

A Collaborative Report by the Urban Land Institute Arizona, Southwest Autism Research & Resource Center and Arizona State University

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"Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders," and the accompanying report, "Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum Disorders," have been made possible by a grant from the Urban Land Foundation through funding provided by the Pivotal Foundation and the Southwest Autism Research & Resource Center.

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I. ADDRESSING IMPERATIVES: STUDY OBJECTIVES

Earlier this decade, the Wall Street Journal reported on the Tullis family. The poignant story involved Tim Tullis, a 49-year-old man with autism, who shared a cramped apartment with his 89-year-old father. Tim's mother died about five years prior and, at that time, Mr. Tullis assumed all of Tim's care--bathing and shaving him, packing lunches for his day program and enjoying comforting routines. Every week day, Mr. Tullis had popcorn and water waiting when Tim came home and, in the evenings, they watched Lawrence Welk reruns. Father and son also took great pleasure in their long weekend drives in the country and stops for lunch at their favorite fast-food restaurant (1).

But in April 2004, Tim's comforting routines came to an abrupt end when he returned home from his day program and Mr. Tullis was gone. How do you break the news to an adult with autism that everything familiar to him is about to change?

Within the next 15 years, more than 500,000 Americans with autism spectrum disorders (ASDs) will enter adulthood, based on the rising incidence of the disorder (2). Conservative projections indicate nearly 400,000 (3). Either way, the numbers are staggering. Today, many adults with autism are being cared for by aging parents who, in most cases, will not outlive their children, leaving them limited options for lifelong support. This growing new subset of the developmentally disabled population – too old for continued support through the special education services of a public school system and too fragile to live without support in the larger world – and their families face a complicated system of vocational rehabilitation services, Medicaid, disconnected government agencies and a lack of appropriate residential care options beyond the obvious ones of keeping them at home or within institutional settings.

How do we as a society respond to the pressing question that troubled Mr. Tullis and that's looming today for millions of parents of children with autism: Who will care for my child when I'm no longer able to do so?

The impact that millions of children and young adults diagnosed with autism and other developmental disorders, who are transitioning to adulthood, cannot be overstated. The dramatic increase in the population of individuals



with autism gives rise to serious concern among families, service providers, government and the community at-large that residential services for post-school-age adults with autism and developmental disorders must be created as an integral part of a healthy community's housing plan and opportunities.

"Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders" focuses on the residential concerns of adults living with autism and related disorders and is designed to advance the development of replicable residential models that offer quality, affordable housing options within the fabric of their communities. This study addresses current and projected demand for life-long living options that support the segment of individuals with autism spectrum and related disorders unable to live on their own. It also explores the financial catalysts needed to spur new investment by the private and public sectors to meet projected demand.

"Opening Doors" is a collaborative study by the Urban Land Institute (ULI) Arizona, Southwest Autism Research & Resource Center (SARRC), the Arizona State University (ASU) Stardust Center for Affordable Homes & the Family and the ASU School of Architecture and Landscape Architecture. The information included in this study is intended to highlight existing residential options, guide the development of new ones and support the creation of models so they may serve as organic living and learning laboratories for scholars, social workers and families. The study proposes actionable steps that address the increasing demand for supportive housing and communities, which have the power to maximize independent living.

MAJOR OBJECTIVES

- Evaluate existing residential programs (referred to as "soft" infrastructure in this report) as well as the housing itself (referred to as "hard" infrastructure) dedicated to individuals with special needs; identify best practices and recommend improvements, innovation and areas for continued research into support services, design and financing.
- 2) Develop a set of goals for sustainable residential community design that address the unique environmental needs of individuals with autism spectrum and other developmental disorders, taking into consideration the need for affordable solutions and the resulting demand for collaboration among the public, private and nonprofit sectors.
- 3) Identify and analyze available financing options for both the hard and soft infrastructure that support scalability and serve as catalysts for engaging the private sector and facilitating public-private-nonprofit partnerships.
- Guide the design of residential options in terms of physical space and appropriate locations to support the health and well-being of the resident population – both the affected adult and the community at-large.
- 5) Increase public awareness of the growth trends in the population and advance public policy recommendations for successful public-private-nonprofit collaborations.

STUDY PROCESS

The Urban Land Institute (ULI) Arizona and the Southwest Autism Research & Resource Center (SARRC) commenced their collaboration six years ago through the ULI Arizona Technical Assistance Program (AZ TAP). ULI and SARRC formed a panel of real estate developers, financiers, specialists in affordable housing options, architects and planners, public sector officials and public policy leaders to address the pressing issues for long-term residential concerns for adults with autism spectrum and related disorders and potential private-public-nonprofit collaborative solutions.

SARRC also reached out to families to identify their most pressing concerns, evaluated the body of research on this subject, sought a national collaboration through Advancing Futures for Adults with Autism (AFAA) and secured



funding from the Urban Land Foundation, made possible by the Pivotal Foundation and SARRC donors, to conduct this study.

Based on the recommendations of the 2004 panel, a ULI-SARRC Steering Committee was formed to direct the research for this study. SARRC and ASU assessed the current options and best practices in the industry based on the identification of more than 100 properties serving developmentally disabled, physically disabled and other special needs populations. (Refer to Appendix A.) From this initial survey, 17 projects were selected for more thorough research and/or on-site visits. The team also investigated trends and innovations in housing for other special needs populations; specifically, senior housing and urban high-density options. The research results are based on a variety of factors with particular focus on the design elements as well as economic viability. The complete report by ASU may be found in "Advancing Full Spectrum" Housing: Design for Adults with Autism Spectrum Disorder," the companion document to this study (http://stardust. asu.edu/research_resources/detail.php?id=60).

A 2009 ULI AZ TAP Panel of diverse industry experts was held to evaluate the data collected for this study with a focus on its application in the execution of a financially viable, scalable model. Options currently available, as determined by the research, together with innovative projects now in planning or construction phases were also evaluated for application on a broader scale. Further, a 2009 ULI Capital Markets Panel was convened to review and assess the research and evaluate strategic options.

Represented on the steering committee and panels were low income housing developers, multi-family developers, lenders specializing in tax credits and government financing, nonprofit agency leaders with significant experience in a variety of special needs housing models, land planners and self-funded private equity developers.

ULI-SARRC STUDY TEAM & ULI AZ TECHNICAL ASSISTANCE PROGRAM PANELISTS

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ABOUT AUTISM

The technical term, autism spectrum disorders (ASDs), refers to a group of developmental disorders that are usually first diagnosed in early childhood and include: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS) and Asperger's syndrome. It also includes two rare disorders, Rett's disorder and childhood disintegrative disorder. Individuals affected by the disorder often have difficulties in three main areas:

- Social interaction Difficulty with social relationships; for example, appearing aloof and indifferent to other people.
- Social communication Difficulty with verbal and nonverbal communication; for example, not fully understanding the meaning of common gestures, facial expressions, tone of voice or sarcasm.
- Social imagination Difficulty in the development of interpersonal play and imagination; for example, having a limited range of creative ability, combined with the tendency for routine or repetitive behavior.

According to Advancing Futures for Adults with Autism (AFAA), an individual living with autism may display some or all of the following characteristics, which may present themselves as challenges or strengths.

- Difficulty understanding language, gestures, and/or social cues
- Literal or excessive speech, often with a

concentration on a particular topic.

- Limited or no speech, requiring reliance on alternate forms of communication.
- Difficulty relating to others or participating in a conversation or interaction.
- Social awkwardness.
- Intense interests.
- Repetitive behaviors, such as pacing, hand flapping or rocking.
- More or less sensitivity to light, sound, smell, taste or touch.
- Anxiety, abnormal fear and/or lack of appropriate fear in real dangers.
- Difficulty managing transition, changes in routine, stress, frustration.
- Strong visual skills.
- Good rote and long-term memory (facts, statistics, etc.).
- Adherence to rules, honesty.
- Intense concentration or focus, especially on a preferred activity.
- Understanding of and retention of concrete concepts, patterns and rules.
- Musical, mathematical, technological and/ or artistic ability or interest.

Though most individuals with autism do not have physical abnormalities, they will often avoid eye contact and lack interest in or regard for faces. Their cognitive abilities and skill sets vary from gifted to severely challenged. This report addresses the pressing needs of individuals on the autism spectrum who require support for daily living.

II. WHAT'S NEXT FOR ADULTS LIVING WITH AUTISM: MARKET DEMAND & PRESSING CONCERNS

SCOPE OF THE CHALLENGE

In the 1980s, the incidence of autism was 1 in 10,000 children. Throughout the 1990s, the rate steadily climbed and reached 1 in 500 at the turn of the century. Today, 1 in 110 children are being diagnosed with autism, according to the Centers for Disease Control (4). Of the 1.5 million people who have been identified on the autism spectrum in the U.S., approximately 80 percent are younger than 22 (5). Clearly, one of the most complex and worrisome issues facing families of individuals with autism is providing them with quality long-term living and learning opportunities once they reach adulthood.

A 2008 study by Easter Seals found that more than 80 percent of adults with autism between the ages of 19 and 30 are still living at home (6). Most young adults with ASDs live with their parents, more than double that of young adults without special needs. Refer to Figure 2-1.

Moreover, a statewide study conducted in Florida in 2008 by the Center for Autism and Related Disabilities (CARD) found that two-thirds of the 200 families of 18- to 22-yearolds with autism surveyed did not have knowledge of transition services (7). With this increase in prevalence has come a significant increase in demand for effective services, supports and housing for adults living with autism. The need continues to far exceed the available resources leaving a generation of people with autism and their families in limbo, especially in relation to long-term living and learning options.

Hundreds of thousands of parents of children with autism across the country can no longer afford to wait for new doors to open.

The economic cost of our system's failure to address the housing needs and lifelong care concerns for individuals with autism has far-reaching implications. The disorder costs society billions of dollars annually to care for all individuals diagnosed over their lifetimes. In fact, the lifetime per capita incremental societal cost of autism per individual is estimated to be \$3.2 million (8). This includes direct medical costs to the individual; direct non-medical costs (e.g. child care, adult residential placement, home and vehicle modifications); and indirect costs (i.e. value of lost or impaired work time and income, benefits and household services of individuals with autism and their caregivers because of missed time at work, reduced work hours, etc.).

Moreover, it is estimated that as much as 90 percent of the costs of caring for an individual with autism are in adult services (9). Without a better and more comprehensive understanding of the needs of adults with autism and plans for productive, effective, efficient and respectful solutions, these costs can be expected to grow exponentially.

PRESSING CONCERNS

To date, there has been an absence of federal entitlement legislation intended to support individuals with developmental disabilities including autism, beyond the end of their 21st year, resulting in a tangle of state-by-state initiatives that are often under-funded, confusing and tend to support outdated or inappropriate models of service delivery to a limited number of individuals. Similar impediments exist in aiding the delivery of quality housing for this population—a situation, which if rectified, could engage private industry, nonprofit organizations and the public sector in providing solutions.

While much has been written and discussed, there are no easy answers to addressing the lifelong residential concerns for individuals with ASDs (10-18). Autism and other developmental disabilities encompass a wide range of disorders and a spectrum of capacities and needs. Highly individualized protocols for treatment and services are most effective in providing quality personal development and the greatest opportunity for maximizing independence. Unfortunately, the increased prevalence of autism and related disorders has far outstripped the services available to meet the developmental, educational, employment training and life-skills training needs of this population.

The estimated wave of individuals with autism spectrum disorders entering adulthood is *in addition to* the thou-

sands of developmentally disabled and other special needs populations already waiting for a suitable housing solution. Based on 41 reporting states, approximately 88,000 people in the U.S. are already on state waiting lists. This number continues to grow and does not include individuals waiting to be moved from one type of housing to another or those living with aging parents (19). How will government, the private and nonprofit sectors, and our communities cope with this looming issue in the decade ahead? What options are available to affected individuals and their families?

How can residential housing be created for the diversity of the population which ranges from those needing minimal assistance to those requiring more intensive support?

According to the Organization for Autism Research (OAR), adults with autism suffer poor outcomes in transitioning to independent living and work environments for several reasons (11):

- Poorly implemented transition services to guide individuals from school to adult life.
- A lack of understanding that people with ASDs have the potential to be employed, contributing and active members of their community when the appropriate supports are available.
- A lack of coordination between the educational, behavioral, mental health, vocational, and Mental Retardation/Developmental Disabilities (MR/ DD) systems intended to support individuals into adult life.
- An absence of qualified staff to work with and care for adults.

FIGURE 2-1: CURRENT LIVING ARRANGEMENTS OF YOUNG ADULTS WITH ASDs AND THOSE WITHOUT SPECIAL NEEDS: 2008



Source: Ahrentzen and Steele [20], Harris Interactive/Easter Seals [6]

The goal of lifelong living and learning opportunities for adults with autism is to reduce the dependence of these adults on welfare and empower them to become productive citizens. This population represents a community of workers, many of whom can meet the needs of employers and earn an income, provided adequate supports are in place. The societal costs of providing housing and caring for those with autism over their lifetimes can be dramatically reduced if the right lifelong living and learning opportunities are available.



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III. SUMMARY OF MAJOR FINDINGS

The research conducted for this report uncovered many outstanding, community-integrated solutions that are providing housing and services to adults with autism spectrum and related disorders. Throughout the country, nonprofit organizations and low-income housing consortiums are implementing new technologies and creative funding mechanisms which provide greater opportunities for their clients to live more fulfilling and independent lives. While these solutions are impressive in their nature, the organizational structures and funding mechanisms which brought them into existence cannot be scaled in a fashion which would increase housing supply to meet projected demand in the years ahead.

To ensure economic sustainability, the expansion of viable alternative housing models must be market-driven and represent a feasible model in a variety of market conditions, across state borders and without reliance on charitable contributions.

The question remains: What market forces can serve as catalysts for advancing the design/development of residential options for this population? True success in solving the long-term residential issue requires collaboration not only through a unified and informed coalition of advocates, but through meaningful and open partnerships among non-profit and for-profit providers, the real estate industry, business community and public sector agencies. Further study is needed to clarify the market demand, create a responsive support services industry, refine public policy to simplify funding sources, and develop creative projects with physical and financial innovations.

Following is a summary of major findings from this study:

LACK OF CONSISTENCY IN THE DEFINITION OF RESIDENTIAL OPTIONS

The range of housing and service options currently available today are as diverse as the population itself. A significant finding in the analysis of the research data is the lack of a comprehensive framework for defining and categorizing the various housing models. To organize the discussion of these properties, three areas of classification were identified based on defining features:



SERVICES IN THE HOME

- Transitional Models
- Supportive Living
- Supervised Living
- Accommodated Living
- Group Homes
- Intermediate Care Facility Mental Retardation (ICF-MR)
- Agricultural Communities/Farmstead Programs (Supported and Supervised)

FUNDING FOR THE SERVICES AND THE HOME

- Large Donor/Charitable Organization
- Private Pay
- Low Income Housing Government Funding
- Government Funded and Operated Institutions
- Medicaid, Title XIX and SSI

THE HOME DESIGN AND BUILDING TYPE

- Independent detached home
- Independent attached home (i.e. townhome)
- Cluster of detached homes (i.e. planned residential development)
- Attached home, 2-5 units (i.e. duplex)
- Attached home, 6+ units (i.e. apartment, condominium); no common/shared spaces
- Attached home, 6+ units (i.e. assisted living complex); with common/shared spaces
- Attached efficiency units or guest rooms (i.e. single room occupancy housing)

Resident occupancy of dwelling units also defines the housing option and includes residing with family only; with self-selected friends, roommates or alone; or with agency/ provider selected roommates. Further, resident occupancy of units may be mixed or exclusionary.

