



*Main Street: A Multiple Family Case Study
Final Technical Report*

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Introduction

“Housing is the centerpiece of an individual’s personal life across their lifespan and a cornerstone to living independently” (U.S. HHS, 2022). The dearth of accessible, affordable housing options for adults with disabilities has been described as a growing national crisis (McCormick, Schwartz, & Passerini, 2019). The limited availability of inclusive and affordable housing can lead to social isolation and loneliness among people with disabilities (e.g., Gibson et al., 2012). Furthermore, inadequate housing can depress physical and mental health and increase the risk of institutionalization or homelessness. Despite federal fair housing and nondiscrimination laws, such as the Americans with Disabilities Act (ADA, 1990), as well as the Supreme Court’s *Olmstead* Decision (*Olmstead v. L.C.*, 1999), most people with disabilities live in segregated settings, such as nursing homes, congregate care settings or group homes set aside specifically for people with disabilities (Brucker & Houtenville, 2015). The problem is that most affordable housing is not accessible, and most accessible housing is not affordable (Access Living, 2021).

The benefits of integrated, affordable housing are well documented. Accessible housing allows one to work (Finlayson et al., 2001), to participate in social and leisure activities and to enjoy a more independent and fulfilling life (Roessler, Gitchel, & Bishop, 2013). Inaccessible housing is associated with social isolation, safety hazards (e.g., falling) and generally lower life satisfaction for adults with disabilities (Best et al., 2022; Smith, Rayer & Smith, 2008). A recent review of consolidated state plans to achieve fully integrated housing for people with disabilities found overall slow progress toward meeting this goal in states across the country (McCormick, et al., 2019), and no plans that addressed the need to find community-based residences for people with disabilities who outlive their family caregivers.

The challenge for state and local communities is to design affordable, accessible residential options in integrated community settings. Although a recent national analysis of state plans demonstrated dismal efforts to address this challenge, local or organizational examples offer potential models that can be adopted and replicated across the country (e.g. Accessible Housing Austin, 2020; Arienti & Sloane, 2013). One such unique model is *Main Street*, located in Rockville, Maryland.

Main Street is an inclusive housing complex for residents with and without disabilities. Located in the heart of a metropolitan area, it is proximate to accessible transportation and amenities. Out of the building’s 70 units, 75% are affordable and 25% are set aside for people with varying special needs. Furthermore, this housing complex provides programming for social inclusion of residents and non-residents with and without disabilities, such as cooking, advocacy, self-care and exercise at a low membership cost. *Main Street* also hosts social events both within and external to the complex.

The purpose of this *Report* is to describe the lived experiences of a sample of *Main Street* residents with disabilities and their families regarding the move into the *Main Street* apartments. A prior study ([Fabian et al., 2021](#)) found significant improvements in assessed indicators of quality of life for a sample of *Main Street* residents and their families. In this *Report*, we were interested in learning more about how and which of the features and attributes of *Main Street*

contributed to the quality of life of residents and their families. Such findings should provide useful descriptions for program developers, policymakers and researchers to design, build and evaluate similar programs throughout the country.

Methods

Procedures

Subsequent to approval by the Institutional Review Board (IRB) at the University of Maryland, this qualitative multiple case study was conducted by a team of researchers who partnered with *Main Street* staff on the implementation of the study. The study was originally designed to incorporate multiple in-person interviews, site visits and reviews of various artifacts. However, as the study was launched in fall 2020, we had to modify the procedures to align with COVID-19 research restrictions. In response, we conducted two virtual structured interviews over Zoom with four *Main Street* family dyads consisting of a resident with a disability and a parent or guardian. Family dyads were recruited from a sample of residents who had participated in a related study assessing the impact of *Main Street* on the quality of life of residents and their families ([Fabian, et al., 2021](#)). The first family interviews were conducted in late fall 2020, occurring about 3-4 months after the resident had moved to *Main Street*, and the second was held about one month subsequent to the first, occurring around January 2021. The protocol for each of the semi-structured interviews was designed to understand how residents and their family members experienced inclusive housing at *Main Street*, and the impact it had on their lives. The protocol addressed the following broad areas: (a) processes involved in the decision to move to *Main Street*; (b) prior history, if any, of independent living; (c) the family's attitudes and perceptions of *Main Street* and (d) perceived challenges and benefits to independent living at *Main Street*. Each participant received a \$50.00 gift card upon completion of both interviews.

