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DISABILITY POLICY: ARE WE MAKING PROGRESS?

By Shelley Burtt

Abstract: *This essay criticizes recent trends in disability policy as restrictive of individual liberty and informed by too narrow a definition of what constitutes human flourishing. I defend the value of intentional community settings as one legitimate residential option for people with intellectual and developmental disabilities. Recent federal regulations (HCBS Final Rule) define intentional communities or disability-specific housing as presumptively institutional in nature, misunderstanding the positive, noninstitutional features of intentional, integrated communities created by and for people with developmental disabilities. In addition, current disability policy, despite its stated concern for the autonomy of people with intellectual and developmental disabilities, limits individual liberty by strictly defining the types of settings eligible for Medicaid waiver funding, expressly excluding agricultural communities, disability-specific residential settings, and intentional communities. A robust commitment to the autonomy of people receiving Medicaid waiver services would allow them to choose to direct their program dollars, recognizing that some individuals may choose a life in intentional community or with others facing similar challenges to themselves over an illusory "integration" into a wider society that remains too often unwelcoming and difficult to navigate.*

KEY WORDS: disability, community, Medicaid waiver, Home and Community Based Services, HCBS, autism, intentional community, self-advocacy, disability policy, autonomy, choice, quality of life, inclusion, Camphill

In January 2014, the federal agency in charge of Home and Community Based Services (HCBS) for people with physical and intellectual disabilities concluded a years-long process and promulgated a "Final Rule" regarding the type of programs that would from 2019 onward receive funding in the area of service provision for people with disabilities. The HCBS Final Rule is a culmination of more than four decades of progress in how the government provides services to the disabled, ensures their inclusion in the wider community, offers opportunities for meaningful employment, and in general advocates for their full integration into the wider society. There is much that is positive in the HCBS Final Rule, from its unequivocal condemnation of large-scale institutions responsible for the warehousing of generations of individuals with disabilities to its effort to ensure independence and equality of opportunity for individuals with a wide range of cognitive and physical impairments.

However, when it comes to residential opportunities for people with moderate to severe intellectual and developmental disabilities, the regulation overreaches. In particular, the Final Rule singles out for defunding a type of community-based program currently supporting people with autism, Down syndrome, and other intellectual and developmental

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disabilities across the country: intentional, integrated communities created by and for people with disabilities, purposively set apart from the mainstream or "broader" community, often in a rural and especially agricultural setting, created with the goal of consciously cultivating the type of environment that will enable people with a range of complex needs and developmental disabilities to flourish. Because these service settings do not meet the regulators' ideal of full integration into the wider community, they are condemned as "socially isolating," with such isolation being treated as presumptive evidence of the institutional, and thus illegitimate, character of the setting.

As executive director of a foundation the mission of which is to support a network of lifesharing communities organized around care for and with people with intellectual and developmental disabilities, these developments are politically, philosophically, and financially concerning. Recent interim enforcement of the Final Rule, including regulations that limit the number of disabled people able to share a house if they are to receive funding for residential services, are already impacting our communities, most of which use a model of extended family housing with meals taken in common to build social integration and a sense of belonging for all community members.

We have here not just a difference in policy models, but a disagreement about what constitutes liberty and progress in the realm of human flourishing. For proponents of the Final Rule, requiring that people with disabilities receive Medicaid waiver services without any segregation from people not receiving such funding represents necessary progress away from the shameful historical treatment of people with disabilities. And by "freeing" individuals to receive their services in unsegregated settings, side by side with typically abled individuals in the community, these regulations can appear to advance individual liberty as well as progress. But, as I delineate below, the current regulations, despite their stated concern for the autonomy of people with intellectual and developmental disabilities, in practice limit individual liberty by strictly defining the types of settings eligible for Medicaid waiver funding. The freedom to choose to make one's home in supportive, disability-specific housing or in an intentional community some of whose members have intellectual or developmental disabilities will be an empty promise if funding for that choice is specifically withheld by federal regulations. A robust commitment to the autonomy of people receiving Medicaid waiver services would allow them to choose to direct their program dollars, recognizing that some individuals may choose a life in an intentional community or with others facing similar challenges to themselves over an illusory "integration" into a wider society that remains too often unwelcoming and difficult to navigate.

The idea of progress is also implicated in this discussion, as changes in disability policy are presumably made to secure an improvement in outcomes, services, and civil rights for the people impacted by these policies. In reviewing the Final Rule regulations, one cannot escape the impression

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that "progress" for people with disabilities appears to be measured by increased conformity to the mainstream lifestyle choices of nondisabled fellow citizens. As the majority of US citizens in the twenty-first century become more isolated (27 percent of American adults now live alone, according to 2013 Census Bureau data) and more urbanized (80 percent of American residents), so too will progress for people with disabilities be measured by their move from group homes to single apartments, from agricultural settings to towns and cities. But what underlying assumptions dictate that conformity to dominant forms of living arrangements represents "progress"? Access to such living arrangements for people who choose them, to the extent that such options were previously unfunded, certainly represents progress. But what is missing here is the opportunity for people, regardless of ability, to make a choice to live in community with others, to pursue in the name of social renewal or simply personal preference, a communitarian lifestyle that upholds mutual dependence over independence, and social living over the hyper-individualization of our current world. Others simply value the choice, out of a love of the land and the peace that working with animals provides, to make a life on a working farm, a choice that current regulations specifically single out as ineligible for Medicaid waiver funding.

