

Understanding the Disability Housing Market

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Changes in public policies are altering the U.S. market for housing and residential support services for people with disabilities. In the multi-billion-dollar publicly funded market for long-term services and support for people with developmental disabilities, which serves more than one million Americans, housing models are shifting away from institutions to consumer-driven choices that include community-based residences and living at home. Broader awareness of human rights and human potential are helping inform the expectations of the millions more who do not have access to public support, and many of these individuals are looking for opportunities to live more independently. But supply has not kept up with demand. Affordable, accessible, distributed housing is an increasingly critical need.¹ A challenge for the housing industry is the lack of detailed statistics on market demand.

Disability data sets generally measure epidemiology rather than market size or segments, and U.S. Census Bureau data do not report on the severity of disability (which would provide additional detail on housing needs) or eligibility for or participation in government programs. Sketches of market segments provide an alternative method to understanding the breadth of customers' preferences and needs. Such sketches can serve as a starting point for additional research that begins to identify detailed market segmentation of people with disabilities.

Background

In the United States and globally, housing for people with disabilities has begun to shift away from large institutional settings toward smaller community-based group homes and, more recently, toward individualized supports delivered wherever a person lives. Such services might include help with daily living tasks such as bathing, eating, dressing, and taking medication as well as help with exercise, positive behavior supports, and engaging in community interactions and friendships. This trend is strongest for people with intellectual and developmental disabilities (I/DD). Investments in research demonstrations and systems-change agendas have been small but consistent in the I/DD field for more than 40 years, so it is not surprising that innovation would originate here. The “homeward bound” movement has been driven by policy shifts and supported by mature technologies such as portable respirators and lifts, new technologies such as cell phones and web-based training and management systems, and emerging technologies such as environmental controls and personal coaching, communication, and monitoring systems.

¹ Distributed housing is housing that does not segregate people with disabilities in enclaves, gated communities, or institutional settings. Distributed housing also implies that housing is available in all kinds of neighborhoods and communities. Disability policy experts prefer that such housing is controlled by the resident and not tied to the services or supports received from an agency.

The trend toward individual support can be understood as the organizing force behind a new market. This trend is reinforced by new savings instruments and financial and tax planning policies and tools available to individuals and their families. The trend continues, but not without some bumps in the road. Below is a summary of some of the other forces at work in the marketplace:

- Few housing experts are deeply knowledgeable about disability issues, and few disability experts know a lot about housing policy.
- Information about housing support programs is not easily accessible to most people with disabilities or their families, who may lack community contacts, internet access, or information management skills.
- Family advocacy groups are often more familiar with how to raise funds for cures than they are with how to raise funds to provide information and referrals about community-based housing and supports.
- Many provider agencies know how to raise money for larger building projects but have not experimented with raising money for smaller housing models.
- Consumer-based budgets (versus facility-based budgets) and consumer control of support allocations are emerging models in most states, so management systems are not yet well-defined.
- The cost of individual support can be about half that of congregate care, but it has proven politically easier to cut individual supports during a budget crisis.
- Homeownership is complicated by the asset limits of public support programs such as Supplemental Security Income (SSI).
- In the nationwide push toward universal homeownership, not enough attention has been given to growing the low-income rental housing market; this is true in the disability market as well.
- Aging Baby Boomers will strain disability support systems, especially resources to pay for personal assistance jobs.

The market for people with disabilities who need affordable supportive housing in ordinary communities is large and growing. The current stock of safe, affordable, and accessible housing falls far short of the demand. Official state waiting lists indicate that nearly 100,000 Americans are waiting for residential supports, but estimates based on demography indicate the total may be closer to one million individuals.

