



Autism Society  
of NORTH CAROLINA



# Residential Options

Helping parents prepare for their child's transition to adulthood.

## About the toolkit

This toolkit is for parents and guardians of children and adults on the autism spectrum. It is designed to help parents as they begin to prepare for their child's transition to adulthood by exploring the emotional aspects of planning for their child's future, learning about the options available on a continuum from independent living to group living settings, and learning how to begin planning for their child's future residential options.

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## Beyond the toolkit

If this toolkit raises new questions for you and you want to talk with someone about planning for your child's future, ASNC can help. In every NC county, ASNC has Autism Resource Specialists who are experienced parents of children with autism and trained autism educators and advocates. You can find contact information for the Autism Resource Specialist in your community here: <http://bit.ly/AutismResourceSpecialists>. ASNC also offers several workshops that might be helpful on topics such as guardianship, transitioning to adulthood, and residential options; check the workshop schedule to see whether one is upcoming, <http://bit.ly/ASNCWorkshopCalendar>, or ask your Autism Resource Specialist.

If you would like to read more, please refer to the end of the toolkit for additional information sources that are recommended by the ASNC Advocacy and Bookstore staff. To keep updated on the latest books and DVDs, we invite you to connect with the ASNC Bookstore on Facebook, at <https://www.facebook.com/AutismBookstore>, or by emailing staff at [books@autismsociety-nc.org](mailto:books@autismsociety-nc.org) to tell them you would like to join the newsletter mailing list.

ASNC has about 50 local chapters and support groups across North Carolina, and they can be an excellent place to connect with other parents, gain encouragement, and learn from their experiences. Chapters are parent-run and offer support and education on a wide variety of topics, including residential options. To find one near you, please go to our website: <http://bit.ly/ASNCChapters>.

# Plan for your loved one's future

## How are you feeling?

Time moves all too fast. It can feel as if you just got the diagnosis, and then the next thing you know, your child with autism is an adult. When your child is young, time can almost seem to stand still. You are so consumed with the day-to-day aspects of getting through life: school issues, therapy appointments, doctor visits, more therapy, etc. The day to day can seem overwhelming, leaving you little time for planning. Then when your child does become an adult, it can be difficult to view him or her that way. It is even more difficult emotionally to acknowledge that you as a parent will not be around forever to help your child. The future gives us one guarantee: that it will be upon us whether or not we plan for it. This can leave us with many questions. What will happen to my child when he/she becomes an adult? Where will my child live? What will he/she do? How can I be sure my child is safe and well cared for? These questions lead to many emotions that we must deal with:

- **Fear:** Will he/she be safe without me?
- **Denial:** Can I really allow him/her to move out and live away from me?
- **Guilt:** If I let him/her live somewhere other than home, what will people think of me?
- **Inadequacy:** If only I had tried harder.
- **Protectiveness:** No one will take care of my loved one like I do.
- **Sadness:** What will I do without him/her here with me each day?

What can we do to overcome all of these feelings as parents? One of the best things we can do is to have a **plan**. Many people look to their close relatives, such as siblings, aunts, or uncles, as options for when they are no longer around. This can be a choice for some families, but not everyone has that option. Even if you have an identified person to help support your loved one when you are gone, you still need to do a great deal of planning (financial, medical directives, end-of-life planning) to make sure that person carries out your wishes for your child. You will also need to think about where you would want your child to live. How will you pay for their living situation? A special needs trust, Social Security Disability, their own income?

## Initial steps:

- What are my child's strengths and needs?
- How much care/support does my child need on a daily basis?
- Make a decision based on your answers and then make a plan to get there.

## Initial questions to consider

If you have not already done so, this is a good time to sit down and realistically think about **your child's strengths and needs**. When at all possible, try to involve your loved one in the planning. After all, it is their life, and every person deserves to be independent to the extent that is possible for him/her. What can he/she do independently?

- What is your child good at doing?
- Would your child enjoy a quiet country setting or a city life with lots to do?
- What are his/her likes and dislikes?
- If your loved one can work, how much? What type of work would your child enjoy?

If you have one, a care coordinator can also be helpful in deciding what **types of support your child needs**. Think about assessment tools such as the Support Intensity Scale (SIS) or Special Needs Assessment Profile (NC-SNAP) levels that are often used to determine level of need for individuals with disabilities. (To see the NC-SNAP, go online to <http://www.ncdhhs.gov/MHDDSAS/providers/NCSNAP/>)

- Does your child need full-time care with 24-hour supervision or can he/she live a more independent life with check-in supports?
- Does he/she have medical or behavioral needs that require more supervision?
- Can the individual live with others or does he/she need a private setting or private room?
- Does the individual need to participate in a vocational supported employment program or a structured day program setting?
- If the individual works, what type of transportation will be provided or available?