It is not the purpose of this essay to explicate the reasons the Final Rule took the exact shape it did, or to speculate about the forces, analyses, or interest groups that found it important to single out intentional communities as heinous examples of modern-day institutionalization. Nor will my critique of the regulations be empirically based, documenting the immense distance between the ideal of full inclusion in the mainstream community underlying the Final Rule and the lived experience of individuals for whom a subsidized apartment, a few hours of vocational training a week, and social relations consisting primarily of one's part-time, underpaid social service aides, is a recipe for loneliness, boredom, and existential angst. As early as 1995, McKnight found that relocation "to local places has had almost no positive effect on the participation of labeled people in community" and that adults described as "being 'in the community' [were] . . . completely isolated from community."[1] Robin Jackson's indictment, responding to developments in Great Britain, is more sweeping. Referring to one of the main disability charities in the UK, he writes,

> Mencap's unqualified support for the policy of placing people with an intellectual disability in the open community comes at a cost. This policy is predicated on the assumption that the communities in which

[1] James McKnight, *The Careless Society: Community and Its Counterfeits* (New York: Basic Books, 1995), 115, 120 as quoted in Pamela Cushing, "What Counts as Community? Alternative Approaches to Inclusion and Developmental Disability," *International Journal of Developmental Disabilities* 61, no. 2 (2015): 87.

> people with an intellectual disability are placed are going to be welcoming and supportive. But as [a recent] report . . . found, people with an intellectual disability living independently in the community frequently experienced a disturbing range of crime, abuse and harassment.[2]

Others are taking up with powerful impact these necessary empirical studies, but this important entry point into the debate is one I set aside here.[3]

My critique examines the same regulations through a more philosophical lens, in particular exploring the conflicting conceptions of human flourishing and community inclusion embedded first in intentional communities like Camphill and secondly in contemporary disability policy as reflected in HCBS regulations. From this perspective, two features of the current regulations draw my attention. First is that the expressed values of autonomy, choice, and social inclusion adopted by the Final Rule are at odds with the explicit exclusion of intentional communities from Medicaid waiver funding streams. If autonomy is indeed a value of the Final Rule, then people should be afforded the ability to determine the settings within which they receive services. To rule out certain settings as "too isolating" despite individuals' stated preference for such a life is to act paternalistically, not to advance freedom and autonomy. It could be that the danger of segregation and isolation is so great in the view of the state that such danger trumps the value of autonomy. But then that trade-off should be affirmed explicitly. The regulations as they exist now restrict autonomy, rather than furthering an individual's right of self-determination. This represents neither progress nor liberty.

Secondly, when viewed via the lens of the practice of intentional communities particularly, HCBS regulations reveal a built-in bias towards a highly individualized, indeed hyper-liberal understanding of what it means to live well in the modern polis. Here my argument is that intentional communities like Camphill, which provide social integration as part of an explicit community lifestyle choice, have been swept up in the category of settings "presumed institutional," because of unexamined assumptions about the good life implicitly informing the Final Rule.

[2] Robin Jackson, "Who Cares? The Impact of Ideology, Regulation and Marketisation on the Quality of Life of People with an Intellectual Disability" (London: Centre for Welfare Reform, 2015), 25. See also Roy Brown et al., "Quality of Life and Social Inclusion across the Lifespan: Challenges and Recommendations," *International Journal of Developmental Disabilities* 61, no. 2 (2015): 93–100.

[3] See, e.g., Bob Rhodes and Richard Davis, "Regulation: The Unintentional Destruction of Intentional Communities" (London: Centre for Welfare Reform, 2014); Maria Lyons, "Re-thinking Community Care: The Camphill Village Model, A Critical Appraisal," (London: Centre for Welfare Reform, 2015) and Robin Dunbar, "Realities of Social Life and Their Implications for Social Inclusion," in Robin Jackson and Maria Lyons, eds., *Community Care and Inclusion for People with an Intellectual Disability* (Edinburgh: Floris Books, 2016).

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Well-regarded choices for individuals and their families are being ruled out, not because of qualitative evidence of comparatively poor quality of life outcomes for people with developmental disabilities, but simply because, as a cohesive, integrated community, this particular form of service provision does not embrace the mainstream, highly individualized lifestyle now taken as "normal" by the vast majority of Americans. Here I propose that underlying the expressed values of the Final Rule are implicit assumptions about what it means to be independent, autonomous, not segregated, and free from institutionalization that are shaping, in ways detrimental to intentional communities, the vision of what counts as a good life.

