

## **Preliminary Findings on Best Practices in Residential Models**

### **Introduction**

The Special Friends Foundation has commissioned the research and development of a concept paper incorporating the state of the art and best features of residential services with the intention of designing an exemplary residential model.

Several residential models have innovative features that are attractive to people with autism and their families.

There are no perfect models to meet everyone's needs and preferences. Each person is unique. The living circumstances that suits each person must be defined based upon each individual's desires. Consequently, no "one size fits all." The best elements of each housing model should be considered for each individual in the environment of person-centered-planning.

The following describes several models for community living:

### **Group Homes**

One widely known concept is that of a group home. Staff provide assistance and training to residents at all times that they are in the home. Residents share household responsibilities for chores, shopping and cooking. The number of people living together and settings vary. Most typically, there are four to six people living in a single family home. Most group homes must meet certain standards and are licensed by the state

Finding compatibility among residents is vital to the quality of life for a person living in a group home. If a person is unsettled by the activities or disruptions of other people, it may cause frustration living with others. Historically, the longevity of direct support employees working in these settings turn over quickly. This also leads to frustration among residents and the lack of continuity can influence the quality of service delivery.

Within group homes, positive behavioral supports including Applied Behavioral Analysis (ABA) therapies can be available when needed. Applied behavior analysis (ABA) is the use of techniques and principles to bring about meaningful and positive change in behavior (<https://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba>). AdvoServ, Bancroft and Eden Autism Services are examples of agencies with residential group homes offering these intensive therapeutic services.

For more information regarding Applied Behavioral Analysis (ABA), services go to:

Association for Science in Autism Treatment (<http://www.asatonline.org>)

For more information on residential services go to:

Eden Autism Services (<http://edenautism.org/>)

Bancroft (<http://www.bancroft.org/autism/adults/community-living/#.VjDaUDZdFMs>)

AdvoServ (<http://www.advoserv.com/services/residential/>)

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### **Supervised Apartments or Supported Living**

With supervised or supportive apartments, staff are available according to the needs of the resident. People with developmental disabilities live alone or with a roommate in an apartment, condominium or small house and assume more responsibility for their own activities of daily living. An on-call system is available for staff to respond quickly in the event of an emergency or unusual incident.

This model works well for the person who prefers to live alone or with one roommate, desire easy access to staff and can manage with more independence.

### **Shared Living**

Shared Living is model of residential living that is growing in popularity among those with or without disabilities. In shared living, a few unrelated people share their resources to live in one home. This model may include a person with a disability and housemates with or without disabilities. The individual chooses the people with whom they want to live. Housemates without disabilities receive remuneration in exchange for providing supportive services. Typically, the rent and household expenses are shared. Ideally, the people living together form a long-term friendship.

This type of living arrangement works for individuals with all levels of intellectual abilities. For those with intensive support needs, paid caregivers can supply additional supervision. For example, one family assisted their adult son with autism and a significant intellectual disability to locate a housemate. They interviewed several candidates until they found someone compatible. This person lives in the condominium and provides care and supervision 40 hours per week and overnight. In addition, additional staff are employed to work during the daytime hours and over weekends since this person with autism needs continuous support. They rent a three-bedroom condominium and share the costs of rent, food and utilities. The third bedroom is for paid staff working on overnights or weekends. Since the housemates are close in age, they share many interests and social activities during the time that they spend together.

Shared living is extending among people without disabilities, as well. Since housing is expensive, many people struggle to make ends meet. Some people do not want to live alone. For example, older people with large homes are seeking companionship and reducing their expenses through shared living arrangements. Similarly, for economic

reasons, young adults or college students have interest in this lifestyle and may serve as excellent housemates to a person with a disability.

Choosing people with whom to share one's home must be done carefully. Generic agencies exist to facilitate this screening and matching process. Go to (<http://nationalsharedhousing.org/>) to find resource agencies in each state. For example, HomeSharing Inc. serves parts of New Jersey and connects people (with or without disabilities) who are interested in sharing a home ([www.HomeSharing.org](http://www.HomeSharing.org)).

Various arrangements can be made regarding each person's responsibilities for sharing expenses, chores and caregiving. A published Guide for Shared Living written specifically for people with disabilities is available at (<https://www.nasdds.org/publications/nasdds-titles-for-purchase/shared-living-guide/>). It is recommended that the terms of the relationship be committed to a written agreement. A sample of such an agreement is available at (<http://www.ancor.org/resources/best-practices>). The person with special needs should sign a lease and have the legal right to reside in the home.

