Executive Summary
MA Autism Housing Think Tank: September 10, 2016

On September 10, 2016, a select group of over 50 autistic[1] individuals, family members, service providers, officials from state human services and housing agencies, finance professionals, developers, and designers met to address the challenge of autism housing in Massachusetts. The intent was to brainstorm housing options appropriate to the range of housing needs in the autism community, identifying models that might be built with public funds, private funds, or through public/private partnerships.

The housing challenge

The impetus for the event was to provide input to the Massachusetts Autism Commission, which is charged with developing a plan of action to meet the need for affordable supported housing for the Commonwealth's citizens with autism. The Commission's task is not a negligible one, as it is estimated that there are 75,000 – 100,000 people with autism in the state, and about 80-85% of them will need affordable supported housing beyond what is currently provided by the Department of Developmental Services (DDS).[2][3] While some individuals and their families are currently finding or creating housing successfully, barriers exist to wider adoption of current housing models. These include[4]:

- Poor understanding by individuals and families of existing options;
- Affordability;
- Long waits for housing vouchers;
- A poor fit between the requirements of some MassHealth programs and the needs of the individuals needing support;
- Zoning provisions that bar creation of accessory apartments;
- Lenders who are unaware of Fannie Mae provisions for loans to parents/guardians of people with disabilities;
- Lack of insurance reimbursement and other sources of funding for assistive technology that can facilitate independent living[5]; and
- U.S. Department of Labor (DOL) regulations governing minimum wage and overtime for live-in caregivers.

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[1] Note that language used in this publication is not intended to depart from "People first" concepts and philosophy. The think tank organizers believe children and adults with autism should be accepted as community members first. Some people wish the identity of "autism first." Language is varied throughout this document to reflect the variation.

[2] http://mahousingthinktank.org/defining-the-need/

[3] In this publication, acronyms will be indicated after the first use of a name or term, and then the acronym will be used throughout. A list of acronyms is provided in the Appendices, under Supplemental Materials.

[4] http://mahousingthinktank.org/defining-the-need/#Barriers

[5] http://mahousingthinktank.org/technology/

Even without these difficulties, problems would remain. Existing housing stock frequently does not meet the sensory and support needs of many people with autism; more autism-friendly design is needed to help people maintain tenancy, and find comfort in their homes.[6] [7]

The MA Autism Housing Think Tank was a collaboration of Autism Housing Pathways (AHP), The Arc of Massachusetts, and Advocates for Autism of Massachusetts (AFAM), with additional support from Advocates, Inc., HMEA, and the Massachusetts Developmental Disabilities Council.[8]

Think tank preparation and procedures

In preparation for the think tank, organizers:

- Developed a dedicated website to provide participants and the public with background information on the housing situation for people with autism in Massachusetts;
- Hosted a webinar on the use of assistive technology in independent living;
- Crowd sourced a set of consensus principles on autism and housing, via Facebook;
- Solicited videos describing housing models, and assessed those videos against the consensus principles;
- Derived housing models from the videos that survived the assessment process.

Prior to the think tank, participants were asked, at a minimum, to familiarize themselves with "at a glance" information from the website; look over the consensus principles and housing model descriptions; and view a short video on smart home technology if they had not viewed the webinar on assistive technology.

On the day of the think tank, participants received a background briefing, then broke into working groups:

- Six groups were assigned to a specific type of housing configuration (e.g., sharing living space with an unrelated support provider);
- One group was asked to discuss issues related to homelessness among people with autism, including demographics and improving access to the shelter system for autistics; and
- One group was tasked with brainstorming mechanisms for approval of unusual housing arrangements.