Markets, Information, and Data

Unfortunately, there is a lack of useable data to support planning and marketing efforts. Disability data sets are seldom interoperable. Generally, they track the following measures:

1. Epidemiology and incidence. These data provide an overview of the number of people with disabilities, but do not provide information on how their functional limitations vary—necessary for understanding the housing needs of individuals.
2. Program spending. These are measures of state fiscal effort and are not intended to provide insight into whether individuals' housing and other needs are being met.
3. Functional limitations in activities of daily living (ADLs). U.S. Census statistics include supplemental reports on limitations in ADLs. Generally, these data do not show severity or multiplicity of limitations.
4. Program participation. The Social Security Administration manages large databases for the SSI program (for people who live in poverty with lifelong disabilities) and the Social Security Disability Income (SSDI) program (for adults who become disabled after beginning to work). The databases include names, birthdates, addresses, and disability category codes. They do not track severity of disability or participation in Medicaid Long-Term Services and Supports. Various other federal agencies track data that describe program participation, but the individual measures that underlie these reports cannot be linked to other data sets from other programs.

General market research databases have been collaboratively built by a variety of stakeholders, including the U.S. Census Bureau, consumer goods marketing companies, political interest groups, and financial and other services providers. These databases supply information on individuals' attitudes, lifestyles, values, and opinions, but typically have little information on how or where people with disabilities live. The information-rich databases can tell you which zip codes are likely to contain high numbers of people who hunt or fish, or people who travel internationally for leisure. However, they cannot tell you which zip codes contain a large population of underemployed people with disabilities, concentrations of young people with disabilities graduating from high school or college, or high numbers of families caring for or sheltering a significantly disabled family member into old age.

Without accurate, detailed, and easily accessible data, it is difficult to undertake the classic functions of marketing. Disability programs can identify their key constituencies but are unlikely to know much about the variation of preferences and needs within and among these groups. They might have strong connections to advocacy groups and individual advocates, but rarely do they have access to focus groups or descriptive data. Often, they build new services based not on consumer needs and wants, but instead on legislative and administrative agendas. Human services organizations seldom understand decision-making behaviors of key segments within their target populations, and they generally do not analyze the distribution channels that connect their services to their users. They seldom have data with which to understand how price relates to demand, or even how much demand exists. Because they lack the data that would help them describe key segments in the marketplace, they do not know how to reach potential users with new information.

Marketing Sketches

Marketing theory tells us that a market segment is a group of people who share a want, a need, and a way to pay. Typically, after completing a market segmentation study, a marketer might sketch out the motivations and desires of a “typical person” within that segment to help us understand them in human terms.

The following are some rudimentary market segment personae constructed with the intention of helping housing professionals better understand the variation in housing needs and wants of people with I/DD and other significant disabilities. The personifications here are fictitious and based on experience, not data. They should be used to stimulate interest in market research, not substitute for it. Taken together, the personae are not meant to be a complete representation of all people with disabilities in the United States—just examples of a few key segments of people with developmental disabilities who need housing.

Generation ADA

Andrew is a young advocate who was born on July 26, 1990, the day President G.H.W. Bush signed the Americans with Disabilities Act. Andrew has various significant learning disabilities and some emotional and behavioral difficulties that have emerged over time. He has a history of seizures. He has not yet graduated from high school in the medium-sized state university town where he grew up. However, when he turned 18 his school let him walk in the graduation with his friends, and now he attends the local college as part of his Individualized Education Plan. He was disabled enough to qualify for SSI at age 18. He works as a volunteer at the campus museum. He would like to move into an apartment, but he assumes he needs both a rent subsidy and some minimal supports in place to be able to do so. He is not sure whether he would be allowed to make accessibility changes to a rental apartment. Since he loses his keys a lot, some kind of fingerprint entry system would help. He has heard of a monitoring system that would log him into his house and report any seizure activity to 911. With this feature, maybe his mom would get off his back. His mother insisted he be put on a waiting list for Medicaid services, but the state says it will take 15 years to get to him. Andrew told his mom, “I will never use those services. I am disabled, but I want to work!” His class on civil rights history is currently studying fair housing laws. Andrew does not have a driver’s license. He would like to live within walking distance of the student union for now.

