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Research Brief: Evidence for Integrated Housing

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Since the late 1960s, policymakers, advocates, and service providers have largely moved away from the assumption that people with intellectual and developmental disabilities (I/DDs) are best served in large institutions segregated from the community. From 1977 to 2010, the proportion of American adults with developmental disabilities residing in large, publicly-operated facilities has fallen from 35.8% to only 4.2% (Larson, Ryan, Salmi, Smith, & Wuorio, 2010). Most people with I/DD now receive services while living in their own or family member's homes, or in smaller, often ostensibly “community-based” facilities. Unfortunately, many of the latter facilities, while supposedly more integrated with the community, fail to meet their promises of supporting meaningful self-direction and community integration.

Americans with developmental disabilities primarily receive residential services through two Medicaid-funded programs: Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IDs) and Home and Community-Based Services (HCBS) waivers. Medicaid's HCBS waiver program is targeted at people with disabilities who would otherwise be at risk of institutionalization. This program provides funding for community-based services as an alternative to services provided in more restrictive settings. As of 2011, over 600,000 people with intellectual disabilities hold waivers (Larson et al., 2013). Waiver recipients live in a variety of housing arrangements. The majority receive services either in their own (15.8%) or a family member's (51%) home (Larson et al., 2013). Six percent receive services under a host home/adult foster care model (Larson et al., 2013). Over a quarter continue to live in residential facilities (Larson et al., 2013). It is important to note that residential patterns are highly variable between states. For instance, while 84% of people with I/DD in Nevada live in homes owned or leased by someone with I/DD, only 1% in New Jersey do (Larson et al., 2013).

Residential services can be roughly divided into two types: scattered-site and congregate. In the international literature, these settings are often referred to as “dispersed” and “clustered,” respectively. In scattered-site housing, disabled people live in apartments or homes located in neighborhoods not specifically intended only for individuals with disabilities (Mansell & Beadle-Brown, 2009). They own or rent housing themselves. Residents live alone or with a small number of roommates (Burchard, Hasazi, Gordon, & Yoe, 1991). They may receive nursing care, assistance with activities of daily living, and/or other services, but the agency providing these services is not involved in residential provision (Larson et al., 2013). In congregate housing, many individuals with disabilities reside in a single housing complex. Typically, residents receive services through the agency that owns the residential facility (Larson et al., 2013).

In January 2014, the Centers for Medicare and Medicaid Services (CMS) issued a final rule on home and community-based services. As part of the regulatory process, CMS had invited comments from public stakeholders on earlier proposed drafts of the HCBS rule. The Autistic Self Advocacy Network partnered with Self-Advocates Becoming Empowered and the National Youth Leadership Network to survey 72 individuals with I/DD about the meaning of community living and the characteristics of community-based settings versus institutional settings. Among other characteristics identified by survey respondents as institution-like were residential settings under the control of service provision agencies; settings that required residents to adhere to a set schedule

The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for autistic people. ASAN provides support and services to individuals on the autism spectrum while working to change public perception and combat misinformation. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research and the development of autistic cultural activities. www.autisticadvocacy.org

regarding daily activities, meals, or curfews; and settings that limited residents' privacy and visitors at any time. A facility that imposes a regimented schedule upon its residents, does not allow residents unrestricted access to common areas, or restricts residents' choices cannot provide authentic, meaningful community inclusion, even if it is small and surrounded on all sides by residences owned by non-disabled people (Barrows et al., 2011).

In its Final Rule, CMS adopted many of these recommendations. Under the new rule, residential HCBS settings must be integrated into the community and must include meaningful safeguards for residents' autonomy, privacy, and access to the community. In recognition of the particular risks associated with provider-owned residential settings, the Final Rule includes additional requirements for such settings. Residents in provider-owned settings must, among other things, have lockable doors, access to food or visitors at any time, and be physically accessible (42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi)).

The available research demonstrates that the scattered-site housing model provides the best possible means for fulfilling the requirements of the Final Rule. Scattered-site housing schemes optimize autonomy for individuals with disabilities, integrate residents into the surrounding community, involve the individuals with disabilities in staffing choices, and create access to opportunities for participation in the community.

