• **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?
500,000 will come of age in the next 6 years.

Who will care 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

Institutions.
State Schools.
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
“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:

- **With Family Caregiver**: 3,513,224
- **Supervised Residential Setting**: 613,184
- **Living Alone or with Roommate**: 776,427

**Total**: 4.90 Million Persons


**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.
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

FLORIDA is ranked #50 in the nation 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.

<table>
<thead>
<tr>
<th>Concerned with child’s quality of life – Top 2 Box</th>
<th>Parents of children with...</th>
<th>Parents of children with ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No Special Needs (N=917)</td>
<td>ASD (N=1652)</td>
</tr>
<tr>
<td></td>
<td>38%</td>
<td>78%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>% of Parents Who Agree with Statements – Top 2 Box (Very strongly agree/Strongly agree)</th>
<th>My child will...</th>
<th>Parents of children with ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have the ability to make his/her own life decisions</td>
<td>65%</td>
<td>14%</td>
</tr>
<tr>
<td>Have friends in the community with whom he/she shares interests</td>
<td>57%</td>
<td>17%</td>
</tr>
<tr>
<td>Have a spouse or life-partner</td>
<td>51%</td>
<td>9%</td>
</tr>
<tr>
<td>Be valued by his/her community</td>
<td>50%</td>
<td>18%</td>
</tr>
<tr>
<td>Regularly participate in recreational activities</td>
<td>50%</td>
<td>20%</td>
</tr>
<tr>
<td>Have a strong religious affiliation</td>
<td>36%</td>
<td>19%</td>
</tr>
<tr>
<td>Have developed age-appropriate recreation and leisure skills</td>
<td>-</td>
<td>16%</td>
</tr>
</tbody>
</table>

Autism (N=874) | PDD-NOS (N=398) | Asperger’s (N=300) |
<table>
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<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>83%</td>
<td>73%</td>
<td>67%</td>
</tr>
</tbody>
</table>
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 😞
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 each other is palpable, mutual, interdependence
The Brookwood Community

Video:
http://www.youtube.com/v/eOGga0TY4kk
Melissa Taylor

Bland Diet - No spicy foods, No Mexican food, No Chocolate, No acidic foods
No Dairy products
No Whey products
Avoid bananas & melons during fall allergy season
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:
  • TEACH 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
Hmm... WHAT SHOULD I WEAR TODAY?

Is it warm and sunny? (70 - 90 degrees)
Shorts, T-shirt, something that I will stay cool in & sunscreen.

Is it cool but not cold? (50 - 69 degrees)
Long pants, long sleeve shirt and maybe a sweater or light jacket.

If it's cold? (Less than 49 degrees)
Long pants, warm coat and a hat, earmuffs or a hood. Don't forget warm socks and shoes.
<table>
<thead>
<tr>
<th>Block #1</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00 - 10:30 AM</td>
<td>Maintenance</td>
<td>Equestrian Team (Volunteering) - Barn</td>
<td>Maintenance</td>
<td>Equestrian Team (Volunteering) - Barn</td>
<td>Maintenance</td>
</tr>
<tr>
<td>10:30 - 11:45 AM</td>
<td>Maintenance</td>
<td>Equestrian Team (Volunteering) - Barn</td>
<td>Maintenance</td>
<td>Equestrian Team (Volunteering) - Barn</td>
<td>Maintenance</td>
</tr>
<tr>
<td>11:45 - 12:00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12:00 - 12:45</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
</tr>
<tr>
<td>12:45 - 1:00</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Block #3</td>
<td>1:00 - 2:40 PM</td>
<td>Computers - Computer Lab</td>
<td>Fashion and Design - Media Room</td>
<td>Money Management - Learning Center</td>
<td>Nature Training</td>
</tr>
<tr>
<td>2:40 - 2:50</td>
<td>Special Olypicks - Basketball</td>
<td>Etiquette - Rancher Room</td>
<td>Cardio Workouts - Lunch room</td>
<td>Special Olypicks - Afternoon Activity</td>
<td>MOVIE</td>
</tr>
<tr>
<td>Block #4</td>
<td>2:50 - 5:00</td>
<td></td>
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</tr>
</tbody>
</table>
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

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...

Noah's Ark of Central Florida's Timeline
"Empowering people with developmental disabilities to live, laugh and love."

PO Box 92221 - Lakeland, Florida 33804-2221
Phone: (863) 687-0804 - FAX: (863) 680-1603
Website: NoahsArkFlorida.Org

1996
Noah's Ark Founded (previously a parent support group)

1997
Established Relationship With Gov. Jeb Bush

1998
Started Research

1999
Completed Research & Defined Mission

2000
Facilitated Transition Class Pilot Program at Florida Southern College
Acquired 3 Lots From First Methodist Church

2001
Started Construction of 1st Noah's Nest Home (NN1)

2002
Residents Moved In To Noah's Nest 1

2003
Acquired 56 Acres For Noah's Landing Development

2004
Formed Joint Venture With Polk Co. Builders Association
Awarded $189K Grant From Hurricane Housing Funds

2005
Site Design, Zoning & PUD Approval

2006
Residents Moved In To Noah's Nest 2 & 3

2007

2008
Successfully Advocated For Rules Change At Florida State Medicaid

2009
Presented Noah's Ark At Family CAFE' State Conference

Added Bowling League to Activities
Received SWFWMD Construction Permits

(FL Housing Finance Corp.)
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 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.

Let’s take a closer look at the need in south FL....
2008 UM-NSU Constituent Survey

Who is the population we are trying to empower?

Diagnosis

- Autism
- Asperger
- PDD-NOS
- Autistic-like
- Other

Current Diploma Option

- Standard Diploma: 38%
- Special Diploma: 10%
- GED: 44%
- Certificate of Completion: 7%
- Not Sure: 0%
72% were unsure or did not have any social skills training in high school...
2008 UM-NSU Constituent Survey

What do employment outcomes look like?

**Job Satisfaction**
- Not employed: 65%
- LOVE my job: 11%
- Like my Job: 14%
- Job is just OK: 7%
- Don't like my Job: 2%

Did VR help find or train for your job?
- Yes: 91%
- No: 9%
2008 UM-NSU Constituent Survey

Are they satisfied with their social life?

- Very Dissatisfied: 5%
- Dissatisfied: 14%
- Satisfied: 35%
- Very Satisfied: 46%

60% are dissatisfied or very dissatisfied!
2008 UM-NSU Constituent Survey

Obstacles to Community Participation

- None: 6%
- Time Conflicts: 14%
- Accessibility: 22%
- Other: 27%
- Cost: 31%
- Activities not Available: 36%
- Transportation: 48%
- Need for Supportive Companion: 64%

What are sustainable solutions?
AUTISM HOUSING NETWORK

Bringing together the best ideas in housing for autistic adults.
Step 1: Create your profile to join the network!

Step 2: Check out suggestions for initial resources

Home Page: www.AutismHousingNetwork.com
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!!!
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!
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

- 7% Currently developing a Life Care Plan
- 15% Have Life Care Plan in place
- 78% Do not have a Life Care Plan

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.

Parents of children with ASD (N=1,652)
Be an Advocate!

“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!