The housing configuration groups and the homelessness group were each provided with profiles of hypothetical autistic residents, and asked to identify two housing models they felt would be appropriate for each resident. Collectively, the groups assessed twelve hypothetical resident profiles. Groups also identified environmental design features and assistive technology options for each resident profile. Finally, they discussed funding streams and barriers to implementation for the housing models

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[6] http://mahousingthinktank.org/defining-the-need/#ExistingStock
[7] http://mahousingthinktank.org/autism-friendly-design/
[8] Information about all of these organizations may be found in the Appendices, under About MA Autism Housing Think Tank.

identified for each resident. Participants rotated to a different group after lunch, so that assigned tasks benefited from two assessments.[9] All findings from each group were documented.

Outcomes

Of the twelve housing models considered, five were most frequently selected by the breakout groups:

- Individual apartments or condos in the community, located close enough to one another to permit socialization. A facilitator and a neighbor are both paid to facilitate connections and provide support. (Selected for 7 of 12 hypothetical residents.)
- Shared living in a single family home owned or leased by a family, individual, or a 3rd party not providing the services. It could involve substantially separate space, with a shared kitchen. (Selected for 6 of 12 hypothetical residents.)
- Co-housing in which people with and without disabilities choose to live in community, while having their own living spaces. (Selected for 5 of 12 hypothetical residents.)
- Inclusive, small footprint units, resulting in lower housing costs, with trained management and/or support providers (e.g., micro-units or single room occupancy units). (Selected for 5 of 12 hypothetical residents.)
- Transitional housing that trains residents in the skills they need to live independently. (Selected for 4 of 12 hypothetical residents.)

While these were the models that seemed adaptable to the broadest range of residents, other models remained important for specific resident profiles. For instance, for one hypothetical resident "Terrell", with intensive maladaptive behaviors, licensed congregate living was selected by three breakout groups, and a hybrid model, "licensed congregate living in a small legal multi-unit", was selected by a fourth group. "Terrell", and another profile, "Nancy", represented individuals with intense behavioral/medical needs. Through their choices, the breakout groups recognized that this sub-group of individuals, while small, will require attention to develop models suited to their highly individualized and complex needs.

The most significant funding streams identified were:

- Supplemental Security Income (SSI) (selected for 11 out 13[10] housing models, and 11 out of 12 resident profiles)
- Section 8 portable housing vouchers (10 housing models and all 12 resident profiles)
- Other[11] MassHealth programs (9 housing models and 10 resident profiles)
- Food stamps (9 housing models and 10 resident profiles)
- Project-based subsidized housing (7 housing models and 7 resident profiles)
- DDS individual supports (7 housing models and 5 resident profiles)

The most significant barriers to implementing models were:

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[9] One afternoon group did not meet, as it was inordinately impacted by the attendees who had canceled at the last minute. Its remaining participants dispersed to other groups in the afternoon.

[10] The hybrid model proposed for Terrell is considered the 13th housing model.

[11] "Other" means MassHealth programs other than Adult Family Care (AFC), Adult Foster Care (AFC), Personal Care Attendant (PCA) services or Group Adult Foster Care (GAFC).

- Affordability to individuals and families (8 housing models and 7 resident profiles)
- Voucher shortage (7 housing models and 7 resident profiles)
- Transportation (6 housing models and 6 resident profiles)
- Adequate funding of staff supports (not mentioned for a majority of models, but significant for certain resident profiles)
- Adequate access to staff (not mentioned for a majority of models, but significant for certain resident profiles)

This is not to say that few barriers to implementing housing models were identified; rather, it was clear that barriers were more specific to individual situations than they were to housing models. While only affordability and the voucher shortage were significant barriers for a majority of individuals and settings, some barriers were quite significant for certain profiles. For those with complex medical and/or behavioral needs, staff training and quality were selected repeatedly. The caregiver shortage was also cited for 5 profiles. Similarly, insurance reimbursement was cited as a barrier for 4 profiles, with the need to pay for assistive technology and/or for life coaching mentioned.

