

# “Community-Integrated” Housing for People with Developmental Disabilities

## *Queer and Critical Disability Theories’ Contribution to Self-Determination*

By Jennifer Polish

### Introduction<sup>1</sup>

As debates about extending federal benefits to married same-gender couples rage across the country while marriage cases are processed by the Supreme Court, many other fights for individuals to control their own intimate relationships and living spaces are rarely discussed. People with developmental disabilities—especially those who are queer—are often denied access to family life, having children, and even choosing what clothes they want to wear on a daily basis. Perhaps surprisingly, many individuals with developmental disabilities who are facing these basic denials of self-determination are no longer segregated into institutions, but are in fact living in community-integrated housing.

As one self-advocate, Robert Martin, states in an ‘Our Rights’ guide for people with developmental disabilities, “Living independently is about being able to make our own decisions as to where and with whom we live.”<sup>2</sup> Historically, access to independent living has been stripped from people with developmental disabilities and people who are queer, especially when individuals are both developmentally disabled and queer. Today, this lack of access persists even in many community-integrated housing settings, which were originally designed to counter the oppression and dehumanization found in institutions.

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<sup>1</sup> This paper could not have been written without the invaluable guidance and support of Susan Saegert, for whose class I originally wrote this piece. Hugh English first introduced me to the queer theoretical principles that inform this analysis, for which I will always be grateful.

<sup>2</sup> “We have human rights: A human rights handbook for people with developmental disabilities,” *Harvard Project on Disability*, 2008. <http://hpod.pmhclients.com/pdf/we-have-humna-rights.pdf>.

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People with developmental disabilities who are queer have historically been hospitalized against their will and labeled as diseased and abnormal, both because of their developmental disabilities and because of their queerness (people who are either developmentally disabled *or* queer have also experienced these forced hospitalizations<sup>3</sup>). This paper surveys academic literature; outlines some relevant queer theoretical ideas; and compares these ideas to notions of “community” and “home” in community-integrated housing for people with developmental disabilities. In doing so, I examine how the intersections of these identities continue to negatively impact individuals’ access to making decisions that dramatically impact their own lives, even as people are increasingly living in community-integrated housing rather than institutions *per se*. Community-integrated housing—both in academic literature and in practice—does not adequately take into account the diversity of self-defined needs and desires of people with developmental disabilities.

It is my hope that this paper will serve as a small contribution to those interested in researching or promoting any form of community-based housing and urban planning. Critical disability theorists and activists can hopefully push past the limits of this paper, which is too broad to focus in on specific abilities, levels of functionality, and desires of people with developmental disabilities.<sup>4</sup> Feminists – queer and otherwise – might find interest in this paper for its exploration of power, control, erotic space and constraint. I also hope that this paper serves as a reminder and call to action to queer theorists and activists who often forget that so many of us are in some way disabled, and even if we were not, our struggles have been similar, and we need to connect our work. Finally, this paper highlights shortcomings and oversights of current literature, in the hopes that they will be addressed in the future, especially because this paper highlights important intersections between scholarly literature and service-provision. Therefore, this paper can be widely read as a broad reflection on the real impacts of the assumptions and norms in academic literature on community-integrated housing.

### **Community-Integrated Housing: Broad Overviews and Oversights**

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<sup>3</sup> Flavia Kreig. "Just Say No to Involuntary Heterosexist Psychiatric Treatment-Toward Protecting the Mental Health of Gay, Lesbian, Bisexual, and Transgender Adolescents," *Journal of Juvenile Law* 16 (1995): 117.

<sup>4</sup> Like queer theory, critical disability theory fundamentally challenges what “natural” means, questioning cultural evaluations of “disability” as unnatural and negative. See Robert McRuer, “As Good as it Gets: Queer Theory and Critical Disability,” *GLQ: A Journal of Lesbian and Gay Studies* 9 no. 1(2003): 79-105.

Since the large-scale deinstitutionalization of people with developmental disabilities in the late 1960s (which is still incomplete), there have been a wide array of changes in the types of housing available.<sup>5</sup> These various forms of housing can reasonably be expected to have diverse effects on people with developmental disabilities, and this section discusses some of the many studies examining these impacts.<sup>6</sup>

Dispersed housing is a common form of community-integrated housing in which apartments or houses are dispersed throughout typical residential neighborhoods, and are designed to blend in with the larger community (unless you know what you are looking for). Group homes, for example, are one form of dispersed housing and are now the dominant form of community-integrated housing.<sup>7</sup> Group homes are owned by private agencies that provide services to people with developmental disabilities and employ a paid staff that lives with a small number of service-users.<sup>8</sup>