Once you have determined what would be the optimal living option, set about to **develop a plan** to get there.

- If your child is going to live independently or semi-independently with supports, what are the life skills they will need to make that a reality? Think of cooking, cleaning, taking medications correctly, paying bills, and daily hygiene.
- If your child wishes to live semi-independently, does he/she have funds available to pay for rent, utilities, food, and other essentials? If not, check with your managed-care organization (MCO) and local Department of Social Services about funding sources such as the NC Innovations Waiver, Medicaid, Social Security Disability Insurance (SSDI), or Supplemental Security Income (SSI).
- What would be the funding stream for your child if he/she is going to live in a group setting? You will need to connect with your MCO to learn more about facility options. **Wait lists can be long, so don't wait.**

Whether you want your child with Autism Spectrum Disorder (ASD) to live independently with limited supports or in a more structured supervised setting, it is never too soon to begin planning.

## Types of residential supports

### Group living

**Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/IDD):** This type of setting would be geared toward a person diagnosed with a developmental disability who has a high level of need and would need staff present 24 hours per day to assure safety and to provide habilitative care and training. They provide 24/7 staff levels that meet the needs of the individual and a multi-disciplinary team of professionals is available for consultation and support to the individual and staff. In addition to personal care and habilitative supports, an ICF must provide specialized therapies as needed and an active treatment plan at all times. ICFs must follow state and federal guidelines. They are of varying sizes, but most have six individuals living in this type of setting. With this option, the funding stream is Medicaid and the funding stays within the home, not with the individual. Individuals who have Innovations Waiver services can become eligible for services in an ICF/IDD setting but would lose their Innovations Waiver funding if they are admitted to this type of setting.

**Homes for Developmentally Disabled Adults (DDA):** This type of setting would be geared toward a person diagnosed with a developmental disability who has a low to moderate level of need and would not necessarily require awake staff at night. There is still a high staff-to-consumer ratio to help maintain safety and to provide training to learn new skills. An individual in this type of setting would need limited assistance to build skills in a variety of areas and often must be able to do most self-help activities independently or with just an occasional reminder. Again, state guidelines call for new facilities of this type to house no more than three individuals, but older facilities already in operation may house as many as six. With this setting, the funding stream stays with the individual and might include Medicaid, Innovations Waiver, SSI, and/or SA.

**Alternative Family Living (AFL):** This type of setting would be geared toward a person diagnosed with a developmental disability who has a lower to moderate level of need. The staff working in these settings actually

live in the home as their own residence and provide habilitative services as a provider under the supervision of the local MCO. AFLs are more ideal settings for individuals who would prefer not to live within a larger group home setting and would benefit from living in a more family-oriented setting. Individuals residing in an AFL setting must need a low staff-to-consumer ratio and must need limited assistance to build skills across a variety of areas. Individuals who reside in an AFL setting typically attend a local school or day program or have a job during most of the day. With this setting, the funding stream stays with the individual and might include Medicaid, Innovations Waiver, and/or SSI.

### **Unique living arrangement**

Unfortunately, many parents of children with autism are finding group living options to be limited and often quite scarce. Some parents have been choosing to “think outside the box” and create their own unique living arrangement to meet their child’s needs. How do they do this? Basically, they combine resources, purchase a home, and hire a provider to provide needed services for their children. (To read about one such arrangement, please see the appendix to this toolkit, “The Young Men of Marram Place.”) The parents can work together to get the home licensed through state and local requirement just as any provider goes through licensing requirements. The parents might hold the mortgage, becoming essentially the “landlords” for the home with their children paying rent using a combination of monies from a job and/or their funding stream such as Innovations Waiver services, SSI, or SA. The parents might work at fundraising to help with financial sustainability of the home, and they must work with an attorney specializing in special needs estate planning to help ensure that the home will be sustained for their loved ones when they are no longer around. If using waiver funds, the provider would be responsible for compliance with MCO regulations regarding service delivery, staffing, record keeping, billing, and needed training for staff. The provider would do all of the hiring of staff as well as training and payroll. Some providers are willing to help families create their own residential options. Remember all residential options must have a funding source, so if your child already has a funding stream for services such as Innovations Waiver or SSI, you may be able to get the provider to be more creative in regards to living options. For example, an adult could live in an apartment setting or house with supports paid for via Medicaid, Innovations Waiver, SSI, or SA funding.

