MA Autism Housing Think Tank:
September 10, 2016

Report released April, 2017
Acknowledgments

Collaborating organizations:
  Autism Housing Pathways
  The Arc of Massachusetts
  Advocates for Autism of Massachusetts

Additional financial support was provided by Advocates, HMEA, and the Massachusetts Developmental Disabilities Council.

The MA Autism Housing Think Tank planning committee

At Autism Housing Pathways (AHP):
  Catherine Boyle
  Gyasi Burks-Abbott (also at AFAM)
  Cheryl Ryan Chan
  Alicia Hintlian
  Charlotte Nunez
  Erica Ploof

At The Arc of Massachusetts:
  Leo Sarkissian
  Maura Sullivan
  Judy Zacek

At Advocates for Autism of Massachusetts (AFAM):
  Michael Borr
  Gyasi Burks-Abbott (also at AHP)
  Christine Hubbard
  Karen Mariscal

At Advocates, Inc.:
  Jeff Keilson

At HMEA:
  Michael Moloney

Thanks are also due to our high school interns, who made the work of the day possible.

Recommended Citation:

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Executive Summary

On September 10, 2016, a select group of over 50 autistic 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). While some individuals and their families are currently finding or creating housing successfully, barriers exist to wider adoption of current housing models. These include:

- 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; and
- U.S. Department of Labor (DOL) regulations governing minimum wage and overtime for live-in caregivers.

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.

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.

Think tank preparation and procedures

In preparation for the think tank, organizers:

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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/

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.
- 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 identified for each resident. Participants rotated to a different group after lunch, so that assigned tasks benefited from two assessments. 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-

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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.
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\textsuperscript{10} housing models, and 11 out of 12 resident profiles)
- Section 8 portable housing vouchers (10 housing models and all 12 resident profiles)
- Other\textsuperscript{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:

- 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\textsuperscript{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)

\textsuperscript{10} The hybrid model proposed for Terrell is considered the 13\textsuperscript{th} housing model.
\textsuperscript{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 (GAF).
\textsuperscript{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://parenttoparentny.org/images/uploads/pdfs/Making_Homes_That_Work_A_Resource_Guide_%282%29.pdf.
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. 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 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. “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.
- 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

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

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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.
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:
   - 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.
   - A survey be conducted to identify existing supported housing serving individuals with ASD, and the types of supports provided.
   - 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.
   - 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.
Think Tank Impetus and Structure

A 2014 law, Chapter 226, colloquially referred to as the Autism omnibus bill, newly reconstituted the Massachusetts Autism Commission. It also charged the Commission with making:

An investigation and study of the present, and anticipated future, statewide affordable supportive housing needs for the commonwealth’s population of persons with autism spectrum disorder. The commission shall develop and conduct a statewide housing survey to determine the current status of affordable supportive housing stock for adults with autism spectrum disorder and shall make recommendations in regard thereto. Additionally, the commission shall review the rise in the prevalence of autism spectrum disorder diagnoses among children in the past 30 years and shall make estimates of the number of children, aged 21 or younger, with autism spectrum disorder who will become adults in the coming decades and the resulting need for affordable supportive housing for those individuals and shall recommend a plan-of-action for the commonwealth in regard thereto.

In order to better help the Commission complete achieve these goals, three Massachusetts organizations, Autism Housing Pathways (AHP), The Arc of Massachusetts, and Advocates for Autism of Massachusetts, organized a housing think tank. The goal of the MA Autism Housing Think Tank was to provide the commission, and the broader Massachusetts autism community, with an in depth assessment of the problem by a broad set of stakeholders operating from a common core of information. The think tank was organized by a committee of representatives from these three non-profit organizations, and representatives from two human service providers, Advocates and HMEA. Additional support was provided by the Massachusetts Developmental Disabilities Council.

Invitees to the September 10, 2016 think tank comprised autistic individuals, family members, representatives of human services organizations, representatives of state human services and housing agencies, finance professionals, developers, and designers. To prepare them for the day, a dedicated website, www.MAhousingthinktank.org, was created. The website included a summary of the current housing environment for people with autism in Massachusetts; information on autism-friendly housing design and environmental modifications; the use of assistive technology to facilitate independent living; a discussion of best practices; and links. Information was presented at three levels: “at a glance” bullets; longer descriptive text, and embedded links of in-depth material. While much of the information on the website was static, the pages on assistive technology and best practices evolved to reflect additional activities that were taking place prior to the think tank.

These additional activities proceeded in parallel. On the one hand, organizers of the think tank hosted a webinar on the use of technology. Kelly Charlebois, Executive Director of TechACCESS of Rhode Island, discussed the use of both low- and high-tech options to increase independence, and Catherine Boyle, President of Autism Housing Pathways, discussed smart home technology. Think tank participants and the public were invited to participate. The slides and a recording of the webinar were both subsequently posted onto the think tank website’s technology page.

Simultaneously, a public Facebook page, MA Autism Housing Think Tank, crowd sourced consensus principles on housing to meet the needs of people with autism. The decision to crowd source principles was made due to the fact that, aside from literature on architectural and environmental design principles, best practice in supported housing for people with autism is currently still a subjective phrase. Generally, people have extrapolated from the literature on people with developmental disabilities. Participants on the Facebook page were invited to proposed principles. Other readers could either “like” a principle to endorse it, or reformulate into something with which they could agree. The reformulation needed to be liked in turn to take the place of the original. Over the course of July, 2016, over 750 readers viewed the page, and approximately 60 participated actively in the formulation of the 20 principles. These principles were posted to the think tank website (and appear later in this publication).
Once principles were finalized, the public was invited to submit short (1-3 minute) videos of housing models to the Facebook page. Think tank organizers assessed the videos for consistency with the principles\textsuperscript{16}, and in the end distilled 12 housing models from them. The videos and model descriptions were posted to the think tank website (and, again, appear later in this document).

Prior to the think tank, participants were asked to review (at a minimum) the “at a glance” bullets on the website, the list of crowd sourced principles, and the list of housing model descriptions. If they had not viewed the webinar, they were asked to watch the short video on smart homes.

On the day of the think tank, the 50+ participants heard a 20 minute topic background presentation\textsuperscript{17}, to refresh their memory of key material from the website. They then broke into eight working groups for the rest of the morning, then rotated to a different working group assignment in the afternoon, in order to ensure each working group topic benefitted from two sets of participants. The membership of each breakout group was balanced to try to include representatives of as many stakeholder groups as possible. The breakout groups had three roles:

- To assess the 12 housing models for their ability to meet the needs of a range of people with autism (Groups 1-7). The methodology for this task was as follows:
  - 12 profiles of hypothetical residents were developed by the think tank facilitators and presenter\textsuperscript{18}. Each breakout group was assigned 2 profiles, with the exception of Group 6, which was assigned one profile, that of a homeless individual;
  - For each profile, groups selected (through placing dots on posters) two housing models. They also selected three environmental design modifications and three assistive technology options, using the same method. Groups then brainstormed funding streams for each housing model, and barriers to the implementation of each option. Groups were free to identify housing models outside the 12 options provided. While groups were provided with “cheat sheets” of design modifications, technologies, governmental funding streams, and possible barriers, they were free suggest additional options.
  - Results of all deliberations were recorded on posters and tally sheets, which were collected. Individual participants were also free to leave notes of ideas and opinions that did not make it onto the posters or tally sheets; these were also collected.

- To discuss the intertwined questions of how to better collect data on the numbers of homeless people with autism and how to make the shelter system friendlier to these people (Group 6); and

- To brainstorm ways to gain funding approval for new, innovative (“out-of-the-box”) housing models suited to the specific needs of individuals as the need might arise (Group 8).

This document will summarize the outcome of the breakout group deliberations, and discuss implications of the day’s findings for the work of the Autism Commission.

\textsuperscript{16} Catherine Boyle of AHP recused herself from assessing videos for consistency with the housing principles. She prepared and submitted many of the videos under consideration, in order to ensure a broad range of housing models from around the country were available for the planning committee to consider.

\textsuperscript{17} Copies of many of the materials shared with participants appear either in the body of this document or in the Appendices.

\textsuperscript{18} Cheryl Ryan Chan, Erica Ploof, and Catherine Boyle, all affiliated with Autism Housing Pathways and Person-Centered Planning Partners. Brief biographies appear in the Appendices, under About MA Autism Housing Think Tank.
The Current Situation

Demographics — known and unknown

As of 2017, it is not known how many people in Massachusetts are autistic. The Department of Public Health (DPH) does not currently collect data on the incidence of autism. Up until quite recently, the Department of Developmental Services (DDS) did not keep diagnostic-specific data, either on the number of people eligible for services or the number found ineligible. Nationally, the Centers for Disease Control (CDC) estimates that the incidence of autism is 1 in 68 children.\textsuperscript{19} If one assumes a similar ratio holds in the Massachusetts population\textsuperscript{20} as a whole, one would get a number of just under 100,000 Massachusetts residents. It is known that the Massachusetts Department of Elementary and Secondary Education (DESE) lists 18,572 students ages 3-21 on an Individualized Education Plan (IEP) for autism in 2015-2016.\textsuperscript{21} This number represents a floor, as it does not include students with autism who require accommodations but not special education (those on a “504 plan”) or those not served by the department. If one were to extrapolate this number to the population as a whole (by multiplying by 4), one would get a number just under 75,000. It would appear likely that the number of autistic residents in Massachusetts is between 75,000 and 100,000.

Housing demand — known and unknown

Translating the above numbers into demand for housing is an inexact process, at best. However, some things are known. According to the Bureau of Labor Statistics, only 18.5% of people with disabilities were employed\textsuperscript{22} in May of 2016. Employment among young people with autism is lower than that of other young people with disabilities\textsuperscript{23}, meaning that the percentage of autistic adults who are not working is most likely over 80%. It is a safe assumption that these individuals are not likely to afford housing on their own.

DDS is the lead agency serving individuals with autism in Massachusetts. In FY16, there were 855 young people with developmental disabilities found eligible for services from the department upon turning 22. 237 were identified as needing Community Based Residential Services\textsuperscript{24}, or some 28%. Currently, the department is budgeting for residential supports only for people who also have an intellectual disability (ID). According to the CDC, 31% of individuals with autism have an ID, and another 23% are borderline. Assuming half of those with a borderline IQ are determined by DDS to count as having an intellectual disability, a rough calculation (28% of 42%) would show that about 12% of those with autism would receive Community Based Residential Services at 22.

A survey done by Autism Housing Pathways in 2011-2012\textsuperscript{25} found that about only about 3% of those with autism were completely independent in both their Activities of Daily Living (ADL) and Instrumental ADLs (including items like handling finances, shopping, and taking medication). The rest presumably need some supportive services in their homes. These

findings are roughly consistent with a 2008 study (cited in a 2009 report)\textsuperscript{26} that found 4\% of autistic adults living independently; another 2\% lived with a spouse, partner, or a family member who was not a parent or guardian. (It is possible that better training of transition-age youth in daily living skills might improve these percentages. This is significant, as adaptive behavior is highly correlated with both employment and quality of life in middle adulthood.\textsuperscript{27}) Taken together, as of now some 80\%-85\% of Massachusetts autistics are likely to need some form of affordable, supported housing beyond that currently provided by DDS\textsuperscript{28}.  

Funding streams and housing models  

Individuals and families trying to find or create housing need to combine their own resources with a range of government funding streams. All of these are governed by rules that dictate where and when they can be used, as well as whether (and how) they can be combined. The graphic “Funding streams” illustrates the “Housing equation”, which identifies funding streams available for housing, food, and services, with funding streams appearing under the uses to which they can be put.\textsuperscript{29} 

In terms of the family contribution to housing creation, AHP’s housing survey\textsuperscript{30} found that about 50\% of families indicated they could sustainably contribute $500-$1,000 per month toward housing, some of whom could pay


\textsuperscript{28} An analysis undertaken by Autism Housing Pathways since the completion of the think tank estimated that about 14,000-15,000 individuals in the 2025 cohort of 18-37 year olds are likely to need affordable supported housing as adults. \url{http://autismhousingpathways.org/analysis-of-potential-adult-asd-population-in-mass-can-provide-insight-into-housing-demand/}

\textsuperscript{29} An explanation of the acronyms used in the “Housing Equation” graphic can be found in the list of acronyms in the Appendices. A brief description of the rules governing the use of these resources can be found in “Housing, in a month’s worth of tweets”, a blog post on the Autism Housing Pathways’ website, which also appears in the Appendices, under Supplemental Materials.

\textsuperscript{30} Ibid. \url{http://autismhousingpathways.net/wp-content/uploads/2014/05/AHP_Survey_results.pdf}
considerably more. Similarly, while about half could not afford even $5,000 toward a down payment, a significant number could afford more than $35,000, indicating there is potential for mixed market housing options, with some families acting as patient capital.\(^{31}\)

There is a range of supported housing models that can be produced using these funding streams. These can be characterized as:

- The family home: a non-custodial family member provides support, or support comes in periodically
- The family as landlord: the individual lives in an attached unit, with support than comes in periodically
- The family as landlord (with live-in support): the individual lives in an attached unit, with live-in support
- Live-in support: the individual lives in a separate unit, with live-in support. The unit may be owned or rented by the individual, the family, or the support provider.
- A group home: a number of people live in a small group residence, with support provided by hourly workers provided by the state or an agency. The home may be owned by families, the state, an agency, or a third party landlord.
- Assisted living or subsidized supported housing: individuals may live in an assisted living facility or subsidized housing, with support that comes in periodically.
- Community: an individual lives in an apartment or home in the community, with support that comes in periodically.

These arrangements, with the funding streams used to support each one, are summarized in an infographic, Mass. living arrangements for persons with developmental disabilities, which appears in the Appendices, under Supplemental Materials.\(^{32}\)

**Barriers to wider adoption**

There are a number of barriers to the wider adoption of existing models. Lack of awareness, affordability, financing, zoning, support program requirements, insurance reimbursement, voucher shortages are among them.

**Lack of awareness:** Many families are simply unaware of available resources. A survey done by Autism Housing Pathways\(^ {33} \) found that over half of families whose family members appeared to be eligible for Adult Family Care either had never heard of it or thought their family member did not qualify. Teachers of transition age students are often unaware of housing options and therefore fail to provide information to students and their families. Additionally, those families frequently are unaware that they need to plan well in advance for housing, and therefore are averse to taking steps to prepare while students are still in school.

**Affordability:** For many families and individuals the ability to control the property means stability. In many program models, if the individual lives with a support provider, the individual needs to move when the support provider no longer wishes to give support. However, affording real estate or the cost of adding an accessory unit to the family home is cost prohibitive to many families. A bill to allow families to take out loans from the state for the creation of an accessory apartment, S. 2202, was proposed in the 2015-2016 session; a variation is expected to be introduced in the next session.\(^{34} \)

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\(^{31}\) The AHP survey did not constitute representative sampling. Participants were located through list serves and outreach at local autism fairs and walks. 276 useable responses resulted. More work needs to be done in understanding family financial capabilities, but the results show there is interest on the part of families in participating in public/private housing solutions.