Finally, to better understand the culture clash that HCBS regulations set up with intentional communities, it is helpful to say a little bit about Camphill, since my enthusiasm for this model, and interest in defending its relevance, lies behind my critique of HCBS regulations. As described in internal Camphill literature, "Camphill is a worldwide movement of vibrant lifesharing communities where people with and without disabilities strive together to reach their full potentials. We value the profound significance of each human being and foster sharing of resources and responsibilities to enable each individual to actively contribute to the community's well-being." According to Dan McKanan, author of one of the few scholarly studies of Camphill, Camphill is a mission-driven countercultural movement best understood in the tradition of Christian utopian community building.[4] Camphill leaders in North America often describe Camphill as a three-fold organization: a service provider to people with disabilities, an anthroposophical organization seeking to put into practice the esoteric insights as well as the practical teachings of the philosopher Rudolf Steiner, and a Camphill Community, aspiring to community building grounded in principles of radical equality, robust inclusion, and faithful environmental stewardship, all as a means to spiritual healing and social renewal.[5]

Camphill was founded in 1939 by an Austrian pediatrician, Karl Konig, deeply influenced by the philosopher Rudolf Steiner and interested in applying Steiner's teachings to the care of disabled children. When the Nazis invaded Austria, Konig fled with a small group of his students and children to Scotland. Here the distinctive qualities of Camphill communities took hold (on the donated land of Camphill estate, from which the movement takes its name) — including, importantly, a commitment to lifesharing and equality of resources. Unpaid labor given freely and

[4] Daniel MacKanan, *Touching the World: Christian Communities Transforming Society* (Collegeville, MN: Liturgical Press, 2007). See also the essays in Robin Jackson, ed., *Discovering Camphill: New Perspectives, Research and Development* (Edinburgh: Floris Books, 2011).

[5] See "Principles of the Camphill Movement," Camphill Association of North America by-laws, document in the possession of the author.

compensated only by support from the community to meet the immediate needs of one's family, while increasingly problematic to uphold, remains an ideal.

Camphill's lifesharing communities arrived in North America in 1961 and now the Camphill Association of North America comprises twelve communities and several affiliated organizations serving over sixteen hundred people, half of whom have developmental disabilities, sharing lives together in intentional communities, often rural, but increasingly urban outposts. Without explaining the nature of the communities in detail, it is worth mentioning here three distinctive elements of Camphill as a service provider that bring it into conflict with HCBS regulations.

- Foundational commitment to service based volunteer lifesharing
- An inclusive and self-sufficient nature that can read as "segregated"
- Highly routinized schedule and concentration of daily activities on-site

These qualities are not accidental but essential elements of Camphill life, considered by its practitioners intrinsic to their therapeutic mission. Thus, the Final Rule strikes at the heart of what Camphill does. Lifesharing volunteers make a short or long-term commitment to live in community with other people, some with more complex needs than others, and strive to live out of a social ideal articulated by Steiner as the "Fundamental Social Law": "The more an individual works for the benefit of society or the needs of others, and the more society ensures that each worker is supported sufficiently to lead a dignified existence, the greater the well-being and prosperity of society will be."[6] Although regulations have increasingly forced Camphill coworkers to accept salaries, these are often returned *in toto* to the community, in order to enable the volunteers to live in accord with this fundamental ideal. Even this brief account drives home what a stark contrast this is to the HCBS-mandated employment of aides, to be paid at the Medicaid set reimbursement rate, working on shifts. HCBS envisions these aides assisting their "clients" to access community-based services and activities in which or through which they can develop natural, organic friendships and supports. But as one Camphill resident said about those with whom he shared his life, "This isn't their job; it's their life!"

Camphill is often criticized for its insular nature. This stems in part from its dual nature as a service provider also engaged in a spiritual task of deep community building. But this inward focus also stems from a commitment to a holistic form of support for those with special needs, based on the teaching of Rudolf Steiner, called "social therapy" and an environmental

[6] Gary Lamb, ed., *Selected Passages from Writings and Lectures Related to the Fundamental Social Law* (Loma Mar, CA: Institute for Social Renewal, 2007).

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vision (also found in Steiner's work) of the value of a self-sufficient community. There is something healthy and enlivening when one's own work produces the food one eats; when waste is recycled on site; when a community gathers together to make its own entertainment together rather than dispersing to pursue independent preferences. Under pressure from the state, Camphill will become more outward looking and some communities have enthusiastically embraced the challenge of connecting more closely with the outside community. For example, a number of the communities now host weekly suppers for their town's residents either on-site or at local soup kitchens. Cafés and gifts shops on Main Street and open to the public are also increasing, and one community sponsors an after-school program in which at-risk youth are paired with disabled Camphill residents in a food preparation and healthy eating workshop. But these overtures continue to be part of a consciously chosen community activity rather than a facilitation of individuals to pursue independent preferences in the wider community.