For example, research on dispersed housing models in Europe shows that those who live in dispersed housing schemes have larger social networks, live in more home-like settings, participate in more activities in the community, and have more opportunities to make choices than residents of congregate programs (Emerson, 2004; Emerson et al., 2000; Mansell & Beadle-Brown, 2009; McConkey, Abbott, Walsh, Linehan, & Emerson, 2007).¹ They also experience less depersonalization, less regimented scheduling, and are less likely to experience seclusion or to receive anti-psychotic medications (Emerson, 2004; Emerson et al., 2000). These patterns remain true even when adjusted for severity of impairment (Emerson, 2004; Emerson et al., 2000). A study of an early supported living program in Vermont shows similar benefits for participants' well-being and community integration. People who received support in apartments situated in the community were more likely to participate in community activities and reported greater personal well-being and satisfaction with their residences than did residents of group homes (Burchard et al., 1991).

When setting size is taken into consideration, smaller settings are associated with even greater choice. In an assessment of scattered site units containing between 1 and 5 residents each, unit size was inversely correlated with the number of choices residents reported being able to make (Stancliffe, 1997). A subsequent study conducted in Minnesota replicates this result. People with I/DD living in semi-independent or supported living settings that serve from 1 to 4 clients exercised self-determination most frequently when they resided in the smallest settings (Stancliffe, Abery, & Smith, 2000). In a large survey of over 8,000 adults with I/DD, those who lived in their own homes reported making key life decisions such as where to live, who to live with, where to work, and how to spend their money at the highest levels (Tichá et al., 2012). Those living in larger, agency-run settings were far more likely to have someone else make those decisions for them (Tichá et al., 2012). Residence size remained a significant predictor of self-determination even after individual characteristics, including level of disability, were accounted for (Tichá et al., 2012). A survey of adults with I/DD living in community-based non-congregate settings and community- or non-community-based congregate settings reveals that non-congregate status is of the utmost importance. Residents of the community-based non-congregate setting had more choice-making opportunities and demonstrated more autonomous behavior than those living in either congregate setting (Wehmeyer & Bolding, 1999). The two congregate settings were statistically indistinguishable on these measures. Location and size are both necessary factors for meaningful community integration.

Additional Factors

The presence of staff also mediates opportunities for self-determination. While individual support needs vary, the logistics of congregate care often demand 24-hour staff presence. This can easily lead to the development of institutional characteristics in the residence, despite the best of intentions among the providers. Stancliffe found that residents in settings with lower staffing levels have higher levels of choice (1997). Similarly, Schalock et al. found inverse correlations between quality of life and staffing intensity,

¹ In Europe, "dispersed" housing may include settings that house up to eight people, which is larger than the type of housing settings that would be considered "scattered site" in the United States. Nevertheless, as noted below, additional studies have shown that smaller scattered-site settings provide greater benefits.

which the authors attribute to “the over-controlling nature of most supervised living environments” (Schalock, Keith, Hoffman, & Karan, 1989). While some adults with I/DD do indeed require some level of staff support in order to exercise self-determination, residents of congregate facilities rarely, if ever, have the power to make decisions about who supports them or provides other services (Tichá et al., 2012). Supported living models, in which individuals with disabilities are able to hire and fire their own staff, show significantly more promise in this regard.

Conclusions

Medicaid's Home and Community Based Services program is intended to enable Americans with disabilities to access the supports they need in order to live as full members of their communities. It exists specifically to provide a community alternative for those who are deemed “at risk of placement in [...] a nursing home or an ICF-ID” (Larson et al., 2013).

Unfortunately, the quarter of HCBS recipients who remain in congregate settings are highly unlikely to reap the full benefits of community inclusion. At the very least, intense monitoring is necessary to ensure that these facilities honor their residents' right to self-determination and facilitate access to the broader community. Models of service provision that enable individuals rather than agencies to hire and fire staff and make decisions about how support is implemented are greatly preferable.

We have largely eliminated the use of large-scale institutions for people with I/DD, yet the specter of institutions may continue to live on and thrive in congregate settings funded through HCBS waivers. If we are to move more fully toward creating and implementing community-based programs for all people with I/DD, we must support housing and service provision schemes that promote true community integration rather than those that are community-based in name only.

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