\(^{34}\) “Accessory Apartments” summarizes how families might benefit from such a program; it appears in the Appendices, under Supplemental Materials.
Additionally, support provided in the home of a provider is not subject to Department of Labor (DOL) regulations regarding minimum wage and overtime.\textsuperscript{35} If a provider lives in a home owned or rented by the individual or a third party (such as family or a provider organization), it is subject to the DOL regulations. Even if the support provider receives free rent (or pays a nominal amount), which counts toward the reimbursement considered by the DOL, this can add over $600/month in cash compensation needed above the Adult Foster Care stipend.\textsuperscript{36}

**Financing:** Many lenders treat borrowers trying to buy property for an autistic family member as if they were buying an investment property. Programs designed for low-income borrowers are generally out of reach for individuals relying on SSI as their primary income, and their family members cannot tap into them, as they are not considered owner-occupiers. Fannie Mae will treat a parent buying a home for a disabled adult child as an owner-occupier\textsuperscript{37}, but only one lender in the state is known to tap into this option.

**Zoning:** Accessory apartments have wide appeal for the reasons outlined in “Accessory Apartments” (found in the Appendices, under Supplemental Materials). However, many municipalities prohibit accessory units or require a special permit. The special permit process, even when available, can force families and individuals into a situation where they have to discuss the nature of an individual’s disability and support needs in a public forum. Neighbors are frequently far from welcoming. Rhode Island has made such units a by right use when created for a family member with a disability, considering them a reasonable accommodation for disability. However, there are difficulties with Rhode Island’s statute. It is important that two bedroom units be permitted so that a live-in support provider can reside in the same unit, in order to meet the requirements of Adult Foster Care. It is also important to allow a special needs trust to be considered an owner-occupier, so that the individual can continue to reside there once the parents are out of the picture.

**Support program requirements:** Adult Family Care does not permit the support provider to be a legal guardian, putting this program out of reach of single parents. Level II of Adult Family Care and Adult Foster Care requires an individual need physical assistance with three or more Activities of Daily Living (ADLS), or with two if a maladaptive behavior is present. Many individuals with autism have more than one maladaptive behavior present and require only cueing to perform ADLS. Despite having intensive support needs, these individuals are only eligible for Level I AFC. The Personal Care Attendant (PCA) program requires an individual to need physical assistance with at least 2 ADLs; cueing is not sufficient. This means there is effectively no MassHealth state plan service for people who need drop-in services for cueing, unless they live in certain settings where Group Adult Foster Care (GAFC) is available. Group Adult Foster Care can be used to provide 2 hours/day of drop-in services, but only in assisted living settings or subsidized housing. The latter means that those who need cueing for ADLS and live in project-based housing served by a GAFC agency can access this program, but those who have a portable housing voucher cannot. Broadening the locations where GAFC can be used might also allow individuals to access SSI-G, which pays a higher amount, but cannot be used in combination with a housing voucher. While this might appear to be a negative, there is no waiting list for SSI-G, while the wait for a voucher can be 10-12 years.

**Insurance reimbursement:** Assistive technology presents many opportunities for individuals to be more independent. Technology can reduce staffing costs, and even allow individuals to live on their own who might otherwise require constant personal supervision. However, getting insurance reimbursement for technology can be difficult.

**Voucher shortage:** For those relying on SSI as their sole source of income and not prioritized by DDS, housing is essentially out of reach without a subsidized housing voucher.\textsuperscript{38} The wait for a portable Section 8 voucher through the


\textsuperscript{37} An excerpt from the Fannie Mae Seller’s Guide describing this provision appears in the Appendices, under Supplemental Materials.

Centralized Waiting List can be as long as 12 years, and many other lists are frequently closed. Except for those able to pay cash for real estate, most family-created housing options also require a voucher to be sustainable in the long-term.

**Problems with existing housing stock**

In congregate settings, there is a fundamental tension between the right to choose those with whom one lives, and the Fair Housing Act. In group homes, compatibility can be a major challenge. However, because public dollars are at play, individuals do not get to choose those with whom they live. The need to provide adequate staffing dictates that small congregate settings (generally five or fewer people under one roof under current DDS policy) will remain an option for some individuals with intensive support needs. Better design options might provide a solution; for instance, individuals might have their own suites, with a variety of shared common spaces.

Features common to multifamily housing and even to traditional single family housing may present difficulties to people with autism. Either sensitivity to sounds or loud self-stimulatory activity can make it difficult for people with autism to live in close proximity to others in the absence of sound-deadening features. Fluorescent lights can be problematic for many people. A desire to avoid interactions with others can make standard entrance areas difficult. Most traditional spaces do not accommodate a need to pace. Some individuals require a more durable environment, such as shatter-proof glass, abuse-resistant drywall, and floor drains. Individuals (or families with autistic children) can find themselves facing eviction in situations that could have been avoided with better architectural design. There is an extensive literature on autism-friendly design that needs to be considered before creating new housing options.

**Homelessness — the unknown factor**

There is little hard information on autism and homelessness. While many shelters ask individuals about a psychiatric diagnosis, they do not generally ask about autism. More is known about homelessness and disabilities in general. In 2008, about 43% of those using a homeless shelter in the United States had a disability. We also know that in Massachusetts in 2015 there were 1,411 chronically homeless individuals, who are defined as both having a disability and being homeless repeatedly or for a long time. While this does not tell us anything on its face about autism, we do know that there is a high rate of comorbidity of mental illness in people with autism. A group in Florida has begun screening patients for autism at a psychiatric facility, and found that 11% are meeting criteria for a fuller evaluation. They are using a readily available screening tool, the AQ10, which could easily be adopted by shelters in Massachusetts. If the percentages found in Florida were to hold in Massachusetts, about 200 homeless individuals might...
have both autism and a psychiatric disorder, since the Department of Mental Health (DMH) assumes that at any given time 2,000 people who are homeless have a severe and persistent mental illness.\textsuperscript{46}

A further challenge is that homeless autistics may be less likely to gravitate toward shelter. In the U.K., there is evidence that people with autism are disproportionately represented among those sleeping on the streets (termed “rough sleepers”).\textsuperscript{47} The characteristics of autism can be a factor in effectively bringing people into shelter. Homeless Link, a U.K. organization, has developed a briefing to help frontline staff dealing with homelessness bring autistic people off the street.\textsuperscript{48} Issues not touched on in the U.K. materials that Autism Housing Pathways has encountered anecdotally are difficulty with the organizational skills needed to secure a bed in a shelter and sensory issues that may make most shelters difficult to tolerate.

\textsuperscript{46} “An Overview of Homeless Individuals in Massachusetts.” \textit{Massachusetts Executive Office of Health and Human Services}. Massachusetts Housing and Shelter Alliance. \url{http://www.mass.gov/eohhs/researcher/basic-needs/housing/an-overview-of-homeless-individuals-in-mass.html}


Autism-friendly Design

Characteristics of autism can be a poor fit with off the shelf housing stock

In 1979, Lorna Wing and Judith Gould described autism as having a triad of impairments: rigidity (lack of flexibility and restricted interests), communication difficulties, and difficulties with social interaction. Sensory issues are usually added to this list. Some specific examples of how these characteristics can impact one’s relationship with the built environment (or with neighbors, landlords, or housemates), are:

- Fluorescent lights can flicker and buzz, creating stress and anxiety
- Reflections off windows can be distracting
- Empty rooms can echo
- Outgassing from fabrics and floor finishes can cause headaches
- Sounds from neighboring units can be distressing
- Sleep disorders can lead to difficulties with neighbors if a person engages in loud self-stimulatory activity at night
- Poor sensory processing can lead to using too much force, breaking door handles or faucets
- A desire to interact with the environment in unusual ways, such as water play, can cause property damage
- The need to avoid uncertainty can create a desire to:
  - Avoid areas (including entryways) that can’t be “previewed”
  - Rigidly control the environment and the people in it
- Difficulty understanding unwritten rules (the “hidden curriculum”) can threaten tenancy

These examples are just that. They do not apply to all people with autism, but they are sufficiently common that they need to be accounted for in creating autism-friendly housing. The 2011-2012 AHP housing survey indicated there were a number of modifications that were deemed helpful or necessary by a significant number of respondents, including over 50% who would benefit from sound-proof bedrooms, durable construction, and a fenced in yard, and over 20% who would benefit from unbreakable glass, and floor drains in bathrooms. Design that anticipates these needs will result in residents preserving tenancy, fewer stress-induced meltdowns, lower repair bills, and less need for costly support staff to facilitate interaction with the environment.

Literature on autism-friendly design

In the last ten years, a robust literature on autism-friendly design has developed. The goal is to accommodate the characteristics of autism in designing housing, with the goal of improving residents’ quality of life. We will look at three examples of the literature. The first two are aimed at elucidating design principles, while the third takes a more practical approach, providing a template for identifying specific modifications to address individual needs.49

Ahrentzen and Steele

Sherry Ahrentzen and Kimberly Steele of Arizona State University were the lead authors on “Advancing Full Spectrum Housing: Designing for Adults with Autism Spectrum Disorders”.50 (This was a companion study to “Opening Doors: A

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49 Autism Housing Pathways has produced two summary documents on autism-friendly design, based on the literature discussed here and on the experience of its members:

2. “Autism design techniques – A cheat sheet”, which appears in the Appendices, under Supplemental Materials.

Discussion of Residential Options for Adults Living with Autism and Related Disorders (“, cited earlier). In addition to drawing on existing literature on autism and design, they used information from visits to and interviews with a range of existing programs considered to be exemplary that were serving people with autism, intellectual disabilities, developmental disabilities, and other “special needs” populations. They derived 10 design goals:

- Ensure safety and security
- Maximize familiarity, stability and clarity
- Minimize sensory overload
- Allow opportunities for controlling social interaction and privacy
- Provide adequate choice and independence
- Foster health and wellness
- Enhance one’s dignity
- Ensure durability
- Achieve affordability
- Ensure accessibility and support in the surrounding neighborhood.

16 design guidelines, referencing the goals, address: neighborhood; floor plan strategies; outdoor spaces; living/community rooms; kitchens; hallways, stairs, and ramps; bedrooms; sensory rooms; bathrooms; laundry room; technology; visual cues; ventilation; lighting; materials; acoustics; appliances and fixtures.

Brand

“Living in the Community: Housing Design for Adults with Autism”\(^{51}\) by Andrew Brand presents the results of a 2010 British collaboration between an autism charity, The Kingwood Trust, and Helen Hamlyn Centre of the Royal College of Art. Researchers reviewed the literature on autism, sensory processing and the built environment; consulted biographies of people with autism; interviewed autistics and professionals; and visited supported residences. They derived concepts and got feedback from focus groups of autistic adults. The group produced four design themes (Brand, p. 15; reproduced in the Appendices, in the Topic Briefing):

- Growth and development: facilitating personal growth through environments that encourage exploration and development of interests and skills. Qualities addressed were:
  - Independence, social interaction, access, affordability, and evolution
- Triggers: minimizing triggers by creating environments adapted to individuals’ sensory need. Qualities addressed were:
  - Sensation, perception, refuge, empowerment
- Robustness: creating environments that can safely tolerate unintended use. Qualities addressed were:
  - Safety, durability, ease of maintenance, tolerance
- Support tools: providing spaces that facilitate person-centered support. Qualities addressed were:
  - Communication, personal support, unobtrusive monitoring

Brand then produced a design guide, divided into five “layers”: planning; massing and layout; mechanical and electrical; furniture, fabric, and finishes; fixtures and fittings.

Braddock and Rowell

George Braddock is a veteran general contractor and housing consultant with over 25 years of designing and modifying homes for people with disabilities. He roots his work in a person-centered planning approach. With John Rowell, of Rowell Brokaw Architects and the University of Oregon, he produced “Making Homes that Work: A Resource Guide for

Families Living with Autism Spectrum Disorder and Co-occurring Behaviors. Braddock and Rowell’s approach is to engage in an environmental assessment and develop an action plan, through five steps:

- Identify caregiver challenges
- Involve the individual
- Assess the home and identify what isn’t working
- Learn about common home modifications and strategies for specific challenges
- Make an action plan for the unique situation and circumstances

Braddock and Rowell identify six most common home modifications for autistics with intensive support needs:

- An autism-friendly home that reduces risks and anticipates activities
- A connected home, with clear lines of sight to provide unobtrusive monitoring
- Essential bathroom modifications
- A walking loop to relieve stress
- Places of control and layers of freedom provide individuals with control and independence
- Tools for housekeeping to address common problems

They also provide strategies to cope with the specific challenges of elopement, self-injury and seizures, property damage, aggression, and neighbor relations.

The context of housing

Autism has sometimes been described as involving “context-blindness”, or difficulty with processing the context surrounding a situation. Like everything else, housing exists in a context. Physical design can help provide clues to that context, but additional supports are frequently needed to translate the social context of the housing environment. These can include explicit explanations of what is expected of a tenant, a neighbor, and a housemate. Clear strategies for addressing conflict need to be provided. Similarly, a readily understood version of the lease can be an important tool, in addition to guides to maintaining tenancy and receiving reasonable accommodations for disability. While many of these tools are not yet commonly available, a few resources are out there, including “Keep Your Housing! A Guide to Helping Massachusetts Tenants with Mental Health Issues Maintain Their Housing” and housing workbooks that touch on the hidden curriculum. Common issues that arise that threaten tenancy are housekeeping and hoarding. A technique that worked with an individual facing eviction was having a biweekly housekeeping inspection paired with a housecleaning rubric. Similarly, hoarding has been addressed by having a clear understanding that items must be kept on shelves. Periodically, the individual would identify items to be removed, but the actual removal would be done by support staff at an agreed upon time, during which the tenant chose to be absent. MassHousing maintains a webpage on hoarding resources.

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Technology

Overview

In 2013, David Braddock reported that only 1% of Medicaid waiver dollars were spent on recipient technology. Yet increasingly organizations are springing up to harness the ability of technology to assist individuals to be more independent, while providing them with a safety net. Two out of three winners in the recent Autism Speaks House-to-Home prize included technology as part of their entry.

Technology can be either low tech (printed picture-based directions, or color-coded measuring cups, for example), or high tech (dedicated voice output devices, apps for a variety of purposes, and home alert systems that reduce the need for overnight paid staff in the home). High tech systems can be comprehensive solutions, or apps that can be used for a discrete purpose, such as grocery shopping, bill paying, or mindful stress relief. As with an exercise program, the right technology is the one the person is willing and able to use (or learn to use).

The technology page of the think tank’s website presents a few examples of technology for a range of uses, as well as links to some tools and resources for finding technology. Examples are taken from all over the country, and may not be currently available in Massachusetts. Presence on the website does not constitute endorsement by any of the organizations sponsoring the think tank and its website, or by their members, officers or directors.

Webinar

On August 30th, the organizers of the MA Housing Think-Tank hosted a webinar on the use of technology. Kelly Charlebois, Executive Director of TechACCESS of Rhode Island, discussed the use of both low- and high-tech options to increase independence, and Catherine Boyle, President of Autism Housing Pathways, discussed smart home technology. The webinar slides appear in the Appendices; nothing in the slides is intended to be an endorsement of any specific product.


