

ADDRESSING THE NEEDS OF ADULTS WITH AUTISM

A LIFE AHEAD

Innovative Housing Trends: Meeting the Demand of the Other Housing Crisis

ESTIMATES OF AUTISM ARE AS HIGH AS 1 IN 50 CHILDREN.

What kind of future will we create for them?

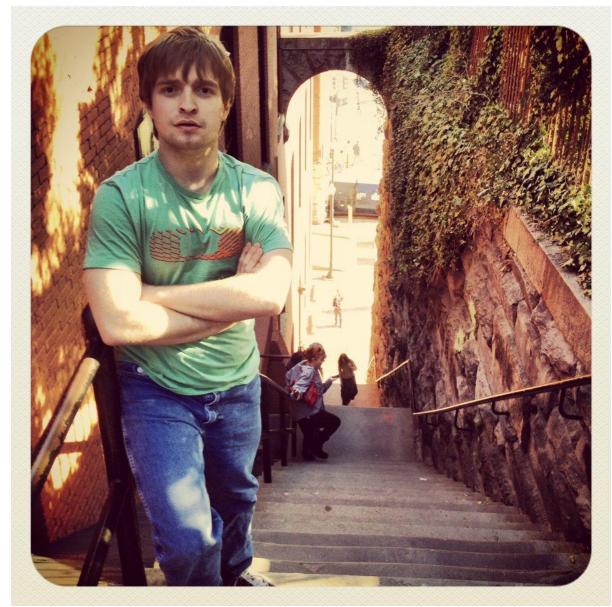








Madison.











"...ADULTS WITH ASD STRUGGLE WITH ONGOING AND MOSTLY UNMET NEEDS FOR EMPLOYMENT, HOUSING, SERVICES, AND SUPPORT."

—Interagency Autism Coordinating Committee REPORT, 2012





A Brief History of Residential Options

"The more you take responsibility for your past and present, the more you are able to create the future you seek." -Celestine Chua



Up until late 1960's



1970's

- Geraldo Rivera investigates Willowbrook and brings media attention to its dehumanizing practices
- •JFK, brother of Rosemary who had a cognitive disability, becomes President of the USA
- Introduction of ICF-MR with use in smaller homes in local settings
- Start of Deinstitutionalization

"It was like a jail scene, a prison...Even the soap stunk."

He said he'll never forget the day he got out, in November 1976. "I was so happy, I jumped for joy. I said thank God I'm coming out."



1980's

- •People with cognitive disabilities and their parents are organized and their voices begin to be 'heard'
- •Funding of services tied to the home poses some barriers to access of support, therefore...
- •The Home and Community Based Services (HCBS) waiver is introduced to provide more choices in service providers and home options.

Supported Living and Personal Assistance programs

began soon after...





1990's

- •Public funding for in community services first exceeds institutional spending (1989)
- Americans with Disabilities Act is passed
- •The Supreme Court *Olmstead* decision offers protection of persons with disability from discrimination and access to desired publically funded residential opportunities and support services.

"recognition and unjustified institutional isolation of person with disabilities is a form of discrimination reflect[ed] two evident judgments",1) "Institutional placements of people with disabilities who can live in, and benefit from, community settings perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life"; and 2) "confinement in an institution severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

-Olmstead, 119 S.Ct. 2176, 2179, 2187



2000 and beyond...

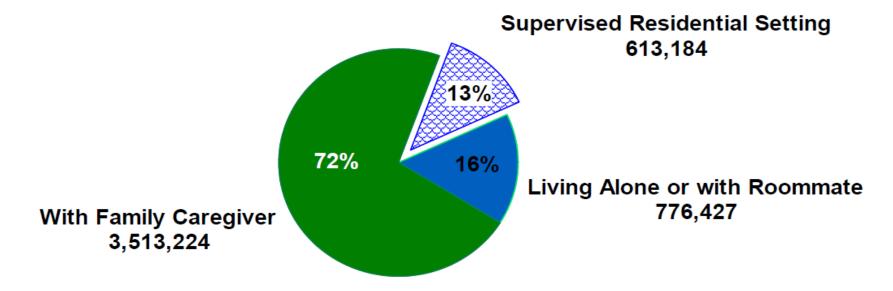


"The growing prevalence of autism in our country doesn't just mean more services for children and youth in school, but, increasingly, more services for adults in the community."