The highly routinized schedule is in part a practical requirement of life in large households and interdependent communities and in part a feature of social therapy's understanding of the human being, in which we all thrive by being enfolded in daily, weekly and seasonal rhythms. The schedule is intended to make this sort of therapeutic routine readily available. The concentration of daily activities on-site reflects in part the commitment to the ideal of self-sufficiency but also, again, the image of the person that is upheld in Camphill and anthroposophy in general. All human beings should be understood as body, soul, and spirit and good care for anyone involves access to activities that feed all three elements of the person. Thus work on-site is concrete, meaningful, creating a sense of worth — milking the cows and seeing that milk on the table the next day — and designed to tap into our artistic needs. Camphill communities offer workshops in weaving, mosaics, pottery, wood-working, candlemaking, papermaking — the opportunity to be artists, to transform organic materials into something beautiful, to be a creator. This is not the opportunity for "competitive employment" as the HCBS regulations will soon require, but it serves other goals. And, for those who argue that even those with disabilities should have the chance to feel valued and worthy by earning a paycheck, even for relatively menial labor, Camphill's alternative philosophy poses a direct challenge to the idea that money and the ability of one's labor to command money is the appropriate measure of self-worth.

A final note: most of the "cohesive communities" threatened by HCBS regulations do not fit the spiritually based alternative community-building model of Camphill. They include farms for young adults and adults with autism built and funded by anxious parents, and campus settings with dorm-like residential options and on-site activities, in which people with disabilities are cared for by staff working in shifts. Some provide outstanding quality of care; in others there is surely room for improvement,

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improvement that may be instigated by the requirement to meet HCBS regulations. However, in the name of maximizing individual choice and social integration, the government is de-funding community options that a significant cohort of people affected by the HCBS Final Rule have chosen as their preferred living situation and where they find, by objective and subjective measures, a high quality of life.

I turn now to the details of the HCBS Final Rule. As explained in the informational documents of the Center for Medicare and Medicaid Services (CMS), the federal agency issuing these regulations, "any residential or non-residential setting where individuals live and/or receive HCBS must have the following five qualities by March 2019:

- "Is integrated in and supports full access of individuals to the greater community
  - Provides opportunities to seek employment and work in competitive, integrated settings, engage in community life, control personal resources, and
  - Ensures that individuals receive services in the community, to the same degree of access as individuals not receiving HCBS
- Is selected by the individual from among setting options including non-disability specific settings and options for a private unit in a residential setting
- Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
- Optimizes individual initiative, autonomy and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- Facilitates individual choice regarding services and supports, and who provides them."[7]

In a provider-owned or controlled residential setting, additional requirements call for housing to be shifted to a rental model in which all residents sign leases or other rental agreements with the organization that serves and houses them. This is to ensure that individuals see themselves as choosing their housing situation and able to choose alternatives if desired. Finally, in these settings, "Individuals [must] have the freedom and support to control their own schedules and activities, and have access to food at any time."[8]

This broad list of admirable requirements would seem to allow for a variety of forms of community living options. But in fact we are already

[7] "Home and Community-Based Settings, Excluded Settings, and the Heightened Scrutiny Process," Center for Medicare and Medicaid Services (2015), 5–7.

[8] "Regulatory Requirements for Home and Community-Based Settings," https://www.medicaid.gov/medicaid/hcbs/downloads/requirements-for-home-and-community-settings.pdf.

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plunged into a contested conception of what counts as a legitimate "community" into which someone with disabilities can be integrated. Above all, states must scrutinize the settings provided to ensure that they do not have "the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS." In practice, this means that residences and services, including opportunities for "competitive employment," must be offered "side by side" with the services, activities, and employment options of the larger, nondisabled population of the town, city, or locality where the disabled person lives. The choice to make one's life with others facing similar challenges and in an environment consciously adapting to one's special needs is ruled out as setting one apart from the general population ("socially isolating") and therefore institutional in nature.[9] Settings with the effect of isolating individuals are listed in the guidance provided by CMS and specifically include: "a farmstead or disability-specific farm community" in which "individuals who live at the farm typically interact primarily with people with disabilities and staff who work with those individuals; daily activities and non-home and community-based services, such as medical and religious services, take place on-site . . . ; people from the broader community may sometimes come on site, but people from the farm seldom go out into the community as part of daily life." Similarly suspect are gated or secured "communities" with similar characteristics (note that the federal regulations themselves place the word community in scare-quotes) as well as residential schools for children with disabilities.[10] As critics have begun to point out, the quality of life that residents of these communities experience is not interrogated by the Final Rule; rather "integration in the broader community" becomes an end in itself.[11]

Ironically, the intentional communities of Camphill are anything but socially isolating. Rather they represent a conscious effort to overcome the hyper-individualism of our modern liberal society and live instead by explicitly communitarian ideals, which include living in extended family homes, sharing income and labor in order to meet the community's needs, taking meals in common, and affirming a shared spiritual practice actively seeking to assist fellow community residents in realizing their full potentials. So while they are "isolated" from the greater society, intentional communities are not socially isolating. HCBS regulations confuse these two states, assuming that independence and quality of life cannot be achieved for people with intellectual and developmental disabilities if "set apart" from the broader society or in settings specifically created to accommodate their special needs. The sad truth is that mainstreaming of individuals is no guarantee of the experience of belonging, friendship,

[9] "Home and Community-Based Settings," op. cit., 13.
[10] Ibid., 17.
[11] Cushing, "What Counts as Community?" 88.

and natural supports from among neighbors, job colleagues, and town residents that is presumably the aspiration of the rule.