Clustered housing features a number of living units that are spatially separated from the surrounding population, in which most individuals are not considered developmentally disabled. Village communities—one form of clustered housing—often host unsalaried support workers and families of people with developmentally disabilities and are designed to be largely self-contained.<sup>9</sup> Residential campuses are distinct from village communities in that they are usually larger and pay staff to support residents, but they are similarly self-contained.<sup>10</sup>

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<sup>5</sup> On continued institutionalization, see Rachel L. Swarns, “After Decades in Institutions, A Bumpy Journey to a New Life,” *New York Times*, September 29, 2012; on types of housing available see Michael J. Ward and Roger N. Meyer, “Self-Determination for People with Developmental Disabilities and Autism: Two Self-Advocates’ Perspectives,” *Focus on Autism and Other Developmental Disabilities* 14, no. 3 (1999): 134.

<sup>6</sup> Many more studies have been conducted in Australia and the UK than in the United States.

<sup>7</sup> Jim Mansell, “Deinstitutionalisation and community living: progress, problems and priorities,” *Journal of Intellectual and Developmental Disability* 31, no. 2 (2006): 66.

<sup>8</sup> Throughout this paper, I will be using “resident,” “service-user,” and “individuals with developmental disabilities” almost interchangeably. I am doing so consciously in order to reflect the diversity of ways of in which these individuals are referred to in various sources and studies (so, when I use “service-user,” for example, I do so because the study I am referring to did so); Jim Mansell and Julie Beadle-Brown, “Dispersed or clustered housing for adults with intellectual disability: A systematic review,” *Journal of Intellectual and Developmental Disability* 34 no. 4 (2009): 14.

<sup>9</sup> By “self-contained,” I refer to the physical separation (in terms of living space) of people with developmental disabilities from those who do not have developmental disabilities in the structure of some forms of community-integrated housing.

<sup>10</sup> Mansell & Beadle-Brown, “Dispersed or clustered housing,” 11-12.

In 2009, Mansell and Beadle-Brown conducted a review of recent scholarship assessing health and quality of life outcomes in two broad kinds of community-integrated housing for individuals with developmental disabilities. This review analyzes nineteen papers (based on ten studies), published in English since 1990, which all compared quality of life and costs of dispersed and clustered housing, two types of community-integrated housing.<sup>11</sup> Mansell and Beadle-Brown's review concludes that clustered housing, despite its lower staff: resident ratio, provides poorer outcomes for most people with developmental disabilities than does dispersed housing.<sup>12</sup> Despite their conclusion, McConkey (included in their review) find that clustered housing residents actually had better relationships than those in dispersed housing. Significantly, this study accounted for residents' relationships with other residents, whereas others did not.<sup>13</sup> Owen et al. also included in Mansell and Beadle-Brown's review) find no difference in outcomes between dispersed and clustered housing. Notably, Owen et al. based their results entirely on extensive participant observation and in-depth interviews with residents.<sup>14</sup> These conclusions—contradicting Mansell and Beadle-Brown's findings—suggest that the more researchers rely on residents to inform their perceptions of housing, the fewer differences between clustered and dispersed housing seem to emerge.

Cummins and Lau critique the assumptions that often underlie the general hesitation to rely solely on resident-created definitions of quality of life.<sup>15</sup> They challenge dominant definitions of “community” and “relationships” used in most quality of life studies, arguing that these understandings prioritize integration into *non-diagnosed* communities and relationships with *non-diagnosed*<sup>16</sup> individuals.<sup>17</sup> The externally-imposed definition of

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<sup>11</sup> Ibid., 5.

<sup>12</sup> Ibid., 5-6.

<sup>13</sup> Roy McConkey, “Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings,” *Journal of Intellectual Disability Research* 51no. 3 (2007): 212.

<sup>14</sup> K. Owen, J. Hubert and S. Hollins, “Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward,” *British Journal of Learning Disabilities* 36 no. 4 (2007): 225.

<sup>15</sup> R.A. Cummins and A.L. Lau, “Community integration or community exposure? A review and discussion in relation to people with an intellectual disability,” *Journal of Applied Research in Intellectual Disabilities* 16 no. 2 (2003): 145-57.

<sup>16</sup> I have chosen the term “non-diagnosed” instead of “non-disabled” in order to unsettle the idea that those who are not diagnosed with some form of condition are “normal,” or even healthy. By choosing to say “non-diagnosed” instead of “non-disabled,” I hope to compel readers to consider how we define disability and health. Diagnosed individuals are considered such because they are diagnosed by medical standards, which are being critiqued in this paper. Thus, I use “diagnosed” and “non-diagnosed” to keep readers aware of the ways

“community” and “relationships” is merely one (albeit significant) mode of neglecting residents' diversity of perspectives in most studies of housing. Another way in which assumptions that people with developmental disabilities do not or cannot create valuable relationships amongst themselves manifest in many studies is in the inadvertent treatment of residents as objects of analysis rather than as individuals capable of self-evaluation. Many studies that Mansell and Beadle-Brown review did not adequately create space for residents to articulate for themselves what they need and desire, placing their responses—if their subjective participation was invited at all<sup>18</sup>—alongside those of family members and service-providers.<sup>19</sup> The subordination of residents' viewpoints about their own lives to “expert” opinions reflects a belief that residents are not capable of complex self-representation.