60 The webinar is archived on YouTube, and a link to it is also available on the think tank website. “Assistive Technology and Independent Living.” YouTube. ccampboyle. Viewed August 30, 2016. https://www.youtube.com/watch?v=svA0a28y21M
Best Practices

Literature on best practices

There is very little specifically written about best practices in supported housing for autistic people. Two comprehensive explorations of the question of creating autism housing options have been published in the last decade. More is available on disability housing in general. Here are summaries and links to a few publications on this topic, beginning with those focused on autism.

Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders: This 2009 publication by the Southwest Autism Research & Resource Center, the Urban Land Institute, and Arizona State University assessed existing successful models from around the country. It identified as next steps: conducting market surveys of demand and price-points; creating an interactive database of housing options; develop and test soft infrastructure support models; develop prototypes to test best practices and new ideas; respond to current and short-term demand; increase and systematize capital resources from public agencies; pursue testing of innovative options. Opening Doors included the design characteristics from the companion study, “Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum Disorders”, which was discussed earlier. Finally, Opening Doors referenced five strategies promulgated by Advancing Futures for Adults with Autism (AFAA):

1. Engage people and institutions that direct capital and influence housing policy by presenting a clear, compelling picture of the market demand for housing for adults with autism.
2. Increase collaboration and coordination between service agencies and housing agencies at the local, state and federal levels.
3. Motivate the overall real estate community (including government agencies, developers and others) to create housing options that are transit-oriented and accessible to employment, shopping and recreation, as well as increase opportunities for independence and integration.
4. Direct support towards residential service models which are person-centered and actively seek to meet the needs and interests of each adult with autism.
5. Expand both public and private funding for residential services for adults with autism.

Housing Options for Adults with Autism Spectrum Disorders: This 2010 publication of the Pennsylvania Department of Public Welfare Bureau of Autism Services produced a typology of seven housing models:

- Remaining at home (although possibly in a separate unit);
- Living with a different family;
- Renting an apartment or home;
- Purchasing a home;
- Sharing housing;
- Intentional communities; and
- Licensed facilities.

The criteria used to select these models were:

- Affordability;

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- Flexibility to meet the range of needs of autistic people as they change over time;
- Attractiveness to the people living there (a function of factors including location, design, cost, services, other residents);
- Utilization of existing housing options;
- Utilization of available community resources; and
- Ease of replication and administration

For each type, several models were identified. Many of the funding streams referenced are specific to Pennsylvania. Another drawback to this report is that it was produced prior to the Centers for Medicare and Medicaid Services (CMS) final rule on what constitutes Home and Community Based Services (HCBS), so a number of the projects described under intentional communities would not be permitted under the DDS policy that elucidates HCBS compliance in Massachusetts. However, together with “Opening Doors”, this is one of the two most exhaustive examinations of autism housing (as opposed to developmental disability housing in general), and contains a broad range of valuable information.

Disability Housing: What’s happening? What’s challenging? What’s needed? Micaela Connery’s 2016 working paper from the Harvard Joint Center for Housing Studies divides the history of disability services into three major epochs: a Kennedy-era focus on the need for adequate care (termed care); the movement toward self-determination and independent living (termed choice); an ADA-era focus on the need for full access and opportunity (termed access). She suggests there remains a tension between these sometimes conflicting values. In developing housing, Connery states, funding must always be available for housing development, housing operations, support services, and medical care. She goes on to identify the following needs: engaging parents and families as advocates and as a potential funding source for public-private housing options; creating a funding and regulatory environment that supports staff; supporting personal choice and individualized supports; and encouraging innovation. Policy and strategy considerations are elucidated: linking disability and other housing needs; engaging millennials as potential neighbors, roommates, and service providers; making direct service a professional career; and understanding disability as individuals age.

Housing and Support Options for People with Intellectual and Developmental Disabilities This 2014 study of housing options, which involved interviews with leaders from around the country and visits to providers in Wisconsin, Michigan and Oregon, was funded by the Coleman Foundation. Its purpose was to inform decision makers in Illinois, and therefore some of the options referred to are not relevant in Massachusetts. The study found several trends:

- Person-centered planning
- Individualized budgets
- Property owned by entities other than service providers
- Independent support brokers
- Flexible Medicaid waivers with a menu of options
- An awareness that many “best practices” are, so far, difficult to scale up

The authors present a grid for planning purposes on page 17; bear in mind that the “ICF/IID” is not an option in Massachusetts, and that the State Operated Housing referred to is not the same as a state-owned and operated group home, but a full-blown state institution, and is not relevant in Massachusetts.

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What all of these works make clear is that the challenge of balancing choice, supportive services, community access, affordability, and scalability is daunting. Design may be one way to break the log-jam, as part of the problem may be a tendency to limit solutions to existing housing forms. Fortunately, American society as a whole is beginning to wrestle with these limitations as they affect other groups, such as aging parents and millennials who cannot afford housing. Solutions for autistics may well prove beneficial to other populations as well. Additional strategies may be innovative forms of lending and property ownership, which could lower the cost threshold for families and individuals. Finally, it is important to find ways to accommodate the needs and desires of some individuals for quiet, predictable spaces and lifestyles while still achieving community integration, as stipulated by the Centers for Medicare and Medicaid Services. (A variation on this challenge is preserving access to community amenities, even when clinical issues present a barrier.)

Crowd sourcing housing principles in the absence of a consensus on best practice

As the above discussion would indicate, best practice in supported housing for people with autism is currently still a subjective phrase. Generally, people have extrapolated from the literature on people with developmental disabilities.

In the absence of a clear consensus on autism-specific best practices, the think tank planning committee decided to crowd source a set of consensus principles on autism and housing. For this purpose, a public Facebook page, MA Autism Housing Think Tank, was created. Participants on the page were invited to propose principles. Other readers could “like” a principle to endorse it, or could reformulate into something with which they could agree. The reformulation needed to be liked to take the place of the original. Over the course of a month, over 750 readers viewed the page, and approximately 60 participated actively in the formulation of 20 principles. These principles are presented in the next section.

66 Aside from the literature on architectural design for autism.
67 https://www.facebook.com/MAAutismHousingThinkTank/
Consensus Principles

(Principles were crowdsourced via Facebook in July, 2016; they do not necessarily represent the views of all of the entities that organized the think tank)

(Note the language of the principles 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 to reflect this variation.)

1. Autistics require a spectrum of adult living arrangements and supports.

2. Adult living arrangements for autistics should not be conditional on their being able to participate in specific types of day programs or "employment."

3. Placement in a residential setting (for those who are eligible) should be based on an individual's vision as developed using Person-Centered Planning processes; not based on the next available "bed."

4. Adults with autism need living arrangements where they can stay in their home when the support provider changes.

5. Autistic adults need to be given the opportunity to make choices about how to spend their leisure time; the food that they eat; and more. The state should provide sufficient oversight and control over agencies running 24/7 group homes to ensure clients have meaningful control over the decisions that affect their daily lives.

6. Adults with autism have the right to change their housing situation and/or provider agency and seek/receive help from the state government, if where they live; with whom they live; or the provider agency makes them feel uncomfortable or unwelcome.

7. Adults with autism have the right to have their parents act (or to select a representative, professional or otherwise, to act) as their advocates, to be their voice in achieving a high quality of life when the autistic adults live in an adult services residential setting.
   a. The individual's designated advocate (family or otherwise) or legal representative (guardian, conservator, designees to assist in supported decision making, etc.) can be present at any meetings, provider or otherwise to plan or make decisions in regard to services.

8. Direct support staff who work in adult services residential settings need to have much more comprehensive, extensive, mandatory training in evidence-based practices. Training should be relevant to the individuals with whom they will work, based on a person-centered planning process, and should take place prior to working with individuals.
   a. Direct Care staff need background checks, fingerprinting and other protective procedures such as a registry which would identify individuals with substantiated abuse or neglect reports.

9. Adult living arrangements for autistic adults should help them live the best life possible.

10. People with autism need housing that is designed and constructed to encourage growth and independence, minimize environmental triggers that cause decompensation, facilitate support needs, and reduce friction with housemates, neighbors, and landlords. Because home is where you should feel comfortable in your own skin.

11. Adults with autism should be supported in integrated settings with other adults who are not autistic with the appropriate supports to do so. It is understood that some individuals may require other individually designed settings based on the person centered plan.
12. Those people with autism who are not safe outdoors on their own should have housing with a backyard and safety measures as deemed necessary to support the individual, so they can safely spend time outdoors.

13. Autistic adults need their living situations to provide 1) Ample options for solitude to decompress and recover from social situations, as well as, 2) The ability to regularly schedule periods of unavailability.

14. Autistic adults have a right to housing they can afford.

15. Autistic adults have a right to access public transportation regardless of where they live.

16. Autistic adults need housing options that are scalable, either by virtue of being affordable to families, attractive to a larger market, or readily incorporated into new, multifamily developments serving the broader community.

17. Adults with autism have a right to housing that allows them interact with animals and the natural world, including the ability to own pets and garden.

18. Autistic adults have a right to live in rural areas, engage in gardening, and work with animals, provided their living arrangements are separate from the location of their activities during the work day.

19. Families should be able to network openly with each other for the purpose of establishing housing opportunities.

20. Autistic adults with complex medical conditions, including those that may occasionally present as maladaptive behaviors, need housing where medical conditions and required care, along with dietary restrictions, are prioritized in the care provided at the house. Dietary considerations and medical management may require additional qualifications and training for staff, but are critical to maintaining long term wellness, reducing maladaptive behaviors, and persuading families it is safe to access housing supports.
Housing Models

Once the consensus housing principles were developed, short videos of housing models were solicited from the public via the think tank Facebook page. The videos were assessed by the planning committee for consistency with the consensus housing principles. Those deemed consistent were used by the committee to generate a list of housing models. During the think tank, these models were evaluated as options for a broad range of people with autism. Participants also had the opportunity to suggest additional models.

Included with some of the models are lists of short video clips, explaining the model, describing a potential exemplar, or outlining ways in which supports might be provided. The videos are embedded in the think tank website page at: http://mahousingthinktank.org/best-practices/#models. Participants were expected to have read the list of models prior to the think tank, and were asked to consider watching the video clips to broaden their understanding of the models.

1) Small legal multi-unit owned by a family or families, a special needs trust, or a 3rd party not providing the services. May take the form of a duplex, an accessory unit attached to the family home, or a triple decker. Units might be re-configurable, to facilitate changes in support needs. Videos:
   a) Using Adult Foster Care to create living options outside the family home
   b) Accessory apartment attached to the family home
   c) James’ cool space
   d) Triple decker
   e) Duplex, combining Shared Living in one unit, with AFC in another
   f) Configurable housing

2) 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. Videos:
   a) Shared living in a family-owned home with a lease agreement with a provider
   b) Shared living with substantially separate living space

3) Licensed congregate living owned by families or a 3rd party not providing the services, with services from a provider chosen by residents/families. May be suite-based with multiple common areas that are shared and can be reserved. Videos:
   a) Homes for Life and The Arc of Delaware
   b) Constellation Cooperative Housing

4) 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. Video:
   a) Changing Housing into Community (CHIC)

5) Intergenerational housing, co-locating elderly with younger adults with disabilities. Video:
   a) 29 Palms

6) Transitional housing that trains residents in the skills they need to live independently
   a) SUCCEED and Safety Connection

7) Rural housing that facilitates active involvement with the land and animals, while maintaining community involvement. Video:
   a) Shared Living Collaborative

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68 Catherine Boyle of AHP recused herself from assessing videos for consistency with the housing principles. She prepared and submitted many of the videos under consideration, in order to ensure a broad range of housing models from around the country were available for the planning committee to consider.
8) Co-housing in which people with and without disabilities choose to live in community, while having their own living spaces
   a) Brooklyn Street

9) Large inclusive multi-unit housing.
   a) Developments that are inclusive, but have providing supported housing for those needing autism-friendly features as a core mission from the project’s inception. Videos:
      i) Hope House: 24/7 on site supports
      ii) Dave Wright Apartments: services available during certain hours
      iii) First Place: concierge services for permanent residences as well as onsite transitional housing
   b) Percentage of units with autism-friendly design features incorporated into new construction of multi-family housing. Ideally, other autism-friendly features are implemented into common areas. Units could be one-, two-, or three-bedroom, to meet the needs of a range of people, including those not DDS eligible, DDS set-asides, or families with children with autism. Video:
      i) Set asides in new units, including for families with autistic children

10) Inclusive, small footprint units, resulting in lower housing costs, with trained management and/or support providers. These could be either new construction or retrofits, possibly of existing 4-6 unit multi-families. Videos:
   a) Micro-units
   b) Single Room Occupancy

11) Co-provision of medical and behavioral supports. For those with medical issues that may present either alongside or as maladaptive behaviors, staff or support providers with both training in behavioral supports and as Certified Nursing Assistants may be critical. In theory, any of the models above could co-provide medical and behavior supports. Video:
   a) Medically and behaviorally intensive

12) “Smart homes”, in which assistive technology has been deployed to the fullest extent required to provide optimum support to the resident. (In theory, any of the other models described could be a smart home.) Video:
   a) Smart homes (Think tank participants who had not viewed the assistive technology webinar slides or webinar archived on the technology page of the think tank website were asked to view this video prior to the think tank.)
Hypothetical Resident Profiles

For the purposes of assessing housing models as options for a broad range of people with autism, the think tank facilitators developed hypothetical resident profiles. The profiles were composites of actual individuals. The goal of developing profiles was neither to stereotype autistic people nor to say that these profiles reflected the full range of people with autism. As it has been said, when you’ve met one person with autism, you’ve met one person with autism. Rather, it was both to facilitate a person-centered approach in the breakout groups that were assessing housing models, and to make sure a broad range of needs was addressed.

1. Alejandro has a part-time job, and likes to go to the gym and work out. He generally does fine with activities of daily living (ADLs), such as eating and hygiene, but has difficulties with instrumental activities of daily living (IADLs), such as money, cooking, shopping, and cleaning. He is eligible for DDS individual support hours.

2. Binh has aged out of foster care. He has no job. He has been couch surfing, but has run out of places to stay. He has not been able to get into a shelter because difficulties with executive functioning have made it hard for him to get to the right place at the right time to get a bed. He is eligible for DDS individual support hours.

3. Caiti, who is neurotypical, has a 13 year old with autism. They have been evicted twice, once due to complaints from neighbors about her son’s loud vocals, and once due to property damage (her son flooded the bathroom repeatedly, and twice punched holes in walls).

4. Dora can only afford $500 a month in rent. Her family can give her another $250 for rent. Dora has tried living with roommates several times, and it has always ended badly, either due to Dora’s sensory issues, or to roommates taking her money. She is not DDS eligible. She is on CommonHealth.

5. Eddie has a high school diploma, and volunteers 10 hours a week at an animal shelter. He wants to live on his own. He has the skills to live independently, with a few hours a week of coaching. However, he is having difficulty getting into subsidized housing, due to his criminal record. He is eligible for DDS individual support hours.

6. Henry is turning 22. He has been at a residential school that has farm activities, and has enjoyed these more than any other activities. He particularly likes working with animals. He is Priority 1 for DDS residential supports.

7. Justin is 21, has accepted a diploma, and is about to leave a psychiatric hospitalization. He cannot go home, as his family has a restraining order against him. His case manager feels he will not be able to cope in a shelter. He is eligible for DDS individual support hours.

