**Discussion Paper-**
**NH Housing Strategies for Persons on the Autism Spectrum**

## Background

The "Autism Tsunami"…hyperbole or a reasonable call to action? The literature is compelling. As recently as 1967, Autism Spectrum Disorder (ASD) was widely believed to have its roots in behavioral dysfunction. In that year, Psychologist Bruno Bettelheim popularized the theory that "refrigerator mothers," as he termed them, caused autism by not loving their children enough. Subsequently, more rational analysis and a disturbing growth in the incidence of this Intellectual/Developmental Disability (IL/DD) led to more clear focus on environmental conditions as a causal factor.

The popular movie "Rain Man" brought more widespread attention to this emerging medical condition. As recently as 1990, the Center for Disease Control (CDC) estimated the incidence of ASD at approximately 1: 2,500 births, and the federal government established ASD as a special education category. In 2007, the CDC radically revised its estimate of the incidence of ASD to 1:150 births, a 1,667% increase in 15 years. Two year later (2009) the CDC again increased its estimate to 1:110 births. In its most recent estimate (2014), the CDC determined the incidence of ASD to be as high as 1:68 births, and growth rates in ASD have been projected to be as high as 10-17% per year.

A more detailed discussion of causal factors associated with this startling growth in diagnosis of ASD is beyond the scope of this brief paper. However, as housing and policy professionals it is important that we understand the shape and dimensions of this rapidly emerging challenge, particularly as it applies to NH. The growth in the incidence of ASD, and its adoption as a federal special education category, resulted in significant increases in federal funding for research and educational resources, with an understandable focus on early childhood intervention. Unfortunately, there has been no commensurate response in resources for the emerging group of individuals who are aging out of the educational support system, and will soon begin to challenge the already overcommitted housing resources in NH.

## ASD Housing Demand/Need

Interestingly, NH was the second state in the nation to establish a legislatively mandated statewide registry for all new diagnoses of ASD. However, the information tracked is disappointingly narrow and limited to new diagnoses of ASD offering little understanding of the aggregate case load and offering no information with respect to the needs or capacities of that population. The 2014 NH ASD Needs Assessment indicates that 150 children were newly diagnosed with ASD in 2013 and reports a *six-fold increase* in children receiving special education services associated with the ASD designation… a total of 2,419 children in 2013. This growth rate mirrors national trends, but does little to clarify the number of individuals with ASD who are departing the protective blanket of special education services and transitioning into a workplace and housing market for which they may be woefully unprepared.

Nationally, it is estimated that 500,000 individuals with ASD will become adults over the next ten years. Approximately 46% of those individuals are believed to be High Functioning ASD (HFASD) persons with IQ's above 85, but who may be characterized by deficits in reciprocal social interaction or clinically significant delays in receptive language or cognitive development. These individuals comprise one key market segment for the affordable housing industry.

Despite their relatively high functioning status, these individuals are characterized by low levels of employment, extremely low income, and very limited access to services once they transition out of the educational system at age 22. Reportedly, as many as 90% of these individual live with their parents. However the financial impact on the parents are significant, particularly if they are forced to play the role of caregiver and are therefore unable to sustain employment. Further, as parents age the responsibility of caring for adults with ASD can raise physical challenges that are beyond the capacity of the family to absorb. Couch surfing, homelessness and more dire forms of inappropriate institutionalization may be the direct consequence.

While it is difficult to quantify the number of persons with HFASD who transition to adulthood in NH each year, for the purpose of our discussion it seems reasonable to assume 75-100 individuals, given the documented level of ASD (2,419) and the number of cases which are added each year (150+/-). These individuals will often have limited skills/employment history, difficulty in sustaining social interactions, and extremely low incomes. Without significant and ongoing family support the prospect for successful integration within the conventional housing market is bleak.