Finally, while most studies indicate the severity of participating residents' disabilities, other differences amongst residents—such as race, age, class background, gender identity, or sexuality—are not even mentioned. Two exceptions reviewed in Mansell and Beadle-Brown account for gender differences and both gender and age differences, respectively.<sup>20</sup> This general oversight overlooks many forms of diversity in communities of people with developmental disabilities, assuming a uniform experience, goal, and identity.

The general review of housing literature above suggests dangerous holes in current academic discussions. To reiterate, these are:

- the implicit definition of “community” as “non-disabled” and the connected assumption that integration into surrounding non-diagnosed communities is and should be an end-goal for individuals with developmental disabilities;

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in which the medical field penetrates even our language and thus informs how we think about ourselves and others.

<sup>17</sup> R.A. Cummins and A.L. Lau, “Community integration or community exposure?” 145; 147.

<sup>18</sup> R. McConkey, D. Walsh-Gallagher, D. and M. Sinclair, “Social inclusion of people with intellectual disabilities: The impact of place of residence,” *Irish Journal of Psychological Medicine* 22 no. 1 (2005): 10-14.

<sup>19</sup> C. G. C. Janssen, et al. “Quality of Life of People with Mental Retardation—Residential Versus Community Living,” *The British Journal of Development Disabilities* 45 no. 88 (1999): 6-15; P.N. Walsh, C. Linehan, J. Hillery, J. Durkan, E. Emerson, C. Hatton, and A. Netten. “Family views of the quality of residential supports,” *Journal of Applied Research in Intellectual Disabilities* 14 no. 3 (2008): 300-309.

<sup>20</sup> J. Mansell, J. and F. Beasley, “Small staffed houses for people with a severe learning disability and challenging behavior,” *British Journal of Social Work* 23 no. 4 (1993): 333-44; L. Young, “Community and cluster centre residential services for adults with intellectual disability: long term results from an Australian matched sample,” *Journal of Intellectual Disability Research* 50 no. 6 (2006): 424-31.

- the lack of perspectives of individuals with developmental disabilities within the current literature; and
- a great silence on differences amongst individuals with developmental disabilities within most studies.

Queer theory can contribute a great deal to an analysis of community-integrated housing, and will thus be the focus of the next section.

### What's Queer Theory Got To Do With It?

A foundational text for understanding the impact of dominant views of bodies that don't

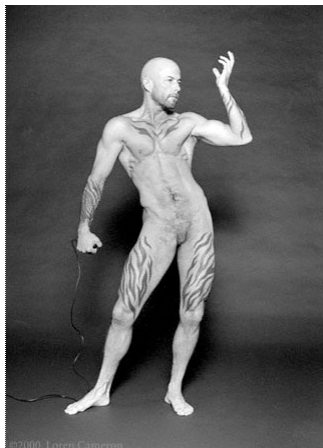


Figure 1 Self Nude 2000

conform to mainstream expectations—non-normative bodies—is Singer's article "From the Medical Gaze to *Sublime Mutations*: The Ethics of (Re)Viewing Non-normative Body Images." Singer argues that service-providers' responses to people with non-normative bodies are shaped by an inability to comprehend the vast complexities of possible configurations of individuals' bodies.<sup>21</sup> He asserts that these inability to imagine the possibilities that exist outside of a gender binary (which insists that there are only two genders—female and male and only one way to be 'female' or 'male' respectively)

largely stem from the medical field. This teaches service-providers to view non-normative bodies as dehumanized medical oddities, rather than as manifestations of human diversity.<sup>22</sup> He contrasts medical textbooks' images and captions of intersex and trans individuals—often, positioned in front of backgrounds that evoke popular conceptions of mug shots—with trans and intersex self-representations (such as Loren Cameron's photography: figure 1<sup>23</sup>) to demonstrate the stripping of dignity from individuals with non-normative bodies in medical textbooks.<sup>24</sup>

<sup>21</sup> T.B. Singer, "From the Medical Gaze to Sublime Mutations: The Ethics of (Re) Viewing Non-normative Body Images," in Susan Stryker and Stephen Whittle *The Transgender Studies Reader* (Routledge, 2006), 602-20.