-Secretary Sebelius, US Dept. of Health and Human Services



1.) HUGE demand without nearly enough supply:



Total: 4.90 Million Persons

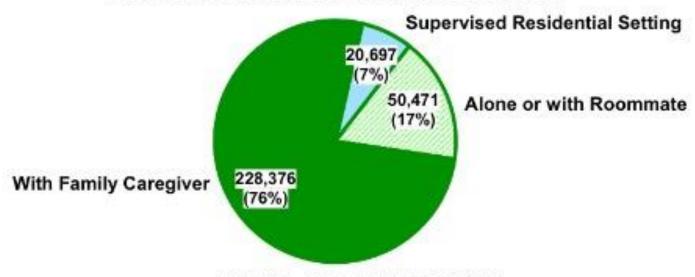
Source: Braddock et al. 2013, based on Fujiura, 2012.

Over 850,000 individuals with I/DD are living with family caregivers over the age of 60!

FYI: Between 1977 and 2010, only 219,029 additional supervised residential placements were funded.

FL Specific Statistics:

ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD BY LIVING ARRANGEMENT: FY 2011



TOTAL: 299,544 PERSONS

Braddock et al. 2013, based on Fujiura 2012

How many individuals are living with caregivers over the age of 60?

75,538!



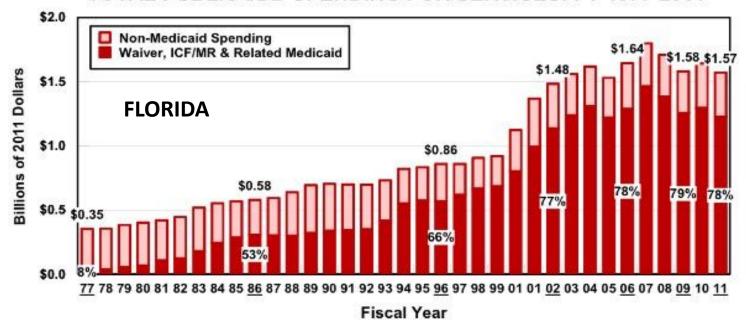
2.) Very little is being done to increase the supply.

Nationally: For the 1st time in over 33 years of data history:

•Growth in funding for I/DD services went into the negative (-0.2%, declining since 2003)

.30 states had cuts in spending in 2011

TOTAL PUBLIC I/DD SPENDING FOR SERVICES: FY 1977-2011



FLORIDA is <u>ranked #50 in the nation</u> for financial support of I/DD support services. (2011)



3.) Institutional attitudes and abuse still occur in 'community' settings.

Video:

http://www.youtube.com/v/PmQVXV4aG0U



4.) Homes geographically located in communities does not equal one's experience of relational community.

	Parents of children with		Parents of children with ASD			
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)	
Concerned with child's quality of life - Top 2 Box	38%	78%	83%	73%	67%	
% of Parents Who Agree with Statements – Top 2 Box (Very strongly agree/Strongly agree) My chi	ld will					
Have the ability to make his/her own life decisions	65%	14%	13%	12%	17%	
Have friends in the community with whom he/she shares interests	57%	17%	17%	16%	14%	
Have a spouse or life-partner	51%	9%	8%	7%	12%	
Be valued by his/her community	50%	18%	19%	14%	16%	
Regularly participate in recreational activities	50%	20%	20%	19%	15%	
Have a strong religious affiliation	36%	19%	17%	19%	21%	
Have developed age-appropriate recreation and leisure skills	-	16%	17%	13%	14%	

Visionaries. Innovators. Parents.





L'Arche: Greater DC

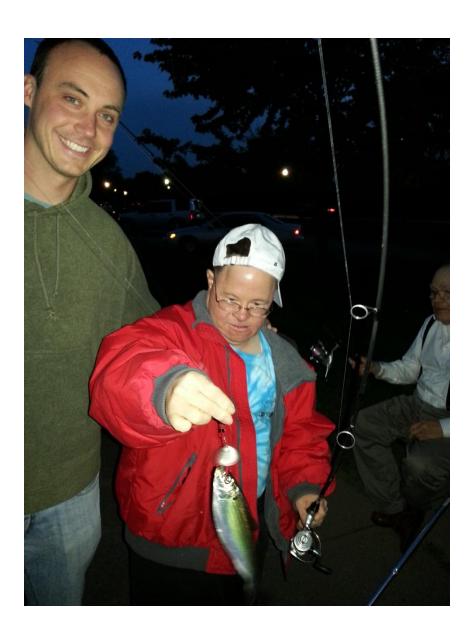


Video:

http://www.youtube.com/v/VaYyiE5G2g8

L'Arche: Greater DC





3rd time is a charm!