The second major demographic within the ASD community is represented by persons who have lower levels of cognitive ability, typically IQ's of less than 70-85, and who require sustained support to maintain stability in their adult lives. In the past, this group was typically served within the State institutional network. However, NH is one of the States that has been most successful in de-institutionalizing residential settings for persons with developmental disabilities, consistent with the provisions of the Olmstead Agreement. Group homes and adult foster care appear to be the predominant housing options. I defer to our more learned colleague (Don Shumway) for a more thoughtful discussion of the sufficiency of these resources. However, the parents I have spoken with express concern for the long term reliability of these community based resources, citing concerns for the sufficiency of staffing, high turnover, and allegations of abuse within the system. As a result, two of the more recent attempts to provide an alternative to group home living (Concord Independent Living and Greengard Center Portsmouth) are both attempting to develop new models of supported housing that will be discussed later in this paper.

**Barriers to Supported Housing Development/ASD**

Although NHHFA has done an excellent job of accommodating new models of supported housing, the most successful prototypes have typically focused on individuals who are at risk of homelessness due to *episodic* bouts with mental illness, catastrophic events, and/or substance abuse (e.g. Families in Transition). With the exception of elder housing, these models tend to focus on the transitional housing needs

of families who are expected to graduate to the mainstream housing economy as a result of targeted interventions in counseling, education and employment assistance.

With respect to the ASD population, the principal barriers to development of permanent housing solutions are significant, including:

- Scarcity of long term project based rental assistance tiered to SSI income
- Local Permitting barriers against "special needs" housing.
- Access to permanent capital, including equity capital/grants to offset high cost of specialized housing for persons with sensitivities to noise, lighting, and allergens.
- Potential inclusion of resident caretaker income, parental gifts, endowments, etc. in determination of eligibility for housing and/or services
- Absence of specialized design (e.g. sound deadening, sensitivity in lighting, opportunities for social interaction, etc.) in conventional multifamily units
- Availability of respite housing and crisis intervention services to enable retention of permanent housing during crisis periods
- Negative impact of Olmsted Agreement on evolution of new forms of "intentional" supportive housing communities, including CCRC's, gated communities, shared living arrangements, etc.
- Negative impact of Olmstead Agreement upon scale-able housing solutions

These barriers are profoundly exacerbated by competition for resources in a housing finance/Medicaid system that is undercapitalized and over committed. Despite the fact that ASD is the most rapidly growing form of development disability, the 50,000 people with ASD who enter the adulthood each year are competing for resources with the 10,000 baby boomers who become eligible for Medicare and Social Security <u>every day</u>.

**Housing Resources**

The resources available to underwrite affordable/supported housing are limited and over-committed. In this context, there is understandable reluctance to create special allocations for particular populations. Notwithstanding that assumption, NHHFA has historically recognized the need to prioritize certain public policy goals and/or populations, including the elderly, neighborhood revitalization projects, etc. For the sake of discussion, the principal capital resources of interest are as follows:

- Low Income Housing Tax Credit (LIHTC)- allocated to NHHFA annually, and sub-allocated to developers once per year subject to policies and priorities promulgated by NHHFA. In 2016, NHHFA allocated slightly more than $3m in federal LIHTC's, with an estimated market value of approximately $28million. This resource is by far the biggest federal capital subsidy available for affordable rental housing, and is capable of funding the new construction of 200+/- affordable housing units per year. However, LIHTC developments typically result in rent levels (say $750-900 for a 1BR unit) that may exceed the reach of an adult with ASD.

- HOME Investment Partnerships- a flexible grant program administered by NHHFA, City of Manchester and City of Nashua. Total State allocation in 2014 of approximately $3.7m. May be used in conjunction with LIHTC, or as standalone resource. Flexible financing tool, often used for supportive housing.

- National Affordable Housing Trust- a new federal resource, estimated to bring as much as $3m in new capital to NH each year, with a laser focus on persons at 30%MAI. A challenging resource to use for conventional MF housing, NAHT may be a good ft for supported/ASD housing.

- Community Development Block Grants- administered by CDFA and five entitlement municipalities, NH receives approximately $11.3m in CD block grants. Competition for resources is extremely tight and the range of eligible uses includes a broad variety of public works, social services, housing, and economic development projects. CDFA also administers a NH Tax Credit program that allocates state tax credits for donations to non-profit sponsored housing and community development projects. The most recent allocation of $3.75m in NH tax credits are designed to leverage $5m in donations for eligible projects, including supportive housing.