8. Michelle likes spending time with people she knows well, but dislikes small talk, and needs plenty of quiet time alone to destress. She has a lot of independent living skills, but can panic if something unexpected happens, like a clogged toilet, a smoke alarm going off, or a stranger friending her on Facebook. She is not DDS eligible. She is on MassHealth.

9. Nancy is fond of listening to the Spice Girls, and doing adaptive yoga. She has complex medical issues (including uncontrolled seizures, pica, mitochondrial decompensation, and extended episodes of catatonic posturing during which she won’t eat), as well as maladaptive behaviors. Sometimes her medical issues can present behaviorally, and, even when the medical issue is resolved, the presentation can continue as a learned behavior. She is Priority 1 for DDS residential supports. Her parents are very concerned about keeping Nancy safe, and would like her to live near them, but cannot physically care for her themselves.

10. Rosa loves weaving and bowling, and lunch dates with a former baby sitter. She has no maladaptive behaviors, but she also has no sense of danger, and cannot cross a street independently. She is unable to shower.
independently. Her communication issues interfere with her ability to express and receive information, especially with strangers. She is Priority 2 for DDS residential supports.

11. Sanjay recently finished his degree at UMass Lowell, commuting from home and taking 2 classes at a time. He has just received a Section 8 voucher. His family is very concerned about his ability to maintain tenancy, as he has a history of hoarding. He is not DDS eligible. He is on MassHealth.

12. Terrell loves to swim and ride his bike. He has extreme maladaptive behaviors (biting, head-banging, stripping in public) that are triggered by anxiety and OCD (obsessive-compulsive disorder), or by eating foods to which he has an allergy or an intolerance. He uses visual supports. He will entirely self-isolate if he doesn’t live with others, refusing to leave the building, but he also needs private space he can retreat into. He is Priority 1 for DDS residential supports.
Outcomes

This section will address obvious trends in the data generated by the think tank. Comprehensive tables are provided in the Appendices, under Outcomes.

Analysis of the think tank outcomes was complicated by the following factors: one afternoon breakout session did not meet, due to a shortage of participants; one profile was assigned to more than one breakout group; and in numerous instances, groups chose to combine the brainstorming of funding and barriers for both of the housing models selected for a resident profile onto a single sheet.

Housing models and resident profiles

Despite the complications mentioned, clear outcomes emerged for both housing models and funding streams. It became equally clear that barriers are more specific to individual situations than they are to housing models.

Housing models selected for the greatest number of resident profiles:

<table>
<thead>
<tr>
<th>Model</th>
<th>Profiles (out of 12)</th>
<th>Funding streams suggested for the majority of profiles assigned to the model</th>
<th>Barriers suggested for the majority of profiles assigned to the model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual apartments or condos</td>
<td>7</td>
<td>Section 8, SSI, other MassHealth(^69), project-based housing, other affordable units, food stamps, AHVP/MRVP vouchers</td>
<td>Voucher shortage; transportation</td>
</tr>
<tr>
<td>Shared living</td>
<td>6</td>
<td>Section 8, food stamps, DDS residential</td>
<td>None apply to the majority of profiles</td>
</tr>
<tr>
<td>Co-housing</td>
<td>5</td>
<td>SSI, food stamps, Section 8, other MassHealth, DDS individual supports</td>
<td>transportation</td>
</tr>
<tr>
<td>Small footprint (micro-units or SRO)</td>
<td>5</td>
<td>Section 8, SSI, other affordable units, other MassHealth, food stamps</td>
<td>None apply to the majority of profiles</td>
</tr>
<tr>
<td>Transitional</td>
<td>4</td>
<td>Section 8, SSI, other MassHealth, food stamps</td>
<td>None apply to the majority of profiles</td>
</tr>
</tbody>
</table>

Certain models did not represent a large number of profiles, but were very important for certain profiles. For instance, licensed congregate living was selected 3 out of 8 times for one profile, “Terrell”; “co-provision of medical and behavioral supports” was selected twice each for that same profile, and for another profile, “Nancy”. For a third profile, “Henry”, rural housing with land/animal involvement was selected twice. One breakout group also selected a hybrid model “licensed congregate living in a small legal multi-unit”, and assigned it to “Terrell”. (Interestingly, a breakout group that had selected licensed congregate living for “Terrell” made a similar suggestion of using suites to provide privacy).

It is notable that small, legal multi-units, such as accessory apartments, duplexes, or triple-deckers was not among the models most widely chosen. There may have been some confusion about the term “shared living” as shorthand for “shared living in a single family home”. Given that shared living in a single family unit was one of the most widely chosen models, families are still likely to lean toward small, legal multi-units as the most affordable means of creating shared living situations controlled by individuals and their families.

Most significant funding streams:

\(^{69}\) Other MassHealth is MassHealth other than AFC, GAFC, or PCA services.
An odd anomaly crept into selection of funding streams. In a number of instances, groups selected AFC or PCA for situations where individuals would not qualify, either due to the living arrangement or not needing physical assistance. The implication is that what individuals might really need is drop-in services for cueing, which is not currently available, except through Group Adult Foster Care. Similarly, the inability to use food stamps in AFC and Shared Living is not well understand, indicating how confusing understanding these programs can be.

Most significant barriers:

<table>
<thead>
<tr>
<th>Barrier</th>
<th># of models (out of 13)</th>
<th># of profiles (out of 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affordability to individuals and families</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Voucher shortage</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Staff training, quality</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Transportation</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

Only affordability and the voucher shortage were considered significant barriers for the majority of individuals and settings. Transportation, not included on the cheat sheets provided to groups, was spontaneously raised for about half of models and profiles. Some barriers were not important across the board, but 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.

Design and technology

Breakout groups were also asked to select three architectural design features for each resident profile. 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). 70

Design features selected for the greatest number of resident profiles:

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

In addition, the following features were selected for 25% or more of profiles: connected home with clear lines of site (42%); door and window alarms (42%); abuse-resistant drywall or bead board (33%); tempered glass or shatter-resistant

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window film (25%); and bathroom modifications, such as floor drains, water shut-off devices, and a wall-hung toilet (25%).

The results of the design selection have certain strong similarities to those of Autism Housing Pathways’ 2012 housing survey, which found over 50% would benefit from soundproof bedrooms; over 40% of those with ID or needing assistance with Activities of Daily Living would benefit from shatterproof glass; and about 25% of those with ID or needing assistance with Activities of Daily Living would benefit from floor drains in bathrooms.

Similarly, breakout groups were asked to select three assistive technology options for each resident profile.

Technology features selected for the greatest number of resident profiles:

<table>
<thead>
<tr>
<th>Assistive technology</th>
<th># of profiles (out of 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coaching/decision making apps</td>
<td>10</td>
</tr>
<tr>
<td>Cueing apps</td>
<td>9</td>
</tr>
<tr>
<td>Apps for daily living</td>
<td>9</td>
</tr>
<tr>
<td>Alert systems (including central call stations and/or web interface with support team)</td>
<td>6</td>
</tr>
</tbody>
</table>

Scheduling apps were suggested for 42% of resident profiles, and communication apps for 33% of resident profiles.

Insurance reimbursement was cited as a barrier in 6 out of 13 housing models. One of the reasons cited in comments was the need to fund assistive technology (the other reason cited was the need to cover life coaching).

**Homelessness**

One breakout group was asked to perform double duty: in addition to evaluating housing models for a hypothetical young man who was described as couch surfing, they were tasked with considering two broader issues related to homelessness in the autistic community. Specifically, its members were asked to discuss options for quantifying the numbers of homeless people with autism, and to discuss options for improving the ability and willingness of people with autism to access the shelter system. This breakout group was provided with two background documents: the Autism Spectrum Quotient (AQ-10), a ten question screening tool for autism in adults without an intellectual disability71, and “Autism and Homelessness: Briefing for Frontline Staff”72. Both were developed in the United Kingdom, where evidence 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.73

Thoughts around quantification involved training staff in shelters, emergency rooms, and prisons to recognize signs of autism or to utilize the AQ-10 tool. “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;

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71 [http://docs.autismresearchcentre.com/tests/AQ10.pdf](http://docs.autismresearchcentre.com/tests/AQ10.pdf)
73 [http://mahousingthinktank.org/defining-the-need/#Homelessness](http://mahousingthinktank.org/defining-the-need/#Homelessness)
Improving autism awareness among shelter staff, and connecting shelters to DDS to verify eligibility; and
Using a broader definition of homelessness, including those kicked out of home, under-housed, couch surfing.

A complete listing of bullet points from the homelessness group reporting sheets may be found in the Appendices, under Outcomes.

Out-of-the-box models and mechanisms for approval of unusual arrangements

The eighth breakout group was charged with considering non-prescriptive approaches to housing options. This resulted in an extremely wide ranging discussion. Generally, comments on recording sheets could be categorized as either delineating difficulties in the existing system, or proposing new approaches.

Difficulties included inadequate funding for housing, poor communication and understanding of housing options, unhappiness with existing housing options, the lack of entitlement to adult services, and the risk of depression and isolation in community housing. Poor support for service providers was mentioned. Accommodations through the Americans with Disabilities Act (ADA) speak to physical disabilities, not invisible disabilities, such as autism. The need to organize a highly diverse disability community to affect change is a challenge.

Improved communication about housing options and regulations, including information sharing across agency silos, is seen as critical to an improved approach. SHINE counselors, who already help Medicare recipients understand benefits could play a role in information sharing, as could the Autism Commission. It was suggested that the housing committee of the Autism Commission expand its membership to include representation from HUD and from the Massachusetts Association of Community Development Corporations. Additionally, starting transition earlier, and embedding housing in an approach that includes independent living skills, employment, social skills, and connections to the community, is seen as a path to better quality of life. Participants called for a person-centered approach to housing, rooted in self-advocacy and responsibility, and addressing sensory, clinical, and physical needs, the use of technology, and administrative roadblocks.

The complete comments, organized into difficulties and new approaches, appear in the Appendices, under Outcomes.
Implications

Throughout the think tank process, including the development of consensus principles, the discussions of the “out-of-the-box” breakout group, and in the assessment of housing models and barriers, a consistent theme was the need to start with the needs of the person, and identify housing options and supports that would facilitate success. While think tank participants were able to identify a small core of housing models that could be collectively adapted to the needs of the residents considered, it was clear that the supports needed and the barriers to be surmounted for each model varied with the resident.

The models that were primarily selected by participants were:

- Individual apartments and condos, close enough to socialize;
- Shared living in a single family home;
- Inclusive small footprint housing, such as micro-units or single room occupancy;
- Co-housing, in which people with and without disabilities choose to live in community, while having their own living spaces; and
- Transitional housing, which trains residents in the skills they need to live independently.

At the same time, participants also made it clear that there is still a role for congregate housing for some individuals with extreme maladaptive behaviors. Even in such a case, however, breakout groups found ways to increase self-direction and quality of life, with one group proposing a hybrid model that separated control of the property from provision of services, while another proposed suites to provide privacy. These proposals raise interesting questions about ways to re-envision current congregate models.

While not explicitly mentioned, the tendency of breakout groups to select AFC or PCA as a funding stream in situations where individuals would not qualify implies there is a deficiency in the supportive staffing models.

Despite individual variations, certain barriers emerged sufficiently often to indicate they are systemic issues. These are: affordability, the shortage of vouchers (which could also be reframed as the long wait to receive a voucher), staff training and quality, and transportation.

Two of these barriers, the voucher shortage and transportation, were cited as an issue for the majority of profiles selected for the most widely chosen housing model, individual apartments and condos. Although not specifically mentioned, affordability, in the absence of a voucher, is an implied issue. One way to tackle this might be through an infusion of capital to buy down the rent for a percentage of units in a development; this might be a way to repurpose some funds from the Facilities Consolidation Fund. Set asides for DDS and DMH clients already exist for some units financed through MassHousing. They are still unaffordable to many, unless families sign a contract to pay a fixed amount to bring the individual’s income high enough; however, many DDS offices are unaware of this option, and these units frequently wind up being rented to those with no tie to DDS. Additionally, families that are in a position to buy a condo need to be aware of the option of a mortgage through Fannie Mae, which allows family members of a person with disability to pay 5% down and receive owner-occupier rates despite not living in the unit. The full description of this housing model stated that a facilitator and a neighbor are both paid to facilitate connections and provide support. These kinds of supports help to fend off the risk of depression and isolation raised in the “out-of-the-box” breakout group. It will be important to ensure these supports are fundable, either through DDS individual supports or MassHealth.

The second most widely chosen option was shared living in a single family home. It was noted earlier that there may have been some confusion at the think tank about the term “shared living” as shorthand for “shared living in a single family home”. If the goal is a self-directed shared living situation, assisting families to create accessory apartments is a clear way to meet this goal while addressing the crisis of affordability. Such units also allow the individual to remain in their home when the support provider moves on. Such separation of services from control of property was highlighted in the consensus principles. Empowering families to create accessory units is less expensive for the state than creating housing itself, and allows families to move ahead when the time is right for the individual, rather than waiting to be
prioritized by DDS. A major challenge to this model will be the need to find sufficient live-in support providers. Options that might be considered are having providers sign on for a defined period, possibly connected with a degree program or for tuition assistance, similar to what is offered through AmeriCorps. Additionally, current limitations on zoning present a challenge to adoption of this model.

Inclusive small footprint housing, which has a lower per unit cost of construction and was also one of the most widely chosen models, is another approach to achieving greater affordability. When it takes the form of micro-units, it can have the advantages of apartment living, the most commonly selected housing model. Small footprint units also provide greater privacy for individuals than sharing a traditional apartment, circumventing the challenge of roommate compatibility. Inclusive small footprint housing is most likely to be created in an area close to public transportation, helping to address another frequently cited barrier. Finally, it may be possible to class a percentage of units in, for instance, a micro-unit project, as assisted living, making it possible to access SSI-G and Group Adult Foster Care.

While transitional housing, another widely chosen option, is undoubtedly more expensive than certain other options in the short term, it has the advantage of being temporary and may reduce long term support costs. By considering transitional housing prior to age 22, cost sharing with the Department of Elementary and Secondary Education (DESE) may make this option more feasible for DDS.

The final model identified by the think tank for at least 25% of resident profiles was inclusive co-housing. Co-housing, by its nature, is intentional. While often envisioned as a separate, cordoned off, housing model, the example highlighted in the video on the think tank website, is not only inclusive of people with and without disabilities, it is also thoroughly ensconced in the broader community. Participants (not all of whom have a person with a disability in their household) are purchasing homes close to each other, but non-participants continue to live on the block. Community and relationships are intentional, but property lines are fungible. This type of co-housing is clearly an option that individuals are able to pursue with private funding, but it will be necessary to clarify how individuals might be able to use support dollars in these types of arrangements.