***No others pictures because I broke my camera before downloading \odot

Things to know about L'Arche GWDC:

This is SHARED LIVING!

Details:

- Urban single family home
- •4 Core members, 4 Assistants
- •There is no live-in staff, just neurotypical (NT) roommates aka Assistants
- •Services are provided through waivers and other public funding options
- •Low to Moderate support needs, ID only
- •This is part of an international network called L'Arche started by Jean Vanier
- •Common meals, prayer, and volunteering are voluntary
- •Many volunteers!

Characteristics:

- •Family-like
- Faith-based intentional community
- Generous and very hospitable
- Out and about around town
- Multi-generational
- Very intimate
- •Core members truly at the center in all decision making
- Everyone is "around the table"
- •Commitment to eachother is palpable, mutual, interdependence



The Brookwood Community



Video:

http://www.youtube.com/v/eOGga0TY4kk

The Brookwood Community











Things to know about Brookwood:

This is a BIG OPERATION!

Details:

- ~100 residents on-site, plus 80 off-site
- •Residences are large single family, detached homes just outside of Houston
 - 3-12 Citizens, + House Parents
 - Multiple levels of support and assisted living opportunities
- Private pay tuition, uses NO public \$
- Large endowments help sustainability
- •On-site clinic with 4 fulltime RN's and uses telemedicine and volunteer Dr.'s
- •On-site employment opportunities in multiple social enterprises
- •Lots of volunteers and customers are always at Brookwood (60,000 annually)

Characteristics:

- Hospitality is high
- •Citizens are BUSY!
- Multi-generational
- •Everyone is together regardless of support needs
- Employment focused (8:30-4pm)
- Very strong job/life skills training:
 - TFACH Method
 - •EBT (Experiential Behavioral Therapy)

"Institutional structures are 4 walls, but institutional thinking is hard to break!" –Director of Outreach



Down Home Ranch



Video:

http://www.youtube.com/v/cNynLLZAsTI





Rancher: Aaron

Semester/Quarter: Winter 2013

Job: Maintenance / Equestrian Team (Volunteer)

			Monday	Tuesday	Wednesday	Thursday	Friday
-	Block #1	9:00 - 10:30 AM	Maintenance	Equestrian Team (Volunteering) - Barn	Maintenance	Equestrian Team (Volunteering) - Barn	
1	Block #2	10:30 - 11:45 AM	Maintenance	Equestrian Team (Volunteering) - Barn	Maintenance	Equestrian Team (Volunteering) - Barn	Maintenance
		11:45 - 12:00					
		12:00 - 12:45	Lunch	Lunch	Lunch	Lunch	Lunch
		12:45 - 1:00					
	Block #3	1:00 - 2:40 PM	Computers- Computer Lab	Fashion and Design- Media Room	Money Management- Learning Center	Special Olypics/ Afternoon Activity	Nature Training
		2:40-2:50	7/1004				
	Block #4	2:50-5:00	Special Olypics Basketball	Etiquette- Rancher Room	Cardio Workouts- Lunch room Village Councel	Special Olypics/ Afternoon Activity	MOVIE



Things to know about Down Home:

This is a RANCH!

Details:

- •Residences are 6 single family, detached homes in rural TX
 - •4-6 Ranchers, + 1 Resident assistant
 - Staff live on-site
 - •1 Rancher lives alone on-site
 - •A couple Ranchers live off-site
- •ICF-IR, but wants to change that...
- •Low to Moderate support needs
- On-site Employment and classes
- •Hosts summer camps which offer parents a chance to see very empowered young adults with I/DD in leadership positions
- •Ranchers go off-site every weekend and decide at the "Village Council" what they will do and what church they will attend.

Characteristics:

- One BIG family
- Young Adult community
- •Lots of Romance!
- •Little distinction in attitude between staff and Ranchers, real friendship is apparent!
- •Purposeful employment, "I want to be a Rancher because my Father was a Rancher..." –Kyle
- Very intimate
- •Invests in development of their staff



Marbridge- Lifelong Education







Marbridge



Video:

http://www.youtube.com/v/3PSuJfrmM8k

Things to know about Marbridge:

This is a place of LIFELONG LEARNING!