Our analysis and reporting treat each family as a separate case. Each of the semi-structured interviews lasted around 45 minutes to one hour. We audio-recorded and transcribed each interview verbatim (Creswell & Creswell, 2017).

We organized the interview transcripts using *NVivo* qualitative software for data storage, coding and theme development. We coded the data using a combined deductive and inductive approach (Maxwell, 2013), and generated reports for each case and across cases. The trustworthiness of the findings was established by using rich and thick descriptions of the cases, member-checking and by reviewing and resolving disconfirming evidence (Creswell & Creswell, 2017).

Participants

Despite similarities, the families represented the diverse socioeconomic, cultural and linguistic background of the community. In the following section of the *Report*, we provide a brief description of each of the four dyads. Ethical guidelines required that we change the names of all participants to protect their identities.

Family 1: Mike (resident) and Richard (father): Mike is a 28-year-old Caucasian male with an intellectual disability. He has a married sibling who resides in another state. Mike has been

competitively employed for about six years in a federal government position. Prior to his move to Main Street in 2020, Mike had been living with a roommate in an apartment building located in an urban setting. Mike's father, Richard, is an active participant and advocate for disability issues within his local community, including involvement around housing issues for people with disabilities. Mike and his father learned about Main Street through their activities in the local disability community. Mike applied for and moved into his Main Street apartment in early fall 2020. The first family interview occurred about three months after his move-in date.

Family 2: Jonah (resident) and Sarah (mother): Jonah is a 30-year-old male with a developmental disability from a mixed-race family. Jonah is competitively employed and has worked in a large hospital facility for the past several years. Jonah's mother, Sarah, has been involved in disability issues in her local community. Jonah had prepared for independent living for years, ever since his graduation from secondary school. His family learned about Main Street through their participation in local disability organizations, and Jonah moved into his apartment in fall 2020.

Family 3: Janet (resident) and Dean (father): Janet is Asian American, in her late 30s, and has an intellectual disability as well as some mobility impairments. Janet has been competitively employed for the past several years, with an administrative job at a local school. Janet had been on a waiting list for federal housing vouchers for six years, before she finally was able to move into an apartment building about two years prior to her move to Main Street. Janet heard about Main Street through a story in a local magazine and decided to apply. She moved into her apartment in fall 2020.

Family 4: Kathy (resident) and Louise (mother): Kathy is in her late 30s and has developmental and mental health disabilities. Prior to her move to Main Street, Kathy had been living in various residential settings, and experienced multiple hospitalizations. Kathy had been living in her mother's house at the time she saw an advertisement about Main Street apartments in a local newspaper. She decided to apply and moved into an apartment with a roommate in fall 2020. Because of COVID-19 in the community, Kathy spent part of her time at the apartment, and part of her time at her mother's house.

Results

For this *Report*, we identified three major themes that emerged from our data analysis: (a) Finding Community; (b) Bring Your Own Independence and (c) Accessibility, Affordability and Integration.

Theme 1: Finding Community

All the families were initially interested in *Main Street* because of its promise of inclusion and community and, subsequent to the move-in, all of them were positive about finding it. As Mike's father Richard put it, "*Main Street is housing with a community built around it,*" and differentiated it from Mike's prior living situation which was "*just an apartment building*" that, although it offered integrated housing in an urban area, lacked the spirit of community. For Mike and his father, the *Main Street* community meant "*having a critical mass of people who*

have similar life experiences [as Mike], so that it facilitates the development of spontaneous relationships and friendships.” Or as Mike put it, community means “having neighbors across the hall who can become friends.” Janet noted that she was motivated to move to *Main Street* because it offered the “community support” that she lacked at her prior apartment living situation, and that “I finally found what I needed.” Her father, Dean, defined the community experience at *Main Street* as having “like-minded residents and families” involved in the experience, adding that he appreciated the network of information sharing and mutual support that are “the additional benefits of community” involved in the *Main Street* experience. Sarah, Jonah’s mother, explained that the family searched for a residential option that would offer “more than just a place to live” and in the process they discovered *Main Street*. “It’s a gift,” she said.