In many states, funding from a Medicaid Home and Community-Based Services Waiver can pay for some services for a person in shared living. Expenses for rent, utilities and food are generally paid for through one's earnings and social security benefits. Various names exist to identify this type of residence. In its State Policy Bulletin, Pennsylvania uses the following definition: "Lifesharing means living with and sharing life experiences with supportive persons who form a caring household. Lifesharing is recognizable as being both a close personal relationship and a place to live." California uses the term supported living to describe when a person with a disability lives with other housemates and shares life experiences as well as housing expenses.

This living arrangement can exemplify integration when a person with a disability shares his/her life with those who do not have a disability. In order to work well, the person with special needs must be a full participant in the household with all the rights, responsibilities and privileges that it entails.

*Home of the Sparrow matches women and their children as well as people with disabilities to shared housing in Chester County, Pennsylvania*  
(<http://homeofthesparrow.org/services>)

## **Support Families**

With some similarities to shared living, support family homes present another option to lead an inclusive lifestyle within a family unit. Many states such as Texas, New Hampshire and Vermont support families who are willing to include a person with a disability into their lives. Unlike a foster home, support families are well compensated and connected to a professional agency that supplies training, ancillary therapies and supervision.

Many parents are resistant to the notion of another family to care for their loved one. If they are struggling, they might question how another family can manage. Support

families, however, receive on-going resources including respite, professional supervision, positive behavioral supports, training and crisis intervention. Within the support family concept, the natural family remains fully invested into their child's life. They continue to be a significant advocate involved in the ongoing life of their child. The person with a need and their family should be permitted to interview and select the support family. Careful screening and oversight assures compatibility of the family to the person with a disability. Ideally, the person with a disability forms a close bond with the members of the support family and the relationship is long-standing.

Each state has different terminology and nuances to family-based settings. New Hampshire's term is Enhanced Family Care. The Mentor Network has Family Teaching Homes. Research validates that individuals with disabilities, particularly children, respond well in a family environment rather than institutional care. Texas utilizes support families as a preferred home for the children with disabilities that they serve (<http://www.everychildtexas.org>).

*Generations of Hope, a non-profit corporation based in Illinois develops housing for families who foster children with special needs. Senior citizens also live in affordable housing within the neighborhood and volunteer as foster grandparents.*

*Brenda Eheart, Founder*

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*Champaign, IL 61820*

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*<http://www.generationsofhope.org/>*

### **Receiving In-Home Supports while Living with Family**

Previously, to receive assistance a person left their family home and moved into a residential placement. A shift is underway to provide more support so that a person with a disability can continue to live within the family home. Services including respite, behavioral support, personal care assistance, training, day habilitation/ employment services and more may be available to support the person with a disability to continue to reside with his/her family. Some states permit relatives to be paid for care giving. These are accessed through the agency servicing people with disabilities, Medicaid, state plan services, the Managed Care Organization, and personal funds. To locate the governmental agency in each state that is responsible for developmental disabilities services go to <http://www.nasdds.org/state-agencies/>.

### **Intentional Communities**

Designed with a specific mission or philosophy, intentional communities support a group of people in one location. Some communities are designed to support people with disabilities. Others are developed to support people who are aging or have a special need. People living within an intentional community agree to uphold the agreed upon philosophical principles.

L'Arche Homes and Camphill Village are two well-known intentional communities serving people with disabilities in a campus style setting. People without disabilities live within this communal setting and provide supports.

*L'Arche Erie*

*3745 West 12th Street*

*Erie, PA 16505*

*814-452-2065*

*<http://www.larche.org/>*

*office@larcheerie.org*

*An article about L'Arche Community being established in Richmond, Virginia can be found at*

*<http://www.catholicvirginian.org/archive/2008/2008vol84iss4/pages/article2.html>.*

**Farmsteads** are intentional communities established on a farm or ranch to provide housing and work for people with disabilities.