Details:

- ~240 residents on-site
- •Residences are:
 - large single family, detached homes with single bdrm, 6 residents
 - •3 independent cottages
 - Senior dormitory
 - Assisted living opportunities
- Private pay tuition, uses NO public \$
- •Focuses on off-site employment opportunities, high success with Project SEARCH (some earning \$13hr!)
- Offers summer camp
- •Lots of class options which have less than 10 participants each!
- Heavily involved in Special Olympics

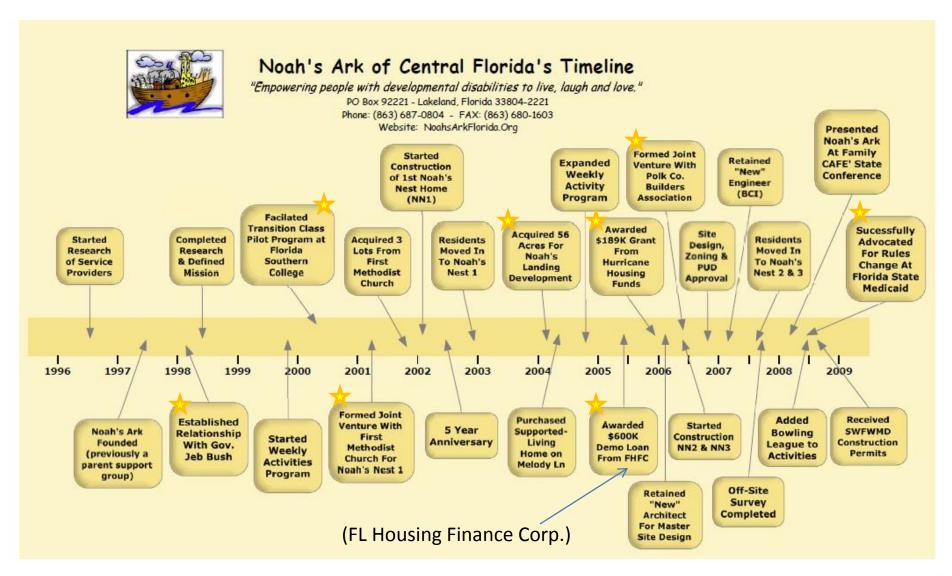
Characteristics:

- •Everyone is focused on goals towards more independence
- Very college campus-like
- •Individual Directed, lots of choice!
- Multi-generational
- •Huge variation in support needs
- •Relationships are deep as many residents have been there for over 30 years.
- •There classes everyday for so many needs and interests: life skills, job skills, horticulture, art, movement, sports, health, hospitality, etc...





Community Support...



Things to know about Noah's Ark FL:

This is an organization with strong COMMUNITY SUPPORT!

Details:

~12 residents on-site at Noah's Nest

- •Residences are:
 - single family, detached homes with 4/3 bdrm, 4 residents
 - •1 loft for Resident Assistant
- •Focuses on off-site employment
- •Only 3 residents have support services (waiver and private pay)
- Sustained by natural (unpaid) supports
- •Supported by local churches, small businesses, college students through Best Buddies

Characteristics:

- •'Home Sweet Home'
- •Clear friendship and interdependence among residents
- Lots of unplanned hanging out
- •Staff relationship is based on friendship, very informal
- •Strong support and pride from the greater community

Policy Influenced:

- •Amended the 1000ft rule for licensed group homes. Now ok in planned community (at least 8.5 acres)
- •10% density rule (only 10% could be people with disabilities) It was not clearly defined...
- •Homes with people who have I/DD continuous to one another are restricted (no legislative authority!)
- Approved zoning for PUD because they saw NN!



The Villages at Noah's Landing



General Design Items

- Family Homes
- Group Homes and Apartments
- Supported-Living Homes and Apartments
- Clubhouse with Wellness Center, Activities, Education, Optional Dining, and Pool





Noah's Ark of Central Florida, Inc.

The vision of Noah's Landing is a safe, secure, and sustainable community-for independent living and support for the developmentally challenged. Within the framework of the community partnership and families, these citizens will be enriched to lead full, satisfying lives with dignity and purpose. Noah's Landing will provide opportunities for residential, social, vocational, and recreational choices.

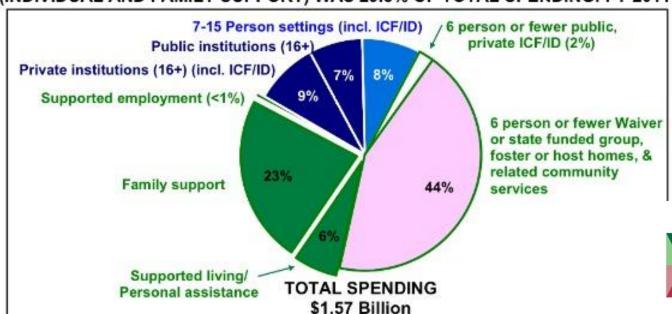
www.visualizecadd.com

www.noahsarkflorida.org

How do we respond to these things:

- 1.) HUGE demand without nearly enough supply.
- 2.) Very little is being done to increase the supply.
- 3.) Institutional attitudes and abuse still occur in 'community' settings.
- 4.) Being physically located in 'community' does not equal one's experience of relational community.