Much of this discussion has focused on affordability as it presents in different housing models, and less on the other barriers: shortages/long waits for vouchers, transportation, and staff training. The Boston Center for Independent Living continues to advocate for an increase in funding for the Alternative Housing Voucher Program. In addition, it is important for families, teachers, transition specialists, and transition coordinators to be aware of the importance of applying for a mobile voucher as soon as a young person turns 18. Transportation is a difficult problem. No panaceas present themselves, but access to transportation needs to be a key consideration in determining the location of new housing, or in selecting a housing option for an individual. Staff training was cited as a barrier by think tank participants most frequently for hypothetical residents with intensive behavioral challenges. The Association of Developmental Disabilities Providers (ADDP) has a working group examining the issue of training, and it is hoped those efforts bear fruit. However, it is also important to consider the issue of people who may not have such overt challenges who may struggle to preserve tenancy because they do not understand the hidden curriculum of interacting with their landlord or neighbors. Training for property managers, landlords, and public housing authority personnel may also be a worthwhile proposition.

Think tank participants identified six design adaptations as appropriate for at least half of the hypothetical residents considered. It would make sense to incorporate these into a percentage of units in new housing developments, just as other units are wheelchair accessible. Similarly, 25% or more of residents may require more intensive modifications (such as tempered glass or floor drains in bathrooms), and this should also be anticipated in new developments. Increasing the availability of autism-friendly units will help to maintain tenancy, including for families with autistic children, and may even help to delay referrals of children with autism to residential placement. Certainly, any housing specifically developed to meet the needs of people with autism should incorporate these features.

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74 Bear in mind that “shared living” in this context simply refers to sharing living space, not to shared living through DDS. The funding stream for the support provider may well be Adult Foster Care.
In an era when staffing is both expensive and scarce, the ability of technology to help reduce staffing costs by increasing independence should not be ignored. To facilitate uptake of technology, individuals and their families need to be able to have both technology assessments and technology itself (including apps) covered by MassHealth and through DDS family and individual support dollars. If housing is a social determinant of health, it is logical that apps that facilitate a person’s ability to live independently would be covered.

The above discussion underscores that successful provision and maintenance of housing is a highly individualized endeavor. As participants in the “out-of-the-box” group indicated, good communication, education about options, and a person-centered holistic approach that starts early is conducive to a good outcome. To achieve these goals, a concerted effort to bring families, educators, transition specialists, and housing specialists together will be necessary. It makes sense to incorporate applying for affordable housing and developing independent living skills into transition goals. It would also be logical for the housing committee of the Autism Commission to incorporate the suggestion that it expand its membership to include representation from HUD and from the Massachusetts Association of Community Development Corporations. Getting autism on the radar screen of housing professionals will be essential to scaling up production of housing that can meet the needs of the autism community.

The first question housing professionals are likely to ask, however, will be about quantifying those needs. Data are essential. How many apartments? How many accessory units? How many micro-units? How many transitional units? Data will also be needed to answer our questions about homelessness. What little we know is of concern. The Massachusetts Healthy People 2020 Autism Roadmap Report: Understanding Needs & Measuring Outcomes was recently submitted to the Autism Commission. It states, “A recent survey of clinicians found that out of the 650 DCF/DMF shelter beds they monitor, 35% were occupied by autistic youth across all programs.” Getting answers to these questions will require data collection, such as the survey that Chapter 226 charges the Autism Commission with undertaking.

To summarize:

- 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.
- 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.

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- 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
   a. Combining individual suites with shared common space, and
   b. 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 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:

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76 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.
a. 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.

b. A survey be conducted to identify existing supported housing serving individuals with ASD, and the types of supports provided.

c. 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.

d. 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.
Appendices
MA Autism Housing Think Tank is a collaboration of:

**Autism Housing Pathways:** Autism Housing Pathways (AHP) is a family-driven, membership-based organization serving the Massachusetts autism community. We provide training and resources to families about housing options. AHP also engages in research into the housing needs of the autism community in Massachusetts. We have a further interest in improving the quality of training for direct support staff, and have produced free online training videos suitable for new hires.

**The Arc of Massachusetts:** The mission of The Arc of Massachusetts is to enhance the lives of individuals with intellectual and developmental disabilities and their families. We accomplish this through advocacy of supports and services based in the community. Through advocacy and collaboration with others, The Arc of Massachusetts has helped to establish and maintain significant legislation and funding on both the state and federal levels.

**Advocates for Autism of Massachusetts (AFAM):** AFAM is a grassroots membership organization of families and concerned citizens. We serve as the primary advocacy vehicle protecting the rights and needs of individuals with ASD and their families throughout the state. Our mission is to strive to assure the human and civil rights of individuals of all ages across the entire Autism Spectrum and promote the availability of essential supports so that they may live fully and enjoy the same opportunities as other citizens of the Commonwealth. We will educate individuals with ASD, their families and other AFAM members/supporters to be effective, vigorous agents of change.

Additional support is provided by:

**Advocates:** Advocates offers a full range of services for individuals with autism and their families at all stages of life. From the Autism Alliance, which supports families from diagnosis through early adulthood, to our specialized adult residential and day services, we strive to create opportunities for rewarding and productive lives.

**HMEA:** HMEA provides lifelong support to individuals with Autism Spectrum Disorders, including early intervention, family supports, Autism Waiver services, DESE/DDS prevention program services, transition services, and a full range of adult services and supports. HMEA is the parent organization of both Autism Resource Central and The Darnell School.

**The Massachusetts Developmental Disabilities Council:** The Massachusetts Developmental Disabilities Council (Council) is an independent agency funded by the federal government to work with the state of Massachusetts to better support people with developmental disabilities and their families. The Council believes individuals with developmental disabilities must have the opportunity to live full, productive and independent lives in the community. Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities.

**September 10, 2016 Facilitators**

Cheryl Ryan Chan is, first and foremost, Mom to Nicky – a 23-year-old man severely impacted by autism. Cheryl has spent over 17 years in Massachusetts, integrating her son and family into the disability community and becoming a well-known leader in community organization, legislative activism, mentoring and public speaking. She is a social media and marketing consultant to nonprofit organizations. Her work as a Person-Centered Planning facilitator began in 2010 and has become her greatest passion, leading to the development of Person-Centered Planning Partners, Inc, (www.personcenteredplanning.com) a program of her nonprofit Community 4 Each, Inc.

Erica Ploof is a long serving member of HMEA’s Autism Resource Central Family Advisory Board. She serves as their liaison to AFAM. Erica also serves as AFAM’s representative to the Supporting Families Coalition. Erica is a person-centered and group planning facilitator with Person-Centered Planning Partners, Inc. She is mom to 2 boys, one with
Autism Spectrum Disorder. She is an independent contract consultant and financial analyst. Erica is a graduate of UMASS Amherst.

September 10, 2016 Presenter:

Catherine Boyle is the president of Autism Housing Pathways, a non-profit that works with families to identify and create housing opportunities for their adult family members with disabilities. She is a commissioner of the Winchester Housing Authority, and a member of the Winchester Housing Partnership Board. A former Foreign Service Officer, Catherine is a graduate of Dartmouth College, has her M.A. from Simon Fraser University, and holds a certificate of graduate studies from UMASS Boston in adapting curriculum.
Assistive Technology and Independent Living

Kelly Charlebois, Executive Director, TechACCESS
Catherine Boyle, President, Autism Housing Pathways
August 30, 2016

TechACCESS (A Program of HMEA)
www.techaccess-ri.org

• Provides a variety of services in RI and MA: (MA Health approval pending)
  • Evaluation
  • Consultation
  • Training
  • Technical Support
  • Professional Development
  • Assistive Technology Conference of New England
    • November 17th and 18th
    • www.assistivetechnologyconference.com

77 Nothing in these slides is intended as an endorsement of any specific product.
What is Assistive Technology?

“Assistive Technology (AT) device is any item, piece of equipment or product system, whether acquired commercially, modified or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities.”

~IDEA

Assistive Technology can...

- Increase access
- Increase independence
- Increase communication
Low Tech vs. High Tech

- Low tech tools are usually more readily available/easier to manage
- Training needs and the “learning curve” can vary significantly
- The “tiered” approach to AT...a combination of both low and high tech tools

Cooking/Daily Living

- Cooking Aids: [www.independentliving.com](http://www.independentliving.com)
  - The Pot Minder (keeps pots from boiling over)
  - Liquid Indicator (alerts when liquids are close to top of cup/mug)
  - Cut Resistant Glove (protects hand when using sharp utensils/knives)
  - Cool Touch Oven Rack Guard
  - Magic Chef Talking Microwave Oven (press button for auditory cue of what its function is)
  - Color Cue Measuring Cup and Spoon Set
  - Adapted Utensils/plates/etc.
  - Voice Activated Phone (stores 17 names)/Picture Phone (dial by photo)
  - Talking Indoor/Outdoor Thermometer
Visual Recipe Resources

- Visual Recipes: http://visualrecipes.com/
- Your Special Chef: http://www.yourspecialchef.net/
- Bry-Backmanor: http://www.bry-backmanor.org/picturerecipes.html

- I Get...Cooking app
  $4.99

iDevices

- iPad
- iPod Touch
- iWatch

- Use built-in features:
  - Reminders
  - Calendar
  - FaceTime
  - Videos
  - Accessibility Features

Remember:
You may need a cellular plan for full access to all features
Match features of apps with individuals
Not all apps are available on all devices
Apps for Communication

- ProloQuo2Go ($249.99)
- GoTalk Now (also has visual scenes) ($79.99)
- Assistive Express (typing) ($24.99)

Apps for Scheduling/Social Stories

- Visual Schedule Planner ($14.99)
- Video Scheduler ($12.99)
- CanPlan (Free, then paid)
- Pictello ($19.99)
- AutisMate ($149.99)
- Functional Planning System ($4.99)
Misc. Apps

- Money Trainer for Kids and Adults with Autism ($19.99)
- Functional Planning System ($4.99)
- ShoppingList 3 (.99)
- QuickCues ($4.99)
- Everyday Skills ($49.99)
- Living Safely ($34.99)

Things to consider...

- Access to Internet
- Staffing levels
- Training needs
- Clear expectations
- Implementation plan
Smart home technology

• “Smart home” technology can facilitate greater independence while maintaining safety, both in the home and beyond
• Technology can:
  • Interface with residents
  • Act independently to stop a dangerous situation or prevent property damage
  • Interface with support providers
• Ethics
  • Technology should be implemented in the context of a person-centered planning process that ensures privacy and informed consent

Smart home technology: interface with residents

• Scheduling (may include reminders and/or the ability to check tasks off)
• Step-by-step directions (including daily tasks, recipes, etc.)
• Simplified email and web access
• Secure social networking
• Environmental controls (including control of lights, temperature, doors)
• Navigation (independent travel in the community)
• Decision-making
• Answering questions
• Dispense medication or take vitals
Smart home technology: interface with residents (examples)

- Scheduling
  - Endeavor 3 (AbleLink)
  - Functional Planning System (Conover)
  - TouchStream Solutions
  - Things (Cultured Code)
- Step-by-step directions (including daily tasks, recipes, etc.)
  - Visual Impact 3 (AbleLink)
  - Functional Planning System (Conover)
- Simplified email and web access
  - Endeavor Desktop Pro (AbleLink)
- Secure social networking
  - Community Tyze has a wall to post updates, messaging, a calendar, and can store files

Smart home technology: interface with residents (more examples)

- Environmental controls (including control of lights, temperature, doors)
  - SimplyHome
  - RFID wrist band or key fob to unlock a resident’s bedroom door
- Navigation (independent travel in the community)
  - Wayfinder 3 (AbleLink) is an accessible GPS that provides verbal and visual cues
- Decision-making
  - Smart Steps is an app that uses Q&A decision trees and suggests when to call for help
- Answering questions
  - Identifor
- Dispense medication or take vitals
  - Pill dispensers (epill, SimplyHome)
  - Blood sugar (TouchStream, SimplyHome)
  - Weight (TouchStream, SimplyHome)
  - Blood pressure (TouchStream, SimplyHome)
Smart home technology: act independently

- Stove safety sensors
  - Homesensor (search on AbleData site) and iGuardStove (available through Sengistix) shut off the stove if no motion is detected after a period of time
  - FireAvert (search on The Alzheimer’s Store) shuts off the stove if it detects a smoke alarm going off
- Magnetic induction cooktop shuts off if pot is removed or overheats (e.g., because water has boiled away)
- Water flooding sensor
  - FloodStop (search on plumbingsupply.com) shuts off the water valve if water is detected on the floor

Smart home technology: interface with support providers

- Receive alerts (text, email, or phone)
  - A trigger might be a low blood sugar reading, for instance
- Call center (may be overnight only or 24/7)
  - Resident may call, or a panic button or sensor may trigger a call from a center
  - If necessary, support staff may be contacted to respond
  - One advantage of a full-blown monitoring system is the ability to make sure the technology is working
- Web-interface
  - Support provider uses web-interface to check status
Smart home technology: interface with support providers (examples)

- TouchStream is a dedicated tablet which provides scheduling and directions, has the capacity to take vitals, can send alerts, and has a web interface.

- Safety Connection is an overnight call center. Individuals call in when they are home for the night, and the center alarms doors/windows, smoke detectors, etc. Individuals can call for assistance, and the center can talk them through situations or contact the person’s support team.

- SimplyHome provides a call center that can be contacted by an individual through a panic button, or by sensors. The call center will contact the support provider or family.

- Night Owl Support Systems connects an array of non-camera sensors to an overnight monitoring station. Staff at the station respond to alerts or calls in accordance with a support plan, and can dispatch responders who might be support staff, family members or friends.

Putting it all together: Imagine!

- Imagine! is a provider in Colorado. Beginning in 2005, they started their SmartHomes initiative.

- Residents use AbleLink technology for scheduling, step-by-step directions, web-surfing, etc.

- In the initial SmartHomes, the interface with the provider was a homegrown product, using a programmable logic controller. They suggest this would not be something to duplicate. In newer homes, they have adopted SimplyHome technology.

- Imagine! is also implementing technology to train staff, communicate among staff, track medications, etc.
Thank you for joining us!
MA Autism Housing Think Tank: Topic briefing

Demographics and housing demand

• Probably 75,000-100,000 people with autism in Massachusetts
• Likely about 80%-85% need (or will need) affordable supported housing beyond what is currently provided by DDS
• Current housing stock may be a poor fit for many with autism
  • Some people need to live alone to succeed, but can’t afford to
  • Design features can trigger sensory issues, cause conflict with neighbors; a heightened risk of eviction, including for families with autistic children
• More questions than answers about homelessness in autism
  • No certain numbers, but 10+% of those with mental illness may also have ASD, implying 200+ individuals in Mass. may be autistic and homeless
  • Homeless autistics may be less likely to gravitate toward shelters
Funding streams for supported housing

- Bricks and mortar expenses
  - SSI
  - SSDI
  - Section 8
  - Other “affordable housing”
  - DDS
  - Energy/utility assistance
  - Private resources

- Food
  - SSI
  - SSDI
  - Food stamps (SNAP or Bay State CAP)
  - DDS
  - Private resources

- Supportive services
  - SSI
  - SSDI
  - MassHealth (Medicaid)
  - DDS
  - Private resources

Current supported housing models based on funding streams (1)

- The family home: a non-custodial family member provides support, or support comes in periodically
- The family as landlord: the individual lives in an attached unit, with support than comes in periodically
- The family as landlord (with live-in support): the individual lives in an attached unit, with live-in support
- Live-in support: the individual lives in a separate unit, with live-in support. The unit may be owned or rented by the individual, the family, or the support provider.
Current supported housing models based on funding streams (2)

• A group home: a number of people live in a small group residence, with support provided by hourly workers provided by the state or an agency. The home may be owned by families, the state, an agency, or a third party landlord.