These categories and findings are described in greater detail in sections IV, V and VI. More can be learned about specific buildings types and existing models through the companion report to this study, *Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum Disorders*, <u>http://stardust.asu.edu/research_resources/detail.</u> <u>php?id=60</u> (20).

VOID OF MARKET DATA

Projecting the size of the population affected by autism and developmental disorders is a challenge. Most adults with autism live with their parents and, as a result, very little is known about the demographics and corresponding market demand. Assembling the additional data on needs, skills and functional capacities of this population poses an even greater obstacle. In order to secure capital, assess the appropriate service provisions and design suitable housing alternatives, the target population must be assessed, quantified and properly segmented. A survey of a statistically significant portion of the population is needed to determine housing needs, transition planning, service level requirements and financial resources that will be recognized by the private and public sectors, particularly the capital markets.

How deep is this market? What are the income bands of these clients? What rent/mortgage level is affordable?



LACK OF DOCUMENTED DESIGN GUIDELINES

The development and launch of a successful consumer and scalable product requires a quantifiable assessment of demand that addresses the home itself and the services in the home. Indicators of consumer value can drive product design, construction, the suite of services and pricing.

The homes and neighborhoods where adults with ASDs live can significantly impact the quality of their lives and level of independence. Housing providers, urban planners and architects need to know how best to create autismfriendly environments and how residents can be supported in their homes and their communities. Optimal design and neighborhood selection at the outset can help avoid later problems that may necessitate a subsequent move, which could prove debilitating for residents who need stability and consistency in their lives. Since autism is a heterogeneous disorder, finding design solutions is not a "one-sizefits-all endeavor" -- what is mandatory for one individual with an ASD might be irrelevant to another. Designing for a range of needs, with a focus on accommodating the issues that occur most frequently such as sensitivity to noise, demand for personal space and the tendency toward physical exuberance, may be sufficient for most residents.

SHORTAGE OF TURN-KEY SUPPORT SERVICE MODELS

Residential developers generally work in a project-oriented 'build and sell' strategy with a non-repetitive customer engagement or a 'build and lease' strategy where tenant retention is key to profitability. Properties are either sold to an end user (individual) or an investor group, or maintained in the portfolio of the development entity and leased to tenants. In both cases, financial success rests upon customer satisfaction with the product and price, and customer retention. To the extent a developer perceives that developing housing for individuals with autism means the risks of customer satisfaction or retention are higher, they will choose another path. In the case of housing for special needs populations, the safety needs and precautions are greater. Risks of disturbances at the property are also likely to increase if proper support services are not in place.

There is a dearth of quality service providers to meet the needs of the population once individuals are placed in an independent housing environment. While there are many organizations which offer these services, quality is highly



variable and no program working at scale exists to ensure caregivers are properly trained, assessed and monitored. Turnover of caregiver staff, which exceeds 50 percent annually, is also a major challenge.

Support models vary widely by market and project depending on state and federal funding models, supplemental services offered by nonprofit organizations and additional services paid through private sources. Also, the needs of the growing population of adults with ASDs are relatively new and have not been widely studied and documented in the independent living model. A program for providing reliable quality services must be developed as a turn-key service solution for residents of community integrated projects for developmentally disabled adults.

The ability to create a turn-key approach to the service requirement of most individuals with ASDs and related disorders would dramatically improve the ability for developers and investors to tackle the challenge of creating housing.

LIMITED AND CUMBERSOME ACCESS TO CAPITAL

Between the limited financial resources of adults and families affected by ASDs and the regulatory challenges of obtaining government funding, capital resources for the home itself and the services and supports inside the home represent the greatest obstacle to an executable housing solution. While many local and national developers are corporately and personally committed to engaging in real estate projects that serve society, the current risks and opportunity costs to do so are too great.

The majority of individuals with ASDs qualify for Supplemental Security Income (SSI), the federal program that



provides financial support for people with significant long-term disabilities who have virtually no assets and who are unable to pay market rate for rental or for-sale housing. In 2006, for the first time ever, national average rents for one-bedroom and efficiency apartments exceeded the entire monthly SSI payments for people relying on SSI for income (18).

This issue is exacerbated by the limited potential of young adults and adults (14 years of age and older) with autism

to become employed. Unemployment rates for adults with autism hover around 90 percent – largely a result of their social challenges, lack of training and on-the-job supports (21). By comparison, 67 percent of adults with disabilities are unemployed. Further, the SSI benefit system, which provides benefits to this population, significantly limits the amount a qualified beneficiary can earn, further crippling their ability to maintain themselves financially.

Charitable foundations and nonprofit organizations provide some support, but the majority of housing funds for this group come from government programs. These programs have several flaws, including insufficient funding; difficult and lengthy processes for funding approval; and lack of flexibility in how the funds are applied. Adequate funding and improved financing mechanisms need to be developed which allow government funding to flow through the system in a more simplified and useful manner.

CRITICAL SHORT-TERM NEEDS

The majority of adult children living with autism today are being cared for by aging parents who, in most cases, will not outlive their kids, leaving them limited options for a reasonable quality of life. The impact that millions of children and young adults, who have already been diagnosed with autism and other developmental disorders, cannot be overstated. The dramatic increase in the population of individuals with autism alone gives rise to serious concern amongst families, service providers, government and the community at-large that residential services for post-school-age adults with autism and developmental disorders must be created as an integral part of a healthy community's housing plan and opportunities. One promising funding source may be found through Community Development Financial Institutions (CDFIs), which focus on serving low income individuals or economically distressed communities, often working in market niches that may be underserved by traditional financial institutions.

The potential crisis in housing and services for this population is an issue not only for families and local communities, but for society as a whole.

--Joe Blackbourn, SARRC Board Member, Former ULI Arizona Chairman



The current economic environment has created significant financial shortfalls, both in government resources and philanthropic funding for long-term needs. As a result, workable solutions will require more creative use of the resources currently available and a community-based effort to build a healthy, integrated community for a diverse population.

While new housing development will be critical to resolution of the projected demand, the existing population of adults with autism needs solutions now. This study identified more than 100 agencies currently providing housing solutions to special needs populations. (Refer to Appendix A.) Connecting families with existing resources is an immediate prospect for response to the current demand.

"Overall, the demand for community services is growing rapidly due to aging family caregivers, litigation promoting access to community services, the increasing longevity of persons with developmental disabilities, and the downsizing of public and private institutions. This growing demand is frequently unanticipated by federal, state, and local agencies, resulting in a crisis for families and state and local service delivery systems."

--David L. Braddock, Ph.D., Executive Director Coleman Institute for Cognitive Disabilities



Under the leadership of Advancing Futures for Adults with Autism (AFAA), the autism community at-large is advancing an aggressive agenda focused on lifelong living and learning opportunities. AFAA's vision is to create meaningful futures for adults with autism that include homes, jobs, recreation, friends and supportive communities.

The consortium's five-year residential vision for adults living with autism is to provide an increasing number of housing choices as the necessary underpinnings – financial, educational and political – are put into place. This vision will be achieved through the following strategies for the residences and support services:

- 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.

http://www.afaa-us.org/

AFAA ORGANIZATION CHAIRS

Autism Speaks http://www.autismspeaks.org New York Center for Autism

http://www.newyorkcenterforautism.com Global Communities of Support (honorary) http://www.gcosinc.org/

AFAA REGIONAL PARTNERS

Alpine Learning Group http://alpinelearninggroup.org/ The Autism Program of Illinois http://www.theautismprogram.org/ The Daniel Jordan Fiddle Foundation http://www.difiddlefoundation.org/ Easter Seals http://www.easterseals.com/ Hallmark Community Solutions http://www.hallmarksolutions.org/ **Organization for Autism Research** http://www.researchautism.org/ **Rethink Autism** http://www.rethinkautism.com/ Southwest Autism Research & Resource Center http://www.autismcenter.org/ **Trinity Services** http://www.trinity-services.org/ **UM-NSU Center for Autism and Related Disabilities** http://www.umcard.org/

"The times I most need help are the times I am least able to ask for it." --Participant in 2009 AFAA National Town Hall



IV. RESIDENTIAL MODELS: SERVICES IN THE HOME

Adults with autism spectrum and related disorders need lifelong living options that respect and support their rights, individuality and future. These living options also need to empower families and individuals to make good choices and have control and flexibility over support services based on person-centered planning. All residential models should provide a secure, respectful and nurturing environment for residents and day visitors, and promote independence, choice and integration with the community. This can be accomplished, in part, by maintaining uncompromising integrity in the design, development, management, programming and financing of the hard and soft infrastructure.

Discussion about housing for special populations can quickly become confusing as features and their definitions vary greatly. For the purpose of this study and to support and clarify the national dialogue on the issue, three areas for classification of housing models have been identified and include the following: (1) services in the home; (2) funding for the services and the home; (3) the home design and building type. Programs and services are critical components of all housing for special populations regardless of funding and design. While it is common for the provider of services to control the real estate, a new trend is emerging that separates the two. Increasingly, states are exploring the separation of service provision and control of the real estate to ensure that a person can change service providers to meet their evolving needs without threatening their living arrangements.

PROGRAM AND SERVICE SUPPORT

According to the Organization of Autism Research (OAR) 2009 report commissioned by the New York Center for Autism for Advancing Futures for Adults with Autism (AFAA) and third party sources, a variety of residential housing models exist although not all models are available in all states. The description of program and service support primarily relates to the facility in which the adult with an ASD lives, the number of people who live there, the intensity of staff support provided and the level of community integration. With few exceptions, the housing structure is not tied to the type of services provided. In nearly all cases, however, the expenses associated with operating the programs exceed the cost of the real estate (10). Six different levels of service and support for residential housing have been identified. They include transitional models, supported living, supervised living, group home living (including teaching family model), agricultural communities/farmstead programs and Intermediate Care Facilities – Mental Retardation (ICG-MR). Brief descriptions follow:

TRANSITIONAL MODELS

Transitional residential programs offer a relatively shortterm (e.g., one month to two years) residential experience with the expressed goal of transitioning the individual back to their previous environment or a new residence upon completion of the program. Transitional programs generally fall into one of three categories: 1) programs providing intensive, inpatient behavioral evaluation and intervention for individuals with severe behavior disorders, 2) programs providing an intensive life skills course of instruction for individuals who, upon completion of the program, are expected to live independently, and 3) college support programs.

SUPPORTED LIVING

Supported living programs provide residential services to adults with developmental disabilities who are able to live in self-owned or leased homes in the community.



Among the core tenets of supporting living are that 1) everyone, independent of current skills sets, can benefit from supported living; 2) programming and instruction are directed by the consumer and not by the program; 3) to be effective, communities of support must be built around the person and promote their involvement, and; 4) smaller numbers result in greater levels of community integration. Supported living is designed to foster the individual's full membership in the community as they work toward their long-term personal goals.

SUPERVISED LIVING

Supervised living is a residential model designed to provide services to individuals with ASDs with greater oversight and direction than might be provided in a supported living context but less than group home living. In supervised living, the homes may be self-owned or leased. Although individual residences may be small (generally no more than one or two adults with autism per residence) there may be a number of such residences scattered throughout the apartment building or housing complex allowing for greater staff accessibility and oversight.

GROUP HOMES (SUPPORTED AND SUPERVISED)

With the onset of deinstitutionalization came the movement of individuals with ASDs and other developmental disabilities from large, congregate care facilities to smaller, more typical homes in the community. Group homes exist in every state. They are small, residential facilities (i.e., actual homes) located in the community and designed to serve children and adults with ASDs, intellectual disabilities or other chronic conditions. Typically, group homes have eight or fewer occupants and are staffed 24 hours a day by trained agency staff. Ownership of the house usually lies with the provider agency (as do staffing decisions) and not with the residents of the house. A primary goal of



group home living is to promote increasingly greater levels of independence in the residents. As such, instruction in daily living and self help skills including meal preparation, laundry, housecleaning, home maintenance, money management, hygiene, showering, dressing and appropriate social interactions are provided by the agency staff.

INTERMEDIATE CARE FACILITY – MENTAL RETARDATION (ICF-MR) (INSTITUTIONAL)

The ICF-MR is a residential program that was established in 1971 by the Federal government as an optional Medicaid service. The funding for this facility-based program, which includes both the facility and the support services, stays with the facility, not the person. Programs range from large congregate settings to those which are community -based and sized much like a group home. The underlying philosophy is that individuals with developmental disabilities can continue to learn and develop skills when supported by adequate programs and services tailored to their individual strengths and needs. The ICF-MR is responsible for providing active treatment, consistent training and health support allowing individuals to maximize their independence. Currently, all 50 states have at least one ICF-MR facility. The ICF-MR has traditionally served individuals with complex needs and who are medically fragile and multi-challenged. There has been a shift away from the development of new ICF-MR facilities and a transition to more person-centric funding models.

AGRICULTURAL AUTISM COMMUNITY/FARMSTEAD PROGRAMS (SUPPORTED AND SUPERVISED)

Agricultural autism community, or farmstead programs, are proven hybrid models that generally combine residential living arrangements, typically in several single family homes or individual apartments in multi-unit dwellings located on site or in nearby locations, with stable agricultural science and community-based employment. A few of the communities are residential only. Most offer day programs, job training and employment both on- and off-site for adults with autism who live with their families in nearby areas.

Occupations are chosen by residents according to their individual preferences and skill levels. Vocational training and generalized life skill instruction is also provided. The employment options are varied and flexible, but some adults choose specialization (e.g. farmer or greenhouse manager, cook, store or office manager, mechanic, computer specialist, as in any typical community). Recreational and leisure activities are abundant and accommodate all lifestyles, including very active ones. This combination of housing and flexible, stable, individualized and meaningful work in a non-urban setting is appealing to many adults with autism and their families.

Many communities start with families coming together to create a model. Waiting lists at all of the communities



studied are long and openings are rare. Most models are located in rural, exurban, suburban and urban locations, which are chosen for their proximity to small towns and large cities. These "near to town" (many within walking distance) locations enhance integration into the larger community through many available activities, including innovative community supported agriculture (CSA) programs, greenmarket and food bank initiatives, and partnerships with other community-based nonprofits and faith-based groups. Existing programs are located throughout the country.

The financial profile of agricultural autism communities varies, including privately funded operations, historic ICF-MR and DD licensed facilities, wavier-based operations or combination of these funding mechanisms. The recent trend in newer communities is toward person-centric funding. Although demand for this model far exceeds availability, significant financial and bureaucratic challenges impede wider proliferation of the agricultural autism community model.

"People with autism spectrum disorders are like fingerprints. We need to respect their differences. We need to think beyond what's currently available." --2009 AFAA National Town Hall

SERVICE PROVIDER CHALLENGES

The ability of any program or agency to provide quality services to adults with ASDs rests, at least in part, on the ability of the program to attract qualified, professional staff (12). Unfortunately, and with certain exceptions, the issue of staff recruitment and retention has proven to be a difficult one for many programs providing services to adults with ASDs. Salaries for residential staff are low. The work is hard, hours are long and the prestige, limited. The potential crisis is further complicated by an absence of training, supervision and any state or federal credentialing standards for adult services professionals.

The U.S. Department of Health and Human Services (2004) reports the combined, annual staff turnover rate for programs serving adults with developmental disabilities is 50 percent.