SUPPORTED LIVING, FAMILY SUPPORT, AND SUPPORTED EMPLOYMENT (INDIVIDUAL AND FAMILY SUPPORT) WAS 29.8% OF TOTAL SPENDING: FY 2011



Let's take a closer look at the need in south FL....

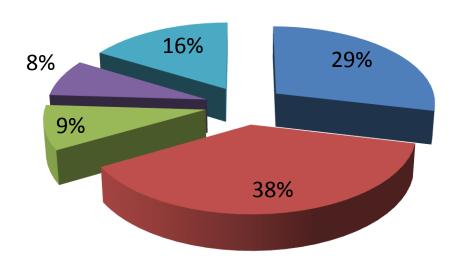


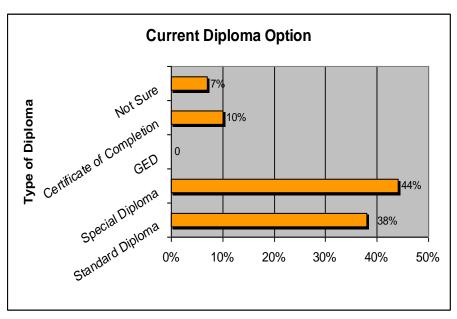
Who is the population we are trying to empower?

Diagnosis

■ Autism ■ Asperger ■ PDD-NOS

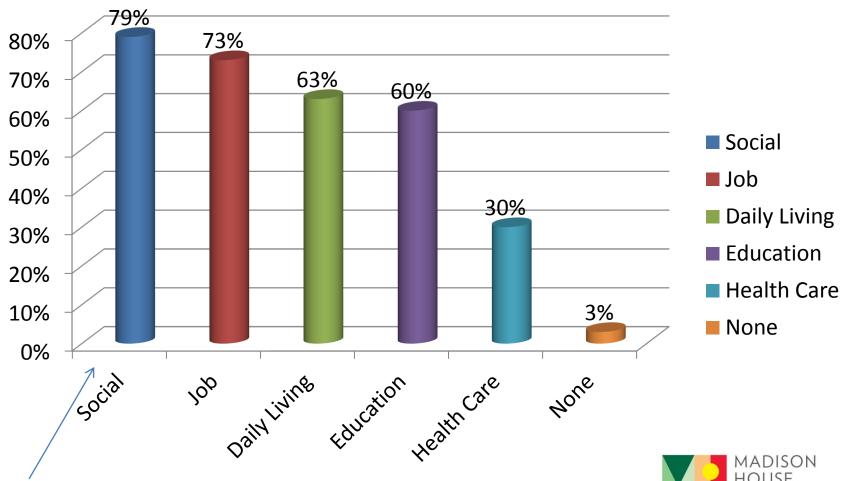
■ Autistic-like ■ Other







What specifically are their support needs?



72% were unsure or did not have any social skills training in high school...

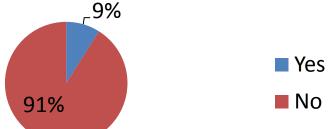


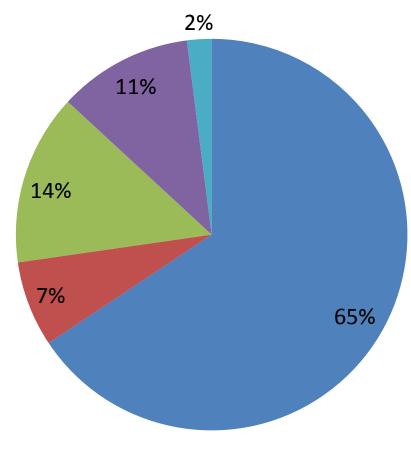
What do employment outcomes look like?

Job Satisfaction

- Not employed
- LOVE my job
- Like my Job
- Job is just OK
- Don't like my Job

Did VR help find or train for your job?