Another consideration raised by contrasting the side by side settings preferred by the HCBS Final Rule and intentional communities concerns different understandings of equality and social integration. At Camphill, meals are taken in common as part of extended family households, at a dinner table of ten to twelve people up to half of whom have intellectual disabilities. Everyone has helped prepare the meal and all will help clean up. Under current Medicaid Waiver regulations, such meals are ineligible for funding as too many people with disabilities are seated together, creating, in the regulators' mind, an institutional or segregated environment. But consider the implicit bias in this judgment. "Normal" settings do not include a critical mass of people with intellectual disabilities eating or working together; normal life is one characterized by people without disabling characteristics and thus true integration of people with disabilities requires them to be sprinkled in among the rest of us. The test of successful integration is, ironically, de facto isolation — the one person with disabilities bagging groceries at the local supermarket, the one person with Down syndrome greeting shoppers at the local Sephora (as in my town). The implication is that people with intellectual and developmental disabilities are better off and experience greater quality of life when not sharing activities or residential life together. As Cushing points out in her critique of the metanarratives driving contemporary disability policy, "to discourage and discount the value of friendships between PWDD [sic] however is effectively to make a negative valuation of PWDD [sic]."[12]

As a practical matter, the ratio of people with and without special needs in Camphill communities is typically 1:1, with several communities including more typical adults, including frail elders, than those with special needs. Such "equilibrium of abilities" is both a social experiment and impossible to achieve in the broader community. To those living in the community setting, the equilibrium of abilities is a strong protection against stigma and a powerful valorization of equal worth and dignity of people of all abilities.

To HCBS regulations, written to exclude "cohesive community" alternatives to truly institutional settings, this equilibrium of ability levels is deemed socially isolating because there are "too many" disabled individuals concentrated in one place. Disability scholars skeptical of the current regulations direct a withering critique at this Goldilocks version of community integration: not too much, not too little, but "just right" numbers of people with disabilities in contact with each other and with those who do not have similar challenges.[13]

[12] Cushing, ibid., 87.
[13] Ibid.

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In conclusion, current regulations do not concern themselves with the personal or existential experience of "social isolation" and ask how it might be overcome. Rather current regulations satisfy themselves with a policy of normalization — as long as those with developmental and physical disabilities are physically integrated into the typical residential patterns of a town or locality, and isolated by regulation from each other (for example, no home serving a person with disabilities can be within eyeline of another such home), equality of rights and community integration is achieved. The felt experience of loneliness versus belonging, opportunity for meaningful contribution versus activities chosen to fill the empty hours in one's days, are not criteria by which the HCBS Final Rule assesses successful community building or integration.

Just as community and its presumptive opposite ("institutional living") are defined by the Final Rule in particular ways that work together to rule out intentional, cohesive communities as a legitimate (or at least *funded*) life-choice for people with developmental disabilities, so too do the regulations deploy a conception of individual well-being and personal autonomy that has the functional consequence of narrowing a person's actual life-choices by valorizing only certain ways of relating to others as appropriate for state funding.

As we have seen, the HCBS Final Rule has a valid, indeed admirable aim, of encouraging states to end the warehousing of individuals with disabilities in nursing homes (this is mostly an issue for people with severe physical disabilities) and other limited segregating settings. These regulations err in treating all forms of cohesive communities, including intentional communities like Camphill and those created by parents to accommodate the perceived needs of their children and maximize their well-being, as institutional and inherently suspect in nature. But the philosophical significance of the Final Rule goes beyond the mainstream liberal image of "community" that it valorizes at the expense of other valid community conceptions. The Final Rule also (and unintentionally) enshrines a particular, and equally contested, understanding of the individual as most free and thriving when living as an independent, preference-maximizing consumer, untethered by responsibilities or obligations. In fact, if we examine the regulations, in their concern to prevent the very real excesses of institutionalization, they also remove the opportunity for PWDD to experience a sense of belonging, mutual dependence and even conscious self-sacrifice which can characterize members of a cohesive or intentional community.