<sup>22</sup> Ibid.

<sup>23</sup> Reproduced with permission from Loren Cameron. *Self Nude 2000*. Accessed via [www.lorencameron.com](http://www.lorencameron.com).

<sup>24</sup> Singer, "Sublime Mutations" 606.

These textbook representations of people as an assortment of “disordered” or “diseased” body parts—rather than as people with variant anatomies—create a situation in which medical professionals and other service-providers simply cannot imagine “disordered” individuals as fully human. This severely constricts the degree to which service-providers take seriously the abilities of people with developmental disabilities to assert control over their own care.<sup>25</sup>

In other words, he argues that the mainstream medical profession, and by extension, service-providers for people with developmental disabilities, insist on viewing people who



Figure 2 by Saddi Khali

are queer, who have disabilities, or who are both queer and have disabilities as lacking some quality or qualities needed to be ‘normal.’ Thus, a service-provider viewing Saddi Khali’s photographs of Edward Ndopu, a self-identified “black queer femme man who lives with a visible disability,” may, due to their training, view Ndopu’s body as diseased, warped, or dysfunctionally contorted (figure 2).<sup>26</sup> Thus, they might not be able to imagine Khali’s nude photographs of Ndopu as his “attempt to challenge the white, hetero, cis normative, ‘able’ bodied standards against which desirability and body acceptance is measured.”<sup>27</sup>

Singer’s analysis of trans and intersex bodies can be extended to include developmentally disabled people because of the ways in which the “medical gaze” powerfully shapes the lives of individuals with developmental disabilities, both historically through institutionalization and currently through the practices and academic literature involved with housing. Similarly, Singer’s analysis applies here because of the ways that dominant US culture dictates that body and mind are one. For example, transgender people who need

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<sup>25</sup> Ibid., 609.

<sup>26</sup> Reproduced with permission from Saddi Khali. Accessed via [www.thefeministwire.com](http://www.thefeministwire.com); Edward Ndopu, “A Photo-Essay: Decolonizing My Body, My Being,” *The Feminist Wire*, December 12, 2012. Accessed via [www.thefeministwire.com](http://www.thefeministwire.com).

<sup>27</sup> Cisgender is a term that refers to people who are not transgender. Cis-normative is a term that refers to the assumption that everyone is or should be cisgender; Ndopu, “A Photo-Essay.”

hormones or surgery to affirm their gender are classified as having a mental “dysphoria,” thus unifying a state of mind with a state of body.<sup>28</sup> Similarly, in more popular cultural understandings, the unification of mind and body in US culture can be seen in popular singer Lady GaGa’s “Born this Way” and similar phenomena such as President Barack Obama stating that he believes being gay is innate, which insist that sexual desire is something ingrained in the body and mind from birth.<sup>29</sup>

### **Whose “Community” is Integrated into Housing?**

Tackling the question of what academics and service-providers mean when they discuss “community-integrated housing” is, of course, crucial. As mentioned, Cummins and Lau widely critique both literature and service-providers for their widespread assumptions about what “community” is portrayed to mean. They write, “So which ‘community’ do authors target when they measure integration? The answer, almost inevitably, is the general community of non-disabled persons.”<sup>30</sup> This statement calls attention to the unintentional undervaluing of relationships and senses of community amongst individuals with developmental disabilities that often underlie housing studies.

A recent academic debate over clustered housing—which, again, is often self-contained and is not designed for physical integration into non-diagnosed communities—offers an illustrative example of the increased visibility of the debate about what “community” means. Cummins and Lau and others have called attention to the assumed superiority of non-diagnosed communities within the academic literature on community-integrated housing. Emerson argues that clustered housing presents greater risks to individuals' quality of life than dispersed housing, asserting that clustered housing exposes individuals to more restrictive management practices than forms of housing that more explicitly aim to integrate individuals into a non-diagnosed community.<sup>31</sup> In response,

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<sup>28</sup> Dani Hefferman, “The APA Removes ‘Gender Identity Disorder’ from Updated Mental Health Guide,” *Gay and Lesbian Alliance Against Defamation*, December 3, 2012. Accessed via [www.glaad.org](http://www.glaad.org).

<sup>29</sup> Lady Gaga, “Born This Way,” *MetroLyrics*. Accessed via <http://metrolyrics.com>; “Barack Obama on Gay Marriage,” *The Political Guide*, July 24, 2012. Accessed via <http://www.thepoliticalguide.com>; Joseph Osmundson, “‘I Was Born this Way’: Is Sexuality Innate, and Should it Matter?” *LGBTQ Policy Journal at the Harvard Kennedy School*, 2011. Accessed via [www.harvard.edu](http://www.harvard.edu).

<sup>30</sup> Cummins and Lau, “Community integration or community exposure?” 187.