*The Center for Discovery provides residences and employment for people with autism on its organic farm in Harris, New York (<http://www.thecenterfordiscovery.org/our-program/residential-services/>.)*

*Bittersweet Farm in Whitehouse, Ohio opened in 1983 for people with autism. Twenty adults live in three homes. The services utilize the principles of Applied Behavioral Analysis. Its stated mission is "to address the needs of autistic people for growth in every area of life, using the rural, extended family community as the model.*

*Bittersweet Farm*

*12660 Archbold-Whitehouse Road*

*Whitehouse, OH 43571*

*419-875-6986, ext. 1209*

<http://www.bittersweetfarms.org/>

While full inclusion into the community is the goal, the concept of intentional communities is re-emerging as a popular housing theme. Finding a peer group of friends with common interests can be challenging for someone on the autism spectrum. A community designed for a person with a disability may create an environment of feeling included and accepted. Ready access to supportive and specialized services is desirable. When establishing an intentional community, safety features, technology to support independence and the building design can be enhanced to accommodate the needs of the residents. Advocates fear, however, that living only with people who have disabilities lends toward further isolation from the larger community.

### **The Supreme Court Decision of Olmstead**

Based upon an interpretation of the Americans with Disabilities Act (ADA), the Supreme Court decided that people with disabilities have a right to receive care in the most integrated setting that is appropriate for their care. Unnecessary institutionalization is a violation of ADA. Since this decision, states have been closing large institutions and funding people in smaller community settings ([http://www.ada.gov/olmstead/olmstead\\_about.htm](http://www.ada.gov/olmstead/olmstead_about.htm)).

With concerns for compliance with ADA, the Centers for Medicaid and Medicare Services (CMS) has issued guidance on the issue of funding for community services that provide the least amount of restriction necessary to support a person with a developmental disability.

### **CMS Final Rule**

The Centers for Medicaid and Medicare Services (CMS) funding through Home and Community-Based Services Waivers (HCBS) will not pay for settings where people with developmental disabilities tend to be isolated. Consequently, HCBS Waiver funding for supportive services may not be available to people living on farmsteads and gated communities. Each state must submit a transition plan describing how they will bring all non-compliance services into compliance. An intentional community must demonstrate that they provide many opportunities for people with disabilities to socialize and integrate with people who do not have disabilities. Cohousing could provide such an opportunity.

### **Cohousing**

*Coho Ecovillage in Corvallis, Oregon is a diverse, planned and multi-generational community for singles, couples and families since 2008. Thirty-four units are reserved for households that earn under 80% of area median income. One unit is owned by a not-for-profit organization. It is fully accessible and accommodates a person with a disability.*

*Home Life, Inc. owns a 4-bedroom, accessible home within Coho Ecovillage and provides housing for three adults with developmental disabilities. One staff member lives in the fourth bedroom. The residents of the home in the cohousing community can take part in the activities, responsibilities and governance of the community(<http://homelifeinc.org/programs/#residential>).*

<https://www.cohoecovillage.org/>

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<http://ecovillageithaca.org/live/>

Similar to an intentional community for people with disabilities, **Cohousing** refers to a planned community with a shared belief system that becomes the mission of the members of the neighborhood. Members join the community making a conscious decision to live as a part of the community. Cohousing is based upon a core belief of caring for one another and the environment. People of all ages and lifestyles live together in one community linked together by shared space and activities.

Elderly, people with disabilities, young families, empty nesters and all lifestyles have needs for socialization, support and involvement with others in their communities. Although not exclusively designed to meet the need of people with disabilities, the cohousing complex becomes a small community of residents concerned about caring for self, each other and the environment. There is a balance between privacy and socialization. The residents consciously choose to live together and support one another within this setting.

In today's society, many people feel isolated and seek a sense of community. For others, the cost to live independently is prohibitive. As adults are aging and living longer, people are seeking alternatives to living alone during their twilight years. Senior citizens are seeking alternative living situations such as shared living, senior retirement communities, settings that offer progressive supports as a person ages and housing designed for accessibility and safety. Young adults and professionals continue to live with their extended families as the cost of housing is beyond their reach. Many people with limited incomes search for affordable, permanent housing. Cohousing can accommodate people who are seeking sustainable housing, accessibility, as well as the support of neighbors and friends.

Common activities and spaces are designed into the setting to promote socialization among neighbors and friends. Usually a common place becomes a meeting area to share comradery. Many meals are prepared and enjoyed together. Life events are celebrated. A community garden, common recreational spaces, meeting places,

gazebos, laundry room, community room, and fitness center are amenities included in the complex to bring people together formally and informally.