I examine first the evidence contained within the regulations for my claim that their implicit ideal is the preference-maximizing consumer. As the Final Rule nears full implementation, states are charged with scrutinizing residential options and community settings that, because of their congregate care nature, are at risk of being institutional in nature. The "Exploratory Questions to Assist States in Assessment of Residential Settings" is a list of twenty-two criteria against which all suspect settings

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should be assessed, with a number of questions provided for each criterion indicating the sorts of practices that must be present in the setting to qualify it for HCBS funding.[14]

Many of the criteria seek to assure unobjectionable, important elements properly present in any noninstitutional supportive community setting. For example, under criterion 17, the state must determine that "the individual has unrestricted access in the setting." No gates, locked doors, or other barriers should impede a person moving around his or her home. Further HCBS recipients should have the same access to the site's facilities (e.g., pool, gym, game room) as others not receiving funding. Criterion 21 specifies that "individuals who need assistance to dress are dressed in their own clothes appropriate to the time of day," and criterion 22 sets out that "staff communicates with individuals in a dignified manner." In fact, it is sad to imagine the conditions found often enough in institutional or group home settings that it appeared necessary to specifically ask: "Are individuals wearing bathrobes all day long?" "Are individuals moving about inside and outside the setting as opposed to sitting by the front door?" "Does staff address individuals in the manner in which the person would like to be addressed as opposed to routinely addressing individuals as 'hon' or 'sweetie'?" We can all agree that any setting funded for someone with a disability should reach these thresholds of personal dignity and autonomy.

Other criteria create immediate and sometimes profound challenges for intentional communities. This is because the regulations simply do not contemplate or seek to anticipate an integrated, inclusive community in which members' activities are primarily organized not around the maximization of day-to-day individual preferences but rather around contributions to long-term community well-being. Thus, a number of the criteria seek to ascertain that a person receiving HCBS funding can do what she likes when she likes: "Does the individual shop, attend religious services, schedule appointments, have lunch with family and friends, etc. in the community, as the individual chooses?" "Does the individual come and go at any time?" Implied in these questions is a standard that an individual has complete control of her schedule and that those paid to support her are to organize their schedules to ensure that these activity preferences are met. The idea that the individual may have responsibilities that might require setting aside such immediate preferences to contribute to the well-being of a group of people who depend on her contribution is simply not contemplated. Yet that is the fundamental therapeutic concept of a Camphill community: all are important; all are needed. If this means milking a herd of dairy cows by hand rather than by automated machines,

[14] "Exploratory Questions to Assist States in Assessment of Residential Settings," https://www.medicaid.gov/medicaid/hcbs/downloads/exploratory-questions-re-settings-characteristics.pdf.

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low-tech triumphs over "efficiency." In fact, the agricultural nature of so many of these communities stems from the fact that the necessary tasks and rhythms of gardening (or of crafts such as weaving, pottery, and mosaic work) lend themselves to the meaningful contribution of people of all abilities. But this inclusion comes at a cost. In a community that relies on its own members to prepare common meals, feed the farm animals, weed the garden, support others through sharing leisure time activities that are fully inclusive of all abilities, it simply is not the case that, as criteria 5 dictates, "The individual chooses and controls a schedule that meets his/her wishes . . . The individual chooses when and what to eat." The Exploratory Questions indicate that there is to be no set schedule for waking, bathing, eating, exercising, and so on, but in a community, as in a family, schedules for at least some of these activities make perfect sense. Rarely in our everyday lives, do those of us without significant physical or cognitive disabilities "choose and control a schedule" without regard to shared commitments to others with whom we make our lives.

Here I want to underline the way in which the Exploratory Questions are building into the governmental definition of noninstitutional living an expectation that an individual's liberty and self-determination are evidenced by his or her ability to make preference-maximizing choices, ungrounded by responsibility to others. We have here a sadly impoverished conception of human freedom and well-being that is elevated into the touchstone of what counts as a noninstitutional setting for people with intellectual and developmental disabilities. The possibility that a person receiving HCBS might join with others in a common venture to sustain a life lived with and for others in an environment of mutual care and commitment is not entertained by these regulations. There are no questions in this assessment about the presence of genuine friendships, meaningful work, or sometimes arduous responsibilities taken on for the good of others or of the whole of which one sees oneself a part. Rather liberty and progress will be measured by the extent to which those who cannot live independently are supported by individuals (reimbursed hourly at minimum wage) whose job it is to help their "clients" construct from a menu of available activities, untethered to community responsibilities, a busy, satisfying life. The conditions that philosophers and others have long recognized as creating meaning and human flourishing — a sense of belonging, reciprocal care and responsibility, nontransactional human relationships — are not contemplated by the regulators as characteristics of a noninstitutional life or setting. Although the ideal behind the regulations is absolutely to ensure equality of opportunity and access, the image of how that ideal will be implemented is so distorted by its antipathy to farm-based and gated communities that important elements of human flourishing are ruled out of consideration.