<sup>31</sup> Eric Emerson, “Cluster Housing for Adults with Intellectual Disabilities,” *Journal of Intellectual and Developmental Disability* 29 no. 3 (2004): 192.



Cummins and Lau assert that Emerson compared incomparable groups in his study, and that he overgeneralized his results. They state that they are not advocates of a blanket policy of segregation, but that it is important for individuals to have a strong sense of belonging. Thus, the option to access feelings of belonging with other diagnosed people should be open.<sup>32</sup> Emerson then responds by arguing that subjective senses of well-being rank lower than medical standards of physical health.<sup>33</sup>

This academic debate nicely frames the tensions between people's desires about where and how to live and community-integration. Emerson states that his prioritization of community-integration of diagnosed people into non-diagnosed communities is motivated by a concern for physical safety. In effect, however, this prioritization constrains the choices of individuals who desire diagnosed communities (which clustered housing arguably facilitates better than dispersed housing).<sup>34</sup> Singer would surely assert that a hesitancy to trust people with developmental disabilities with decisions that might involve making trade-offs between their physical health and social fulfillment is characterized by an inability to imagine these individuals as fully capable of making decisions for themselves.

While the above-referenced debate about clustered housing highlights assumptions about community and self-determination within academic literature, Thorn et al. illustrate nicely how the assumption that "community" means "non-disabled" dominates service-provision as well. While Thorn et al. argue that goals and staff trainings within residential facilities for people with developmental disabilities should be designed based on how each individual wants to live, they continue to make assumptions about community that undermine their stated goals.<sup>35</sup> Centering their study on small group homes, Thorn et al. state that "community presence" . . . incorporates the basic concept of physically being in a community integrated setting and *occupying the same social space as non-disabled people*" (emphasis mine).<sup>36</sup> A goal-oriented strategy for creating opportunities to develop senses of community

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<sup>32</sup> R.A. Cummins and A.L. Lau, "Cluster housing and the freedom of choice: a response to Emerson," *Journal of Intellectual and Developmental Disability* 29 no. 3 (2004): 199.

<sup>33</sup> Eric Emerson, "Cluster housing and freedom of choice: a response to Cummins and Lau's and Bigby's commentaries," *Journal of Intellectual and Developmental Disability* 29 no. 3 (2004): 207.

<sup>34</sup> Ibid.

<sup>35</sup> Shannon H. Thorn, Amanda Pittman, Rachel E. Myers, and Connie Slaughter, "Increasing Community Integration and Inclusion for People with Intellectual Disabilities," *Research in Developmental Disabilities* 30 (2009): 900.

<sup>36</sup> Ibid., 894.

amongst individuals with developmental disabilities cannot be found in Thorn et al., but relationships between diagnosed and non-diagnosed people are given high priority. Indeed, the study premises much of its methodological strategy of assessing training programs on the basis that “every interaction between an individual and staff has therapeutic potential.”<sup>37</sup>

The tendency to locate “community” within the context of non-diagnosed relationships reinforces Singer’s argument that it is difficult for service-providers to imagine diagnosed bodies, minds, and relationships as equally valuable and self-aware as non-diagnosed bodies, minds, and relationships. By forming goals oriented around valuing able-bodied community as the unstated ‘natural’ and ‘desirable’ state, service-providers inadvertently devalue what they claim to value at the outset: service-users’ own goals. These ideas about what is ‘desirable’ also perpetuate a dangerous assumption that individuals with developmental disabilities can only belong to one kind of community. The erasure of differences amongst people with developmental disabilities further erases their personhood. Despite these obstacles, most individuals with developmental disabilities—particularly queers—develop their own multi-faceted, dynamic communities, constructing self-identities based both on personal choices and on various experiences of exclusion in multiple communities.<sup>38</sup>

By arguing that “community-integration” goals devalue the desires of people with developmental disabilities, I certainly do not mean to imply that all or even most people reject community-integration. Quite the contrary: many individuals with developmental disabilities do desire integration into non-diagnosed communities. Self-advocates and self-advocate organizations such as the Self Advocacy Association in New York State are often strong advocates for integration.<sup>39</sup> Among their ranks are many who advocate powerfully for an end to institutionalization.<sup>40</sup> However, self-advocates often clarify their desire for integration with the caveat that social and economic equality must be achieved alongside this integration.<sup>41</sup> I concur and suggest—especially in light of the many other gross social and

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<sup>37</sup> Ibid.

<sup>38</sup> Michael Brothers, “It’s Not Just About Ramps and Braille: Disability and Sexual Orientation,” *Re-Thinking Identity*, 58.

