be in a nursing home, or when staff said they still had “a lot to give.” One 54-year old woman, Nikki, had refused to leave post-acute care because she had lost the lease on her apartment and was waiting to find a new one. One day, people started buzzing: social worker Alyssa had convinced her to go to her sister’s house. Alyssa described her negotiation in these terms: “I think she [Nikki] had her ‘aha’ moment. She was giving me all these reasons why she couldn’t go home and then I told her Nikki, shut up for a minute ... You are so creative and have so much life, this is not the place for you ... Don’t look at this like the end of the road, just cause you’re going to your sister’s now doesn’t mean your journey will end there, you can still move to another apartment.”

These negotiations suggest that autonomy is an ever-moving target. While for Nikki autonomy initially means to find a place of her own, Alyssa reformulates the goal: if Nikki can accept to rely on her sister’s care and housing, her “journey” can continue. By extending the horizon of autonomy, Alyssa situates dependency in the momentary present as a stepping stone for the “real” goal of autonomy. In this sense, Oakville is akin to what Eliasoph (2015) calls “empowerment projects:” civic organizations that treat participants as perpetual future potentials whose goals are located in an indefinitely receding horizon.

Similarly, success at MTIC does not require participants to demonstrate complete independence from others. Indeed, the program is intended to be a permanent source of support that will continue after parents pass away. Success is measured instead by a singular focus on improvement.

Brendan was reluctant to engage the program when he first entered. Because he did not have an intrinsic motivation to work toward autonomy, his parents and staff organized their support to provide external motivations for Brendan to work. For example, they established a strict budget for Brendan, one that would make him “uncomfortable” and induce him to work. In one care planning meeting, Brendan was particularly upset by reports from staff and his parents about his lack of progress, “It just makes me feel worthless.” His father, Ari, quickly responded, “Brendan, you are not worthless, but I will not let up on you because that’s my job.” He goes on to describe what he sees neighbors going through with their children who have ‘profound

disabilities,’ “The fact that I can use the word profound and you understand it is an indicator of how much you are capable of. You are great at your living skills. Not only are you independent but you are a member of a community.” He continues to describe his expectations for Brendan explicitly as progress, “Stage one is independence, stage two is integration, stage three is to have a purpose.”

Brendan’s parents do not expect him to be completely independent in all areas of his life but they do expect him to orient his life toward future progress. *Independence*, *integration*, and *purpose* are ill defined goals that, in reality, are never achieved. For them, successful autonomy involves discharging isolated goals once Brendan achieves them *and* replacing them with something new. And so Brendan’s autonomy horizon moves forward.

As described earlier, MTIC is intended to provide lifetime support to participants and so does not share Oakville’s use of discharge as a metric of successful autonomy. Over time, some participants stop working with ComHab altogether, moving into a new stage of their independence in which their daily lives are not as deeply scrutinized. However, fully discharging clients was fraught with contradictions, since it could be seen as proof of failure rather than achievement.⁵

Munson’s time at MTIC overlapped with a partial program redesign in which they allowed select participants to “step-down” to half time support from their social workers (i.e. meeting twice a month instead of weekly). While the program was still in the process of defining the requirements for step-down, staff were extremely reluctant to offer decreased services simply because long-term participants utilized few of the program’s services and demonstrated limited interest in pursuing increased independence. Elsa was one of the program’s founding members and had been a participant for 10 years. When her parents approached Nancy, the program director, about step-down, the staff was conflicted. Elsa wasn’t autonomous yet, in part because her parents “sabotage her” by accommodating her lack of progress with extra support rather than pushing her to pursue *moral autonomy* through the program’s process of goal setting, discharge, and goal replacement. Other participants, like Tyler, were obvious candidates for step-down both for their demonstrated physical autonomy and for how they demonstrated a desire to continue improving.

When autonomy projects fail In one extreme case, MTIC made the decision to discharge a participant altogether. During Munson’s last few months of fieldwork, Charlotte stopped eating. At 26, she felt that it was her choice when and what to eat and resisted any intervention from staff, her parents, or her aunt to order her eating. She shed pounds weekly until her weight hovered around 80. The only time staff could reliably convince Charlotte to eat was when they were with her, watching her put food into her mouth and reminding her to take bites. The problem was that most of the time staff was not with her, leaving Charlotte alone to continue choosing not to eat. To work around this, staff created a complicated system to monitor Charlotte’s eating.