- Sec 8PBV- Project Based vouchers are an extremely valuable resource, providing long-term contract rental assistance limiting tenant contribution to rent & utilities at a fixed proportion of income (30%). Housing authorities may "project base" up to 20% of the their vouchers, but are generally loathe to do so because it limits the flexibility of voucher holders to move to better opportunity as the need arises.

- Existing Public Housing/Sec 8 projects- a precise inventory of these resources is beyond the scope of this paper, and is not a high priority for consideration given the lengthy waiting lists associated with these assets.

- FHLBB AHP- a flexible grant program allocated by FHLBB through its member banks. Strong focus on ELI and service enriched projects, but highly competitive. Typical allocation to NH projects in the range of $1-5.2.5m in the aggregate.

While this list of resources is not all-inclusive, it provides a pretty comprehensive listing of the principal resources available for the development of new supportive housing developments. One resource that is not listed above is the growing availability of "Year 15 LIHTC" developments. These developments have satisfied their initial LIHTC compliance requirements and may be available for recapitalization and repositioning to meet the needs of a new sponsor and/or emerging market (ASD). Generally speaking, these properties will be in reasonably good physical condition, will be unencumbered by high levels of amortizing debt, and may be available for purchase under favorable conditions by investors who have already satisfied their investment objectives.

Interestingly, ASD is more typically experienced within affluent families. Thus, it is conceivable that new models of permanent supported housing may rely, in part, upon the financial contributions of family members, whether through life estates, endowments, or ongoing financial supports. However, the ability to leverage this capital in support of new development will require sensitivity to the desires and needs of the family members, with a clear emphasis on long-term security and quality of life. However, current versions of family sponsored housing appear to be subject to underdeveloped organizational capacity, and suspect continuity. This issue will need to be addressed before sources of private/institutional capital can be accessed.

**Housing Options/Models for Discussion**

1. Individual Ownership- conventional, perhaps NHHFA FTHB, with Medicaid waiver. Provision for family gift toward down payment/principal reduction

2. Tenants In Common/Shared Living- In PA a group of three ASD individuals purchased a home through HFA FTHB program, using family donations and grants to reduce PITI. A binding Ownership Agreement provides for sale of the asset, or withdrawal of any individual participant, with provisions for right to re-sell individual units to new eligible tenant. Medicaid waiver bed provides 24 hour attendant care and shared overnight support.

3. Cooperative/Co-Housing- perhaps best suited to HFASD, this model provides for ownership of housing asset by (limited equity?) cooperative corporation, thereby enhancing access to capital (?) and proving somewhat more liquidity for individual ownership transfer within the cooperative. A hybrid of this model, the leasehold cooperative, may provide access to LIHTC, Sec 8 PBV and other conventional housing resources (e.g. Merrimack Place, a project I developed in Manchester)

4. L'Arche/Mutual Housing- L'Arche was founded by a Catholic community in France and has since expanded to an ecumenical network of 130 communities in 30 countries, including two in the US (one of which is complete). The concept assumes a communal family of persons with and without development disability, is largely philanthropic in nature, and wide scale replication would be extremely challenging. However, the underlying legal and ownership constructs may be somewhat analogous to mutual housing, which could have more potential for replication.

5. Set-aside of conventional MF units- in 2014, NHHFA adopted an incentive based strategy to encourage the establishment of marketing preferences for persons with mental illness within existing multifamily properties. Consistent with the Olmstead Agreement, these preferences would be limited to 10% of any existing building. Tenants seeking to exercise their rights to these preferences would need to me the reasonable credit and character reference criteria that apply to all residents within the MF industry, and would need to be provided with services independently of their landlord. As such, this option is perhaps most suited to HFASD residents, particularly those with family supports and/or Section 8 vouchers. It would be interesting to get an initial update on the efficacy of this strategy from Chris Miller.