An important aspect of community is having an array of social events in which to participate. Residents did not entirely lose social engagement even during the social distancing restrictions implemented during the COVID-19 pandemic. Mike and Jonah, for example, were still able to select from an array of virtual activities available at *Main Street*, such as interest clubs or cooking classes. Mike joined some of these activities as they offered social engagement and connections, explaining that he joined the cooking class even though, “I don’t really cook, but I like to see my friends online.” All the families emphasized the benefits of the voluntary nature of the social engagement. As Richard, Mike’s father, asked about adding various events to the shared calendar they maintained, “How many times do you tell me it’s my choice?” And Mike replied, “A lot.”

Some families viewed the array of community activities as a way of offering what Louise, Kathy’s mother, described as a “host of built-in social supports.” Kathy agreed with this, noting that, “I have a social structure here....I’m not really naturally social, but I want to be, so I do benefit from it.” Her mother, remarking on Kathy’s move added that, “at *Main Street* you lose a child, but you gain a community.”

Theme 2: Bring Your Own Independence

“Bring Your Own Independence” is a key part of *Main Street*’s philosophy, and it was clear that all of the families appreciated the option to exercise the appropriate level of independence based on the unique interests, skills and experiences of their adult child. As *Main Street* is not a state-supported service provider, residents need to be able to live independently, or to have the support in place to enable them to do so. Two of the residents in this study accessed paid support personnel from local community providers, one of them purchased *Main Street* coaching and all four relied, to some extent, on family. Although all the residents in the study had histories of living independently in the community, these experiences did not necessarily occur within a community or inclusive environment. Sarah, Jonah’s mother explained that “no one’s holding his [Jonah’s] hand here” but the experience of choosing and participating in *Main Street* events enhanced his sense of autonomy and independence through the exercise of choice.

All the parents described the long path they travelled toward preparing for independent living. For example, Jonah completed two post-secondary programs to prepare him for living on his own, and his mother explained that he is now where they hoped he would be, but that “he

couldn't possibly have moved successfully” without the years of investment in planning and training. Janet’s father, Dean, acknowledged that she was not prepared at first for living on her own, and lacked basic skills, such as cooking: *“For the first three or four months, my wife would go over to her apartment regularly to assist her with cooking and other tasks.”* After moving to *Main Street*, Dean proudly indicated that Janet is *“able to do some of the cooking herself, and handle that.”* Kathy, who had been living with her mother several years prior to her move, believed that *Main Street* offered sufficient support and structure that helped them make the decision that *“she was ready”* for independent living. As Louise, her mother said, *“we worked so hard to get her there...and now she’s kind of set for life, and it’s such a great community for her and she’s not going to find this anyplace else.”*

Theme 3: Accessible, Affordable and Integrated Housing

Accessible and affordable housing is a major imperative for adults with disabilities, and the existing and anticipated growing need far outweighs supply. Accessible housing for adults with disabilities refers to both built features and technologies that enable independent living, and location features that are proximate to transportation and community goods and services that enable participation. All the families indicated the benefits of the internal and external accessibility of *Main Street* on the lives of the residents. For example, ready access to public transportation enabled three of the four residents who were competitively employed to easily commute to work, as well as access expanded community activities. As Kathy, who didn’t have a job explained, *“Since I now live across the street from the metro, it feels like I have a lot of independence without having to get a car.”* *Main Street’s* proximity to a diversity of community amenities was frequently mentioned as a key benefit. As Mike said, *“I can walk to my favorite pizza place with my friends.”* Or as Janet said, *“I can take long walks in the neighborhood, and it feels safe.”* Building accessibility was also frequently mentioned. For example, several parents pointed to construction features such as lowered kitchen counters or sinks, and technological features such as oven alarms and elevator access fobs that enhanced safety. Janet expressed appreciation for the safety features of *Main Street* as compared to her prior residence this way, *“Here, they don’t let people just come into the building.”*