In addition, such programs report an ongoing staff vacancy rate of about 10 to 11 percent.

Inexpensive housing in various forms could be widely available; however, without confidence in a service provider families are reluctant to allow individuals with autism to live an independent life until the situation reaches a crisis level. In addition to providing therapy and care giving, families also want service providers to assist with transportation, ensure the resident's safety and security, sup-

TABLE 4-1

DIRECT SERVICE TURNOVER IN RESIDENTIAL/IN-HOME AND VOCATIONAL/DAY SERVICES, 1998-2003SETTING TYPENUMBER OF STUDIESAVERAGE RATERESIDENTIAL/IN-HOME1153.6%VOCATIONAL/DAY646.0%BOTH948.1%COMBINED AVERAGE2650.0%

Source: The Supply of Direct Service Professionals Serving Individuals with Interllectual Disabilities and other Development Disabilities. Report to Congress (2004). Department of Health and Human Services; Washington DC. Available online at http://www.ancor.org/issues/shortage/aspe_dsp_11-09-04.doc.

port cleaning and meal preparation, and generally look out for the individual's well being. These expanded services may be provided in a similar manner to apartments and dormitories with concierge services.

To be scaleable, these support services must be offered by larger, regional or national organizations. National dormitory (student housing) and multi-family management companies may be interested in expanding to manage services for individuals living with autism. Local community-based organizations with growth capacity may also be interested in expanding to provide services.

To be cost efficient, support service providers must take advantage of the economies of scale and be focused on this population. To be effective, they must provide credentialed staff who are supported through training, compensation and opportunities for career advancement, thereby reducing the historically high rate of turnover for caregivers and leading to a greater continuity of care for adults living with ASDs.

Photo by: Steve Dreiseszun

V. FINANCIAL FRAMEWORKS: FOR THE SERVICES AND THE HOME

Today, the number of housing choices for adults living with autism spectrum and related disorders is extremely limited. Current financing options, both public and private, have been insufficient in size and scope to support the creation of appropriate housing at scale for the current population, much less the anticipated growth. While the quality of government-funded affordable housing programs is actually quite high (i.e. Low Income Housing Tax Credits, HUD 811), they meet only a fraction of the demand for low-cost housing in this country. Government programs vary from region to region and are often insufficient on their own to make a project work, leading mission-driven developers to assemble a patchwork quilt of local resources to get to the finish line. This assembly takes a tremendous amount of time and is rarely replicable, even within the same community. In addition, due to the small size of these government programs, accessing this funding is highly competitive, translating into greater risk for developers to pursue.

Until structural problems are addressed, the current model will not support the demand for housing.

The following includes a report on current housing options, existing capital sources and alternative means for funding.

GROUP HOMES

By far the most prevalent residential service programs are community-based small group home settings operated by either nonprofit or for-profit organizations under contract with publicly funded organizations, either government agencies or nonprofit intermediaries. These facilities range in size from very small (1- to 2-person) homes to larger group residences with 12- to 14-person capacity, with most being in the 6- to 8-person range. The intent is to have these facilities integrated into the community close to families and community services that play an important part in the residents' ongoing support system.

Each person typically has an individualized service plan (ISP), but the nature of group living often results in a modified service package with residents receiving group services as well as some individual service programming. Funding to operate the group homes frequently comes from a variety of resources, often a combination of resources from the served individuals (pensions, SSI benefits, etc.), public



funds from Federal Title XIX (Medicaid for medically necessary services) and state matching funds from non-Title XIX costs, such as residential services.

Residents effectively are controlled by the state, which directs the resident's income, provides a minor stipend to the resident for personal necessities and provides contractual funding to the group home provider for all of the resident's housing, living and service costs.

These group home settings are often in leased facilities which are subject to the whims of the real estate market and do not provide permanent, long-term housing options that are controlled by the system which is paying for them.

While some group home sponsors have been able to purchase their facilities through nonprofit entities accessing public affordable housing funds, most remain leased and pose a threat to the long-term availability to the growing ASD population. In Arizona and other states, simply rising to the top of the waiting list does not assure placement in the next available slot. If an individual and/or his family is in a crisis, which may involve medical, financial or safety concerns, then that individual may "jump the line." Making that determination for an individual with an ASD should be based on criteria developed by experts in the field.

SEMI-INDEPENDENT AND TENANT-BASED OPTIONS

Semi-independent living models of supportive housing exist, but on a small scale. Unlike the traditional group home model that is funded through fee for service contracts supported through public dollars, these facilities separate the rental housing payment component from the funding for individualized supportive services. Typically in these models, the resident pays rent, usually based on a percentage of their income; receives services based on their eligibility for publicly funded individualized services; and can choose to not receive services at their discretion.

For low-income individuals with disabilities, who have the personal and/or the financial capabilities to live independently, with the availability of individualized supportive services as needed, several housing options are available on a limited basis. Tenant-based rental assistance programs allow qualified program participants to choose apartments of their own provided the landlord is willing to accept rental assistance payments. For example, the landlord receives payment from SSI, which is approximately 30 percent of the tenant's allotment, and the balance of the rent is to be paid from public funds through vouchers.

TABLE 5-1: OVERVIEW OF FUNDING SOURCES

FEDERAL ENTITLEMENTS

MEDICAID – TITLE 19 http://www.ssa.gov/OP_Home/ssact/title19/1900.htm

For medical necessity, paid directly to the service provider. Not specific for housing. Based upon services delivered. A person who is enrolled in ALTCS/DDD. States have a required match which can be used for room and board.

SUPPLEMENTAL SECURITY INCOME (SSI) http://www.ssa.gov.ssi/

Paid directly to recipients.

Income in lieu of working – intended to cover everything but medical care. Must be disabled or over 65 and have limited income; \$674 per month limitation on personal earnings to maintain qualification.

ASSISTED RENTAL APARTMENT COMPLEXES

The third category of independent housing options for low income individuals with disabilities lies in assisted rental apartment complexes. Traditional public housing units, while limited in unit availability for single individuals, provide potential for affordable housing for disabled persons. New public housing units are not being developed, but there is a large inventory of existing units in many communities. There also exists a limited number of existing apart-



ment complexes that receive project-based Section 8 rental assistance whereby qualified residents pay 30 percent of their income as their rental payment, and HUD pays the difference to the landlord. While new units are not being built under this program, many apartment complexes still exist with this assistance.

Public policy considerations that do not allow for the congregating of special needs populations and basic economic considerations typically limit the number of set aside special needs units from 10 to 20 percent of the total units in any project, if the developer/owner is willing to set aside any units at all.

CAPITAL & FUNDING SOURCES

Capital is the most complex issue facing organizations involved in the land purchase, facility construction or renovation, and ongoing operations of residential properties for special populations. It also represents the greatest obstacle to scaling projects and replicating successful models which would respond to the anticipated surge in market demand. Although there are a variety of sources for capital funding, organizations most often use two to three sources to cobble together a workable financial model for the projects.

Based on properties evaluated by ASU through their case studies, as well as additional research of innovations in this sector, projects are frequently developed based on the constraints and design demands of the available financing versus the model typically used in a capital market transaction: create a model for the housing product that responds to market demand, then search for a capital source to finance it.

Beyond the initial project capitalization, additional phases of project financing have been required for virtually all the properties included in this study:

- Land acquisition, design and construction
- Property maintenance and management
- Services and soft infrastructure

For this study, project models were stratified into the following major capitalization categories:



LARGE DONOR/CHARITABLE ORGANIZATION MODEL

A single donor or multiple donors contribute the construction/acquisition funding through a 501(c)(3) organization that serves the developmentally disabled population. **Pros:** Perhaps the simplest model from an execution perspective, it does not require ongoing government compliance and the asset can stay with the nonprofit in perpetuity. **Cons:** A highly unreliable source of revenue; cause and relationship related, which prevents the creation of a consistent funding source for replication and scale.

PRIVATE PAY

Families with resources pay for all services and the facilities together with other families. **Pros:** Provides a model which is quickly executed once the decision is made by the family(ies). **Cons:** May not provide for social integration with other populations; only affordable to a small segment of the total ASD population.

LOW INCOME HOUSING

Federal and state funds are granted to construct housing for low-income and special needs populations. **Pros:** By far the greatest single source of funding, this resource has the potential to allow for the scale needed to meet projected needs. **Cons:** Complex process which takes years to complete; funds are inadequate to meet the total need; high compliance issues throughout the life of the project.

GOVERNMENT FUNDED AND OPERATED INSTITUTIONS

Individuals are placed in state housing based on availability. **Pros:** Housing and supports are combined, no fundraising required. **Cons:** Families have no say as to location and proximity; space is limited; long waiting lists; quality of care is inconsistent.



MEDICAID/TITLE XIX AND SUPPLEMENTAL SECURITY INCOME (SSI)

Federal entitlement funds paid to the service provider (Medicaid) or directly to the recipient (SSI), these funds are intended to cover the ongoing housing and care for the individual with a disability. **Pros:** As entitlement funds, all qualified individuals receive them without concern for market conditions. **Cons:** Funds are inadequate to cover housing costs and SSI funding can be reduced or eliminated if the individual earns a modest income. (Refer to Table 5-1.)

"Accessing private equity challenges even the most patient developer or nonprofit. In today's extremely tight credit market, seeking bank funding or underwriting will require a balance sheet that would appear not to need the credit." -- Pat Gilbert, Marc Center

CHARITABLE MODEL AND PRIVATE-PAY ANALYSIS

Perhaps the most commonly used form of funding, private funds from foundations and individuals find their way to housing and support services for persons with disabilities through grants and contributions to a variety of housing and service providers. Major gifts of real estate to nonprofits help donors avoid taxes on capital gains, eliminate estate taxes on the property and provide a federal income tax deduction. In addition, families and friends of individuals with special needs can make tax deductible contributions to charitable organizations to advance the overall support of the population.

In 2004, the Maricopa Association of Governments (MAG) in Arizona reported a total of almost \$18 million from foundations and private donors for housing services. In 2007, the Arizona Community Foundation (ACF) launched the ACF Fund for Affordable Housing. One of the main reasons cited for starting the fund is because 19 percent of individuals with disabilities in Arizona live below the poverty line.

LOW INCOME HOUSING AND PUBLIC SUPPORT OPPORTUNITIES

Federal spending for community services for the developmentally disabled has more than tripled since the Americans with Disabilities Act passed in 1990. Yet federal money only covers a portion of what states need. While there are some minimum federal standards for the disabled, it is largely up to each state to determine what other services it will offer and how much it will spend.

Federal and state funding models can be complex, and require significant planning and administration on the part of



the organization. (Refer to Table 5-2.) The major categories for government funding include:

HUD SECTION 811

Provides interest-free capital advances to nonprofit sponsors to develop rental housing for low-income persons with disabilities.

LOW INCOME HOUSING TAX CREDIT (LIHTC)

Allows qualified for-profit and nonprofit developers to apply, on a state-by-state program, for federal tax credits that they can sell to investors and use the proceeds as equity for the development of apartment complexes for persons below 60 percent area median income.

HUD SECTION 202

Similar to 811, this program is available only to nonprofit organizations that target both low-income seniors and frail elderly by providing capital advances to finance the construction, rehabilitation or acquisition of structures, and also provides rent subsidies for the projects to help make them more affordable.

HOME PROGRAM

Provides formula grants and loans to state and local participating jurisdictions to expand housing opportunities for low and moderate income individuals and households.

COMMUNITY DEVELOPMENT BLOCK GRANT (CDBG)

Grants to jurisdictions which can be used to support affordable housing through land acquisition and infrastructure development.

HUD SECTION 811 HOUSING CHOICE VOUCHERS (HCV)

Dispersed directly by HUD to persons with disabilities to spend on the housing option of their choosing.

HUD SECTION 8 HCV

Also a voucher program for individuals with incomes below 60 percent of the area median income, including disabled persons.

GOVERNMENT FUNDED AND OPERATED INSTITUTIONS

The 1990 Americans with Disabilities Act as well as the Supreme Court's Olmstead decision found that it is medically unjustifiable to institutionalize persons with disabilities who want to live in a community setting. Further, states have a legal obligation to remedy this situation. As discussed in the study of Hallmark Community Solutions
in Section VII, states like California are working to comply with these laws by decommissioning state institutions and moving occupants into small, community-integrated living arrangements. This trend has been a positive one for the residents, but has not offset the demand for high-quality solutions for special needs populations. "In models where a service provider owns the home and is not providing quality care, the person with the disability has to move out, creating housing instability and inconsistency. These issues are magnified for people living with autism where establishing a routine and building long-term relationships are so crucial." -- Mardie Oakes, Hallmark Community Solutions



TABLE 5-2: CATEGORIES OF FUNDING

FEDERAL GOVERNMENT

PROJECT-BASED GOVERNMENT FUNDING

HUD SECTION 811: Low Income Housing For Persons With Disabilities <u>www.hud.gov/offices/hsg/mfh/progdesc/disab811.cfm</u> DESCRIPTION:

- Provides loans to nonprofits for acquisition, rehabilitation and construction of housing
- Housing must remain purposed for 40 years; loan is forgiven at the end of the term
- Does not cover services
- Maximum of 14 units in the project

INCOME QUALIFICATION: 50% of area median income FINANCIAL RESOURCE: Based upon Congressional allocation. Program budget (including vouchers) is \$250 million and funds fewer than 10,000 units annually.

LOW INCOME HOUSING TAX CREDIT (LIHTC): Low Income Housing

www.hud.gov/offices/fheo/lihtcmoU.cfm DESCRIPTION:

- Provides tax credits to qualified developers (for profit and nonprofit), which are sold to investors to create equity for the project
- Low income, but not specific to disabled populations
- Funded by the Department of Treasury through state agencies

INCOME QUALIFICATION: 60% of area median income FINANCIAL RESOURCE: Allocation is based on population of the area. One million units have been funded nationally in the past 10 years. HUD SECTION 202: Low Income Senior Housing www.hud.gov/offices/hsg/mfh/progdesc/eld202.cfm DESCRIPTION:

- Provides loans to nonprofits for acquisition, rehabilitation and construction of housing
- Housing must remain purposed for 40 years and loan is forgiven at the end of the term
- Does not cover services

• No specific limit on the number of units in the project INCOME QUALIFICATION: 50% of area median income FINANCIAL RESOURCE: Based on Congressional allocation. Allocation is based upon population of the area.