The following design features[12] were identified most commonly:

- Autism friendly home that reduces risks and anticipates activities (11 out of 12 resident profiles)
- Places of control and layers of freedom (spaces that can be navigated without a support provider) (8 resident profiles)
- Walking loop to relieve stress (7 resident profiles)
- Tools for housekeeping to address common problems (commercial washer/dryer, mop sink, etc.) (7 resident profiles)
- Soundproofing (6 resident profiles)
- Alarms (6 resident profiles)

As with housing models, certain other features were important for specific profiles (e.g., floor drains, tempered glass, and abuse resistant drywall), but not for the broader range of people with autism.

Technologies identified most frequently were:

- Coaching/decision making apps (10 out of 12 resident profiles)
- Cueing apps (9 resident profiles)
- Apps for daily living (9 resident profiles)
- Alert systems (including central call stations and/or web interface with support team) (6 resident profiles)

Evidence from the United Kingdom indicates individuals with autism are more prone to homelessness, and they are more likely to "sleep rough" (i.e., avoid the shelter system) than others who are homeless.[13] This research was the basis for asking the group addressing homelessness to consider two issues: strategies for quantifying the number of homeless individuals with autism; and increasing the

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[12] Design options were taken from Braddock and Rowell's "Six most common home modifications" and their additional list of options to mitigate challenges of elopement, self-injury and seizures, property damage, aggression, and/or relationships with neighbors, all described in Making Homes That Work (2011), http://parenttoparentnys.org/images/uploads/pdfs/Making_Homes_That_Work_A_Resource_Guide_%282%29.pdf.

[13] http://mahousingthinktank.org/defining-the-need/#Homelessness

ability and willingness of homeless autistics to access the shelter system. Thoughts around quantification involved training staff in shelters, emergency rooms, and prisons to recognize signs of autism or to utilize the ten question Autism Spectrum Quotient (AQ-10) tool[14]. "Front door triage" could take place in shelters, and questions could also be added to the annual homelessness survey. DDS, the Department of Mental Health (DMH) and Healthcare for the Homeless were specifically mentioned as organizations to involve, either in training frontline staff or as a place to refer individuals potentially identified. One group raised the question of the cost/benefit ratio of quantification.

Ideas for improving the ability and willingness to access the shelter system loosely clustered into several themes:

- Improving street outreach by using an all homeless outreach team and communicating that shelter is a step to permanent housing;
- Making shelter more sensory friendly (privacy tents, capsule hotels);
- Engaging existing players in and resources of the chronic homeless system, such as Healthcare for the Homeless, the foster care system, and Home and Healthy for Good;
- Improving autism awareness among shelter staff, and connecting shelters to DDS to verify eligibility;
- Using a broader definition of homelessness, including those kicked out of home, under-housed, couch surfing

The final breakout group engaged in a freewheeling discussion about difficulties currently faced by individuals and their families in finding housing, and proposals for change. The crux of the discussion was poor communication about housing options and resources. Better communication with individuals, their families, and teachers, across agencies, was seen as critical. Participants called for placing housing in the context of a beefed up process of transition to adulthood, which also encompasses independent living skills, employment, social skills, and connections to the community. Ideally, housing strategies should be developed through a person-centered approach, addressing the full range of sensory, clinical, and physical needs, the role of technology, and the need to resolve administrative issues.

Implications

- There is a small core of housing models that could be collectively adapted to the needs of a wide variety of residents:
    - Individual apartments and condos
    - Shared living
    - Inclusive small footprint units (such as micro-units and single room occupancy)
    - Inclusive co-housing
    - Transitional housing

- There is still a role for congregate housing for some individuals with extreme maladaptive behaviors, but even this model can be re-imagined to create greater self-direction and privacy.
- Drop-in services for cueing are needed.
- Affordability, the shortage of vouchers, staff training and quality, and transportation are systemic problems. Beyond these, most barriers to housing are more individualized.