Getting By

Nancy, 44, was diagnosed with “mental retardation” when she was seven. She went to a special class that provided therapies and taught independent living skills in the city near her small town. Her mother is grateful that she has learned to follow instructions well. Nancy attends a sheltered workshop every day from 9:30 AM to 2:30 PM and attends a dance on the third Friday of every month, but receives no

additional supports. The workshop has contracts for recycling, shredding, and collating packets of documents for local non-profit board meetings. Participants are paid for helping with these tasks, based on their productivity, and are provided supervision and meals. Nancy brings home a check of around \$15.00 every two weeks. Her supervisors consider her unfocused and unproductive. She tells everyone she hates her job. Nancy's mother lives on her Social Security survivor benefits. She recently had knee surgery, and has trouble remembering to do her physical therapy. Nancy's SSI check is larger than most because she is a disabled adult child of a deceased father. If Nancy moves out, her mother cannot afford to maintain the house alone. Nancy's case manager at the workshop has signed her up for a Section 8 lottery for the last four years, with no luck.

Moving On

Justin is 32 years old and sometimes becomes very agitated at his job in the supermarket where he has worked for seven years. He is the produce manager, and has several teenagers reporting to him part-time as stockers. He was sent to special education when he was young, but he does not allow anyone to call him names anymore, not since he left the small town where he grew up. He does not claim any disability benefits. He graduated from a new vocational program after his foster family moved to the suburbs, and he excelled in every class. The program provided work opportunities during school hours and his quickly turned into a full-time job with health benefits. After a year or two, people at the supermarket seemed to forget Justin was "special ed." He loses his temper when one of the young kids at work calls the other one a "retard," and nobody knows what to do about it. He hunts and fishes to help provide for a family of four including his wife Stacy and their two children, ages three and five. He enjoys watching NASCAR races on TV and going to baseball games with his friend who drives, and he hopes to buy a townhouse for his family someday. He is insecure about making big decisions, but has no one to advise him.

24/7

Patrick is a 25-year-old with severe cerebral palsy who has a permanent tracheotomy and uses both a wheelchair and a walker. Patrick grew up with high expectations and with a strong awareness of civil rights. He lives at home with his parents. His mom is a nurse and his dad teaches English at the local suburban high school. Family support programs helped the family construct a first-floor bedroom and bath for Patrick 19 years ago. The accessible space provides room for a hospital bed and other equipment, and a place for overnight staff to work on health records. The bathroom has a ceiling-mounted lift, making the tub and shower useable. Patrick has easy access to the family living room and kitchen. He receives 120 hours per week of individual support including overnight nursing. His parents fill in the rest of the time. He is studying web design at a local community college and has a budding relationship with a young woman he met there. His girlfriend has disabilities, too. He would like to move out of his parents' home—soon!—and he would like to minimize his reliance on staff by using more

assistive technology at home. His state does not yet allow substitution of electronic monitoring for staff oversight. He has looked at low-income apartments, but they do not offer enough room or access for him to be comfortable or safe, especially in the bathroom. He also needs to live near public transportation.

Gone, Baby, Gone

Duke dropped out of "Sobriety High," an alternative high school for youths who have substance abuse issues. He is 16 years old. The school thinks his family moved away, but the fact is his foster family was going to kick him out again so he just left. He is not aware that the family was receiving SSI disability benefits on his behalf. He is living temporarily in a garage behind a friend's house, and uses any drugs he can find to help kill the boredom. Duke tried to apply for a sales clerk job at a big retail chain, but he does not read well enough to fill out the job application. He reads at a third-grade level. Duke is not worried about getting into trouble with the law. He has been in juvenile detention twice already and prefers it to foster care. At least they have pool tables and video games in juvenile detention—and nobody hassles him or calls him stupid there.