⁵ At Oakville, too, discharge was not always evidence of success. Elderly patients were sometimes discharged because their insurance denied payments, or because they or their families members insisted on signing out against medical advice. These cases in which discharge off of post-acute care was not the desired outcome, however, were much less frequent than discharge as a metric of success.

When the system worked, Charlotte shopped and prepared meals on her own. She packed her own lunches on days she had class, and faithfully recorded her meals with a photo that she uploaded to a nutrition app as proof of her success. The system provided a scaffolding for Charlotte's self-care, but when it didn't work it presented increasingly dangerous opportunities for failure. Ultimately, the institutional framework for autonomy provided by MTIC was not adequate to support Charlotte and she was eventually discharged to live in a group home where the institutional dimension of autonomy would more fully support her autonomous project, especially the limits to her *practical autonomy*.

As Charlotte's case shows, "successful autonomy" is only achieved when the practical, moral, and institutional dimensions of autonomy align, enabling a person to move autonomy's horizon forward to reflect new constellations of (in)dependence.

Discussion

As West and Zimmerman (1987) argue for gender norms, autonomy is a practical achievement we do every day without noticing, until it becomes problematic. In this article we have compared two populations for whom autonomy is visibly problematic. This allows us to see the work that goes into fashioning recognizable and coherent autonomous selves.

We began this comparative project to explain an essential paradox we saw in each of our cases, that people were being labelled as autonomous even in the midst of their, sometimes profound, dependence on others. Rather than falling back on interdependence to explain these perceptions of autonomy as fictions, we decided to take seriously that our research subjects did not consider dependence and autonomy to be mutually exclusive. Rather, we find that they are able to identify autonomy by arranging present dependence so that the contours of autonomy in the future remain open. No one at either site talked about dependency as something for the future, suggesting that the ideal self, the autonomous self that organizes action, is never dependent, even if the present one is.

Our analysis of the temporal aspect of autonomy reveals three distinct but interrelated dimensions: institutional, practical, and moral. *Practical autonomy*, the capacity to act independently of others, most closely aligns with traditional conceptions of autonomy yet only makes sense in relation to the other dimensions. *Institutional autonomy* describes the social and organizational constraints on how a person can perform *practical autonomy* and to what extent lingering dependencies will be accounted for. *Institutional autonomy* is especially important for defining what an autonomous future can and should look like. At each of our field sites, staff put these dimensions of autonomy in conversation with one another by defining successful autonomy in terms of progress toward independent living goals. As individual goals were met, staff redefined their expectations for clients by replacing old goals with new ones. This process was both enabled by, and continued to reproduce, *moral autonomy*, the internalized ideal that autonomous people desire progress toward their autonomy horizon. Ultimately an autonomy "success story" (Ezzy 1998; Goffman 1961) required staff and participants to situate this work within a coherent story of past and future selves.

By constantly adjusting and fine-tuning where in time autonomy is, the workers at the two sites we studied navigate the tensions between these three dimensions. To realize their mission (making people “as independent as possible”) these staff members engaged in constant assessment of their clients: not only through institutional indicators and instruments, but also by making local interpretations in which they looked for evidence of people’s motivations and desire to be autonomous. These interpretations were temporally oriented through the analysis of their client’s past capabilities and future possibilities. We have thus argued that producing autonomous people is done by managing the temporal horizon of autonomy through an ongoing calibration of open futures, ideal pasts, and transitory dependencies.

Following feminist scholars and theorists of relational autonomy, we argue that autonomy doesn’t exist in any tangible form but is constructed through social interaction. Departing from this scholarship’s emphasis on demystifying independence as an impossibility, we foreground the importance of autonomous ideals as organizing principles for social life, and we seek to understand how they operate. In other words, while autonomy doesn’t exist, we show that it has very real consequences in shaping social life. It motivates action *because* it is never fully achieved. As we have shown in both of our cases, autonomy’s existence in the future means that there is always something new to work toward, even when one has accomplished the goals set before them. This is the irony of successful autonomy: when an individual achieves independence, being autonomous means having the moral desire to improve still further. This argument builds on Munson’s (2020) conception of *lifework*, a neoliberal strategy to frame dependence as work toward future autonomy. In this paper, we show how dependence becomes invisible when it is framed as a transitory characteristic. By placing our cases in conversation, we are able to demonstrate that autonomy depends on situating dependency not only *somewhere*, in relation to people and things, but *sometime*, according to imagined pasts and future goals.