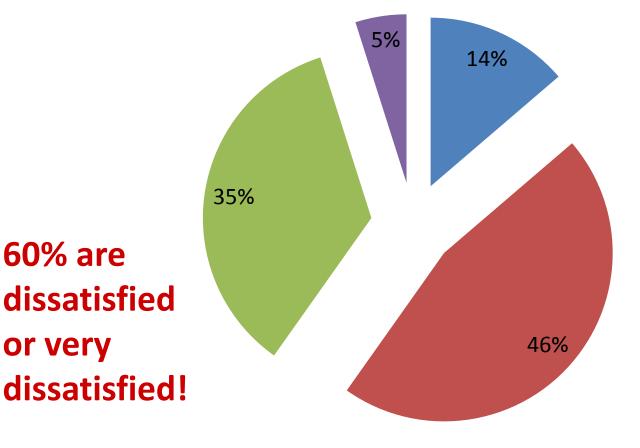






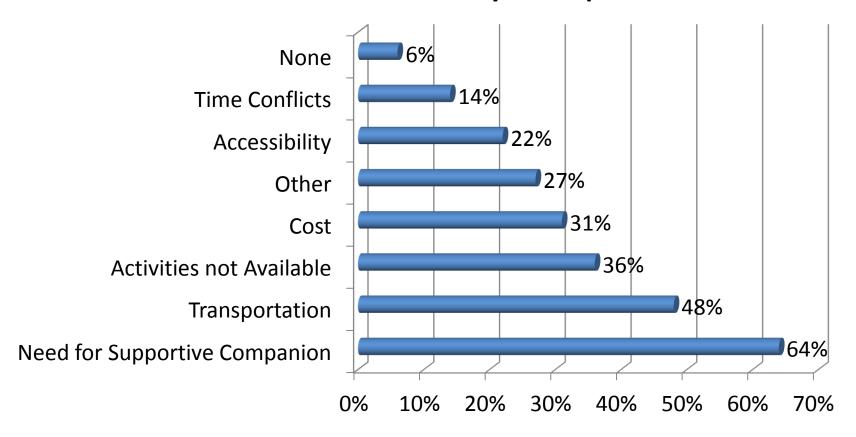
Are they satisfied with their social life?







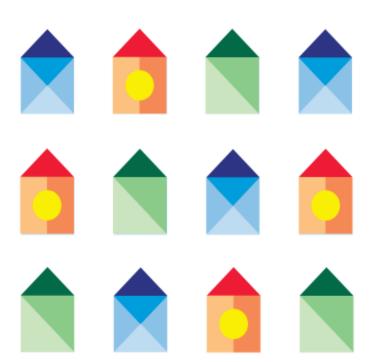
Obstacles to Community Participation



What are sustainable solutions?







Bringing together the best ideas in housing for autistic adults.



HOUSING DIRECTORY

@ RESOURCES ... GROUPS ... FORUMS ...

à LOGIN → JOIN US!

Welcome to the Autism Housing Network! To get started, create your profile →

For Parents



Finding a place to call home is difficult for everyone. It is especially difficult for those on the spectrum or who have an I/DD and need lifelong support services which fit their support needs. Here are some first helpful steps on how AHN can help you find your adult child a place to call home

For Builders



For those who have decided to or are interested in potentially creating their own innovative residential options, there are many, many ways to use this site! Here are several suggestions to get you

For Advocates



☑ BLOG

One of the main functions of this site is to be able to organize and advocate for increased choices in housing options for autistic adults and others with I/DD. Here are some suggestions of how to best use the network for advocacy:

Welcome to a work in progress!

The Autism Housing Network is an open online platform for those interested in creating and sharing better housing options and resources for autistic adults.

This is a beta site, which means we're still ironing out kinks and testing. If you run into any trouble, please let us know using the feedback tab or contact form. Any feedback helps us take AHN from beta to better



Recently Active Members



Featured Story



NEWEST | ACTIVE | POPULAR South Bay & Hawthorne, CA Parents created 1 month, 1 week ago Help and Support created 1 month, 2 weeks ago

Green Design Strategies

created 1 month, 3 weeks ago



Employment/Entrepreneurship created 1 month, 3 weeks ago

Step 1:

Create your profile to join the network!

Step 2: **Check out suggestions** for initial resources

Home Page: www.AutismHousingNetwork.com





Topics

- · Blog
- · Community Highlights
- Featured
- Innovation
- Advocacy
- · Funding/Formation
- Research
- News

Archives

- March 2013
- February 2013
- January 2013
- July 2012
- June 2012
- May 2012
- April 2012
- March 2012 • November 2011
- June 2011

Recent Blog Posts

- · Desiree Goes to Washington, DC
- . The Story of the Autism Housing Network
- · Venture Philanthropy in Housing for Autistic Adults
- · Advocate for Homes
- · Build a Home

Recent comments



Listings



Page 1 of 3 1 2 3

Marbridge

As stated on the Marbridge website: "Marbridge offers a unique Posted on February 18, 2013 full spectrum of residential care and training for adults with special needs from age 18 to the end of life. By creating a

community where people can age in place, Marbridge offers residents (and their families) the security of knowing that they can have →

by Desiree Kameka Average rating (0 votes; 0) 京京京京京

Leave a review

L'Arche Emerging Communities



Locations: Atlanta, GA Richmond, VA Short Description: The process of founding a new L'Arche community takes time.