These considerations lead us back to the question of choice — in what settings can people with developmental disabilities (advised by their

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families) choose to receive services? The Supreme Court's 1999 *Olmstead* decision made it clear that people must have a choice to live in an integrated community setting and not in institutions designed to warehouse those with disabilities. But how is this enactment of self-determination regarded in contemporary disability policy? Unfortunately, the implications of the Final Rule is that there are "right" and "wrong" choices about where one lives. To choose, with the help of one's family, a mainstreamed way of life is "right" and demonstrative of properly autonomous choosing; to choose, with the help of one's family, a gated community catering to people with autism or a farm organized around a communitarian lifestyle with no opportunities for off-site employment, is to make a "wrong" choice that condemns one to an institutional setting and from which one must be "saved" by the withholding of Federal funds. Thus, the CMS regulations require states to show "that the setting in which the individual resides is chosen by the individual" (so far, so good). But in addition, "The State must ensure that the setting chosen by the individual is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community . . . ," a qualification that in essence *restricts* choice, as Camphill or other intentional community settings are defined in the regulations as not meeting this criterion.[15]

These observations point back to the question of how current disability policy understands both liberty and progress. On the one hand, both the philosophical critique of the HCBS regulations and the thrust of contemporary disability policy is all about autonomy. People with intellectual and developmental disabilities have the same right to self-determination (so critical to human flourishing) as everyone else. This championing of self-determination and choice represents true progress in the treatment of such individuals. But it seems that the Final Rule has decided that the autonomy allowed to those with intellectual disabilities will only go so far — autonomous choice of what and when they will eat, yes; autonomous choice of an inclusive community, no. For example, as one parent of a young man now living at a Camphill community told me, "All he has ever wanted since he was eight years old is to live on a farm." From this parent's point of view, the farm-based community where her son finds himself is self-evidently his first choice of residence. Why then are the regulations intended to actualize her son's right of self-determination, by providing funding for his choice, ruling out his preferred residential option?

A charitable interpretation of this ironic disjunction might be that the dangers of institutionalization and the harms of living in an environment that appears to be segregated by ability are too great to leave the choice of residential setting up to the individual. Avoiding even the appearance

[15] https://www.medicaid.gov/medicaid/hcbs/downloads/requirements-for-home-and-community-settings.pdf.

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of segregation is so important that it trumps the right of people with disabilities to choose farmstead or disability-specific housing options even when these settings objectively result in less social isolation and in addition fit the expressed preference of the individual. But if so, then the claim of CMS to be advancing autonomy and choice by instituting these regulations necessarily rings hollow. In actuality, these values are being set aside to advance a particular vision of what constitutes the good life. As Cushing puts it, contemporary disability policy takes for granted that "independence (defined primarily as living alone in an apartment with minimal support needs and unfettered decision making) is the best and most normal way to live" and thus any choice for an alternative is, sadly, evidence either of false consciousness or of outright coercion.[16]

Can someone with a moderate to severe developmental disability successfully exercise the autonomy that current disability policy claims to be facilitating? There is some extremely exciting work taking place in the field of person-centered planning that seeks to develop deeply empowering ways of enabling people of all abilities to have a say in their lives.[17] This process could produce substantive results both for and against intentional community living. As Camphill communities take up this work and engage in deep listening with their residents, they may encounter dissatisfaction as well as affirmation. In fact, a number of Camphill communities in North America have begun to integrate supported living services outside the core community as a response to requests from some of their residents. But the critical feature of such person-centered planning would be that people with developmental disabilities would be offered a real choice based on deep listening to what their desires, preferences, and life plans involve. The problem with the Final Rule is that it interrogates only outcomes, not qualitative experience. It adopts one model of the good life and funds only those residential settings that conform to this model.

How to avoid this imbalance? First, we must avoid false paternalism. If autonomy and self-determination are values respected in contemporary disability policy, then a preference for a non-mainstream integrated community must be allowed. And this goes both ways. Parents and family advocates must also accept that the interests of the family may diverge from the expressed desires of the person with special needs. The exciting challenge here is to create ways and modes of communication in which those of us with typical abilities become true listeners, inquirers into the most profound desires of those we seek to serve.

Second, we need to insist on holistic, qualitative measures of quality of life so that the choice to give up particular "consumerist" patterns of

[16] Cushing, "What Counts as Community?" 88.

[17] Julia Wolfson makes this case specifically in regard to Camphill communities in her dissertation, "Snakes and Ladders: Emergence of Deep Power in Transformational Change," Australian National University, 2013; copy in the possession of the author.

behavior is not conflated with lack of freedom or false consciousness. The important work over the past two decades on the ethic of care and the importance of interdependence can contribute importantly to this discussion.[18] By suggesting that well-being is not found exclusively in independent action and choosing, but in being in relation to those who care about us and for whom we care, we can lay the groundwork for the value of intentional community as one choice for people with developmental disabilities to explore. Recent sociological work on the way in which small-scale and intentional community living contributes to human flourishing can also reinforce this argument, by reminding us that everyone, with or without diagnosed disabilities, could benefit from a less individualistic, more communitarian and connected way of life.[19]

Thirdly, we may find a way forward through the concept of interdependence.[20] Our mainstream community is not characterized by natural supports and an embrace of interdependence, whatever the fantasies are of those shaping contemporary disability policy. The Exploratory Questions cited above include the following test for noninstitutional community integration: "Do individuals on the street greet/acknowledge individuals receiving services when they encounter them?" What world is this government regulator living in? No one says hello to anyone else on the streets anymore — at least not in the greater New York metropolitan area. By contrast, in Camphill, where the value of each individual is lived out in action through each person sacrificing self and individual preferences to meet the need of the other, I am greeted by a string of "hellos" throughout the community. People on site are there to live with and for people with disabilities. The quality of social interaction created by this intentional commitment is both more powerful and deeper than the transactional interactions that necessarily characterize our consumer activity-based model of integration.