Theorizing autonomy as a temporally situated phenomenon thus expands interpretations which have largely criticized autonomy as a myth that obscures other people’s labor (Kittay 1999; Rivas 2011). We show that to uphold the fiction of autonomous subjects, it is crucial to also obscure *moments* of dependency as transitory. Feminists writing about care have implicitly made this argument by pointing out that the autonomous adult forgets, or fails to anticipate, the multiple moments in life in which we are particularly dependent (Tronto 1993), yet this literature has ignored the implications of this temporal dimension of autonomy. We argue that the notion of autonomy is constructed and sustained by strategically managing its temporal aspect. In order to interpret ourselves as autonomous, we must enact situated knowledge of when and how to obscure dependency by situating it as a temporary state within a larger project of autonomy. The autonomous person is one who adapts to these constraints and frames new dependencies as part of a stable and coherent self-identity.

Our findings can be expanded to better understand a variety of institutional settings where making autonomous subjects is a central project. First, while there’s much valuable research on the disciplining power of institutions that aim at inculcating independence in their subjects, we argue that it is key to examine the interpretive grounds on which this discipline operates. For instance, research on state interventions such as nutrition programs for mothers and infants (Mason 2016), group homes for incarcerated women (Haney 2010), or welfare-to-work programs (Little 1999), show

that discourses of dependency as undeserving and morally tainted are mobilized to produce self-surveilling subjects that must work toward independence. By applying our insights about the temporal construction of autonomy, as an ever-moving target, we can better understand how this discourse becomes effective.

Second, the institutions that define life in modern society, from education to romantic relationships to careers, present their subjects with an ever-changing social landscape in which *institutional*, *practical*, and *moral autonomy* enter into conflict. For instance, Gong (2019) shows that psychiatric patients might be considered “independent enough” to live on their own according to institutional standards, even if they lack practical and moral autonomy in the eyes of the state agents charged with overseeing them. In Gong’s account, these agents forgo the expectation of autonomy as a future project for these subjects. We have shown another way in which institutional actors deal with the tensions between the material reality of bureaucratic autonomy and its practical and moral expectations: instead of decoupling these dimensions, they align them in an always-indefinite future.

Importantly, Gong (2019) suggests that the management of mentally ill patients varies by class, with wealthier people closely supervised for compliance and deemed capable of recovery, and more deprived patients afforded behavioral latitude and fewer hopes of “respectable futures.” While our data do not allow to establish variation in the institutional judgement of autonomy based on clients’ race, class, or gender, others have pointed out that the idea of open futures and possibilities is a form of privilege (Auyero 2012; Bourdieu 1997; Frye 2012; Hazan 2015) and that independence itself functions as an axis of inequality (Fraser and Gordon 1994). Further research can explore the ways in which the temporal constructions of autonomy’s horizon unfold along these and other social differences.

Acknowledgements The authors would like to thank Iddo Tavory, Gil Eyal, Diane Vaughan, and Clayton Childress for their comments on this manuscript and for their support of our research. We also benefitted from comments on early drafts from Columbia’s SKAT Workshop, the 2020 Junior Theorists Symposium, and the NYLON working group hosted by the Institute for Public Knowledge. Isabel Gil Everaert and Sebastián Villamizar, in particular, provided insightful comments on our drafts.

Authors’ contributions Study conception, design, and data collection were completed separately for each field site by each author. Both authors contributed equally to the analysis of interpreted data. The manuscript was written simultaneously by both authors who also shared the work of revision and editing. All authors read and approved the final manuscript.

Funding Munson’s research was funded by a National Science Foundation Dissertation Improvement Grant (award #1802591) as well as a research grant from the Department of Sociology at Columbia University. Altomonte’s research was funded by a dissertation fellowship from the Heilbroner Center for Capitalism Studies at The New School and a dissertation fellowship from the Sociology Department at The New School.

Declarations

Conflict of interest The authors declare that they have no conflicting interests related to this study.

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