Some cohousing complexes involve co-operative ownership of one's home. However, this is not essential to the success of cohousing. A mix of rental and home ownership is also a possibility. Rules of the community are agreed upon by a consensus of its members. All members have equal status.

Intentional communities, such as Camphill Village and L'Arche homes, support a campus type of living where people with disabilities live with others who support them. Farms and ranches exist as an alternative lifestyle for people with autism desiring to live and work within a rural setting. Sunridge Ranch has two homes with four residents in each located in the college town of Ellensburg, Washington (<http://thesunridgeranch.com/>). Residents live with house parents on this 20-acre ranch and care for the animals on the ranch. The primary mission of these communities is to support people with disabilities.

Using low-income housing tax credits, Project Freedom is a non-profit corporation that has constructed several barrier-free housing complexes in New Jersey to enable people with disabilities to live independently (<http://www.projectfreedom.org/>). The concept of cohousing focuses upon a planned community integrating a broader group of people, age groups, cultures and lifestyles.

### **Cohousing Components**

- Intentional community integrated for people of all ages, cultures and lifestyles
- A common vision /mission of caring for each other and the environment
- Can be ownership or rental housing units or a combination
- Size could be large or small / condos or houses
- Common spaces are designed to enhance share socialization and community activities
- Universal design is incorporated into the construction to accommodate accessibility
- Construction is with energy efficiency and sustainable construction materials
- Shared social services are available to accommodate retirees, disabilities, families

For a guide to developing co-ops, go to <http://www.uwcc.wisc.edu/pdf/Home%20BaseBook.pdf>

### **A Potential Model for Further Consideration Incorporating Best Practices**

An intentional cohousing community could be developed for an integrated population of residents of all ages. Some residents will have disabilities. Everyone living in the community including those with disabilities will embrace a willingness to support one another. Natural supports and friendships will develop among all members. People with disabilities become naturally integrated into the complex as givers and receivers of support from their neighbors and friends.

The community would attract people who are empathetic to the needs of others. Many lifestyles could be accommodated. Families could buy a house; elderly parents caring for an adult child could live together and share supportive staffing, meals and social services. Elderly residents could bond with foster adult children or grandchildren. Young families would share friendships with their neighbors. Children would experience living among an inter-generational and multi-cultural environment.

Social services will be accessible to everyone in the community. A coordinator would assist anyone in need to locate medical and social services. Natural supports shared among community members can supplement the needs and reduce reliance upon paid staff.

The setting and location of cohousing could be anywhere. A development of 50 homes, apartment housing or a condominium could all support cohousing as long as opportunities and places to interact are incorporated into the design. Similarly, the location could be in urban, suburban or rural settings. Ideally, however, the location should have easy access to public transportation, community services and desired amenities. A neighborhood in close proximity to a college or university could be advantageous. College students and professionals affiliated with the college could be attracted to the lifestyle of cohousing.

Individuals with disabilities could design their own personal supports based upon their needs and the funding they have available. All models can be accommodated within the cohousing setting including shared living, support families, group homes, supervised apartments, supported and independent living. Each person with a disability would develop a plan. Together with a circle of support, a plan would be developed to describe the type of living circumstances that the person desires. The plan would specify with whom he wants to live, the type of housing and the amount of staff supports. A support coordinator is someone who has knowledge of the service systems and can assist in planning and securing needed supports. Service providers could be employed to provide those services, if needed.

Cohousing could be established with affordable housing funds from low-income housing tax credits or through private financing. Fifty housing units could be made available for rental. Perhaps 25% of the housing units would be rented to people with disabilities. The remaining rentals would be available to people of all ages who qualify with low and moderate incomes.

The housing design would incorporate universal design to accommodate full accessibility. Accommodations would be made for people with autism regarding noise attenuation, lighting, and safety. Technology would be included to enhance safety and independence. Sustainable and energy efficient materials would be incorporated into the design.

### **Plan of Action- Next Steps**

- Continue researching concepts

- Visit a cohousing complex and interview members
- Convene a focus group including:
  - People with autism and their families
  - Housing Developer (Project Freedom)
  - Services provider (Our House)
  - Wealthy entrepreneurs
  - Autism Specialists including Michele Wernsing, Leslie Long from Autism Speaks
  - Special Friends Foundation
  - Deborah Wehrlen, consultant
  
- Determine feasibility of developing a cohousing community that can support some people with disabilities

## Bibliography

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