• Assisted living or subsidized supported housing: individuals may live in an assisted living facility or subsidized housing, with support that comes in periodically.

• Community: an individual lives in an apartment or home in the community, with support that comes in periodically.

Barriers to wider adoption of current models (1)

• Lack of awareness: many individuals and their families don’t know what they are eligible for

• Affordability: control of property by individuals/families means stability when support providers change

• Dept. of Labor regulations regarding minimum wage and overtime

• Limited financing options
Barriers to wider adoption of current models (2)

• Zoning: too few areas permit accessory units
• Support program requirements
• Voucher shortage
• Insurance reimbursement for assistive technology

Autism-friendly design

• Poor design can trigger anxiety, conflict with neighbors, and potentially loss of tenancy for some people with autism.
• AHP’s housing survey showed 50% would benefit from sound-proof bedrooms, durable construction, and a fenced in yard, and over 20% would benefit from unbreakable glass, and floor drains in bathrooms
• There is a robust literature on designing living environments to better fit the needs of people with autism, including Brand’s four design themes
Brand

Assistive technology can increase independence (1)

- Technology is increasingly seen as part of a viable safety net
- Technology can be low tech or high tech
- Insurance reimbursement for technology is a challenge
- Options include
  - Scheduling/to do apps
  - Cueing apps and/or low-tech visual directions (cooking, cleaning, shopping, money, and other daily tasks)
  - Communication apps
Assistive technology can increase independence (2)

- Options include (continued)
  - Daily living aids (including color coded measuring cups, cut-resistant gloves for cutting food, stove shut-off, flood sensor, picture-based phone, etc.)
  - Coaching/decision making apps
  - Secure social networking (prevents strangers from friending someone) and/or simplified email/web interface
  - Navigation technology
  - Alert systems (including central call stations and/or web interface with support team)
  - Vitals/medication system
  - Environmental controls

Best practices and consensus principles

- “Best practice” is still a subjective term in relation to autism and housing, as opposed to developmental disabilities
  - Only two comprehensive publications regarding supported housing for people with autism in the last decade
- Think tank organizers crowd-sourced consensus principles on autism and housing
  - Organizers solicited videos about housing models and reviewed them for consistency with the consensus principles
  - From these, housing models were derived for consideration today
Potential design features

Check off any of Braddock and Rowell’s “Six Most Common Home Modifications” that seem appropriate.

☐ An autism-friendly home that reduces risks and anticipates activities (look at “Autism design techniques – A cheat sheet” to get an idea of what this refers to). Specific recommendations:

___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________

☐ A connected home, with clear lines of sight (allows the resident to preview common areas and decide whether to enter, can also allow a support provider to keep an eye on things without hovering)

☐ Essential bathroom modifications (including floor drains or waterproof membrane, water shut-off device, wall-hung toilet)

☐ A walking loop to relieve stress

☐ Places of control and layers of freedom provide individuals with control and independence (spaces the individual can safely navigate without a support provider)

☐ Tools for housekeeping to address common problems (including commercial washer/dryer, mop sink, etc.)

If there are specific challenges of elopement, self-injury and seizures, property damage, aggression, and/or relationships with neighbors, check off possible modifications.

☐ Door and window alarms

☐ Rounded corners, built in furniture, padded headboards

☐ Abuse-resistant drywall or bead board

☐ Tempered glass or film to cover glass to prevent shattering

☐ Sound-proofing

☐ Break-away curtains
Potential technology options

- **Scheduling/to do apps**
- **Cueing apps** and/or low-tech visual directions (cooking, cleaning, shopping, money, and other daily tasks)
- **Communication apps**
- **Daily living aids** (including color coded measuring cups, cut-resistant gloves for cutting food, stove shut-off, flood sensor, picture-based phone, etc.)
- **Coaching/decision making apps**
- **Secure social networking** (prevents strangers from friending someone) and/or simplified email/web interface
- **Navigation technology**
- **Alert systems** (including central call stations and/or web interface with support team)
- **Vitals/medication system**
- **Environmental controls**
Potential funding sources for services, housing, and individual/family financing

General

☐ SSI
☐ SSDI
☐ SSI-G payment if in subsidized housing or assisted living setting and receiving Group Adult Foster Care

Support services

☐ Adult Family Care (AFC)
☐ Adult Foster Care (AFC)
☐ Group Adult Foster Care (GAFC)
☐ Personal Care Attendant services (PCA)
☐ Other MassHealth funded programs
☐ Food Stamps
☐ DDS
☐ Specialized Intensive Programs and Services (SIPS) through Metro Boston Housing Partnership, including their Hoarding and Sanitation Initiative

Housing

☐ Section 8 (mobile voucher)
☐ Other housing vouchers (AHVP, MRVP)
☐ Project-based subsidized housing (project-based Sec. 8, units for younger people with disabilities in state senior housing, other local housing authority properties)
☐ Other affordable units (set-asides in developments funded by MassHousing, etc.)

Individual/family financing

☐ Fannie Mae loan to family or individual
☐ DHCD loan to family or other homeowner via CEDAC if accessory apartment loan bill passes

Other (in any category – specify; may include CEDAC funds, tax credits, etc.)

☐
☐
☐

Support that would be helpful, but does not currently exist in Massachusetts

☐
☐
Potential barriers to implementation

☐ Affordability to family or individual

☐ Financing availability

☐ Department of Labor regulations on minimum wage and overtime for caregivers

☐ Program requirements a poor fit for the needs of the individual (e.g., single parent legal guardian cannot be Adult Family Care provider; insufficient funding level for those who need cueing with ADLs and have behaviors; no state plan service for drop-in cueing)

☐ Zoning

☐ Insurance reimbursement (for technology, life coaching, etc.)

☐ Voucher shortage

☐ Other (specify)

☐ __________________________________________

☐ __________________________________________

☐ __________________________________________
Acronyms

(Not all acronyms on this list appear in this document; they are included in case they come up during the course of discussions.)

ADL: Activities of Daily Living
AFAM: Advocates for Autism of Massachusetts
AFC: Adult Family Care or Adult Foster Care
AHP: Autism Housing Pathways
CDC: Centers for Disease Control
CEDAC: Community Economic Development Assistance Corporation
CMS: Centers for Medicare and Medicaid Services (federal)
DDS: Department of Developmental Services
DESE: Department of Elementary and Secondary Education
DHCD: Department of Housing and Community Development
DMH: Department of Mental Health
DOL: Department of Labor (federal)
DPH: Department of Public Health
HCBS: Home and Community Based Services
HUD: Housing and Urban Development (federal)
IEP: Individualized Education Program
GAFC: Group Adult Foster Care
MRC: Massachusetts Rehabilitation Commission
PCA: Personal Care Attendant
SNAP: Supplemental Nutrition Assistance Program (food stamps)
SSDI: Social Security Disability Insurance
SSI: Supplemental Security Income
In April of 2016, Autism Housing Pathways posted a series of Tweet length "Autism Month Housing Thoughts of the Day". They comprised a mini-tutorial on housing for individuals with autism and other developmental disabilities, including housing subsidies and supportive services. They are republished here, with three additional comments to add information on Medicaid waivers. Acronyms are spelled out here, as they were not in the original Tweets. To learn more about many of the services mentioned, check out our Turning 18 checklist. Items in bold refer to public funding streams.

1. Of those with family involvement, only about 12% will be both eligible and prioritized for Community Based Residential Services through the Dept. of Developmental Services (DDS) at age 22.

2. It frequently takes 5-10 years to plan and implement a housing strategy; start at 18 if the goal is independent living by 30.

3. The housing equation is: bricks & mortar + food + services = housing. There are subsidies for all, but not all can be combined.

4. **Supplemental Security Income (SSI)** can be used for any part of the housing equation. People can apply based on their own income at 18.

5. **SSI** has asset and income caps; other income can reduce benefits. Try to avoid assets in the person's own name.

6. **SSI** makes someone automatically eligible for **MassHealth** (Medicaid). Medicaid is the main way to pay for services.

7. **Social Security Disability Insurance (SSDI)** can be used for any part of the housing equation. Assets and unearned income do not affect benefits.

8. **SSDI** makes you eligible for Medicare (not Medicaid) after 2 years. Medicare can't be used for long-term services.

9. For those disabled before 22, **SSDI** can be based on their own income or a parent's, once the parent retires.

10. Try not to retire until your child receives SSI as an adult. Otherwise, they may not qualify for **MassHealth**.

11. Those who don’t qualify for **MassHealth** can qualify for **CommonHealth** if they work 40 hours/month.

12. People can also qualify for **CommonHealth** by meeting a one-time spend-down.

13. The most important housing subsidy is **Section 8**. Apply at age 18. Go to [www.18section8.org](http://www.18section8.org) to learn how.

14. The wait for a **Section 8** voucher can be up to 12 years. Apply at 18.

15. A family member can be the **Sec. 8** landlord for a person with a disability. But they can’t live in the same unit.

16. Someone who needs a live-in aide can get a 2-bedroom **Sec. 8** voucher. But the aide can’t be immediate family.

17. **Food stamps** and **Sec. 8** will not result in a reduction of **SSI** benefits. People usually qualify for food stamps at age 22.

18. The **food stamp** recipient needs to buy and prepare food “substantially separately” from the rest of the household.

19. **MassHealth State Plan Services** are the main way to pay for long-term services and supports. [Addendum: other than Medicaid waivers -- waivers are addressed below.]
20. **MassHealth State Plan Services** are entitlements. There are no waiting lists if you qualify.

21. **Adult Foster/Family Care (AFC), Personal Care Attendant (PCA), and Group AFC (GAFC)** are state plan services.

22. You can’t combine **AFC**, **PCA**, and **GAFC**. Pick one.

23. **AFC** pays a stipend to a caregiver who lives with the person. A parent who is not a guardian can be a caregiver.

24. Consider saving the **AFC** stipend while waiting for a **Sec. 8** voucher. It goes a long way toward a down-payment.

25. **AFC** generally can’t be combined with food stamps.

26. **GAFC** can only be used in assisted living or subsidized housing – not with a mobile **Sec. 8** voucher.

27. **DDS** individual support hours can be used with **AFC**, **PCA**, or **GAFC**.

28. **DDS** housing dollars can only be used in settings with 5 people or less under one roof.

29. Senate bill 2202 (formerly S. 708) would let families take out a loan to create an accessory apartment. Learn more: [http://tinyurl.com/j8lbaj5](http://tinyurl.com/j8lbaj5)


**Addendum -- Medicaid waivers:**

1. Those receiving services from **DDS** can apply for a **Medicaid waiver**. The feds reimburse the state for half the cost of waiver services.

2. **Waiver** services are portable, meaning the dollars are attached to the person on the waiver, and can move with the person.

3. There are three kinds of **waivers**: Intensive Supports, Community Living, and Adult Supports. [http://www.mass.gov/eohhs/docs/dmr/hcisis/hcbs-brief.pdf](http://www.mass.gov/eohhs/docs/dmr/hcisis/hcbs-brief.pdf)
Infographic

Mass. living arrangements for persons with developmental disabilities
(Showing potential funding streams)

Family as landlord

Person with disability

Family

SSI and/or SSDI

Family

DDDS family supports OR Adult Supports Waiver

Food stamps

Personal Care Attendant (PCA)

Family home

SSI and/or SSDI

Adult Family Care (AFC) OR PCA

Family

Live-in support

SSI and/or SSDI

Section 8

DDDS shared living OR Adult Foster Care (AFC)

Family

Group home

SSI and/or SSDI

Food stamps

DDDS Intensive Supports Waiver

Assisted living or subsidized supported housing

SSI and/or SSDI

Group Adult Foster Care (GAFAC)

DDDS Individual Supports

Food stamps

Community

SSI and/or SSDI

Section 8

DDDS Individual Supports OR Adult Supports Waiver

Food stamps

Personal Care Attendant (PCA)

1 Supplemental Security Insurance (SSI) and Social Security Disability Insurance (SSDI)
2 May also use some other type of housing voucher, such as a voucher from the Mass. Rental Voucher Program (MRVP) or the Alternative Housing Voucher Program (AHVP)
3 Department of Developmental Services
4 May also be Community Living Waiver, but not combined with AFC or PCA

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Accessory apartments

DDS is increasingly emphasizing Shared Living for those prioritized by DDS, and Adult Foster Care for those who are not. However, unless the individual has at least a two-bedroom unit of his or her own, in such arrangements the provision of services is not separated from the provision of housing. Individuals may find themselves having to move every few years as support providers move on. This instability is not good for anyone, particularly those with autism.

Those not prioritized by DDS face daunting waiting lists for subsidized housing that meets their support needs. For instance, while state elderly housing may appear to represent a shorter wait than a portable Sec. 8 voucher (2 years versus 10-12), for those who need a two-bedroom unit to accommodate an Adult Foster Care caregiver, the waiting list for a state elderly two-bedroom unit may be 20 years.

As a result, the default option for families is to continue to have their child live at home, with a family member acting as the Adult Family Care support provider. This is not a sustainable, long-term solution. However, a two-bedroom accessory ("in-law") apartment, attached to the family home, may be. It allows the individual to stay put when the caregiver moves on; allows the family to provide respite; allows the family to act as the Sec. 8 landlord when a voucher is obtained; and, when the family moves out, can provide a source of rental income to help cover respite costs. The value of the Sec. 8 voucher can also help the family to make payments on any construction loan that was needed to add the accessory apartment.

There are two major barriers to this arrangement. One is zoning; many municipalities rigidly limit accessory apartments. The second is the financial barrier of paying for any respite not provided by the family or through DDS individual supports, combined with payments on the construction loan. To address the first, Autism Housing Pathways has proposed municipalities consider adopting a model zoning bylaw, which would permit accessory apartments for elderly or disabled relatives of the homeowner as a “by right use” (definition below)

Bill S. 2202 (formerly S. 708), which made it as far as the Senate Ways and Means Committee last session and will be reintroduced next session, would help address the second barrier. It would allow homeowners to take out a loan from the state, potentially with deferred payments and 0% interest, for 50% of construction costs or $50,000, whichever is less. This makes the following scenario possible:

- The individual with a disability signs up for Sec. 8 (preferably at age 18).
- A family member becomes the Adult Family Care provider, and receives a stipend of about $9,000/year.
- The family member saves the Adult Family Care stipend in a separate account.
- In approximately 10 years, the individual receives a Sec. 8 voucher and the family has saved $90,000.
- The family member takes a loan from the state for $50,000; the family now has $140,000 to devote to creating an accessory apartment.
- Construction costs in greater Boston range from $150-$200/sq. foot. At the lower end, a 900 sq. foot accessory apartment would cost $135,000, and costs are completely covered by savings and the loan. At the higher end, the family might need to take out a home equity loan for $40,000. A smaller unit would obviously cost less, and could completely avoid the need for a home equity loan.
- The Sec. 8 voucher can cover the cost to pay for the home equity loan.