With all these considerations in mind, the Camphill movement faces a number of options as it considers how to respond to this moment in contemporary disability policy. Should it make common cause with other community-based service providers in contesting the Final Rule? Should we concede that our villages are socially isolated while arguing that for some people such settings are their preferred choice and provide superior outcomes? Or should we argue that we are not socially isolating and so have been mistakenly targeted for defunding?

Alternatively, Camphill could pursue a policy of "strategic accommodation." Camphill communities can meet most regulatory expectations of

[18] See importantly, Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency* (New York: Routledge, 1999) and the works it inspired.

[19] E.g., Susan Pinker, *The Village Effect: How Face-to-Face Contact Can Make Us Healthier and Happier* (New York: Spiegel and Grau, 2014).

[20] Barbara Arnell, "Disability, Self Image and Modern Political Theory," *Political Theory* 37, no. 2 (2009): 218–42 is a notable example of this move.

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the Final Rule with some creative restructuring of their programming and residential options. For example, the requirement that everyone receiving residential services be in a tenant-landlord relation with the agency providing these services can be accommodated by providing leases to all members of a Camphill community. Even though creating this market-based relationship strikes at the heart of the model of shared responsibility and mutual care we embody, many believe our organic community ties are strong enough to persist even in the face of the pro forma introduction of leases. Required signage can be put up and our common meals can be made explicitly optional rather than mandatory.

Where strategic accommodation will be difficult and possibly a question of civil rights law are in the states that seek to prevent segregation of people with intellectual and developmental disabilities by enforcing distance limits between homes where such individuals are living. Camphill communities seek to offer people of all abilities the chance to live collectively together and derive their meaning and fulfill their mission by offering a sense of belonging grounded in a critical mass of people with disabilities. If the direction of contemporary disability policy, in the interpretations of the Final Rule and *Olmstead* litigation, is strictly interpreted to mandate isolated living arrangements (ironically in the name of closing down socially isolating settings), "strategic accommodation" will not be an option.

A third approach, also on the table, is to stress Camphill's exceptionalism and the distinctive nature of its communitarian mission, which uniquely among community-based service providers avoids the segregation, social isolation, and institutionalization said to be common to any community-based program. Strategic accommodation is not ruled out, but the ultimate goal would be legislative recognition of a special category of Medicaid-waiver-funded programs — "integrated communities" operating under a special dispensation or license in the states where Camphill communities are in operation.

Each of these strategies contains both opportunities and threats for the future of Camphill in North America. But an assessment of the most promising direction of Camphill's advocacy work is not the focus of this paper. Nor was my goal to elucidate what is assuredly the complicated legislative and regulatory history of the policy making that resulted in the HCBS Final Rule. Finally, I am not arguing that intentional communities are the only setting in which people with developmental or intellectual disabilities can flourish. Such integrated intentional communities will not be the personal choice of every person with a developmental disability or their family. Some individuals with special needs are fortunate enough to have strong ties and natural relations in the "broader community" which will help them integrate with the mainstream in a way they find satisfying and meaningful. The argument here is simply that if we seek true non-institutional alternatives for people with a degree of cognitive impairment

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who cannot live on their own and need special supports, then cohesive, intentional communities represent a valid and valuable alternative. They are delegitimized only by an ideology that deploys an anemic understanding of community and an impoverished conception of individual choice to justify its preference for a one-size-fits-all answer to the current crisis in disability care.

In the new world of President Trump, this line of critique may be naïve or purely elegiac, but I don't think so. There is renewed scholarly interest in the positive psychological and social effects of community-based living. With that in mind, it is important to underline the extent to which the HCBS regulations embrace a particular vision of the good and of the free, equal and well-integrated individual that is neither monolithically accepted nor without its difficulties in terms of producing human flourishing. One can argue that human flourishing is not the issue and that ending even any appearance of segregation trumps providing high quality services in any seemingly isolated setting. I suppose it is just possible to argue that anyone with cognitive disabilities who chooses to live surrounded by other people "like them" has failed some prima facie test of being able to choose intelligently. But my personal hope would be that for the small number of people with and without developmental disabilities for whom the option of living together, working together without a salary, and forging a common sense of purpose, it would be possible to see that the values of autonomy, choice, nonsegregation and anti-institutionalization still apply, and the option of doing so while still receiving Medicaid Waiver funding remains accessible.

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