<sup>39</sup> “We Have Choices,” *Self-Advocacy Association in New York State*. Accessed via [www.sanys.org](http://www.sanys.org)

<sup>40</sup> Ward and Meyer, “Self-Determination for People,” 133-34.

<sup>41</sup> Ibid., 134.

economic inequities individuals with developmental disabilities face<sup>42</sup>—that if “community-integration” continues to ignore the diversity of developmentally disabled desires and devalue relationships between people with developmental disabilities, then it cannot result in equality, despite the best intentions of service-providers.

There is some literature, however, that explicitly attempts to reverse the erasure of self-advocates’ perspectives and put alternative desires and definitions of community first. Fields, for example, challenges dominant assumptions about community with her in-depth interviews and analysis of senses of belonging amongst formerly homeless individuals with mental illness living in dispersed housing.<sup>43</sup> Fields’ interviews reveal that most, if not all, participants were involved or identified with multiple communities.<sup>44</sup> She observes that the multi-faceted, diverse senses of belonging that many participants embodied ran counter to prevailing definitions of community-integration.<sup>45</sup> Even though she does not exclusively deal with individuals with developmental disabilities, Fields’ effort to counter dominant ideas by prioritizing perspectives of diagnosed individuals provides a useful methodological means of dismantling hegemonic assumptions about the meaning of “community.”

### Keeping “Home” Out of “Housing”

The dominant academic discussions on housing for individuals with developmental disabilities overwhelmingly deal with service-provision and neglect a consideration of “home.”<sup>46</sup> As Pinfold —whose methodologies influenced Fields’ work—points out, housing

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<sup>42</sup> A. F. Schwartz, “Housing for People with Special Needs,” in A.F. Schwartz *Housing Policy in the United States* (New York: Routledge, 2010), 240.

<sup>43</sup> Desiree Fields, “Emotional refuge? Dynamics of place and belonging among formerly homeless individuals with mental illness,” *Emotion, Space and Society* 4 no. 4 (2009): 261.

<sup>44</sup> *Ibid.*, 263.

<sup>45</sup> *Ibid.* 264.

<sup>46</sup> Queer theory is particularly interested in unsettling binaries (such as that which Pinfold explores), and will be quite instructive in the following analysis of “home.” It is worth noting, however, that many queer theorists would undoubtedly reject any interest in reinforcing a racialized, classed, gendered, nuclear-family, capitalist discussion on “home.” While I deeply share these concerns, I move forward with my consideration of “home” because a sense of “home” is arguably a crucial aspect of life, even for those who consider themselves radical: as Arendt argues in *The Human Condition*, homes are spaces which are not immune to oppressions, but which nonetheless fulfill peoples’ needs to feel secure, to explore thoughts and emotions in private, and to structure public life. Furthermore, most studies of housing for people with developmental disabilities do not seek to challenge “home” as a concept, so the ways in which “home” is still denied to people with developmental disabilities is curious and well worth examining; Hannah Arendt, *The Human Condition*, Chicago: University of Chicago Press (1958): 134.

for people with developmental disabilities is not often thought of, even theoretically, outside the bounds of service-provision. While she finds that many enjoy the benefits of living within a community of other service-users and care provision and thus do not view residential independence as a rehabilitation goal, she also observes that service-users often seek self-defined pathways toward independent living.<sup>47</sup> Pinfold thus recognizes that people have multiple and often conflicting desires that obscure the binary between “independent living” (in a private home) and “dependent living” (in housing that includes service-provision, but is not imagined in the literature as a “home”).<sup>48</sup>

While studying the reported feelings about “home” of people with severe mental illness living in transitional group homes, Padgett notes that the “[m]arkers of ontological security [are]... constancy, daily routine, privacy, and having a secure base for identity construction.”<sup>49</sup> Arguably, individuals living in group homes do not have control over any of these. Turnover rates of staff are extremely high, limiting constancy; privacy is extremely limited, as discussed below; and as discussed both above and below, identity construction is often subtly guided toward assimilation and identification with able-bodied, heteronormative communities. Padgett also observes that goal-oriented transitional housing constantly begs the question of “what's next?”<sup>50</sup> This creates uncertainty about the future based on service-providers' constant re-evaluations of whether individuals are “ready” to live independently. This, she argues, is “designed to ensure that [people] are ‘housing ready’ before approval is given for them to have a ‘home.’”<sup>51</sup> In this way, it is not until people with mental illness (or developmental disabilities) are deemed “ready” under Singer’s medical gaze that they can have access to “home.”

In order to look further into people’s experiences of “home,” it is important to examine people’s abilities to function freely within community-integrated living spaces. Dunn et al. (2010) identifies alarming issues with substitute decision-making in UK group homes. Laws made by non-diagnosed individuals and corporations govern what deems a

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<sup>47</sup> Vanessa Pinfold, “Building up safe havens... all around the world: users’ experiences of living in the community with mental health problems,” *Health & Place* 6 no. 3 (2000): 204.