Over the Hill

Earnest is a gentleman of 67, but he seems older than that. For him, lack of coordination caused lack of activity and general muscle weakness. Earnest walks with a significant limp and has severe osteoporosis. As a young man, he was diagnosed as having intellectual disabilities; his sister thinks he would now be diagnosed as having autism. He lives with his mother, who is 92, in the same apartment building they have always lived in on the South Side of the Metro area. Earnest's mother is still spry, but worries that she might die before her son. Then what will happen to him? She and her husband turned down an institutional placement 60 years ago. Earnest is a fixture at the local library, where he volunteers every Tuesday and Thursday at 10:00 AM. He also helps several "old people" in his building by returning library books for them (he reminds them when they are due) and by assisting them with their checkbooks. Earnest is good at basic math and is also a whiz at fixing dripping faucets. He keeps the apartment spic-and-span and makes his bed and his Mom's bed every day. Earnest does not have a checking account of his own. Earnest does not know how to cook. He says, "Fire makes me nervous." His cousin, who is an insurance salesman, keeps trying to set up an irrevocable trust for Earnest. His mother thinks the cousin is just a hustler, so she won't discuss it. Earnest's mother secretly hopes that after her death her daughter will move Earnest into her home, but there are no such plans in place. Earnest carries his sister's cell phone number in his wallet in case something bad happens.

The Least of These

Violet's mother often refers to her as being among the most severely retarded people in the State. Violet is 52 years old and has lived in a large state-run institution since she was 13, which her mother

says is proof of how "retarded" she is. Violet's mother is proud of her own advocacy, which has landed Violet in Happy Acres, the "best" institution in the state, with an annual per-person cost over \$250,000. The State is making noises about closing its public institutions. Since the dog died, Violet is no longer willing to visit her parents' home, a beautiful country estate. Violet's mother has never seen a community home that she feels would be supportive enough for Violet; she thinks the State has under-resourced its community options. Violet has a very large trust fund that provides for incidental expenses. It appears that the trust could be used for housing, but it may not be used for long-term support costs.

Baby Steps

Angelina is a cute 3 1/2-year-old girl whose mother always dresses her like a little angel. She is the youngest of three children born to a very wealthy family in the leafy suburbs of a large American city. Angelina has been identified as having autism. Her family has heard about a proposed tax sheltered savings account called an ABLE account. It would allow them to save for Angelina's future housing needs in the same way families can save for college costs. However, Congress has not yet authorized such savings plans. Angelina's mother has quit her job to manage the plethora of therapies and interventions that Angelina is scheduled to receive. It is unclear what the family's financial future will be, and it is unclear what the extent of Angelina's disabilities will be as she grows up. Though she currently has some balance and gross motor problems, she seems eager to run away at any opportunity. The family is struggling to try to find ways to adapt their home so that it will be more supportive of Angelina. In desperation, they have installed bolt-type locks on the outside of her bedroom door and are planning to build a tall fence around their yard, but they cannot believe that these are the best options. Support from the Early Intervention Team does not include financial advice or advice about home modifications.

Conclusion

These sketches provide some examples of the ways in which the preferences, needs, and finances of people with developmental disabilities can vary. My hope is that advocates, marketers, policymakers, housing experts, and financial leaders will find some material here for thinking about how to segment markets of people with disabilities to help them reach different groups.

People who live in the same kinds of neighborhoods tend to have similar needs, wants, and aspirations, but it is clear that the presence and extent of a disability can change those underlying needs and wants significantly. Disability may undermine a family's ability to pay privately, but not all people with disabilities are poor. Eligibility for public programs may provide funding opportunities, but at the same time, it may constrain choice. Modern individualized budgets create options and a real market for services and supports where there was no individual choice in the past.

Non-profits are traditionally less experienced than for-profit business with marketing and market research, but these contribute to the focus and effectiveness of programs. While the specific market

data may not exist, housing experts can use traditional approaches to creating market segmentations with what information is available. Every U.S. state and territory has Developmental Disability Act programs and state and local Independent Living Centers. These federally funded programs study and report on the needs of persons with disabilities. Organizations can make progress through exploratory processes such as focus groups and through structured studies of the markets they wish to serve. Low-cost market research may also be available through local business schools and universities.

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