Housing affordability is another challenge to accessibility for these families. Although 75% of the *Main Street* apartments are affordable, all four of the families had to navigate complex federal and state eligibility criteria to qualify for affordable housing, and to secure the benefits necessary to fund it. As Richard, Mike’s father, said, *“housing is a money problem...and you need the housing to support the employment.”* Financial planning can be especially challenging, as parents need to constantly recertify the documentation of disability to ensure their child continues to receive state and federal benefits, such as housing vouchers or Supplemental Security Income (SSI) that are vital to support their living expenses. Jonah’s mother, Sarah, advised that as parents *“the most important thing to know is that you’re entitled to nothing. Nothing.”*

Several of these families described the overwhelming paperwork and long waitlists that characterized the search for suitable housing for their adult children. For example, Janet’s father Dean noted that she was on a *“waitlist for six years before she secured a housing voucher that*

enabled her to live on her own.” Even after independent housing is obtained, Dean described the complex efforts to ensure that residents continue to abide by the guidelines established to maintain the housing. For example, he and the other families had to be careful that their adult children did not exceed income caps which could jeopardize their access to benefits that support their housing, such as housing vouchers, health insurance or disability payments. After the move, the application process for benefits continued. As Louise, Kathy’s mother said, “*and we’ve applied for other services that will help, some of which she’s still on the wait list for, like getting her a disability metro card was something new.*”

Program and Policy Implications

Historically, people with intellectual, developmental, physical and other disabilities resided in segregated and restricted environments (e.g., institutions; Brucker & Houtenville, 2015). In the past 30 years, we have progressed to creating less restrictive living arrangements (e.g., group homes). Unfortunately, some of these options are not really integrated, being congregate care facilities, or inaccessible to public transportation and other amenities (CSH, 2016). Every citizen in the U.S. is entitled to live a life with dignity and independence as maximally as possible, but many adults with disabilities who *can* live independently are denied this opportunity. This circumstance, decades after the enactment of the ADA and the Supreme Court *Olmstead* decision mandating integrated housing, should sound as a call to action for disability and housing policy makers who can advocate for affordable, integrated housing options. Although this qualitative study had a limited sample of participants, it offers several implications for policy makers and others to consider when planning for a better future for people with disabilities.

- 1. Location Matters.** Proximity to community goods and services, such as retail establishments, restaurants, entertainment venues and public transportation were key factors identified by all the participants as contributing to the quality of their *Main Street* experiences. The level of autonomy residents experienced enhanced their quality of life. Planning professionals need to collaborate with disability advocates to ensure that their voices are included in state and especially local housing plans to ensure that new developments offer maximal opportunities for community integration.
- 2. Physical Design.** Retrofitting modifications for accessibility costs substantially more than designing accessibility within public building spaces and within apartment units. *Main Street* adopted Universal Design Principles to enable people with differing abilities to access the entire complex without constraints, including common spaces that allow residents to participate in spontaneous and organized community events that can facilitate both safety and inclusion.
- 3. Community Engagement.** As local communities continue their efforts to meet the mandates of the ADA and the *Olmstead* decision, planning for affordable, safe, decent housing that offers a diverse array of amenities and voluntary opportunities is the basis for community engagement. *Main Street*, with its philosophy of interspersing set-aside units for people with disabilities within an affordable housing development, enables a philosophy of inclusion and fosters interaction and engagement both within and external to the apartment complex.

4. **Promote Independence and Choice.** Parents and residents alike appreciated *Main Street's* adherence to a philosophy of “bring your own independence” and the opportunity to exercise choice, both in terms of where and with whom to live, and whether and what activities or services to select. Policy makers and advocates should ensure that housing options further the rights of people with disabilities to “live in the most integrated setting appropriate to meeting their needs” (U.S. DOJ, 2011), and that adhere to best practices in promoting choice and voluntary access to benefits and services.