HOME PROGRAM: Low Income Housing Rent and Purchase www.hud.gov/offices/cpd/affordablehousing/programs/ home/contacts DESCRIPTION:

- Can provide rental assistance and loans or grants for affordable housing development
- Available to both for profit and nonprofit
- Administered by local jurisdictions

INCOME QUALIFICATION: 60% to 80% of area median income

FINANCIAL RESOURCE: Based on Congressional allocation; \$1.8 billion in 2009

FEDERAL GOVERNMENT	
PROJECT-BASED GOVERNMENT FUNDING (CONT'D)	TENANT-BASED GOVERNMENT VOUCHERS
 COMMUNITY DEVELOPMENT BLOCK GRANT (CDBG): Low to Moderate Income Housing <u>www.hud.gov/offices/cpd/communitydevelopment/programs/DESCRIPTION</u> Provides grants through local jurisdictions Can be used to support land acquisition, infrastructure development and rehabilitation costs for affordable housing. May not be used for hard construction costs of new development Focuses on the elimination of slums and blight INCOME QUALIFICATION: Varies FINANCIAL RESOURCE: Based on Congressional allocation; \$3.6 billion in 2009 	 HUD SECTION 811 VOUCHERS: Low Income Rental Assistance for People with Disabilities www.hud.gov/offices/hsg/mfh/progdesc/disab811.cfm DESCRIPTION: Individual vouchers for persons with disabilities Tenant can choose the unit they want to rent provided the landlord accepts the vouchers Vouchers are administered through government or nonprofit agencies Can be used with for profit and nonprofit residential projects INCOME QUALIFICATION: 50% of area median income FINANCIAL RESOURCE: Based on Congressional allocation. \$250 million voucher program is included in the FY 2010 budget for Section 811. HUD SECTION 8 VOUCHERS: Low Income Housing Rental Assistance www.hud.gov/offices/pih/programs/hcy DESCRIPTION: Individual vouchers for low income persons, not specifically with disabilities Tenant can choose the unit they want to rent, provided the landlord accepts the vouchers Vouchers are administered by government agencies

- Can be used with for profit and nonprofit residential projects, provided they meet housing quality standards and fit within rental rate limitations
- Long waiting list for this program

INCOME QUALIFICATION: 50% of area median income FINANCIAL RESOURCE: Based on Congressional allocation. \$250 million voucher program is included in the FY 2010 budget for Section 811.

VI. THE HOME DESIGN: GOALS & GUIDELINES*

PHYSICAL DESIGN ISSUES

Real estate developers, homebuilders and architects need to know how best to create autism-friendly environments and how residents can be supported in their homes and communities. Optimal design and neighborhood selection at the outset can help avoid later problems that may necessitate subsequent moves.

Good design and community access are also critical for caregivers who can be supported in part by the home environment and resources. Not only does turnover of care providers result in considerable financial costs, it can also trigger behavioral and emotional havoc among residents (22). The more that care providers feel the environment supports them in their work and also allows them opportunity for respite and restoration, the more likely they will be to stay in their positions (23).

Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum Disorders reports on how design can best accommodate and ameliorate the challenges and conditions faced by adults living with autism (20). The full report may be found at <u>http://stardust.asu.edu/research_resources/</u> <u>detail.php?id=60</u>. Based on the evaluation of existing residential building types and accomodations, design goals and accompanying design guidelines were created to serve as guideposts when developing new or renovated homes for adults living with autism. What follows will not apply to everyone. Clearly, there is no perfect model. However, there is a range of options for accommodating individual circumstances, needs and inclinations.

The aim of these design goals and guidelines is to provide a robust platform for use by architects, housing providers, families and residents so they may select design features that best respond to their specific needs and aspirations.

To establish a basis for the design guidelines, the following 10 design goals were crafted from a synthesis of the available research literature as well as case study research which may be found in Appendix B. These goal statements reflect general ways in which the design can enhance and optimize residents' needs. In some instances, goals may overlap or even conflict; however, together they can sensitize housing providers to some of the high-level priorities for designing environments for adults living with autism



and the behavioral health consequences of decisions involving quality control or cut-backs during the design and construction process.

Some of the design features and goals have been systematically tested with populations of individuals with ASDs or other special needs. Yet empirical, systematic testing is rare. In most cases, the recommendations in the source material have been developed from practical experience by housing and service providers, and architects. The following are abbreviated descriptions of 10 resident-based design goals. For further detail and clarification, and to access resources used, please refer to the full report at: <u>http://</u> <u>stardust.asu.edu/research_resources/detail.php?id=60</u>.

DESIGN GOALS



1. Ensure Safety & Security: Ensuring a safe living environment is the top priority. Issues range from providing appropriate security systems to selecting non-toxic products and

materials.



2. Maximize Familiarity, Stability & Clarity: Changes and transitions can be problematic for adults with ASDs so creating continuity and connection with the past is important.

Design strategies include logical spatial layout and use of familiar materials.



3. Minimize Sensory Overload: Simplify the sensory environment by designing spaces to be quiet, visually calm, well ventilated and to have appropriate lighting.



4. Allow Opportunities for Controlling Social Interaction & Privacy: To accommodate personal preferences, the design of any home should provide residents with a variety of

social opportunities including within a singular space.



5. Provide Adequate Choice & Independence: The physical environment should be designed so that options are available but few and flexible so that it can be adapted to changes in

residents' needs over time.



6. Foster Health & Wellness: To address any ongoing health vulnerabilities, the physical design should promote healthy living through the use non-toxic materials, the availability of

natural light, good ventilation and incorporation of universal design strategies.



7. Enhance One's Dignity: Everything from selecting a neighborhood that accepts diversity and supports its residents to designing a home that allows residents to personalize

their spaces and define their living arrangements serves to enhance one's dignity.



8. Ensure Durability: Investing in high quality materials, fixtures and appliances at the outset will result in lower maintenance/ replacement costs and will optimize resident safety.



9. Achieve Affordability: Designing for longevity and incorporating green building practices can lower costs over the lifetime of the home.



10. Ensure Accessibility & Support in the Surrounding Neighborhood: Site selection is critical to the overall success of any residential development. Access to transportation, com-

munity services, entertainment and shopping coupled with a supportive neighborhood community will create the best possible situation for the residents.

DESIGN CONSIDERATIONS

When designing for adults living with ASDs, a series of modifications to standard building strategies may be employed to increase the livability of the home and outdoor environment. To assist architects and builders in deciding what modifications help create an autism-friendly environment, the following recommendations have been developed. These recommendations should serve as a guide during the design process with the understanding that not all of the elements must be included for a home to be successful.

Autism is a heterogeneous disorder, finding design solutions is not a "one-size-fits-all endeavor."

Designing for a range of needs, with a focus on accommodating the issues that occur most frequently such as sensitivity to noise, demand for personal space and the tendency toward physical exuberance, may be sufficient for most residents. The following recommendations are intended to cover all potential areas where appropriate design could make a significant difference in the well-being of residents.

Specific recommendations indicate the particular icon of the design goal it addresses. Linking each design recommendation to one of the resident-based design goals articulates how the modification may aid and support the individual with an ASD to live more independently in the home environment.

The design considerations grew out of the case study research into current housing models for individuals with autism spectrum and related disorders as well as extensive research in therapeutic interventions and findings in the sciences that address autism and the environment. Refer to Appendix C for further explanation of the methodology.

NEIGHBORHOOD

Selecting the right neighborhood and site is a critical first step in developing housing for people with ASDs. Issues to consider include access to amenities and transportation and the potential for residents to be integrated into existing community.



NEIGHBORHOOD ACCESSIBILITY & SUPPORT

- Select a site that provides the most opportunities for residents such as proximity to the following:
 - family, support groups, and service agencies
 - public transportation (many residents do not drive)
 - grocery stores and pharmacies
 - employment opportunities
 - day programs
 - medical facilities
 - entertainment and social options
 - open space, parks, and other recreational opportunities
- Selecting a site that has the appropriate zoning at the outset will diminish the possibility for neighborhood opposition: NIMBYism or the tendency among some to assert "Not in My Backyard."



Neighborhood amenities

- Neighborhoods that are established and stable suggest the best outcomes for new residents: less confusion, stress, and disruption.
- The scale of the proposed housing should be appropriate to the context: potential for acceptability increases

FLOOR PLAN STRATEGIES Space planning should encourage choice, auton-omy and independence for residents. Attention

to connectivity within the floor plan and its impact on wayfinding will lead to a more effective use of all household spaces.



FAMILIARITY & CLARITY

- Predictability in the environment, demonstrated through transparency in spatial sequencing, smooth transitions between rooms and uses, and the potential to establish routines, assists in keeping arousal levels low and minimizing resident stress.
- The spatial layout should be easily understood by providing clear visual access into and between rooms. Use half-walls, vestibules, and cutouts to allow residents to preview a space before entering it. People will be more apt to use common rooms if they can assess the space and potential social interactions before entering them. Minimize the unknown.
- Spaces and rooms should be clearly defined with specific uses and functions, identified legibly (e.g. kitchen is for food preparation, dining room is for eating, etc.).
- A change of material (e.g. wall color or flooring material) could be used to indicate change of use (e.g. active living area vs. quiet area on the periphery).
- To accommodate the preoccupation with order that is common with autism, the design should utilize clean lines, eliminating visual and physical clutter. Avoid overembellishing or overfurnishing.

- Ample storage should be provided to create a clutter-free, less stimulating environment.
- Storage should be available in shared spaces as well as individual rooms.



SENSORY SENSITIVITY

- Separate high stimulus areas (e.g. TV room, exercise room) with low-input transition zones to allow for sensory recalibration.
- Every residence should include "escape" spaces: spaces that are activity free, calming, low-arousal.



HEALTH & WELLNESS

- Design of all spaces should accommodate and encourage physical movement. Spontaneous gross motor activity is common among people with autism and the living environment must support that. Common areas, hallways, bedrooms, and outdoor spaces should be designed to permit jumping, pacing, bouncing, and so on.
- Private areas away from residents should be provided for staff to complete paperwork and take breaks.

OUTDOOR SPACES Secure, shaded outdoor are tend gardens and socialize.

Secure, shaded outdoor areas offer opportunities for residents to tend gardens and socialize.



SAFETY & SECURITY

- Provide adequate lighting on timers (not motion detectors).
- All doors connecting to the outside should have zero-step thresholds for accessibility.



FAMILIARITY & CLARITY

- Include a covered walkway or porch at unit entrance to shield residents from inclement weather and to offer opportunity for neighborhood interaction.
- Courtyards are a good option since they are legible, private, safe, and accessible.
- Treat secured outdoor spaces as extensions of the home.
- A mix of hardscape and softscape provides residents a range of options for using various yard areas.
- Include raised planters for accessibility and to protect plants from trampling.



SOCIAL INTERACTION & PRIVACY

• Facilitate social interaction by planting flower or vegetable gardens for the residents to tend.



HEALTH & WELLNESS

- Install low maintenance landscaping that offers residents the opportunity to care for it.
- Provide adequate shade control in outdoor spaces and awnings over windows and doors.
- Include recreational opportunities on-site.
- Healing gardens positively effect people and should be included when possible.
 - Homelike imagery
 - Places for privacy
 - · Settings to stimulate mental alertness
 - Opportunities for social exchange
 - Family gathering spaces
 - Areas for activities
 - Comfortable seating
 - Sense of security
 - Accessible

MATERIALS AND RESOURCES

Clare Cooper Marcus and Marni Barnes, editors. 1999. *Healing Gardens: Therapeutic Benefits and Design Recommendations*. New York: Wiley.

LIVING/COMMUNITY ROOMS Living rooms should provide residents with a variety of options.



SOCIAL INTERACTION & PRIVACY

- Provide a range of communal areas for different types of interaction.
- · Provide space for residents to meet with their family that is separate from central living area: the presence of unfamiliar people may inhibit other residents.
- Create a central shared space for mailboxes, message board, bill paying, etc: encourages the least social to interact at least once a day.
- Locate common areas in proximity to one another to offer more opportunities to interact (e.g. kitchen, dining room, laundry, courtyard, living room all share a high degree of connectivity to one another).
- A common area should include active and quiet spaces within one contiguous larger space: people with autism often do not prefer to be alone, seeking instead proximity to others rather than active engagement. Window seats and nooks offer opportunities to participate from the periphery.



Comfortable living areas



HEALTH & WELLNESS

Locate a bathroom in close proximity to common areas.

MATERIALS AND RESOURCES

Sources for low-VOC furniture: http://www.greenhomeguide.com/index.php/main/product_detail/335/C124 and http://www.greenyour.com/home/furnishings/couch/tips/opt-for-a-low-voc-couch

KITCHENS Providing ample counter space to accommodate multiple users and independent living aides (e.g. computers) facilitates residents' success and satisfaction.



SAFETY & SECURITY

Food storage areas should be placed away from the cooking surface to reduce accidents related to reaching and crowding.



DURABILITY

- Kitchen countertops need to be extremely durable, fire and heat resistant, and easily cleaned and disinfected.
- Solid surface countertops with an integral backsplash such as Silestone, Corian, granite, or concrete are durable choices for kitchen and bath.
- Butcher block is a good surface for cutting but must be disinfected properly.
- Avoid tiled countertops because of dirt buildup in the grout and because they are easily broken
- Avoid laminate countertops as they are easily scratched and burned and pooling water causes delamination.
- Mix countertop materials according to use (e.g. surfaces dedicated to cutting).
- Select solid wood cabinets over veneers as veneers delaminate and do not wear as well. Avoid particle board substrates because of susceptibility to water damage.



Kitchen with multiple work areas



CHOICE & INDEPENDENCE

- Kitchens should have adequate space including multiple stations and ample counter space for several people to work simultaneously.
- Sufficient storage should be provided such that individuals may have their own cupboards.

HALLWAYS, STAIRS & RAMPS Treat these as opportunities for socializing; provide seating space.



FAMILIARITY & CLARITY

- Hallways should be wide to accommodate people in wheelchairs.
- Each floor should be accessible to all residents. Including a ramp as well as an elevator is preferable: it facilitates social interaction and also eases resident anxiety in the event of a power outage.
- Keep hallways and flights of stairs short.
- Minimize "blind" corners since they introduce unpredictability.
- Provide seating at landings to facilitate socialization and to offer opportunity to preview common areas.



HEALTH & WELLNESS

Opt for single-loaded corridors opening onto shared spaces or a courtyard: allows for crossventilation and natural light and provides more opportunities for social interaction.



DURABILITY

• Install well-secured carpet runners on stairs to reduce noise; carpet runners are economical to replace or clean when soiled.



Seating at stair landings

BEDROOMS Individual bedrooms with en-suite bathrooms, adequate storage, and a desk provide residents with privacy and dignity.



CHOICE & INDEPENDENCE

- Include a desk area with task lighting.
- · Closets should be internally lit and outfitted with a built-in organization system to assist residents with their daily dressing and grooming tasks.



HEALTH & WELLNESS

· Each bedroom should have individual climate control and a ventilation fan.



DIGNITY

· Residents should have their own bedrooms with en-suite accessible bathrooms for privacy and dignity.



Bedroom storage

MATERIALS AND RESOURCES

See "Materials" and "Appliances & Fixtures" section for more information

SENSORY ROOMS Providing a separate room that allows residents to control the atmosphere leads to decreased stress and anxiety.



SENSORY SENSITIVITY

- A room that allows residents to modify the sensory inputs such as lighting and music helps people with autism relax, process the larger environment, and modify behaviors.
- Sensory rooms should be painted white or soft colors to produce a calming effect.
- Texture can be introduced for added sensory engagement.
- The room should have a defined sense of enclosure, to promote feelings of safety and security for the residents.
- The room should be designed to be acoustically contained: do not allow outside noises in and prevent noise from within from escaping.
- Snoezelen Rooms (Dutch for "sniff" and "doze") are an established sensory room model that can be referenced.



Snoezelen sensory room

MATERIALS AND RESOURCES

Snoezelen rooms: http://www.worldwidesnoezelen.com/component/option,com_frontpage/Itemid,1/ Image: Wikipedia Commons, made available by Ciell at http://en.wikipedia.org/wiki/File:Snoezelruimte.JPG. This file is licensed under the Creative Commons Attribution ShareAlike 2.5, at http://creativecommons.org/licenses/by-sa/2.5/

BATHROOMS

At least one bathroom per unit should be fully accessible to accommodate residents with varying levels of mobility.



SAFETY & SECURITY

• Install nonslip tile flooring.