<sup>48</sup> Ibid., 210.

<sup>49</sup> Deborah K. Padgett, “There's no Place Like (a) Home: Ontological Security Among Persons with Serious Mental Illness in the United States,” *Social Science and Medicine* 64 no. 9 (2007): 1925.

<sup>50</sup> Ibid., 1934.

<sup>51</sup> Ibid., 1928.

person with developmental disabilities capable of making decisions for themselves. Those that do not satisfy law-defined criteria may have a service-provider govern all “acts in connection with care and treatment, therefore potentially affecting choices about what clothes to wear.”<sup>52</sup> While relational substitute decision-making—which allows more input from service-users—is becoming increasingly popular, this kind of control over individuals’ personal lives in their housing spaces evokes concerns about where service-providers learn about service-users. Singer’s medical gaze upon service-users subject to substitute decision-making has a particularly powerful influence on people’s lives, and can greatly constrain the ability of service-providers to form meaningful relationships with service-users. Moreover, substitute decision-making does not have to be in effect for service-providers to exert control over service-users’ social and sexual lives. For example, queer disabled individuals often risk further psychiatric evaluation if they come out to their doctors, who only rarely give information about sexuality (especially about non-normative sexualities) to service-users.<sup>53</sup>

Noonan and Gomez are particularly concerned with issues of living spaces for people with developmental disabilities, especially those who are queer. Studying community-integrated housing in Australia, the authors find a great lack of privacy amongst residents.<sup>54</sup> They find that many individuals are not given the chance to choose with whom they live, what daily activities they participate in, nor what clothes they wear.<sup>55</sup> Sexual and gender expression and activities are also severely constrained, they observe, by a lack of non-suggestive information from staff and family members.<sup>56</sup> Historically repressive standards of “acceptable behavior” often govern what forms of affection are considered appropriate, as people with developmental disabilities are largely viewed as either asexual children or as dangerous predators because of a lack of control.<sup>57</sup> The medical and service-providing

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<sup>52</sup> Michael C. Dunn and A.J. Holland, “Living ‘a Life like Ours’: Support Workers’ Accounts of Substitute Decision-Making in Residential Homes for Adults with Intellectual Disabilities,” *Health Care Analysis* 54 no. 2 (2010): 145.

<sup>53</sup> Brothers, “It’s Not Just About Ramps and Braille,” 59.

<sup>54</sup> A. Noonan and Taylor M. Gomez, “Who’s Missing? Awareness of Lesbian, Gay, Bisexual and Transgender People with Intellectual Disability,” *Sexuality and Disability* 29 (2011): 176.

<sup>55</sup> Ibid.

<sup>56</sup> Ibid., 177.

<sup>57</sup> Ibid.

communities' infantilization of people with developmental disabilities dramatically inhibits these individuals' abilities to express cisgendered heterosexuality, let alone any genderqueer and/or sexually queer forms of expression and desires.

Significantly, individuals with developmental disabilities that do not live in community-integrated housing are known to have similar rates of socially-accepted relationships as non-diagnosed individuals. Hall et al. finds that 73% of adult study participants with mild developmental disabilities are married and 62% have children.<sup>58</sup> Studying a similarly diagnosed group, research by Maughan et al. (indicates that 79.5% of men in their early 30's were in stable cohabiting relationships and 94.7% of women of the same age were in such relationships.<sup>59</sup> Despite studies such as these, the regulation of sex and gender expression in people's living spaces persists in community-integrated housing and in medical care.

Indeed, Pinfold et al. find through a series of focus groups with service-users, that service-users ranked problems with psychiatric services as their main concern, citing the education of children and medical practitioners as an important vehicle to advocate for change. The participants (all of whom were white) in their focus group saw service-providers' failure to listen to service-users, as well as the power differentials between users and providers, as major problems that need to be changed.<sup>60</sup> This indicates that issues such as a lack of control of one's identity, expression, and sexuality within one's own living spaces are significant problems in the US. Such oppressive, highly regulated living environments certainly do not constitute "home" living. Again, the medical gaze's penetration into and control of the housing of people with developmental disabilities is seen here with particularly devastating effects on queer individuals in community-integrated housing. Thus, service-providers powerfully constrict the ways in which eroticism can exist within the home-spaces of people with developmental disabilities.

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<sup>58</sup> I. Hall, Strydom, M. Richards, R. Hardy, J. Bernal, and M. Wadsworth. "Social outcomes in adulthood of children with intellectual impairment: evidence from a birth cohort," *Journal of Intellectual Disability Research* 49 no. 3 (2005): 173.