Families do need to be aware they will need permission from the housing authority issuing the Sec. 8 voucher to be the Sec. 8 landlord for a family member. Although typically not permitted, it is often allowed as a reasonable accommodation for a person with a disability.

By Right Use (also called Use by Right) refers to a property owner’s use of property and structures in manners consistent with that which is permissible in the zoning district that the property is located. A ‘by right use’ is a use permitted in a zoning district and therefore not subject to special review and approval by local government.
Overview

Fannie Mae purchases or securitizes mortgages secured by properties that are principal residences, second homes, or investment properties. For the maximum allowable LTV/CLTV/HCLTV ratios and representative credit score requirements for each occupancy type, see the Eligibility Matrix.

Principal Residence Properties

A principal residence is a property that the borrower occupies as his or her primary residence. The following table describes conditions under which Fannie Mae considers a residence to be a principal residence even though the borrower will not be occupying the property.

<table>
<thead>
<tr>
<th>Borrower Types</th>
<th>Requirements for Owner-Occupancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple borrowers</td>
<td>Only one borrower needs to occupy and take title to the property, except as otherwise required for mortgages that have guarantors or co-signers. (See B2-2-04, Guarantors, Co-Signers, or Non-Occupant Borrowers.)</td>
</tr>
<tr>
<td>Parents or legal guardian wanting to provide housing for their physically handicapped or developmentally disabled adult child</td>
<td>If the child is unable to work or does not have sufficient income to qualify for a mortgage on his or her own, the parent or legal guardian is considered the owner/occupant.</td>
</tr>
<tr>
<td>Children wanting to provide housing for parents</td>
<td>If the parent is unable to work or does not have sufficient income to qualify for a mortgage on his or her own, the child is considered the owner/occupant.</td>
</tr>
</tbody>
</table>

Note: If a property is used as a group home, and a natural-person individual occupies the property as a principal residence or as a second home, Fannie Mae’s terms and conditions for such occupancy status as provided will be applicable.
Autism design techniques – A cheat sheet

(Adopted from “Autism and the built environment: using design to improve outcomes”, http://autismhousingspathways.org/wp-content/uploads/2016/06/Autism-and-the-built-environment-using-design-1.pdf. Not everyone needs all features, but a design that facilitates the provision of these can be adapted to meet individual needs.)

General features:

- Quiet street, established neighborhood, near stores, mass transit; “by-right” property
- Clear lines of sight within common areas (consider cutouts in walls)
- Transitional spaces that allow individuals to preview activity
- Quiet spaces that provide a place to be alone; some may also allow observation of a common area
- Layout that clearly defines the function of a space
- Multiple common areas allow individuals to separate
- No fluorescent lights
- Walking loop
- Common areas and at least one bedroom have abuse resistant drywall or bead board
- Solid core doors
- Recessed lighting
- Built-in shelving and storage
- Floors should be impervious to water
- Non-toxic furnishings and products
- Durable furniture that is easily cleanable, does not have crevices that can harbor mold
- High ceilings to accommodate jumping
- Sensory area

- Space for exercise
- Fence
- Breakaway curtains
- Neutral color schemes
- Smart home/technology
  - Wired for internet (or wireless network)
  - House server
  - Tablets, low tech visuals, or rubrics in each room can provide cueing to increase independence
  - Intercom/apps/phone can allow individuals or staff to ask for help
  - May be crucial for some individuals:
    - Unbreakable glass (window film or tempered glass)
    - Alarms

Bathrooms:

- En suite where possible, plus in common areas
- Floor drains (ideal) or waterproof membrane under floor
- Fully tile walls and ceiling
- Water sensor shut-off device
- Water shutoffs in adjacent room
- Wall-hung toilet with concealed cistern, inspection chamber, and push button flushing
- Faucets must be held down for water to flow
- Adjust water temperature to prevent scalding
- Use only standard size toilet paper rolls to prevent clogging or use a wall mounted dispenser of individual sheets
• Wall-mounted dispensers for soap, shampoo, etc.

• Replace towel rods with weight-bearing grab bars

• Non-skid flooring

• Space for staff to assist

**Bedrooms:**

• Sound-proof bedrooms for individuals with sleep disorders

• Large bedrooms to retreat into, with personal sensory items and entertainment systems

• Built in shelving and drawers in closets maximizes floor space and prevents dressers from being pulled over

• Dust-mite barriers for mattresses and pillows

• Some individuals need platform beds with very thin mattresses or they may choose to sleep on the floor

• Bedrooms on ground floor for people who jump up and down to minimize damage to ceilings underneath

• En suite bathrooms where possible

**Kitchen:**

• Reserve space for individuals to store their personal snacks for the day, including a second refrigerator; reserve other cabinets and the main refrigerator for meal preparation and storage

• Magnetic induction cooktops to prevent burns

• Countertops with integral backsplashes that are resistant to scratching, burning, cutting or staining

• Make sure there is no space to wedge materials behind the stove.

• Visual supports for meal preparation and cleanup

**Sensory area ideas:**

• Suspended swing or swing chair
• Beanbag chair
• Body sock
• Weighted blanket
• Therapy ball
• Mini-trampoline
• Basket of “fidgets” (also good to keep one in the living room)

**Sensory regulating activities:**

• MeMoves

• Sensory music from Arcangelos Chamber Ensemble
  ○ Music to De-stress
  ○ Music to Relax

• Short, easily learned yoga routine, such as Salute the Sun

• Sa-Ta-Na-Ma mindfulness meditation

• Short, easily learned indoor exercise routine, such as Leslie Sansone’s 3 minute mini-walk (on YouTube).
Outcomes: Detailed Results
<table>
<thead>
<tr>
<th>Housing model (# distinct profiles chosen for a model)</th>
<th>Resident profile (# of distinct housing models chosen for a profile)</th>
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Red ink denotes selections where the situation appears to conflict with program requirements; in some cases, this skews the number of # of models selected.
### Funding Stream × Housing Model (continued)

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<th>Binh</th>
<th>Caiti</th>
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</table>
# Barriers to Implementation x Housing Model

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<tr>
<th>Barrier</th>
<th>Housing Model (# distinct resident profiles chosen for a model)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>blue</strong> = most popular</td>
<td>Small legal multi-unit (2) Shared living in single family home (6) Licensed congregate living (2) Individual apts &amp; condos, close enough to socialize (7) Intergenerational housing (1) Transitional housing (4) Rural housing w/land, animal involvement (1) Co-housing (5) Large, inclusive multi-unit (2) Inclusive small footprint (5) Co-provision of medical &amp; behavioral supports (2) Smart home (1) Small, legal multi-unit (that is also licensed congregate living) (1)</td>
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<tr>
<td><strong>Affordability to family, individual</strong></td>
<td>1 1 3 1 1 1 1 1 1 1 1 1 1 1</td>
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<tr>
<td><strong>Financing availability</strong></td>
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<td><strong>Dept. Of Labor regulations</strong></td>
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</table>

78 Mismatches are elaborated upon in the tables of Resident Profile Outcomes.

79 Other barriers are described in the tables of Resident Profile Outcomes.
## Barriers to Implementation x Resident Profile

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<th>Barrier</th>
<th>Resident Profile</th>
</tr>
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<tbody>
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<td><strong>Blue = most popular</strong></td>
<td>Alejandro  Binh  Caiti  Dora  Eddie  Henry  Justin  Michelle  Nancy  Rosa  Sanjay  Terrell</td>
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<tr>
<td>Affordability to family, individual</td>
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[^80]: Mismatches are elaborated upon in the tables of Resident Profile Outcomes.

[^81]: Other barriers are described in the tables of Resident Profile Outcomes.
### Environmental Design x Resident Profile

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<tr>
<td>Tools for housekeeping</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>7</td>
</tr>
<tr>
<td>Alarms</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>6</td>
</tr>
<tr>
<td>Rounded corners</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Abuse resistant walls</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Tempered glass</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Soundproofing</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>6</td>
</tr>
<tr>
<td>Break-away curtains</td>
<td>x</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td>1</td>
</tr>
<tr>
<td>Other*83</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>


*83 Other design modifications are described in the tables of Resident Profile Outcomes.
<table>
<thead>
<tr>
<th>Technology</th>
<th>Resident Profile</th>
<th>Profiles represented</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Blue = most popular</strong></td>
<td>Alejandro</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Binh</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Caiti</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Dora</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Eddie</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Henry</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Justin</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Michelle</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Nancy</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Rosa</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Sanjay</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Terrell</td>
<td>x</td>
</tr>
<tr>
<td><strong>Scheduling/to do apps</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Cueing apps</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Communication apps</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Daily living aids</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Coaching/decision making apps</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Secure social networking</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Navigation technology</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Alert systems</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Vitals/med system</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Environmental controls</strong></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

84 Other assistive technology suggestions are described in the tables of Resident Profile Outcomes.
Resident Profile Outcomes

- Note that square brackets indicate a program was proposed where the situation appears to conflict with program requirements
- Some material was taken from tally sheets or note sheets, as opposed to recording posters (wall sheets); where this occurs, it is noted

<table>
<thead>
<tr>
<th>Alejandro: Alejandro has a part-time job, and likes to go to the gym and work out. He generally does fine with activities of daily living (ADLs), such as eating and hygiene, but has difficulties with instrumental activities of daily living (IADLs), such as money, cooking, shopping, and cleaning. He is eligible for DDS individual support hours.</th>
</tr>
</thead>
</table>

| Environmental modifications (# groups that identified a modification) | Autism friendly home (2x); Tools for housekeeping (2x); Connected home; Walking loop; Places of control |
|---|

| Assistive technology (# groups that identified a technology option) | Cueing apps (2x); Daily living aids (2x); Scheduling/to do apps; Coaching/decision making apps; Other -- Tech used for safety; shopping list; travel routes; meal schedule plan; know when staff will arrive |
|---|

<table>
<thead>
<tr>
<th>Models chosen</th>
<th>Shared living</th>
<th>Individual apartments/condos</th>
<th>Transitional housing</th>
<th>Co-housing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>[Adult Family Care]; [Food stamps]; Fannie Mae loan; HMLP; Other – Loan modification “if owned by family”</td>
<td>SSI; [PCA]; Food stamps; DDS individual supports; Sec. 8 mobile; Project-based subsidized housing (811); Other -- Part time job; MBHP (Sec. 811?)</td>
<td>SSI; DDS individual supports; Sec. 8 mobile; Other – “Levels of support?”</td>
<td>Duplicates Individual apartments/condos entry</td>
</tr>
</tbody>
</table>

| Barriers (# groups that identified a barrier) | Affordability to family/individual; Financing availability; Zoning; Caregiver shortage; Other – septic; lack of tax incentives | Voucher shortage; Transportation; Other – “adequate individual supports from DDS; community travel -- transportation?; isolation needs help; adequate $ for gym, etc.; safeguards in community; access to stores and generic resources; safety for social media” | Affordability to family/individual; Dept. of Labor regulations; Zoning | Duplicates individual apartments/condos entry |
**Binh:** Binh has aged out of foster care. He has no job. He has been couch surfing, but has run out of places to stay. He has not been able to get into a shelter because difficulties with executive functioning have made it hard for him to get to the right place at the right time to get a bed. He is eligible for DDS individual support hours.

<table>
<thead>
<tr>
<th>Environmental modifications (### groups that identified a modification)</th>
<th>Autism friendly home (2x); Tools for housekeeping (2x); Connected home; Places of control; Alarms; Other – Triage in shelters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (### groups that identified a technology option)</td>
<td>Scheduling/to do apps (2x); Cueing apps (2x); Daily living aids; Coaching/decision making apps; Navigation technology</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Models chosen</th>
<th>Shared living</th>
<th>Transitional housing</th>
<th>Co-housing</th>
<th>Inclusive small footprint</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding streams (### groups that identified a funding stream)</td>
<td>Adult Foster Care; Other MassHealth; [Food stamps]; DDS individual supports; Sec. 8 mobile; MRC; Other -- OneCare; personal employment</td>
<td>SSI; Adult Foster Care; Other MassHealth; Food stamps; Sec. 8 mobile; MRC; Other – “Family Unification Program voucher; unemployment? Re-employment services; Bridge Over Troubled Waters; Social impact financing (Home and Healthy for Good); cultural programs/organizations (e.g. Vietnamese)”</td>
<td>SSI; Other MassHealth; Food stamps; DDS individual supports; Sec. 8 mobile; MRC; Other – personal employment</td>
<td>Other affordable units; otherwise duplicates transitional housing entry</td>
</tr>
</tbody>
</table>

| Barriers (### groups that identified a barrier) | Voucher shortage; Other – “MRC -- right now is a barrier but is in the process of changing (new autism initiatives); wait list; time/availability; depends on housing authority; might be overwhelming” | Other – “Needs DDS caseworker, advocate to connect him to DDS; Lack of advocate before aging out of foster care; culture/language barriers; needs day program, employment; mental health/willingness to participate in programs” | Voucher shortage; Other – “Case worker load to follow him; shelters are not defined for this population; time/availability of services and supports; MRC” | Duplicates transitional housing entry |
**Caiti:** Caiti, who is neurotypical, has a 13 year old with autism. They have been evicted twice, once due to complaints from neighbors about her son’s loud vocals, and once due to property damage (her son flooded the bathroom repeatedly, and twice punched holes in walls).