HEALTH & WELLNESS

In units with multiple residents, there should

- be one or more bathrooms for general use.
- In multistory units include a main floor bathroom for accessibility.
- Bathrooms should have ample room for staff to assist residents.
- Sinks should be wall hung for accessibility.
- Grab bars should be installed by the toilet and in the shower and bath.



DURABILITY

- Toilets should have concealed cisterns and use a push panel flush system for durability and ease of use.
- Install tile or waterproof panels on all walls to minimize possible water damage.



Wall-mounted sink

MATERIALS AND RESOURCES

See "Materials" and "Appliances & Fixtures" section for more information

LAUNDRY ROOM Each unit should include a bright laundry room with a large folding area and accessible appliances.



FAMILIARITY & CLARITY

- Include ample counter space to accommodate sorting, stain prep, and folding.
- Provide storage for laundry supplies.



SENSORY SENSITIVITY

- Provide adequate ventilation through inclusion of operable windows and ducted fans.
- Provide adequate acoustic insulation to contain noise.



HEALTH & WELLNESS

- Include a laundry sink or commercial hopper to contend with heavily soiled items.
- Install frontload washers and dryers for ease of accessibility; if necessary, raise the appliances to accommodate wheelchair riders.



Laundry room with storage and folding area



DURABILITY

- Install a floor drain to accommodate spills.
- Flooring should be a continuous, durable surface.

MATERIALS AND RESOURCES

Information on accessible washers & dryers: http://www.afb.org/afbpress/Pub.asp?DocID=aw080303 Shake absorber pads for washing machines: http://www.kellettent.com/vib_isol.html

TECHNOLOGY

Technology should be unobtrusive, easy to use and modify, and fail-safe; it should enhance resident independence and support staff. Privacy issues must be considered before selecting any monitoring technology. In-unit security support systems must also be available for staff.



SAFETY & SECURITY

- Install detectors for smoke, carbon monoxide, natural gas, radon, propane.
- Select talking smoke and carbon monoxide detector to minimize stress response and clarify the situation.
- Bed occupancy sensors alert caregivers to resident activity and possible accidents.
- Install lockable fuse boxes to avoid tampering.
- Install window stops to prevent inadvertently leaving window open at night or when away from the home.
- A security fence should be included to inhibit wandering or access from uninvited visitors.
- Appropriate fire safety systems should be installed: select alarms with visual explanations and talking alarms for smoke detectors.
- Install property exit sensors on exterior doors and windows. Select systems that provide an audible warning when any doors or windows are opened.

- Select an entry/exit system that is easy for residents to operate. Options may include keyless locks: radio frequency identification (RFID), biometric, digital keypads, and proximity systems.
- Select door buzzers and intercom systems that feature a visual display.
- Install automatic locks on external doors to eliminate possibility of residents forgetting to lock doors.
- Install emergency call buttons in all rooms or specify wearable call buttons for residents.
- Minimize possibility for furniture to block room access.
- Locks on internal doors must have the ability to be opened externally.
- Electrical sockets and appliances should have an automatic shut-off feature.
- Provide a "Staff Attack" alarm system to allow staff members to call for assistance in the event of an emergency.

MATERIALS AND RESOURCES

Extensive overview of home technologies with links to manufacturers: http://www.toolbase.org Voice Annunciator by Sensorium: http://www.sensorium.co.uk/product/assistive/voice_annunciator.htm For audible alarm products: Cobolt Systems, Ltd: http://www.cobolt.co.uk/Default.aspx?pageId=1

- Include an in-unit intercom system to facilitate communication between residents and staff.
- Install fall sensors to monitor residents prone to seizures or with epilepsy.
- RFID (radio frequency identification) location sensors unobtrusively monitor people and also are suitable for use on items that are easily misplaced.
- Bed occupancy and motion sensors detect resident activity.



CHOICE & INDEPENDENCE

- Select a range of daily activity monitors to assist residents in completing tasks and to alert caregivers when an activity is not completed properly (e.g. too long in the bathroom, meal preparation stalled, altered sleeping patterns, and so on).
- Include task prompting systems for daily independent living tasks such as dressing and grooming, cooking, cleaning.



Security system

MATERIALS AND RESOURCES

QuietCare Lifestyle Monitors: <u>http://www.chubbcommunitycare.co.uk/products/C88/</u> CAMP: Context Aware Medication Prompting by Intel and Oregon State University: <u>http://www.intel.com/healthcare/</u> <u>research/portfolio.htm</u>

TECHNOLOGY (CONTINUED)



HEALTH & WELLNESS

Install high-efficiency, whole-house air filtration system: attached directly to the HVAC system, air filtration systems remove over 90 percent of pollutants. Examples include:

- Trane CleanEffects
- Aprilaire Whole House Air Cleaner
- Fantech Whole House HEPA Filtration
- Enuresis sensors alert caregivers of enuresis incidents—protects against skin breakdown and preserves resident dignity; use in bedding and furniture; alert is communicated through wireless connection to caregiver.
- Include a medication tracking and prompting system to remind residents to take their medications.



FAMILIARITY & CLARITY

- Include temperature and power alert monitors since residents may not be cognizant of temperature shifts or power outages in appliances, etc.
 - Install a silent, battery-powered backup system to maintain seamless power during electrical outages.
- Occupancy sensors connected to lighting turning lights on and off automatically in bathrooms, hallways, kitchens, laundry rooms, and closets.
- Use timers on exterior lighting rather than motion sensors—less startling.
- Include an information exchange system for staff and residents.
- Include dressing aids such as a closet system with compartments for daily clothes.

MATERIALS AND RESOURCES

SmartHome, the Home Automation Superstore, has a wide range of suitable products:

http://www.smarthome.com/_/index.aspx

Architectural Products for Barrier Free Living is a good source for ADA compliant products: www.barrierfree.org

VISUAL CUES Individuals with ASDs often experience attention difficulties and stimulus overse-lectivity. Ameliorate this by keeping visually distracting elements to a minimum. Opt instead to employ appropriate visual cues that assist residents with daily activities.



SAFETY & SECURITY

Incorporate visual signs into the home environment to assist with safe use of features such as appliances, electrical outlets, windows, doors, and on the like. These may be in the form of pictures, words, or warning colors that are understood by all residents.



FAMILIARITY & CLARITY

- Picture schedules can assist residents with daily activities.
- Use color coding to indicate location, room function, activity area.
- Color palettes should avoid using bright, primary colors in favor of softer tones. Bright hues may cause agitation in certain individuals with autism.
- Written or pictorial signage also may be used to denote functions within the home such as an individual's bedroom, bathroom, storage areas, and so on.



Picture exchange communication system



SENSORY SENSITIVITY

Minimize detail since visual clutter may lead to stimulus overselectivity causing an individual to fixate on a particular object or aspect in the environment.

MATERIALS AND RESOURCES

Visual schedules: http://autism.healingthresholds.com/therapy/visual-schedules

VENTILATION

Adequate ventilation reduces unwanted smells that can negatively affect individuals with hyperreactive (extremely sensitive) sensory processing.



SENSORY SENSITIVITY

Use silent, ducted exhaust fans in bathroom and kitchen such as Ultra Silent NuTone ventilation fans.



HEALTH & WELLNESS

- Install high-quality air filters such as HEPA filters.
- Include operable windows in all living areas.
- Selecting blinds enclosed between window panes rather than curtains will reduce dirt and odor buildup and minimize wear and tear thereby increasing the longevity of product.
- Moisture-proof fabrics should be used to minimize opportunities for mold growth.



AFFORDABILITY

- Install dual-glazed windows for increased energy efficiency, temperature control, and minimization of condensation.
- Wire bath exhaust fan to light switch and timer to improve effectiveness and efficiency.



Operable window

LIGHTING

People with autism often experience visual perceptual problems that are exacerbated by lighting conditions. A range of lighting options should be provided with the optimal environment featuring nonglare surfaces, no-flicker bulbs, and lots of natural light controlled by window blinds or other coverings.



SAFETY & SECURITY

- Avoid using high-heat tungsten and halogen light bulbs.
- Use wet-area fittings on all portable lighting and wall outlets.
- Halls, stairs, and landings should be well-lit.
- Install day/night activated exterior lighting at doors and in yard; motion activated lighting may be startling to some individuals.



FAMILIARITY & CLARITY

- Use indirect lighting to reduce glare.
- Bathrooms should have bright, uniform, shadow-free light and include mirror and shaving lights.
- Rooms should have overhead, recessed lighting as well as task lighting.
- Include light fixtures in closets for accessibility and to minimize resident frustration.
- In kitchens, provide lighting under cabinets and overhead recessed lighting.



DIGNITY

 In living/community rooms, avoid institutional atmosphere by using recessed and task lighting.



SENSORY SENSITIVITY

- Natural light should be available in all rooms.
- Use nonfluorescent, no-flicker bulbs.
- Provide opportunity to maintain even lighting levels through dimmer switches, easy-toadjust window blinds, etc.
- Reduce glare through use of indirect lighting, clerestory windows, and awnings.
- Use buzz-free dimmer switches on all recessed and wall-mounted lighting.



CHOICE & INDEPENDENCE

 Provide flexibility by including portable task lighting.

DURABILITY

- Wet-areas require water-proof electrical fittings.
- Recessed lighting minimizes opportunities for breakage.
- Include ample electrical outlets in all rooms to accommodate portable task lighting needs and to avoid outlet overloading.

MATERIALS

People with autism often have underlying health issues that are exacerbated by environmental chemicals. Prevent chronic exposure to indoor air pollutants by selecting durable, nontoxic building materials and finishes. Durability is also a concern.



SAFETY & SECURITY

- Install nonslip flooring in bathrooms, kitchens, and laundry rooms, such as textured ceramic tile.
- Avoid carpet with strong weave or pile as it may be a trip hazard.
- Create smooth, flush flooring transitions between rooms.



SENSORY SENSITIVITY

- Use nonslip area rugs and wall hangings to dampen room noise.
- Avoid materials and finishes with distracting patterns or excessive embellishing: for people coping with stimulus overselectivity, patterns and embellishes may cause them to fixate unnecessarily.
- Choose paint in soft colors rather than bright, primary colors.



HEALTH & WELLNESS

- Use zero- or low-VOC (volatile organic compound) materials including paints, adhesives, caulking, carpets, vinyl tile, linoleum, particle board, plywood, and engineered wood products.
- Use hypoallergenic materials such as marmoleum for floors and wainscoting.
- Use nontoxic, fragrance-free, biodegradable cleaners.
- Avoid using pesticides and insecticides both indoors and outdoors since these persist in the environment long after application.
- · Seal or paint all MDF (medium-density fiberboard) and plywood to minimize off-gassing
- Use zero-VOC eggshell finish paint such as Benjamin Moore Natura or AFM Safecoat for durability, cleaning ease, and a low-glare surface.
- Select non-pressure treated wood for exterior use such as Radiance Thermally Modified Wood, a sustainable, chemical-free option.

MATERIALS AND RESOURCES

Radiance Thermally Modified Wood: http://www.radiancewood.com Marmoleum Click is certified asthma and allergy friendly by the Asthma and Allergy Foundation of America: http://www.forboflooringna.com



FAMILIARITY & CLARITY

- Use contrast (tonal value vs. bright color) to indicate light switches, electrical outlets, and other pertinent features.
- Select materials that create a warm home environment rather than an institutional atmosphere.



Muted color palette

MATERIALS AND RESOURCES

Carpet & Rug Institute-"Green Label" testing program identifying low-VOC products: <u>http://www.carpet-rug.com</u> California recycled materials product directory: <u>http://www.ciwmb.ca.gov/rcp</u> Green Resource Center: <u>www.greenresourcecenter.org</u>

MATERIALS (CONTINUED)



DURABILITY

- Select hard, continuous surface flooring such as bamboo, wood, tile, natural linoleum, or marmoleum.
- Use carpet tiles rather than rolled carpet for easy replacement. Carpet is not as durable as other flooring options and is best restricted to use as area rugs or runners.
- Durable flooring materials to consider include:
 - Flor by Interface www.Flor.com
 - Flotex, www.flotex.co.uk
 - Skatelite Pro and Hemplite: http://www.skatelite.com
- Install wainscoting, corner guards, tall baseboards or chair rails in high traffic areas to protect, walls: marmoleum, wood, tile, stone are all durable choices.
- Kitchen countertops need to be extremely durable, fire and heat resistant, and easily cleaned and disinfected.

- Solid surface countertops with an integral backsplash such as Silestone, Corian, granite or concrete are ideal for kitchen and bath.
- Butcher block is a good surface for cutting but must be disinfected properly.
- Avoid tiled countertops because of dirt buildup in the grout and because the tiles are easily broken.
- Avoid laminate countertops as they are easily scratched and burned and pooling water causes delamination.
- Mix countertop materials according to use (e.g. surfaces dedicated to cutting).
- Select solid wood cabinets over veneers as veneers delaminate and do not wear as well. Avoid particle board substrates because of susceptibility to water damage.

MATERIALS AND RESOURCES

Healthy House Institute: <u>http://www.Healthyhouseinstitute.com</u> National Center for Healthy Housing: <u>http://www.nchh.org</u>

ACOUSTICS To accommodate aural sensitiveness, ambient noise levels should be reduced as much as possible. Building systems and appliances designed for quietness should be selected and sound-proofing insulation in ceiling and walls should be increased.



SENSORY SENSITIVITY

- Choose quiet systems to minimize ambient noise: HVAC, ventilation, appliances.
- With exposed brick, etc, use deeply raked masonry joints to break up sound waves.
- Soundproofing options include the following:
 - Acoustic panels such as Acoustiblok or AcoustiFence
 - Ouiet Batt Acoustic Insulation—cotton insulation has superior soundproofing qualities compared to fiberglass insulation
- Dishwashers, models such as:
 - Bosch 800 Plus quiet series
 - Maytag Quiet Series Sound Package
 - GE Quiet Partner
- Refrigerators, models such as:
 - LG LoDecibel quiet operation with door alarm if left open
 - · Kitchen Aid with Whisper Quiet compressor system
 - GE with quiet package
 - Amana with SofSound II package

- HVAC:
 - Ductless HVAC systems
 - Insulate conventional HVAC system with internal acoustical duct board which is more effective at sound mitigation than wrapping sheet metal ducts with batt insulation
- Ventilation fans, models such as:
 - Ultra silent NuTone ventilation fans in bedrooms and bathrooms
 - Bosch kitchen ventilation systems feature whisper quiet volume
- Washer and dryer:
 - · Mount on sturdy, level surfaces to minimize bouncing
 - Use additional insulation in laundry room walls to help contain noise
- Appliance downdrafts and hoods:
 - Locate blower outside of kitchen using a remote blower

MATERIALS AND RESOURCES

Acoustiblok: http://www.acoustiblok.com/index.html Quiet Batt: http://www.soundprooffoam.com/quiet-batt-insulation.html Ductless HVAC Systems: http://hvacquest.com/ductlesshvac.php

APPLIANCES & FIXTURES

Safety controls on appliances are essential since people with autism often experience inattentiveness, high pain thresholds, and the inability to recognize problems. Durability, quietness, and ease of use also are important.



SAFETY & SECURITY

- Induction cooktops transfer heat only to magnetic materials eliminating risk of burns to users; the stovetop stays cool. Residents with cardiac pacemakers should consult their doctors regarding use of induction cooking.
- Specify cool-touch small appliances in which surfaces do not become exceedingly hot.
- Install lock-out or override feature on appliances to prevent inadvertent use or to keep appliance door from opening.
- Use auto shut-off safety outlets for small appliances: toasters, coffee makers, etc.
- Select appliances with front or side controls: enhances ease of use and eliminates reaching across hot surfaces.
- Select appliances that have automatic shut-off feature or install a motion detector to automatically turn appliance off after a period of inactivity.