Before L'Arche USA ever approves a local project to welcome people with disabilities into the first home, it is essential that the project has a wide network of financial and spiritual support, a well-functioning board and trained leadership, →

Posted on December 5, 2012 by Madison House Posted in NeuroDiverse / Shared Housing, South, United Average rating (0 votes; 0)

电电电电电电

Leave a review

Safe Haven Farms

Safe Haven Farms is a non-profit, tax-exempt organization offering residential, day and community services for individuals on the autism spectrum. It provides a variety of meaningful living, working, learning and leisure activities in a safe and accepting farm environment, where every individual is respected as a valued and contributing community member. Safe Haven Farms offers →

Posted on December 5, 2012 by Madison House Posted in Agricultural Community Average rating (0 votes; 0) 京京京京京 Leave a review

Friends of Autistic People

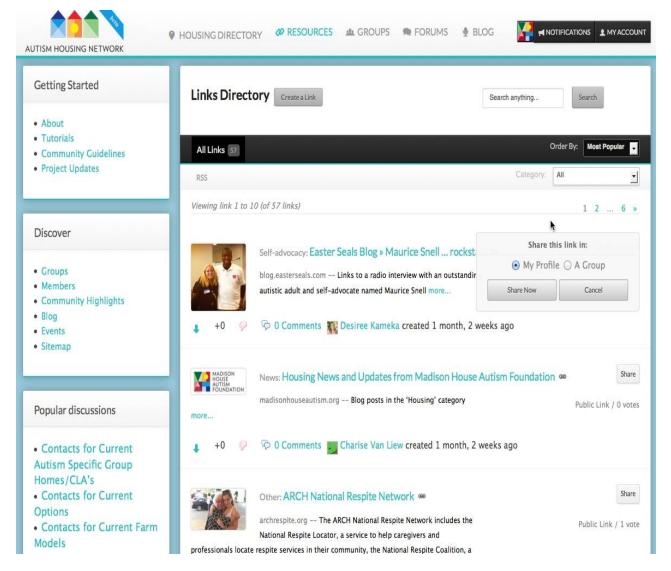
Friends of Autistic People is working to create a Farm Academy in Southwestern Connecticut that will support a community of people with Autism who wish to learn farming and live in a relaxed rural environment. When the FAP Farm Academy is in full operation, it will provide services to 20-25 resident student farmers and 20-30 →

Posted on December 5, 2012 by Madison House Posted in Agricultural Community Average rating (0 votes; 0) 常常常常常

Housing Directory:

- Search all or focus on certain lifestyles, features, location, and funding mechanisms
- Add to the directory residential options currently operating or ones that are in the planning stage!





Resource Directory:

Search for resources from transition tools, to quality of life assessments, to blueprint or site plans...

- Adult Autism Studies
- Transition Guides
- State Specific

Resources

- Factsheets
- ·How-to's
- Templates
- Videos & Site Plans
- •Etc...

And don't forget to add your favorites!!!





HOUSING DIRECTORY



LOGIN → JOIN US

Group Admins





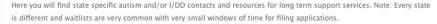
Recent Forum Topics

- Contacts for Current Autism Specific Group Homes/CLA's
- · Contacts for Current Options
- · Contacts for Current Farm Models
- Current NeuroDiverse/ Shared Housing Options:
- Future Live-Work-Play Communities
- · Contacts for Future Farm Models
- Maryland Tips/Resources
- Current Supportive Co-Housing Options

State Specific Tips/Resources

Public Group active 6 months, 4 weeks ago





Please share state specific information and tips related to housing and life long supports in the forum of this group. Start your state's group by adding a discussion in the forum and titling it by your states name.

State/Federal Contacts for Support Services

This forum contains 3 topics and 2 replies, and was last updated by Madison House 9 months, 1 week ago.