Conclusion

People with disabilities constitute a large and growing segment of the U.S. population. Addressing their housing needs for affordable, accessible and integrated options in the community should be paramount concerns of state and local governments. As this study indicated, city planners, families and disability advocates can collaborate to design housing models like *Main Street* that are not simply the production of new units, but that creatively support the multiple needs of diverse populations. These endeavors can address the dearth of housing supply, comply with legislative mandates for integration and inclusion and improve the quality of life of their citizens.

References

- Access Living* (2021). Retrieved from: <https://accessliving.org/defending-our-rights/accessible-affordable-integrated-housing/>.
- Accessible Housing Austin (AHA)*. Retrieved from: www.ahaustin.org
- Americans with Disabilities Act of 1990*, Pub. L. No. 101-336, 104 Stat. 328 (1990).
- Arienti, F., & Sloane, L., (2013). *Strategies for creating integrative supportive housing for people with disabilities*. Issue Brief, February. Technical Assistance Collaborative. Retrieved from: <http://www.tainc.org/knowledge-resources/publications/issue-briefs/strategies-for-creating-supportive-housing/>.
- Best, K.L., Noreau, L., Gagnon, M.A., Barthod, C., et al., (2022). Housing, transportation and quality of life among people with mobility limitations: A critical review of relationships and issues related to access to home and community-based services. *Disabilities*, 2, 204-218. DOI: <https://doi-ort/10.3390/disabilities2020015>
- Brucker, D.L., & Houtenville, A. (2015). People with disabilities in the United States. *Archives of Physical Medicine and Rehabilitation*. DOI: <https://www.10.1016/j.apmr.2015.02.024>.
- Creswell, J., & Creswell, D. J., (2017). *Research design: Qualitative, quantitative, and mixed methods approaches*, 5th edition. New York: Sage Publishing.
- CSH (Corporation for Supportive Housing; 2016). *Supportive housing & Olmstead: Creating opportunities for people with disabilities*. Retrieved from: www.csh.org/resources/supportive-housing-olmstead-creating-opportunities-for-people-with-disabilities/Dialogue.
- Fabian, E., Leone, P., Havewala, M., Zhu, Q., & Lee, Y. (2021). *The impact of inclusive, accessible housing on residents' quality of life: Main Street*. University of Maryland, College Park, MD. <https://mainstreetconnect.org/wp-content/uploads/2021/12/MainStreet-UMD-Report-FINAL-11.15.21.pdf>
- Finlayson, J. (2018). Fall prevention for people with disabilities: Key points and recommendations for practitioners and researchers. *Tizard Learning Disability Review*, 23(2), pp. 91-99. <https://doi.org/10.1108/TLDR-06-2017-0026>.
- Gibson, B., & Mykitiuk, L. (2012). Health care access and support for disabled women in Canada: Falling short of the UN Convention on the Rights of Persons with Disabilities: A qualitative study. *Women's Health Issues*, 22(1), 111-118.
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed., Ser. Applied social research methods series, 41). SAGE Publications.

McCormick, L., Schwartz, A., & Passerini, C. (2019). Housing for people with disabilities: A review of State Olmstead and HUD Consolidated Plans. *Journal of Planning Education and Research*. DOI: <https://doi.org/10.1177/0739456X19844567>.

Roessler, R., Gitchel, W.D., & Bishop, M. (2013). Housing satisfaction: An additive predictor of QOL for adults with MS? *Journal of Vocational Rehabilitation*, 39, 101-109.

Smith, S.K., Rayer, S. & Smith, E.A. (2008). Aging and disability: Implications for the housing industry and housing policy in the United States. *Journal of American Planning Association*, 74, 289-306.

U.S. Department of Health & Human Services (2022). Accessible, affordable housing. Retrieved from: www.acl.gov/HousingAndServices/Accessible-Housing.

U.S. Department of Justice OJ, 2011. Statement of the Department of Justice on enforcement of the integration mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* (2020). Retrieved from: https://www.ada.gov/olmstead/q&a_olmstead.htm.