- Install a drain trap instead of a garbage disposal.
- All sinks should use a drain trap and have captive plugs.
- Equip sinks and toilets with intake alarms: shuts water off in event of leak or overflow.
- Install a flood detector on sinks, baths, and washing machines.
- · Faucets should be single lever, mixing hot and cold water.

DURABILITY

- Select concealed cistern toilets with push panel flush systems.
- Bathtubs constructed of heavy gauge porcelain on steel are longer lasting than those of fiberglass.

MATERIALS AND RESOURCES

Auto shut-off safety outlet: http://www.goldviolin.com/Auto_Shut_Off_Safety_Outlet_p/91574.htm



FAMILIARITY & CLARITY

- Appliances should be easy to operate and not require excessive instruction.
- Appliance handles should allow use of whole hand for doors, drawers.
- Controls should be easy to read: large numbers/letters, nonglare and nonreflective.
- Controls should be easy to see: use color contrast to distinguish knobs/buttons from background surface.
- Controls should be easy to use: easy to turn, click in place.
- Install nightlights in kitchens and bathrooms.
- Select dual signaling appliances with visual and audible alerts.
- Sufficient lighting within all appliances is necessary.
- Laundry rooms should include a sink, folding area, fold-down ironing board.



HEALTH & WELLNESS

- Appliances should be easy to clean: racks and drawers should be removable.
- Accessible appliances and fixtures allow for more flexibility over life of resident:
 - Wall-hung sinks
 - Frontload washer and dryer
 - Adjustable countertops
 - Wall ovens that open sideways
 - Counter-mounted cooktops with undercounter knee space
 - Cabinets with pullout shelves or drawers
 - Roll-in shower
 - Lever door handles rather than knobs



SENSORY SENSITIVITY

Appliances should be as quiet as possible (see "Acoustics" for specific recommendations).

MATERIALS AND RESOURCES

GE Universal Design: http://www.geappliances.com/design_center/universal_design/









































VII. INNOVATIONS IN SPECIAL NEEDS HOUSING

The ULI, SARRC and ASU study team identified several innovations in housing with promising potential applications for the special needs population in general and the ASD population in particular.

The projects identified include:

CLASSIC RESIDENCE/PLAZA COMPANIES

A Continuous Care Retirement Community (CCRC) offering a range of living options including independent units, assisted living, skilled nursing and Alzheimer's care.

CAMPAIGE PLACE / TOM HON GROUP (THG)

Developers of single room occupancy (SRO) projects across the U.S. THG uses Low Income Housing Tax Credits (LIHTC) to create inexpensive rental units in urban areas.

BAY AREA HOUSING PROJECT/HALLMARK COMMUNITY SOLUTIONS

Hallmark Community Solutions developed 60 custom designed group homes serving three, four or five people, each with their own bedroom in the Bay Area using innovative financing techniques designed to retain ownership of the homes within the public/nonprofit care system for individuals with development disabilities, including autism.

MARC CENTER/ VILLAGE AT OASIS PARK

A large Arizona nonprofit with more than 35 group homes in its portfolio, Marc Center is currently developing a project which combines senior Section 202 housing with Section 811 housing, allowing aging parents to live near their developmentally disabled adult child.

BITTERSWEET FARMS/BETTYE RUTH KAY COMMUNITY HOMES

Bittersweet Farms is an agricultural community, located on 80 acres in a rural area of northwest Ohio, offering several choices for living arrangements and employment/day program options for adults with autism spectrum disorders.

"We must restructure the way existing government funding is allocated to housing resources for the developmentally disabled in order to grow a sustainable real estate supply over time." --George Bosworth, Urban Land Institute Arizona

CLASSIC RESIDENCE/PLAZA COMPANIES

The Plaza Companies provide a variety of high-end living options, also known as Continuum of Care Retirement Communities (CCRC), for adults from 55 years and older. Their model of housing allows residents to move easily from an independent living condition to higher levels of care as they age and their health declines. Emergency assistance and social amenities are provided on site. As the level of assistance increases so does the density of the units which allows services to be provided in a cost effective manner. The Plaza Companies provide some medical services on site and locate their properties near hospitals for emergency services. The properties include outdoor activity amenities, fitness rooms and social halls. Residents can also take advantage on-site banking, dining, cleaning service, computer center, scheduled transportation and numerous social, cultural and recreational programs as well as a range of care giving options.

The financial model is a refundable equity-based program with the residents investing cash up front but with a refundable option of up to 90 percent at the end of the contract. Residents are charged a monthly fee for food, maintenance and services. Higher service housing is provided at no additional investment or monthly charge and the majority of the equity in the unit returns to the family when the resident leaves or dies and the unit is re-sold. **Project Name:** Classic Residence by Hyatt and the Plaza Companies

Number of Units: 260

Financing Model: Equity and insurance contract Initial Funding Source: Private equity Supportive Services: Minimal to high Physical Design: Range of options from detached homes to community lodging/adult placement

Applicable Innovations:

- Equity model combined with an insurance contract
- Range in levels of care offered at one facility to accommodate the changing needs of the resident
- Quality of care is very high

Obstacles on Application:

- Actuarial tables for a younger population might make the financing model ineffective
- Cost prohibitive to a majority of the ASD population

Further Evaluation and Considerations:

 Possibility of combining senior populations with adults living with ASDs which would allow more socialization, housing options close to aging parents and potential service jobs for the adults on the spectrum.



CAMPAIGE PLACE/TOM HON GROUP SINGLE ROOM OCCUPANCY

The Tom Hon Group (THG) has developed a number of single-room occupancy (SRO) projects across the country ranging in scope from conversion of a residence hotel in downtown Atlanta to new construction, such as Campaige Place in Phoenix. Campaige Place consists of 300 units and provides low income housing in small individual (or married couple) living spaces. Each unit is studio-style with a bed, bath, desk and kitchenette. The units range in size from 170 square feet to 190 square feet at a monthly cost of \$425 to \$475 respectively, which includes utilities, use of the common rooms, building maintenance and the door man/security service. Cleaning services and underground secured parking are provided at additional fees. The facility is housed in a single building with a single resident entry point and individual units are accessed from an interior corridor. Guests must check in at the front desk which also provides mail service and offers general grocery and laundry supplies. The building has a common room and a laundry room as well as many outdoor upper level common balconies for the enjoyment of its residents.

Project Name: Campaige Place Number of Units: 300 Financing Model: Rent Initial Funding Source: LIHTC and private equity Supportive Services: Minimal Physical Design: High density apartment

Applicable Innovations:

- Low cost construction model allows for construction and maintenance using readily available resources
- Located in urban areas, close to public transit, universities, employment and daily life amenities
- High level of security due to the limited access and smaller unit size
- High social interaction in common areas

Obstacles on Application:

- High density, especially for a special needs population
- Not a living option for those with high service level needs
- Lacks integration with larger base of the population
- Often located in low income neighborhoods

Further Evaluation and Considerations:

 Possibility of combining current population with adults living with ASDs to stimulate more socialization. This might be accomplished by dedicating a percentage of the units or a floor of the complex to individuals with ASDs requiring similar levels of support and staffing those floors accordingly.









BAY AREA HOUSING PROJECT/HALLMARK COMMUNITY SOLUTIONS

In response to the California State Department of Developmental Services' decision to close Agnews Development Center, a large institution built in 1885, Hallmark Community Solutions (HCS) embarked on an initiative to relocate the 240 individuals housed at the facility. A nonprofit housing developer, HCS endeavored to bring major innovation to housing for people with developmental disabilities in the state. Between 2006 and 2009, an unprecedented collaboration of public and private agencies, with HCS serving as master developer, created 60 homes in 19 communities specifically designed for the individuals from Agnews, utilizing a new and innovative financing structure and ownership model.

In California, funding flows through 21 state Regional Centers, which are private nonprofits that receive 100 percent of their funding from the state and are responsible for ensuring that consumers benefit from services. The Regional Centers have historically paid service providers to operate community care homes through established monthly rates per resident. This monthly payment, which varies based on the level of services provided, in actuality pays not only for services, but for the service provider's mortgage on the home where their consumers live. In this traditional group home scenario, the service provider controls both the ownership of the home as well as the delivery of services, meaning that taxpayer money is used to acquire property on behalf of the service provider rather than for the benefit of the disability community. When a provider exits the business, the house also exits the system and a new home

must be identified at current development costs.

Through a legislative process, the California State Department of Developmental Services and HCS were able to effect state legislation which deemed that dollars spent on housing qualified as service dollars, enabling the statefunded mortgage payment be eligible for a 50 percent match of federal funds, reducing the cost burden on the State of California while also improving quality of life for residents. This allowed HCS to monetize the State's implied long-term commitment to pay for services into capital used to acquire and renovate or newly construct 60 homes. This paved the way for HCS to obtain 100 percent financing from a traditional private lender for acquisition and construction (Bank of America) and California Housing Finance Agency (CalHFA) for permanent financing. The permanent financing is structured as a combination of taxable and taxexempt bond financing with a 15-year, long-term residency lease agreement and a Regional Center lease assurance agreement serving as the crux of the deal.

Further, the guiding principles of the Bay Area Housing Project required that the owner of the home be separate from the provider of services. Once HCS completes the development of each home, the ownership is transferred to a nonprofit owner, and a service provider leases the opportunity to provide services in the home. This ensures that the homes remain available for the developmentally disabled population in perpetuity and allows a higher level of care as the service provider is separate from the property owner.
This project represents a breakthrough in housing finance for individuals with disabilities and has national potential as both states and the public finance market assess the public obligation to provide services to this population and the risk potential for default on bonds used for these purposes. The legislative authorization, which was originally limited to three Regional Centers for residents of Agnews, was expanded to all 21 Regional Centers in January 2009 through the passage of SB1175, sponsored by California Senate pro tem Darrell Steinberg, paving the way for the BAHP model to be replicated statewide.

Project Name: The Bay Area Housing Project
Number of Units: 60 homes, 240 individuals housed
Financing Model: Monetization of Title XIX and CA State match to provide a reliable long-term income stream sufficient for debt repayment (Bank of America and CalHFA)
Initial Funding Source: Debt secured by evidence of historical State and Federal commitments to funding this population as well as the underlying real estate.



Supportive Services: Moderate to high Physical Design: Modified group homes

Applicable Innovations:

- State legislative reforms which allow Title XIX funds to be securitized
- Separation of the housing provider from the service provider

Obstacles on Application:

- Only available in California at this time
- Private funding significantly curtailed since the State "guarantee" has limited value in California's current economic climate

Further Evaluation and Considerations:

 Nationalization of the model through collaboration of HHS and HUD to provide a federal program which provides security for private debt.



MARC CENTER/VILLAGE AT OASIS PARK

Based in Mesa, Arizona, the Marc Center has been providing services to the developmentally disabled population for more than 50 years. In addition to behavioral health, community day services, job training and life skills, Marc Center also owns and manages 35 group homes, triplexes and apartment facilities. Most recently, they have received funding under HUD Section 811 to commence construction of The Village at Oasis Park (Oasis). This community will include 68 units in four separate buildings. Forty of the units are dedicated to seniors who are parents of adult children with disabilities as a primary target. The other 28 are planned for adults with developmental disabilities with a primary target of those whose parents are housed in the project.

The Oasis project will be a campus environment with a community center serving the broader population on a daily basis, which will serve as an additional source of revenue for the project. Increased levels of care are built into the design and job opportunities for the developmentally disabled population on campus will be incorporated into the model.

In addition to the HUD funding, the project includes a donation of the underlying land from Maricopa County to Marc Center and from Marc Center to HUD, local CDBG and HOME funds as a part of the total model. Marc Center also has private equity to invest from a recent tax-exempt bond transaction.

Project Name: Marc Center/Village at Oasis Park Number of Units: 68 Units, 50-60 individuals housed Financing Model: Everything available -- HUD 811 & 202, Charitable Gift, CDBG, HOME and private equity Initial Funding Source: Donation of land by Maricopa County

Supportive Services: Moderate to high Physical Design: Exclusive apartment complex

Applicable Innovations:

- Side-by-side community of interest combining seniors with developmentally disabled adult children
- Community center for both ongoing revenue and integration into the broader community

Obstacles on Application:

- Complex funding model
- Partial reliance on charitable gifts/large donor

Further Evaluation and Considerations:

 A potential model for quality of life for individuals with ASDs and aging parents. Can this model be replicated and/or altered to incorporate a full pay component to offset the need for donor involvement?





BITTERSWEET FARMS/BETTYE RUTH KAY COMMUNITY HOMES

Bittersweet Farms opened in 1983 as an ICF-MR facility serving the residential and vocational needs of adults with autism. Due to demand they've expanded to multiple sites, using a variety of funding mechanisms, including a HUD 811 grant and other housing grants. In recent years, Bittersweet created affordable apartment living with innovative designs offering both autonomy and community as part of the structure.

Founded by a group of parents and professionals, Bittersweet Farms provides a holistic lifestyle of living and working in an agricultural environment, which is desirable to many individuals who respond well to meaningful tasks related to gardening, arts and crafts; opportunities for gross motor work; and a quality of life that includes working in outdoor settings.

From the beginning, there was a waiting list of individuals requesting to live and work at Bittersweet. The residential program served 20 adults before the funding mechanism (ICF-MR) was frozen in 1989 by the State of Ohio. Using the Individual Options Waiver in 1994, Bittersweet began to serve individuals in the supported living model in their own homes in the community. These homes were sub-standard due to the limited income participants could apply for rent. As a result, some individuals were forced to acquire roommates to share expenses which made household living spaces congested. To better serve these individuals, Bittersweet secured a HUD 811 grant to develop apartments for residents on the autism spectrum and designed one bedroom apartments as well as common areas to allow individuals the opportunity to socialize with their peers. In addition to the HUD grant, other funding was secured to enhance the property, add safety features and increase the overall durability of the apartments.

The housing project is owned by a separate nonprofit known as the Bettye Ruth Kay Community Homes. A third party firm provides the management, giving more division between the service provision and the housing. Since opening in September 2008, all 12 apartments have been occupied and no vacancies are anticipated in the future. Residents enjoy subsidized rents. They have the option of preparing their own meals or participating in a community meal in the evening. Staff is shared among the 12 apartments, allowing for much greater support, supervision and operational efficiency. The profile of residents ranges from those who work and drive to those with intense behavioral challenges requiring close supervision.

Project Name: Bittersweet Farsm/Bettye Ruth Kay Community Homes

Number of Units: 12

Financing Model: HUD, State of Ohio Housing Development Assistance Program Grant, Federal Home Loan Bank of Cincinnati's Affordable Housing Program Grant Initial Funding Source: HUD grant, Bittersweet Farms Supportive Services: Minimal to high

Physical Design: One bedroom apartments attached to a common space that includes a great room, a large kitchen and a laundry area.





Applicable Innovations:

- HUD 811 focused specifically on meeting the needs of adults with autism spectrum disorders.
- Incorporates apartment living with opportunities for socialization in a generous common area.
- Close to campus of Bittersweet Farms within walking distance of day programs and employment opportunities.
- Offers opportunities for greater efficiency in sharing staff supports.
- Opportunities for more recreational activities with their neighbors.

Obstacles on Application:

- Location is not accessible for public transportation.
- All showers, no tubs in order to meet HUD requirements.
- Complexity and recertification processes involved in working with HUD.