6. Gated Community (w LIHTC)- surprisingly, at least one non-profit sponsor in Florida has been able to develop the first phase of a "gated community" which is devoted to persons with intellectual/developmental disabilities. The first phase of the development includes 52 "homes", comprised of 2-4 bedroom suites and shared common areas. The entire phase of 52 homes will eventually house 132 residents, most of who will have Intellectual/Developmental Disabilities, and specifically ASD. The homes are not licensed, and care is provided by third party agencies. The development is funded much like any NH affordable rental housing development, with LIHTC, Section 8 PBV, FHLBB AHP and state funding. Apparently, the Olmstead Agreement did not preclude this form of development in Florida.

7. Other "Intentional" MF/ASD Rental Developments- In Haverhill MA the Katydid Foundation secured HOME and FHLBB AHP financing to finance a 7 unit SRO development to house 3 individuals with ASD and four caretakers. A newly formed, family driven non-profit, Katydid has wrestled with changing policies for licensing and with the demands of organizational capacity but appears to be meeting its mission. In Pittsburgh, PA, the Autism Housing Development Corporation is constructing a new 42 LIHTC property with a 50% preference for persons on the ASD spectrum. MHRA (Manchester) will soon break ground on a 20 unit LIHTC development for persons with a range of disabilities including autism. In Concord, NH, a small community of NH families undertook a joint venture with CATCH to develop a 12 unit supported housing community for persons with ASD. This group was very successful in securing capital for the development (NHHFA, FHLBB, CDFA/CDBG), but ultimately failed to proceed, apparently due to objections raised by NH Dept. of HHS. Finally, the Greengard Center in Portsmouth is in the formative stages of developing an innovative 4 unit shared living home with a private caretaker residence. Sources of capital and likelihood of success are difficult to ascertain at this early stage.

In considering these options, it is essential to note that the NH Dept. of HHS has recently issued new rules to ensure that "HCBS recipients are able to live in and have opportunities to access their community as well as to receive services in the most integrated settings. This includes opportunities to seek employment and work in competitive settings, engage in community life, control personal resources, and participate in the community just as people who live in the community, but who do not receive HCBS, do".

It will be interesting to discuss how this new policy affects the development of "intentional" supported housing communities for persons with ASD. Family members appear to be very divided about this policy, welcoming the "person centered" nature of the goal, but fearing the inherent insecurity that may arise from the more independent residential settings that emerge from this policy.

**Conclusion**

In the interest of brevity, I have refrained from discussing many topics that inform the challenging world of supported housing, most notably the shifting sands of institutionalization v de-institutionalization, and the impact those uncertainties have on access to private capital. However, I hope that two points are clear. First, the demographics of demand for supported ASD housing are compelling, and it is not at all clear how those demands will be met within the current system. Second, there are literally dozens of family groups forming to confront this challenge. They have access to family capital, are highly motivated to provide capital in exchange for long term security for their loved ones, and they are contributing new housing models and leadership resources. With their support, it seems reasonable to suggest that we can develop cost effective housing solutions that are responsive to the needs of this vulnerable population and consistent with the Supreme Court Decision that ultimately gave rise to the Olmstead Agreement.

**Suggested Discussion Agenda/Policy Issues**

1. Dimensions of Market Demand- Autism Spectrum Disorder

   - How many ASD? Socioeconomic Characteristics
   - Market segments (ASD v. HFASD)
   - Level of support required (24 hr. vs. case management)

2. How is the market currently served?

   - Group Homes, ICF's etc.
   - Living w Parent/Family
   - Other?? Risk of homelessness?

3. Impact of HHS Draft Transition Framework for Establishing Home and Community Based Services Residential Settings Compliance & Olmstead Agreement

   - Projected impact on supported housing
   - Possibility of legislative/regulatory relief or flexibility (HCBC)?

4. Discussion- New Models Supported Housing (intentional v. integrated)

   - Shared Living Arrangements
   - Limited equity coops/mutual housing
   - Gated communities
   - Scattered site LIHTC?
   - NHHFA 5% policy… how is it working?
   - Other

5. Resources

   - LIHTC?
   - Yr. 15 LIHTC developments?
   - New sources of capital
   - Strategic application of family capital

6. Organizational/Development Capacity

   - Sponsor/Developer- key weakness of family sponsored housing
   - "Upper tier" Strategies to support family sponsored housing
   - Other