<table>
<thead>
<tr>
<th>Environmental modifications85 (# groups that identified a modification)</th>
<th>Bathrooom modifications; Abuse resistant walls (2x); Tempered glass (2x); Soundproofing (2x); Autism friendly home (W); walking loop (from note sheet)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Cueing apps (W); Communication apps (W); Daily living aids (T); Coaching/decision making apps (W); Alert systems; Environmental controls (T)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Models chosen</th>
<th>Individual apartments/condos</th>
<th>Inclusive multi-unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>PCA; Other MassHealth; DDS family supports; DDS/DESE; “If eligible, any housing assistance” (interpreted as: Sec. 8 mobile, Project-based subsidized housing, Other affordable units); Fannie Mae loan; Other – residential school placement</td>
<td>Duplicates individual apartments/condos entry, except that it omits Fannie Mae loan</td>
</tr>
<tr>
<td>Barriers (# groups that identified a barrier)</td>
<td>Affordability to family/individual; Financing availability (from note sheet); Insurance reimbursement; Voucher shortage; Other – “Behavioral; availability of DDS family support - DDS/DESE*; child support?<em>; funding for home renovations (&quot;DDS would be the benefactor&quot;)</em>; shortage of housing* (all but ‘affordability’ from note sheet)”</td>
<td>Duplicates individual apartments/condos entry, except that it omits Financing availability.</td>
</tr>
</tbody>
</table>

85 Wall and tally sheets disagreed for this group. “W” represents wall sheet only; “T” represents tally sheet only.
**Dora:** Dora can only afford $500 a month in rent. Her family can give her another $250 for rent. Dora has tried living with roommates several times, and it has always ended badly, either due to Dora’s sensory issues, or to roommates taking her money. She is not DDS eligible. She is on CommonHealth.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Autism friendly home; Walking loop; Soundproofing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Daily living aids; Coaching/decision making apps; Environmental controls</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Models chosen</th>
<th>Inclusive small footprint</th>
<th>Individual apartments/condos (from note sheet)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>SSI; Food stamps; DDS family supports; Sec. 8 mobile; AHVP/MRVP; Project-based subsidized housing; other affordable units</td>
<td>SSI; SSDI; SSI-G; [Adult Family Care]; Adult Foster Care; Group AFC; Other MassHealth; Food stamps; Sec. 8 mobile; AHVP/MRVP; Project-based subsidized housing; other affordable units</td>
</tr>
<tr>
<td>Barriers (# groups that identified a barrier)</td>
<td>Affordability to family/individual; insurance reimbursement “(for tech and life coaching)”; Voucher shortage; Other – “sensory issues”</td>
<td>Affordability to family/individual; Financing availability; Insurance reimbursement; Voucher shortage; Other – “Needs advocacy, group therapy, life coaching”</td>
</tr>
</tbody>
</table>
**Eddie:** Eddie has a high school diploma, and volunteers 10 hours a week at an animal shelter. He wants to live on his own. He has the skills to live independently, with a few hours a week of coaching. However, he is having difficulty getting into subsidized housing, due to his criminal record. He is eligible for DDS individual support hours.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Tools for housekeeping (2x); Autism friendly home; Places of control; Alarms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Scheduling/to do apps (2x); Coaching/decision making apps (2x); Cueing apps; Secure social networking</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Models chosen</th>
<th>Small, legal multi-unit (accessory apt.)</th>
<th>Individual apartments/condos</th>
<th>Co-housing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>SSI; SSDI; Food stamps; DDS individual supports; HMLP; Other – “family; potential employment; DDS employment support; traditional financing”</td>
<td>SSI; SSDI; Sec. 8 mobile (conditional); AHVP/MRVP; Other affordable units</td>
<td>SSI; SSDI; Food stamps; DDS individual supports</td>
</tr>
</tbody>
</table>

| Barriers (# groups that identified a barrier) | Affordability to family/individual; Insurance reimbursement; Transportation; Other – “criminal record; too few support hours; need for day program/scarcity of good programming; employment; transportation” | Transportation; Other – “criminal record; service coordination/navigation; lack of income -- unemployed; access to community; vulnerable; transportation” | Affordability to family/individual; Financing availability; Transportation; Other – “Criminal record; lack of income -- unemployed; transportation; co-housing governance -- getting along with others” |
Henry: Henry is turning 22. He has been at a residential school that has farm activities, and has enjoyed these more than any other activities. He particularly likes working with animals. He is Priority 1 for DDS residential supports.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Autism friendly home (2x); Walking loop (2x); Places of control; Tools for housekeeping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Cueing apps (2x); Communication apps; Daily living aids; Coaching/decision making apps; Secure social networking</td>
</tr>
<tr>
<td>Models chosen</td>
<td>Shared living</td>
</tr>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>DDS residential; Sec. 8 mobile</td>
</tr>
<tr>
<td>Barriers (# groups that identified a barrier)</td>
<td>Mismatch between programs and needs (farm may not be near home); Other – “Sufficient turning 22 funding; creating unique placement may take work (shared living on farm? That arrangement would meet CMS)”</td>
</tr>
</tbody>
</table>

Duplicates shared living entry
**Justin:** Justin is 21, has accepted a diploma, and is about to leave a psychiatric hospitalization. He cannot go home, as his family has a restraining order against him. His case manager feels he will not be able to cope in a shelter. He is eligible for DDS individual support hours.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Tools for housekeeping (2x); Places of control; Alarms; Abuse resistant walls; Tempered glass; Soundproofing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Scheduling/to do apps (2x); Coaching/decision making apps (2x); Cueing apps; Alert systems; Vitals/med system</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Models chosen</th>
<th>Individual apartments/condos</th>
<th>Transitional housing</th>
<th>Inclusive small footprint (chosen 2x)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>SSI; Other MassHealth; Food stamps; DDS individual supports; “other housing” (interpreted as Sec. 8 mobile, AHVP/MRVP, Project-based subsidized housing, and other affordable units); DMH; MRC; Other – life coaching, transportation</td>
<td>SSI; PCA; Other MassHealth; Food stamps; DDS individual supports; Sec. 8 mobile; DMH; Other – private health insurance</td>
<td>Duplicates individual apartments/condos entry</td>
</tr>
<tr>
<td>Barriers (# groups that identified a barrier)</td>
<td>Transportation; Staff training/quality; Other – “Autism/BH-trained staff; transportation; support accessing community; support to community; education of police, emergency responders; social isolation &amp; lack of family support; peer mentoring models”</td>
<td>Zoning; Voucher shortage; Caregiver shortage; Staff training/quality; Other – “DMH client? (lack of outpatient psych care); possible criminal record; finding affordable housing/finding a landlord willing to lease; identifying housemates; finding new housemates when they turn over; staffing (recruitment/retention/training); employment; policy changes (funding/ideology); lack of family support”</td>
<td>Duplicated individual apartment/condos entry</td>
</tr>
</tbody>
</table>
**Michelle**: Michelle likes spending time with people she knows well, but dislikes small talk, and needs plenty of quiet time alone to destress. She has a lot of independent living skills, but can panic if something unexpected happens, like a clogged toilet, a smoke alarm going off, or a stranger friending her on Facebook. She is not DDS eligible. She is on MassHealth.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Places of control (2x); Soundproofing (2x); Autism friendly home); Connected home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Secure social networking (2x); Environmental controls (2x); Coaching/decision making apps; Alert systems</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Models chosen</th>
<th>Individual apartments/condos</th>
<th>Co-housing</th>
<th>Inclusive small footprint</th>
<th>Smart home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>SSI; [Adult Foster Care]; [PCA]; “health insurance” (interpreted as Other MassHealth); “affordable housing” (interpreted as Sec. 8 mobile, AHVP/MRVP, Project-based subsidized housing, and other affordable units); ABLE account</td>
<td>“SSI?”; Other MassHealth; Food stamps; Sec. 8 mobile; Fannie Mae loan; HMLP; Other – employment, family resources</td>
<td>Sec. 8 mobile; other affordable units (extrapolated from “private development set-asides”)</td>
<td>SSI; ABLE account; technology grant</td>
</tr>
<tr>
<td>Barriers (# groups that identified a barrier)</td>
<td>Voucher shortage; Transportation; Other – “Employment under SSI, long wait for affordable housing, [finding PCA/AFC], anxiety with unexpected events, social access, transportation, need for day program/job”</td>
<td>Other – “Expectations for community participation; limited options with design characteristics in right location”</td>
<td>Other – “May be hard to get to know people; less common space; SRO may not meet her needs; is management on site?; what’s available when they need/want to be?”</td>
<td>Duplicates individual apartments/condos entry</td>
</tr>
</tbody>
</table>
### Nancy

Nancy is fond of listening to the Spice Girls, and doing adaptive yoga. She has complex medical issues (including uncontrolled seizures, pica, mitochondrial decompensation, and extended episodes of catatonic posturing during which she won’t eat), as well as maladaptive behaviors. Sometimes her medical issues can present behaviorally, and, even when the medical issue is resolved, the presentation can continue as a learned behavior. She is Priority 1 for DDS residential supports. Her parents are very concerned about keeping Nancy safe, and would like her to live near them, but cannot physically care for her themselves.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Autism friendly home; Connected home; Tools for housekeeping; Alarms; Abuse resistant walls; Soundproofing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Daily living aids (2x); Alert systems (2x); Vitals/med system (2x)</td>
</tr>
<tr>
<td>Models chosen</td>
<td>Shared living (chosen 2x)</td>
</tr>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>SSI; [Adult Foster Care]; [Food stamps]; DDS residential; Sec. 8 mobile; AHVP/MRVP; Project-based subsidized housing; Other – family contribution</td>
</tr>
<tr>
<td>Barriers (# groups that identified a barrier)</td>
<td>Dept. of Labor regulations; Zoning; Caregiver shortage; Respite provider shortage; Other – “Suitable day option (what does the individual do when caregiver isn’t there); home--day program; $ for home modifications/accessibility; medical care (access to doctors); policy changes (funding/ideology, etc.)”</td>
</tr>
<tr>
<td></td>
<td>Staff training/quality; Other – “Low staffing ratios; home design; training; access to community recreation”</td>
</tr>
</tbody>
</table>
**Rosa:** Rosa loves weaving and bowling, and lunch dates with a former baby sitter. She has no maladaptive behaviors, but she also has no sense of danger, and cannot cross a street independently. She is unable to shower independently. Her communication issues interfere with her ability to express and receive information, especially with strangers. She is Priority 2 for DDS residential supports.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Alarms (2x); Autism friendly home; Connected home; Bathroom modifications; Walking loop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Daily living aids (2x); Cueing apps; Communication apps; Coaching/decision making apps; Secure social networking; Navigation technology; Alert systems</td>
</tr>
<tr>
<td>Models chosen</td>
<td>Shared living (chosen 2x)</td>
</tr>
<tr>
<td>Funding streams (# groups that identified a funding stream)</td>
<td>[DDS residential]</td>
</tr>
<tr>
<td>Barriers (# groups that identified a barrier)</td>
<td>Dept. of Labor regulations; Caregiver shortage; Caregiver may move; Respite provider shortage; Other – “IRS regs; hard to get away from cookie-cutter shared living model; possibly not enough structure in shared living; need for a good day program; lack of data on need”</td>
</tr>
</tbody>
</table>
Sanjay: Sanjay recently finished his degree at UMass Lowell, commuting from home and taking 2 classes at a time. He has just received a Section 8 voucher. His family is very concerned about his ability to maintain tenancy, as he has a history of hoarding. He is not DDS eligible. He is on MassHealth.

<table>
<thead>
<tr>
<th>Environmental modifications (groups that identified a modification)</th>
<th>Tools for housekeeping (2x); Autism friendly home; Connected home; Bathroom modifications; Walking loop; Places of control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (groups that identified a technology option)</td>
<td>Cueing apps (2x); Scheduling/to do apps; Daily living aids; Coaching/decision making apps; Environmental controls</td>
</tr>
<tr>
<td>Models chosen</td>
<td>Small legal multi-unit (accessory apt.) (from note sheet)</td>
</tr>
<tr>
<td>Funding streams (groups that identified a funding stream)</td>
<td>Left blank</td>
</tr>
<tr>
<td>Barriers (groups that identified a barrier)</td>
<td>Left blank</td>
</tr>
</tbody>
</table>

86 Accompanied by the note: “We chose this because: feels like a good transition from in family home to place with more independence but family nearby to check in and provide support and oversight around hoarding and he can maintain Section 8 status.”
**Terrell:** Terrell loves to swim and ride his bike. He has extreme maladaptive behaviors (biting, head-banging, stripping in public) that are triggered by anxiety and OCD (obsessive-compulsive disorder), or by eating foods to which he has an allergy or an intolerance. He uses visual supports. He will entirely self-isolate if he doesn’t live with others, refusing to leave the building, but he also needs private space he can retreat into. He is Priority 1 for DDS residential supports.

<table>
<thead>
<tr>
<th>Environmental modifications (# groups that identified a modification)</th>
<th>Autism friendly home (4x); Places of control (3x); Abuse resistant walls (2x); Tempered glass (2x); Walking loop; Soundproofing; Other – “All safety design features” (apparently from ‘specific challenges’); circular driveway for exercise; large yard; bike path in semi-restricted area”; “Good HVAC and fresh air controls”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive technology (# groups that identified a technology option)</td>
<td>Communication apps (3x); Alert systems (3x); Cueing apps (2x); Daily living aids (2x); Vitals/med system; Environmental controls; Other – “Fitbit that lets you know body signals that are confirmed antecedents to behavioral incidents and strategy is in place; high tech bike with screens; video on bike; lap pool with safeguards; tech to help relay wants and needs; visual supports to ID what foods are OK; recipes to offer textures &amp; tastes of allergic foods; would camera in room be acceptable?”</td>
</tr>
<tr>
<td>Models chosen</td>
<td>Small legal multi-unit that is also licensed congregate living</td>
</tr>
<tr>
<td>Funding streams</td>
<td>Left blank</td>
</tr>
<tr>
<td>Barriers</td>
<td>Staff training, quality; Other – “Quality staff; staff ratio; medical supports; safety &amp; sound; end unit of apt. /sound-proofing; sensory overload -- needs space; access to swim and bike”</td>
</tr>
</tbody>
</table>
Information from the Homelessness Group Reporting Sheets

Thoughts around quantification:

- Survey prison populations, shelters using the AQ10 tool
- Tap Healthcare for the Homeless to collect data
- ERs to collect data
- Add questions to annual homelessness survey
- Train staff in shelters, ERs, etc. to ID autism or assist individuals to use an assessment tool
- Front door triage at shelters
- What are the cost/benefits of quantifying?
- Front door triage at the shelters to determine assessments
- DDS providers to work with shelter and designated DDS contractors to work with shelter staff and provide training and help with referrals to DMH and DDS
- Someone to make a connection with the shelters at the local area/site offices of DDS and DMH

Thoughts around ability and willingness to access the shelter system:

- All homeless outreach team (doing street outreach)
- Use a broader definition of homelessness, including those kicked out of home, under-housed, couch surfing
- More education at the shelters about autism
- Access to vital records in order to get DDS eligibility
- Create programs/shelter environments that are autism friendly
- Communicate this is a step to permanent housing
- Chronic homeless system
  - Healthcare for the Homeless
  - Foster care
  - Privacy tent
- Capsule hotel
- Social impact financing
  - Home and Healthy for Good
Information from Out of the Box Models and Mechanisms Reporting Sheets

Difficulties:

- Inadequate funding
- Lack of awareness
- Poor communication
- Aging out of services
- Unhappiness with existing models
- Parents and teachers disconnected from housing options
- ADA codes don’t address silent disabilities
- Wants vs. needs
- Workforce (service providers need to be supported)
- Disabled community very diverse with a wide variety of issues; not organized to effect change
- Depression and isolation are dangers

New approaches:

- Start earlier (at 14); transition should address housing, employment, independent living skills, social skills – make schools responsible for helping families create “good” transition plans
- Design for person and their needs first
- Housing solutions encompass individuals, mechanisms, clinical needs, physical needs, administrative issues, and technology
- Consider design options: sensory space, transitional space (e.g., in entryways)
- Use models outside disability as templates for disability services
- Develop case studies (good and bad)
- Stakeholders need to be educated, cooperate, and take responsibility
- Information sharing is critical; ideas include
  - A system to delineate housing-related information
  - The Autism Commission website should have hyperlinks to agencies
  - Stakeholders (including families) need to know what is allowed
  - SHINE counselors may be helpful
  - Diverse channels of information sharing are necessary, including state agencies and schools
  - Agencies need to get out of information silos
  - Stakeholders need to be aware of what is going on in Washington
    - Information about the political environment needs to be shared with community residents
  - Better communication between funding agencies and families/providers
- Self-advocacy should lead the way
- 688 process should be triggered by families, not just the school system – use it as a way to educate families
- Change or increase members of the housing committee of the Autism Commission to include HUD, Mass. Association of Community Development Corporations
- Independence should be the goal, not just housing – better connections to community, services, amenities
- Create a full life, better quality of life
- Higher expectations