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VIII. OPENING DOORS: RECOMMENDATIONS & NEXT STEPS

The solutions for addressing an issue as complex and sweeping in scope and impact as housing for a special needs population of more than 500,000 individuals and growing must be addressed on multiple fronts. Based on research from ASU, the ULI AZ Technical Assistance Program panels and the investigative work of ULI and SARRC, the following recommendations will not only advance publicprivate-nonprofit collaborations in the development of community housing initiatives, they will also provide short-term benefits to adults living with autism and their families.

CONDUCT NATIONAL AND MARKET SPECIFIC SURVEYS

Tantamount to the success of any real estate development is a complete understanding of the market(s) being served. Establishing the depth and breadth of the product demand will be a critical first step to attracting investors, whether a donor, lender or future resident. The data needs to be systematically collected by a trusted and reliable source, contain a sufficient level of detail and cover a significant portion of any demographic group targeted. This largescale survey will involve individuals with ASDs and parents/ guardians. Data collection recommendations include:

- Completing a demographic and geographic study of the population of individuals with autism spectrum and related disorders to better evaluate impact and demand at the community level.
- Assessing the population from the perspective of service needs, financial capacity and desired physical housing options.
- Determining the financial capacity of the population; this includes work income, private pay from personal resources and federal funding through Medicaid and other programs.
- Evaluating transition models which respond to the needs and interests of the individual and their family. Considerations would include phasing the transitions over six months to two years, training in independent living skills and geographic proximity options.

This study would be conducted in collaboration with a national network of non-profit and for-profit organizations working within this arena so that an ongoing information dialogue can be established. Initially the market study will



be broad-based to establish the overall size of the demand on a national scale as well as the projected service needs and financial statistics of the population. As a specific project is identified, a local area market study will be needed to address issues specific to that geographic area.

Survey results will drive the financial viability of investment in the program and will be used to engage developers, financial institutions and public policy officials in the process of setting forth new solutions. They will also serve as a basis for product design, transition services, on-going service models and financial projections. In addition, survey participants will have the option to become part of an on-going interactive database for connecting families with housing needs to providers with housing solutions.

CREATE AN INTERACTIVE DATABASE OF HOUSING OPTIONS

Many local agencies serving special needs populations receive frequent inquiries from parents hoping to find healthy and nurturing long-term care solutions for their adult children with autism. To date, no national resource model has been developed which connect these families with housing providers and properties that meet their needs.

In the course of researching best practices in design for housing adults with developmental disabilities, ASU's research team accumulated information on more than 100 properties currently providing housing options to special needs populations. Ten fields of data were collected on each of these providers with more in-depth data collected on 20 percent of them.

In order to connect community needs with available resources in this arena, an interactive website should be developed. This site may operate in the following ways:

- Using similar technology as other interactive match sites such as volunteer match, eHarmony and Craigslist by searching information based upon the criteria of the user. These items could be city and state, number of roommates, type of facility (single family home vs. apartment), cost, access to resources and support needs of the individual.
- Serving as a resource for locating housing options. The website could also create a notice board for needs.
- Applying the technology imbedded in the current match websites, families will have the ability to confidentially post their needs criteria and receive information through anonymous email listings. Open questions and answers would also be available via a related web log.
- Addressing security and safety issues, which are paramount.

DEVELOP AND TEST SOFT INFRASTRUCTURE SUPPORT MODELS

The availability of quality service providers to meet the needs of the population once individuals are placed in an independent housing environment is essential. While there are many organizations which offer these services, quality is highly variable and no program exists to ensure that the skills required to meet the needs of the ASD population are properly trained, assessed and monitored.

To advance the development of soft infrastructure support models, a coalition of local and regional providers should be created that spans a variety of populations. Armed with the results of the market survey, this group will work to develop cost effective programs for execution within a variety of housing frameworks and may include:



- Creating a list and profiles of current regional and national support providers.
- Developing a training and certification curriculum specific to caregivers for adults with ASDs and related disorders, which is offered through community colleges, universities, vocational training institutes and nonprofit organizations.
- Creating a consortium of nonprofits that are successful service providers and establishing standards of care, training programs and standardized models which can be consistently implemented.
- Developing a residential model to test best practices in service delivery, safety and soft infrastructure support.
- Developing supplemental service models (based upon ability to pay).
- Creating a monitoring and maintenance plan.
- Integrating the service provider model into website technology.
- Identifying insurance coverage models.

With consistent, scalable support models in place, many developers will seek out the organizations that can confidently manage the soft infrastructure support to make development projects successful for their residents.

DEVELOP PROTOTYPES TO TEST BEST PRACTICES AND NEW IDEAS

While public policy reform needs to be a primary focus of a national coalition, advancement of the issue may also come in smaller increments through projects which successfully demonstrate alternative models to financing, population integration and services. Once executed, these projects would become templates for financial expansion of models. Additionally, these test projects could serve as labs for the development of best practices, supportive service delivery models which might be scaled to meet the projected demand for trained and certified care givers for adults living with autism.

Philanthropists, parents and other stakeholders are willing to participate in the development of model projects that could serve as incubators for best practices in community housing; incorporating diverse populations such as seniors, families and individuals from diverse socio-economic levels. Concepts to be evaluated in this environment include:

- Combining options of equity/ownership and rental units.
- Testing of the insurance model used by senior living communities.
- Mixing populations of seniors and their adult children with ASDs.
- Mixing residents in a full-pay model to help offset the shortfall in government funding.
- Creating an innovative supportive service model.
- Providing training and certification for service providers.
- Offering support models that allow for purchased services in addition to government-funded allowances.
- Optimizing resident self sufficiency through employment within the property and the surrounding community.
- Creating models for transitioning individuals to a home outside of their current residence before making more permanent moves.
- Evaluating technology and communications platforms that allow for more personal independence while providing appropriate levels of safety and security for residents.



RESPOND TO CURRENT AND SHORT-TERM DEMAND

SARRC and many of its collaborating partners envision residential models for adults located in both urban and suburban areas that are integrated into the community fabric, and support transitions to adulthood and greater independence. Plans to advance models that may be replicated at sites across the country must be advanced to build capacity for meeting the ever-increasing demand. Specific initiatives under consideration for advancement in this are include:

- Creating lease guarantees with multi-family housing developers which acknowledge the long-term lease potential of this population. Lease rates should be low, reflecting the low turnover rate and consistent performance of the tenants.
- Working with low-income housing develop-

ers who currently use Low Income Housing Tax Credits (LIHTC) as their primary funding source. States would give funding preference to projects that carve out 10 percent or more of their projects for special needs populations. If a consistent and reliable source for tenants and necessary services is available, several national developers may look favorably on a collaborative effort.

 Developing test projects that incorporate many of the ideas developed in this study including innovations in supportive services, design and financial models.

ULI Arizona and SARRC are also in discussions on convening a National ULI Technical Assistance Panel to further engage the real estate industry to refine and act upon recommendations included in this study.

INCREASE AND SYSTEMATIZE CAPITAL RESOURCES FROM PUBLIC AGENCIES

Clearly, the strongest source of sustainable funding remains in the public sector. With a few critical improvements to the system, viable funding vehicles could be created which would achieve the scale and mass needed for the developmentally disabled population. Top priorities in this area include:

> Developing improved capital resources. For the large number of individuals with autism and developmental disabilities which are likely to require supportive, group-home residential settings, the development of improved capital resources for small, single-purpose facilities is critical. Development of a strong partnership between HUD and HHS that recognizes the use of Title XIX match dollars as housing dollars and allowing

these funds to generate capital (e.g. the Hallmark Community Solutions tax-exempt bond model) is likely to attract private long-term capital to these projects.

- Increasing capacity. As more capital resources are attracted to develop housing options, there is a corresponding need to increase the capacity of local, regional and national nonprofits to develop, own and manage more housing facilities, separate from the service provider that operates the home. Assistance from HUD and national non-profit intermediaries to develop these capacities will be essential. Technical assistance funding from both HUD and HHS for this effort should be requested.
- Advocating for increased federal support. As the population of individuals with autism and developmental disabilities continues to grow and age, there will be a growing need for more semiindependent supportive housing such as the HUD Section 811 and 202 programs, which provide both capital development and operating subsidies for low-income persons with disabilities. National advocacy is needed for increased Congressional authorizations and appropriations for both programs, particularly the 811 program which serves only individuals with disabilities through nonprofit sponsors/owners. It would also be advisable to request Congress to allow projects to focus on specific disabled populations, rather than requiring open access to all disabled populations as required by current fair housing regulations. The nature of some disabilities makes it incompatible to have multiple service programs operating simultaneously.
- Modifying the LIHTC program. Federal tax credits are potential sources of capital equity to sup-

port the development of affordable housing for individuals who are capable of fully independent living with the availability of supportive services. The sale of federal tax credits provide the upfront capital needed to develop affordable housing. One option is to seek Congressional direction for the IRS to require all Low Income Housing Tax Credit (LIHTC) projects to reserve a modest percentage of their units for disabled populations (10% at a minimum). Several states already require this in their local Qualified Allocation Plans (QAP). A second option is a state-by-state advocacy effort to have the local LIHTC authorizing agency modify their QAPs to encourage set asides for special populations and to allow more flexible leasing arrangements, such as master leasing for groups of units by non-profit service providers. Use of the tax credit vehicle allows for full integration of housing units for disabled persons into the private housing market. The tax credit program is the largest affordable housing development program in the country and over time would provide stable housing options for many people.

- Establishing an alternate tax credit program. In lieu of modifying the existing LIHTC program, another option is to request Congress to establish an alternative tax credit program designed to meet the housing needs of many special needs populations, particularly in small, communitybased settings. While an ambitious pursuit, this option would allow the valuable equity provided by saleable tax credits to be used for many of the housing types needed by persons with disabilities, including small group homes, semi-independent and fully independent living.
- Capitalizing on funding available through CDFIs.

Community Development Financial Institutions (CDFIs) offer products similar to those provided by larger, mainstream financial institutions, such as mortgage financing for low income or first time homebuyers, small business lending and lending for community facilities. CDFIs generally lend to and make equity investments in markets not served by traditional financial institutions; may offer rates and terms that are more flexible; and provide services that help ensure credit is used effectively. CDFIs include regulated institutions, such as community development banks and credit unions, and non-regulated institutions, such as loan funds and venture capital funds.

PURSUE TESTING OF INNOVATIVE OPTIONS

In addition to the existing models serving populations with developmental disabilities, the study team investigated several projects which incorporated potential new concepts in addressing the growing need for quality housing options. These innovative approaches, described more fully in Section VII of this report, present an opportunity to test the application of non-traditional ideas in special needs housing.

Developing projects which integrate senior populations with adults with autism and related disorders. As the baby boomer generation ages, there is a boom in senior housing needs. Approximately 10,000 people turn 60 each day in the U.S. As strategies are sought for both housing and serving the needs of this population, consideration should be given to integrating the adult population living with autism. The Marc Center approach to community integration which incorporates a senior housing model with adults with disabilities as well



and a large central community center, promotes a new approach to building communities.

- Combining diverse populations in a high-density urban model. The SRO projects developed using Low Income Tax Credits (LITC) provide highly economical housing solutions. These projects, located in urban centers, allow connections to a variety of work, school and living amenities through pedestrian access and public transportation. The small size of the units combined with the high-density of the projects (300+ units), lower the property construction and maintenance costs considerably. Large common areas allow residents opportunities for social integration and provide convenient facilities for supportive services. The possibility of developing residential properties which mix the general population with those who have special needs presents a compelling alternative that can meet many of the social and accessibility issues as well as scale at an accelerated rate.
- Creating a model which allows for a diverse economic base in the special needs population. The Plaza Companies model caters to a higher net

worth demographic of the senior population. The model, which involves both an equity investment as well as a monthly living expense, is targeted to individuals who have accumulated a reasonable net worth and have earnings which allow them to live comfortably in their retirement. Families of adults with autism include a diverse economic group, some of whom fall within this demographic. Regardless of their financial circumstances, however, these families want a safe, nurturing and healthy environment for their loved ones. Combining an equity model similar to Plaza Companies with a lower income model paid for through rent subsidies might bridge the current gap in construction and maintenance costs which exists in fully government subsidized housing.

Who will care for my loved one when I'm no longer able to do so? We can more effectively support adults living with autism and provide families with the peace of mind they are searching for by advancing housing solutions in demand today.

Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders recognizes the urgency and complexity of the topic. Solutions must be diverse and addressed through a series of new, retrofitted and/or integrated properties developed through public, private and nonprofit sector collaborations. Service models must be an integral part of the solution by creating a suite of affordable options and alternatives that can efficiently plug into the real estate. Best practices must be scalable, replicable and able to be developed within the fabric of our communities, near families, friends and the comfort of familiar places and faces. OPENING DOORS

APPENDIX A: INVENTORY OF PROPERTIES STUDIED

INNOVATIONS IN SPECIAL NEEDS HOUSING

NAME	LOCATION	INFORMATION SOURCE	
The Bay Area Housing Project Marc Center	San Francisco, CA Mesa, AZ	http://www.hallmarksolutions.org http://www.marccenter.com/	
The Plaza Companies	Scottsdale, AZ	<u>http://www.hyattclassic.com/</u> <u>http://theplazaco.com</u>	
THN Group	San Diego, CA	http://www.tomhomgroup.com/	
INVENTORY OF PROPERTIES SURVEYED			

NAME	LOCATION	INFORMATION SOURCE
1811 Eastside	Seattle, WA	<u>http://www.smrarchitects.com/?p=affordable_</u> <u>housing&name=1811_eastlake</u>
AdvoServe	Mount Dora, FL (near Orlando)	http://www.advoserv.com/florida.html
AdvoServe	Bear, Delaware & Maryland Area	http://www.advoserv.com/delaware.html
AdvoServe	New Jersey (across entire state)	http://www.advoserv.com/newj.html
Ardmore, Inc.	Akron, OH	http://www.ardmoreinc.org/Ardmore%20Inc/services.htm
Aspen Court	Pacheco, CA	http://www.pyatok.com/portfolio/aspen.html
Atlantic Ave Apartments	Brooklyn, NY	http://www.dunndev.com/L3/atlantic.html

NAME

LOCATION

INFORMATION SOURCE

Autism Treatment Center	San Antonio, TX	http://www.atcoftexas.org/index_enter.htm
Autism Treatment Center	Dallas, TX	http://www.atcoftexas.org/index_enter.htm
Avalon Mutual Housing	Seattle, WA	http://pyatok.com/portfolio/avalon.html
Avondale House	Houston, TX area	http://www.avondalehouse.org/
Aware Home Research	Atlanta, GA	http://awarehome.imtc.gatech.edu/about-us
Initiative @ Georgia Institute		
of Technology		
Baptist Village North (Green	Youngtown, AZ	http://www.abrc.org/
House Home)		
Bay Bridge	Oakland, CA	http://www.pyatok.com/portfolio/baybridge.html
Benhaven	North Haven, CT	http://www.benhaven.org/
Big Wave	El Granada, CA	http://www.bigwaveproject.org/
Bittersweet Farms	Whitehouse, OH	http://www.bittersweetfarms.org/
Carolina Autism: Supported	Charleston, SC	http://www.carolinaautism.org/
Living Services (CASLS)		
Carolina Living and Learning Cente		http://www.teacch.com/regionalcenters/cllc/cllc.html
Casa de Amma	San Juan Capistrano, CA	http://www.casadeamma.org/about.html
Casa Feliz Manor House	San Jose, CA	http://www.sjhousing.org/project/cfmh.html
Cerebral Palsy Center Housing	Oakland, CA	http://www.cpcoak.org/index.html
CHAI of Jewish Family &	Boston, MA	http://www.jfcsboston.org/disability/index.cfm
Children's Services		
Chapel Haven East	New Haven, CT	http://chapelhaven.org/che/
Chapel Haven East*	New Haven, CT	http://chapelhavenaspergerprogram.org/
Chapel Haven West	Tucson, AZ	http://chapelhavenwest.org/
Community Builders	New England Area	http://www.tcbinc.org/
Community Vision	Portland, OR	http://www.cvision.org/
Community Living	Lawrence, KS	http://www.clokansas.org/pages/Adultservices2.html
Opportunities (Family		
Teaching Model)		
Community Services for Autistic	Montgomery County	http://www.csaac.org/
Adults and Children (CSAAC)	Area in Maryland	
Concern Housing -	Suffolk County, NY	http://www.concernhousing.org/programs.shtml
Transitional Housing		