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[14] http://docs.autismresearchcentre.com/tests/AQ10.pdf

- Incorporating Braddock and Rowell's "Six Most Common Home Modifications", plus soundproofing, into new housing for people with autism, and into a percentage of new housing generally, would meet the needs of a majority of people with autism, while more significant modifications would be needed for about a quarter of autistics.
- Technology can improve people's ability to live independently, but they will need options to pay for assessments and the technology (including apps), whether through MassHealth, DDS, or other insurance.
- Good communication, education about housing options, and a person-centered holistic approach that starts early is conducive to a good outcome. This approach should be embedded into a beefed up transition process that incorporates applying for housing vouchers and improving independent living skills.
- The housing sector needs to better understand autism. The housing committee of the Autism Commission should consider expanding its membership to include more representation from the housing sector. Training for housing professionals in autism should be explored.
- Data collection should be undertaken to answer questions about overall housing demand, demand for the models discussed, and homelessness in the autism community. These data can be the basis for establishing housing production targets.

Recommendations

1. DESE recognize its Independent Living mandate under IDEA by insuring cities and towns incorporate into the transition process applying for housing vouchers, improving independent living skills, and education about housing options.
2. DDS/DESE partner with the state university system to offer an expanded transitional housing program aimed at college-aged students, utilizing technology options to increase independence, and considering design modifications as necessary. Vermont's SUCCEED and Safety Connection should be considered as models.
3. DDS consider options to increase consumer choice, control, and privacy in in its community-based residences, including
   - Combining individual suites with shared common space, and
   - Separating ownership of housing from the provision of services through methods including allowing residents and/or their families to buy shares in existing homes, or having a third party own the property and rent directly to residents. Any third party should have experience with tenants with disabilities and training in autism; one option might be one provider acting as a landlord, while supports are provided by other agencies, as occurs in Delaware.
4. DDS would pay special attention to co-housing by reviewing property density restrictions to allow for individuals/families to live together on the same street or complex with and without people with disabilities.
5. Increase self-direction as a percentage of the DDS budget to allow people with autism and their families to access a full range of housing models.
6. DDS/DHCD consider joint RFRs for inclusive small footprint units and for transitional housing for adults, using technology options to increase independence and incorporating Braddock and Rowell's design principles, plus sound proofing. Options would need to be available for those with forensic issues.

7. DHCD/MassHousing consider incorporating Braddock and Rowell's design principles, plus sound proofing, into 5% of dwelling units or one unit, whichever is greater, into new multi-family dwellings of ten or more units receiving DHCD or MassHousing funding or financing.
8. MassHealth consider options to cover technology that permits more independent living (and technology assessments), as housing is a social determinant of health.
9. Drop-in services for cueing should be an option through MassHealth, either through a re-definition of PCA, or through expanding the settings where GAFC may be used.
10. Steps be taken to facilitate the creation by families of sustainable shared living[15] situations, including: deferred or low interest loan options, by right zoning, and a system for repeatedly finding support providers for a defined period.
11. An information clearing house on autism and housing be developed, including online trainings, to serve individuals, families, providers, housing professionals, and homelessness professionals.
12. Person-centered planning be considered for individuals determining housing options/transitioning into housing, since barriers to housing implementation are highly individualized.
13. Data collection in the following ways is needed:
    o Voluntary data be collected on possible incidence of autism among the homeless, including both information on individuals with a diagnosis, and through utilization of the AQ-10 screening tool.
    o A survey be conducted to identify existing supported housing serving individuals with ASD, and the types of supports provided.
    o Autistics served by DDS, DMH, MRC, the Centers for Independent Living, ASAN, and their families (as appropriate), be surveyed on their housing needs, preferences, and independent living skills, including the need for environmental modifications and assistive technology.
    o The level of independent living skills (defined as ADLs, IADLs, and ability to initiate) be measured and recorded for students served by DESE in their last year before exiting.

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[15] In this instance, shared living refers to DDS Shared Living, living with an Adult Foster Care provider, or some other arrangement where a support provider lives with an individual with disabilities in property controlled by the individual or their family.