<sup>59</sup> B. Maughan, B., S. Collishaw, S., and A. Pickles, "Mild mental retardation: psychosocial functioning in adulthood," *Psychological Medicine* 29 no. 2 (1999): 355.

<sup>60</sup> Vanessa Pinfold, Peter Byrne, and Hilary Toulmin, "Challenging stigma and discrimination in communities: a focus group study identifying UK mental health service users' main campaign priorities," *International Journal of Social Psychiatry* 51 no. 2 (2005): 130.

The erotic space of the home may be particularly crucial to queers with developmental disabilities, in that disabled bodies are subject to a great deal of rejection, discrimination, indifference, and policing in many ableist queer communities.<sup>61</sup> Many queers with developmental disabilities respond to the multiple forms of policing they experience, from both straight service-providers and queer ableist communities, by creating their own dynamic communities.<sup>62</sup> The potentially erotic spaces provided by housing can be a vital resource for these communities because as Johnston and Valentine point out, “home” is theoretically imbued with privacy, especially regarding sexual intimacy.<sup>63</sup> However, sexual intimacy is deeply regulated within community-integrated housing, and options for community formation are constrained by forces outside of housing spaces, such as ableism in dominant queer culture and gay bars.<sup>64</sup> In situations such as these, bodies are forced into imposed norms (of heterosexuality and able-bodiedness, for example) even within their own living spaces, marking these spaces as a location in which one sleeps and has services provided, but cannot be called “home.”

### Conclusion

Applying queer theory to community-integrated housing for people with developmental disabilities, especially those who are queer, deeply disrupts dominant assumptions about “community,” “integration,” and desire. The overwhelming majority of current literature about community-integrated housing assumes that “community-integration” involves participation and investment in non-diagnosed communities; treats individuals with developmental disabilities as objects rather than subjects; and erases differences (racial, ethnic, sexual, gendered, class, age, capacity, etc.) amongst these individuals. Queer theory allows us to understand these oversights as products of a dehumanizing “medical gaze” on anyone with bodies and/or minds that don’t match expectations of ‘normalcy.’ This limits the ability of service-providers to imagine people with developmental disabilities as capable of controlling their own lives.

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<sup>61</sup> Brothers, “It’s Not Just About Ramps and Braille,” 56.

<sup>62</sup> Ibid., 58.

<sup>63</sup> Lynda Johnston and Gill Valentine, “Wherever I lay my girlfriend, that’s my home,” *Mapping Desire: Geographies of Sexualities*, (1995): 104.

<sup>64</sup> Edward Ndopu and Darnell L. Moore, “On Ableism within Queer Spaces, or, Queering the ‘Normal,’” December 7, 2012. Accessed via [www.prettyqueer.com](http://www.prettyqueer.com).

In many ways, regulations within community-integrated housing arrangements continue the oppressions of institutionalization for individuals with developmental disabilities (especially queers). Infantilizing regulations of personal affairs, gender expressions, and sexualities within one's home-space, combined with persistent assumptions about what community "should" look like, has created another form of institutionalization. Here, individuals are not isolated and tortured as they used to be, but are subjected to similarly controlling assumptions and mandates regarding what is normative and what is undesirable. All people with developmental disabilities may not be subject to the unique brand of oppression that was institutionalization, but the very definition of "community-integrated housing" still reeks of the assumption that disability is deviant, and deviance should be sanitized by eliminating differences enough to assimilate people with developmental disabilities into non-diagnosed culture.

Moving forward, access to publishing in academic journals should be made more widely available to people with developmental disabilities, opening opportunities to transform definitions of what constitutes "expertise." Living goals and definitions of "community" must similarly be created by self-advocates rather than by well-meaning academics and service-providers. Additionally, using qualitative methods like those of Fields and Pinfold to ascertain what individuals with developmental disabilities desire and need can be quite helpful to help academics and service-providers in beginning to truly value the varied perspectives, needs, and desires of individuals with developmental disabilities. This must be done bearing strongly in mind Pinfold's reminder that her interviews alone constituted an invasion of people's living spaces.<sup>65</sup> More broadly, a diversity of understandings of belonging and of 'disabled' sexualities should be promoted within housing and academia. This includes breaking down dominant understandings of "home," while also broadening understandings of "home" to include whatever service-provision may be desired by people who will use it.

Future research needs to focus extensively on queer-specific concerns about control of home spaces, such as comprehensive clothing choices, privacy, sexual health education and care, etc. Doing so will make it more likely that people with developmental disabilities

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<sup>65</sup> Pinfold, "Building up Safe Havens," 203.



will have much easier access to self-determination, so that recognition of developmentally disabled people as both non-normative and as fully human persons can ensue.

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