NAME	LOCATION	INFORMATION SOURCE
Concord House	San Leandro, CA	<u>http://www.jswdarch.com/projects/multiFamily/concord.</u> html
Croydon Service	Surrey, UK (outside London)	 http://www.nas.org.uk/nas/jsp/polopoly. jsp?d=139&a=2290
Cupertino Duplexes	Cupertino, CA	http://www.charitieshousing.org/cupertinoduplex.htm
DeKalb Avenue Apartments	Brooklyn, NY	http://www.dunndev.com/L3/dekalb.html
Ecology House	San Rafael, CA	http://www.tikvah.com/cc/eh/
Eden ACRES (A Community	Princeton, NJ	http://www.edenautismservices.org/index.php/adult-
Residence Experience		services/
Evans House	Seattle, WA	http://www.smrarchitects.com/?p=affordable_
		housing&name=evans_house
Evans Lane Apartments	San Jose, CA	http://www.satellitehousing.org/pages/projectsindevelop- ment.html
Folsom & Dore	SFO, CA	http://www.dbarchitect.com/project_detail/34/Fol-
		som%20%2B%20Dore.html
Fuller Lodge II (Fuller Gardens)	San Leandro, CA	http://www.pyatok.com/portfolio/fuller.html
Garden Villas	North Hollywood, CA	http://www.homesforlife.org/
Gorse Farm: Autism	North Solihull, UK	http://www.autismwestmidlands.org.uk/gorsefarm.html
West Midlands		
Grace Commons	Santa Cruz, California	http://www.pyatok.com/portfolio/grace.html
Grafton School, Inc.	Berryville, VA	http://www.grafton.org/locations/berryville.html
(Berryville Campus)		
Grafton School, Inc.	Midlothian, VA	http://www.grafton.org/locations/richmond.html
(Richmond Campus)		
Grafton School, Inc.	Winchester, WV	http://www.grafton.org/locations/winchester.html
(Winchester, VA)		
Grove House CASA	Jacksonville, FL	http://www.chicagofed.org/community_development/
		lesle/housing_development/grovehouseahp.doc.
Hallmark (SB 962 Group Home)	San Jose, CA	http://www.hallmarksolutions.org/houses.html
Halcyon Center (The	North Attleboro, MA	http://www.halcyoncenter.org/
Groden Network)		
Hallmark (SB 962 Group Home)	San Jose, CA	http://www.hallmarksolutions.org/houses.html
Hart United CLA	New Haven & other	http://www.hartinc.org/comm-living.php
	cities, CT	

NAME	LOCATION	INFORMATION SOURCE
Hart United CTHP	New Haven & other cities, CT	http://www.hartinc.org/comm-training.php
Hercules Senior Housing	Hercules, California	http://www.pyatok.com/portfolio/hercules.htm
Home Safe I	Santa Clara, CA	http://www.charitieshousing.org/homesafei.htm
Home Safe II	San Jose, CA	http://www.charitieshousing.org/homesafeii.htm
Homeport	San Jose, CA	http://www.sjhousing.org/project/hp.html
Hoover Apartments	Los Angeles, CA	http://www.projectnewhope.org/PNHinde.html
Imagine Smart Home (Boulder)	Boulder, CO	http://www.imaginesmarthomes.org/BOULDER.htm
Imagine Smart Homes (Longmont)	Longmont, CO	http://www.imaginesmarthomes.org/LONGMONTrender- ings.htm
Independence Hill	Moscow, ID	http://www.hud.gov/local/id/news/independencehill.cfm
Jay Nolan Community Services	Mission Hills, CA	http://jaynolan.org/index.php?option=com_
		frontpage&Itemid=1_
Jespy House	South Orange	http://www.jespyhouse.org/default.htm
	Village, NJ	
Lincoln Oaks Apartments	Fremont, CA	http://www.hceb.org
Linwood Center	Ellicott City, Columbia and Catonsville Area, MD	http://www.linwoodcenter.org/
Lithia Place (Living on Track)	Medford, OR	<u>http://www.greencommunitiesonline.org/projects/profiles/</u> profile_living_on_track.pdf
Mercy House: Guadalupe Residence	Santa Ana, CA	http://www.mercyhouse.net/?page_id=32
Mercy House: San Miguel Residence	Santa Ana, CA	http://www.mercyhouse.net/?page_id=32
Merlo Station Apartments	Beaverton, OR	http://www.lihtccompliance.com/products_and_services/ downloads/Merlo-Station_05-08.pdf
Milagro Independent Living	San Jose, CA	http://www.midpen-housing.org/properties/profiles/mila- gro.pdf
Mission Creek Community	San Francisco, CA	http://www.mercyhousing.org/ViewProperty.aspx?Propert yLocationID=27&LocationID=1_
Monterey Glen Inn	San Jose, CA	http://www.sjhousing.org/project/mgi.html
Near North Apartments	Chicago, IL	http://www.nefinc.org/nefweb07/projects/profiles/near- north.pdf

NAME	LOCATION	INFORMATION SOURCE
Newport Service	Caerleon, UK	http://www.autism.org.uk/wales/residential
Nueva Vista	Santa Cruz, CA	http://www.globalgreen.org/i/file/Green%20Urbanism/
		GGUSA_CaseStudy_NuevaVista.pdf
Oakfield House: Autism	Birmingham, UK	http://www.autismwestmidlands.org.uk/BirminghamRe-
West Midlands		gionalDevelopment.html
Octavia Court	San Francisco, CA	http://www.satellitehousing.org/pages/projectsindevelop- ment.html
Options in Community Living	Madison, WI	http://www.optionsmadison.com/
Page Mill Court	Palo Alto, CA	http://www.parca.org/page%20mill.html
Pensione Esperanza	San Jose, CA	http://www.dbarchitect.com/project_detail/65/Pensio-
		<u>ne%20Esperanza.html</u>
Plaza Apartments	San Francisco, CA	http://casestudies.uli.org/Profile.aspx?j=8084&p=1&c=5
Reservoir Cooperative Apartments	Madison, WI	http://www.designcoalition.org/projects/Reservoir/reser- voir.htm
Richmond House	Richmond, VA	http://www.richmondhouse.org/home.htm
Rusty's Morningstar Ranch	Cornville, AZ	http://www.rmr.org/about.html
Seventh Landing	St. Paul, MN	http://www.cermakrhoades.com/seventh_landing.html
Shalom House	Phoenix, AZ	http://www.charityadvantage.com/cjsnorg/ShalomHouse.
		asp
Sky Vista (Living on Track)	Medford, OR	http://www.greencommunitiesonline.org/projects/profiles/
		profile_living_on_track.pdf
SmartBo	Stockholm, Sweden	<u>http://www.deafblindinternational.org/standard/review1_h.</u> html
Specialized Housing Cambridge	Cambridge, MA	http://www.specializedhousing.org/news/index.html
St. Paul's: Autism West Midlands	Smethwick, UK	http://www.autismwestmidlands.org.uk/stpauls.html
Step Up on Fifth	Santa Monica, CA	http://www.stepuponsecond.org/services.cfm#housing
Stoney Pine Villa	Sunnyvale, CA	http://www.charitieshousing.org/stoneypine.htm
Surrey Service	Surrey, UK	http://www.nas.org.uk/nas/jsp/polopoly.
,	<i></i>	jsp?d=139&a=2285
The Cove Center (The	RI (throughout state)	http://www.covecenter.org/
Groden Network)	-	
The Drive: Waltham Forest	Essex, UK	http://www.guardian.co.uk/society/2008/apr/02/social-
Housing Association		care.housing

NAME	LOCATION	INFORMATION SOURCE
The Homestead	Des Moines, IA	http://www.thehomestead.org/enriching-lives/campus- program
The Timbers Independent	Wichita, KS	http://www.cprf.org/housing.asp
Living Facility		
Thirsk Service	North Yorkshire, UK	http://www.nas.org.uk/nas/jsp/polopoly.
		jsp?d=139&a=3628
Touchpoint Autism Services	St. Louis Metro	http://www.touchpointautism.org/
(previously Judevine)	area, MO	
West London Service:	London, UK	http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1986
Golden Manor		
West London Service:	London, UK	http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1987
Halliday Square		

APPENDIX B: CASE STUDIES OF EXEMPLARY RESIDENTIAL DEVELOPMENTS

From the 101 cases in the inventory, visited sites were selected based on their proximity to ASU researchers and diversity of residential types, amenities, resident populations and development types. A data collection form was developed to gather consistent information across the various site visits. The following sites were visited between May and October 2008:

Bay Area Housing Project, (Bristol Place & Sand Beach), San Jose, California Casa de Amma, San Juan Capistrano, California Chapel Haven West, Tucson, Arizona Charles SmartHome, Boulder, Colorado Community Living Options Family Teaching Model Homes, Lenexa, Kansas Garden Villas, North Hollywood, California Home Safe II, San Jose, California Laguna Senior Apartments, Los Angeles, California Lincoln Oaks, Fremont, California The Mark, Pasadena, California Milagros Independent Living, San Jose, California Mission Creek Senior Housing, San Francisco, California Step Up on Second & Step Up on Fifth, Santa Monica, CA Stoney Pine Villas, Sunnyvale, California Vista Nueva, Los Angeles, California

While not visited, documents were acquired and phone interviews were conducted with staff at CHAI Community Services, of Jewish Family & Children's Services in Boston, Massachusetts. In addition, several interviews were conducted and plans analyzed of an innovative multigenerational development with HUD Sections 202 and 811 funding – Village at Oasis Park – currently under development in Mesa, Arizona, sponsored by Marc Center.

Profiles of some of these case studies are available at: <u>http://stardust.asu.edu/research_resources/detail.</u> <u>php?id=60</u>

APPENDIX C: METHODOLOGY

DEVELOPMENT OF INVENTORY

A systematic and comprehensive search was conducted to identify residences for adults with ASDs, intellectual/ developmental disabilities, or other special needs that were considered as exemplary models. To sift through the thousands of such residential developments, ASU solicited recommendations from staff in relevant organizations and agencies of residential models or programs that they considered exemplary. From recommendations of Southwest Autism Research & Resource Center (SARRC) and from web searches, 54 service-based organizations were identified from which to solicit this information. These organizations include:

Accessible Housing Society Adaptive Environments Center Alzheimer's Association Senior Housing Finder American Association of Homes and Services for the Aging American Association of People with Disabilities American Seniors Housing Association Arizona Bridge to Independent Living Arizona Statewide Independent Living Council ASSIST- Community Design Center Assisted Living Consumer Alliance Assisted Living Online ASU Center for Inclusive Communities Autism Society of America Canadian Centre on Disability Studies The Center for an Accessible Society (U.S.) Center for Excellence in Assisted Living Center for Health Care Strategies Center for Housing and New Community Economics Center for Persons with Disabilities Center for Universal Design Center on Community Living and Careers Centre for Accessible Environments Community Living Exchange Collaborative Clearinghouse **Concrete Change** Consumer Consortium on Assisted Living **DIRECT** Center for Independence EIDD Design for All Europe Eldercare Locator The EQUAL Research Network Illinois Network of Centers for Independent Living Independent Living Research Utilization Institute for Recovery and Community Integration Institute on Community Integration, Adult Services and Community Living Center, U of Minnesota

Liberty Resources

MAAP Services for Autism and Asperger Spectrum Minnesota Association of Centers for Independent Living National Alliance for the Mentally III (NAMI-Arizona) National Autism Association National Center for Assisted Living (NCAL) National Council on Independent Living National Down Syndrome Society National Resource Center on Supportive Housing and Home Modification (NRCSHHM) NCB Capital Impact New Horizons Pioneer Network Research and Training Center on Community Living, University of Minnesota Research and Training Center on Independent Living, University of Kansas RISE, Inc. Seniors for Living (search assistance for various types of homes) SMILE Services Maximizing Independent Living Empowerment SNAP for Seniors SocialWorks Inc, (Arizona based)

Total Living Choices Upenn Collaborative on Community Integration

In addition to these organizations, all 23 State Associations of Independent Living were identified. Each organization was sent an email with follow-up phone contact when determined necessary.

In addition to the recommendations from these organizations, ASU also conducted a search of electronic docu-

ments that identified exemplary developments or "best practices" of housing for adults with autism, I/DD, or other special needs.

CLASSIFICATIONS

ASU's search resulted in the identification of 101 projects that had sufficient information about the program or residential complex. For each development, ASU gathered and classified the following information.

1. NAME OF RESIDENCE

2. CITY AND STATE

3. PRIMARY RESIDENTS

- A: Only adults with ASD
- O: Other populations (can include ASD)

4. NUMBER OF RESIDENTS

5. RESIDENTIAL BUILDING TYPE

- D: Independent detached home
- A: Independent attached home (e.g. townhome)
- C: Cluster of detached homes (as planned residential development)
- AH: Attached home, 2-5 units (e.g. duplex)
- AN: Attached home, 6+ units (e.g. apartment complex, condominum), with no common/shared areas
- AC: Attached home, 6+ units (e.g. assisted-living complex), with common/shared areas
- E: Attached efficiency units or guest rooms (e.g. single-room occupancy housing)

5. DEVELOPMENT TYPE

- G: Government agency
- N: Nonprofit organization/developer
- P: Private development

6. CONSTRUCTION TYPE

- E: Existing and not rehabbed
- N: New construction
- R: Rehabbed

7. TYPES OF RESIDENTIAL AND SERVICE SUPPORT

- O: Supported and personal assistance (service staff living off-site)
- S: Supervised (staff living on-site or working office is on-site)

- I: Long-term institutional (constant) care (extensive offices/service spaces on-site; some staff may be live-in, staff there during sleeping hours)
- T: Transitional training (supervised but only temporary)

8. INNOVATION TYPE

- B: Business model (e.g. homeownership, special on-site facilities produce external revenue used to cover operational expenses of housing)
- I: Fosters functional independence (can be at the level of site, of building complex, interior/outdoor/ technological features of dwelling unit)
- Q: Quality of life enrichment (e.g. opportunity to attend community college classes)
- S: Facilitates opportunity for socializing
- X: Support services on site

9. SOURCE OF INFORMATION

The list of the 101 residential developments is available at: <u>http://stardust.asu.edu/research_resources/detail.</u> <u>php?id=60</u>

APPENDIX D: REPORTS AND REFERENCES

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This report may be viewed online at: http://www.autismcenter.org/openingdoors.aspx