Viewing 3 topics - 1 through 3 (of 3 total)

Voices	Posts	Freshness
1	1	7 months, 3 weeks ago R Desiree Kameka
Ī	3	9 months, 1 week ago
1	1	9 months, 1 week ago
	Ī	1 1

Viewing 3 topics - 1 through 3 (of 3 total)

You must be logged in to create new topics.

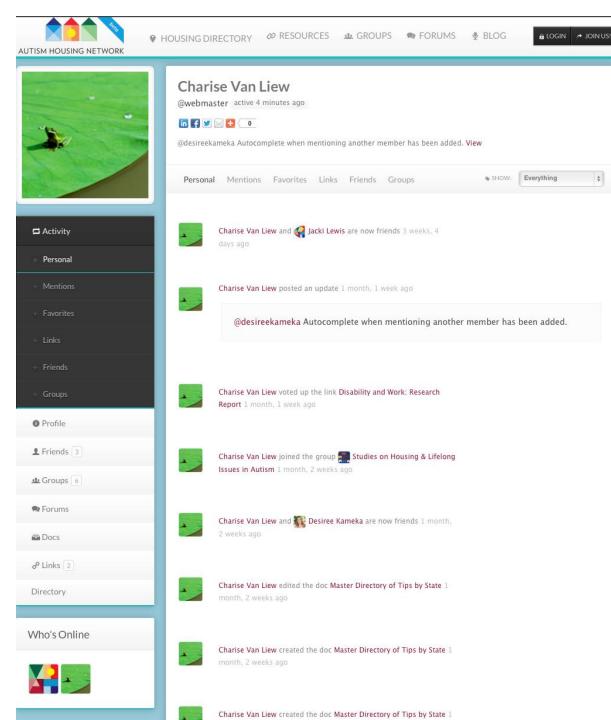
Groups:

These are working groups which anyone can join and/or form with the following tools:

- Forums
- Group Messaging
- Collaborative Docs
- Privacy Settings
- Activity feeds
- DropBox for Resources
- No more email chains or searches... everything is in one place!



We're in Beta! **Getting Started** Explore



Member Profiles:

Connecting with others is easy:

Look at their interests, connection with autism or I/DD, and contact info provided in 'Personal' info
Check out their recent activity on the network
Send a message or question directly to them
See their favorite links and groups
Tag them in comments and see tags of others



WHAT ELSE IS MADISON HOUSE DOING?

- One of the first and leading organizations focusing solely on issues of adults with autism.
- Advancing shared financial models and sustainable, replicable housing solutions in partnership with government, private sector, and non-profit organizations with direct, proven life-affirming results.
- Creating unique awareness opportunities which showcase the strengths, talents, but also support needs of autistic adults.





WHAT CAN YOU DO?



To start:

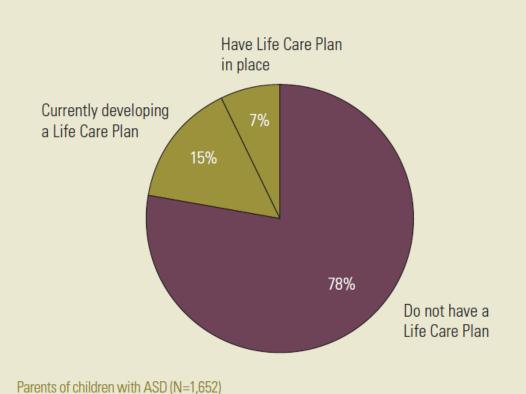
Join and share with others! www.AutismHousingNetwork.org



Create a Life Plan!



Percentage of parents who have a life plan in place for their children



Most parents of children with ASD do not have a Life Care Plan for their children. Developing a Life Care Plan requires individuals to look inward and forward – imagining the hopes and dreams they want for themselves and their family with special needs – and taking action to help make it happen.

Be an Advocate!

AGE 0-21

AGE 21-80+

CHILDHOOD (SCHOOL)

ADULTHOOD

Autism Prevalence:

Out-of-Home Placements in FL:

1 in 88

1 in 917

"RESEARCH ON LIFESPAN ISSUES RECEIVED JUST 2% OF AUTISM SPECTRUM DISORDER RESEARCH FUNDING." —FEDERAL INTERAGENCY AUTISM COORDINATING COMMITTEE, HHS, 2012



In Florida, a total of 20,697 individuals currently receive out-of-home residential support services and waitlists are long.

75,538 individuals are living with caregivers over the age of 60...



Please join
us in
addressing
the needs of
autistic
adults...

Working together, solutions are possible!



Prepared and Presented by: Desiree Kameka May 2013

Dkameka@MadisonHouseAutism.org

www.MadisonHouseAutism.org