### **Independent or semi-independent living**

Many individuals with ASD may need very little support to live completely on their own or with limited supports. This can be a little daunting for many parents to consider, especially when they begin to think ahead to the future when they may not be present to provide support. However, there are resources that could be used to enable more individuals with autism and/or other developmental disabilities to live independently or semi-independently. Some of the services include customized living systems, security equipment, environmental controls, video monitoring, and other various sensors and modes of communication. These would help in monitoring daily patterns of living and could proactively alert caregivers of changes in behavioral patterns and possible need for assistance. Some agencies also provide monitoring by trained call staff on a 24/7/365 basis to ensure that an individual living alone has support as needed. Other factors to consider are transportation, options for leisure time, and distance to natural supports such as grocery stores and banks. Funding streams for independent living options may include income from a part- or full-time job, Innovations Waiver services, SSI, Medicaid, SA, and Key Program Assistance. Many adults with long-term disabilities are eligible for support within a framework of low-income housing such as apartments specially designed for people with disabilities.

*DHHS-managed funds are subject to approval under the federal Home and Community-Based Services regulations, which ensure choice and access and encourage freedom and integration in congregate settings. (For more information, see <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/home-and-community-based-services.html>.)*

# Preparing for independent living

As your child approaches adulthood, it is important for him/her to learn independent living skills and self-advocacy. Start these lessons early and keep them going on a daily basis. Begin by observing your child. Remove yourself from the equation and consider how your child would function without you there. Think about his/her hygiene, grooming, and behavior. How would your child react in an emergency? Can he/she prepare a snack or meal for himself? Can your child choose appropriate clothing for the weather or event?

You can teach these skills to your child over time, and now is the best time to begin. Start with basic skills, such as making a meal – even a sandwich – and doing laundry. Use schedules, breaking tasks down into smaller pieces. Below is a list of skills you may want to help your child master before it is time for him/her to leave your home.

Ask yourself whether your child can...

## Grooming/dressing

- Dress/undress self
- Choose appropriate attire for occasion, weather
- Comb/style hair

## Hygiene/health

- Use private and public bathrooms
- Wash hands
- Bathe without assistance
- Manage menstrual care
- Shave
- Use deodorant
- Brush teeth
- Floss, use mouthwash
- Treat a cold or other minor illness
- Call a doctor
- Manage medication – taking it as directed and getting refills
- Manage medical appointments

## Planning/scheduling

- Tell time
- Follow daily routines
- Show up on time, in the right location
- Adapt to change in routine

- Prepare for a special outing
- Arrange special activities

## Time management

- Plan homework time
- Make time to study
- Plan time for chores
- Arrange transportation

## Social skills

- Use a telephone
- Practice proper telephone etiquette
- Take, relay a phone message
- Arrange a leisure activity
- Give gifts
- Remember birthdays
- Send thank-you cards

## Household chores

- Keep living spaces neat
- Make bed, change bed linens
- Do laundry
- Plan, purchase, and cook meals
- Operate appliances
- Arrange for trash collection and utilities
- Plunge a toilet

- Identify things that require professional to fix

## Money/shopping

- Handle money exchanges
- Make a budget
- Understand budgetary constraints
- Follow a list in a grocery store
- Ask for help in a store
- Make choices with cost comparison
- Withdraw cash from an ATM
- Write a check
- Pay bills on time

## Restaurants

- Read menu (or alternative)
- Communicate with server
- Use manners
- Tally bill with tip

## Leisure time

- Make travel arrangements
- Navigate an airport or train or bus station
- Use public transportation
- Navigate a new place when visiting

Perhaps most importantly, does your child know when and how to ask for help? Make sure he or she knows to call you when in doubt. Use the old clichés: "There's no such thing as a stupid question," and "It never hurts to ask!"

# Group living

## Get a list of facilities

Because of the various and frequent changes in service definitions and delivery for individuals with disabilities in North Carolina over the past several years, it is difficult to create a complete list of all specific facilities that might be an option.

To get the most comprehensive and up-to-date listing of options, parents should contact their local MCO. (If you are not sure how to connect with your MCO, go to this link <http://www.ncdhhs.gov/mhddsas/lmeonblue.htm> to find which MCO serves your county of residence.)

Let the MCO know you are searching for residential supports. All residential supports need a funding source such as Medicaid, Innovations Waiver, SSI, or Special Assistance (SA). If you do not have a care coordinator or community guide, ask the MCO to connect you with one for help in navigating this process.

Another source for a list of residential providers is the Division of Facility Services website at <http://www.ncdhhs.gov/dhsr/reports.htm>. You can check to see whether a licensed facility has any violations listed at the following link: <http://www.ncdhhs.gov/dhsr/acls/adultcarepenalties.html>

## Tour the facilities

If you're interested in a provider, ask to tour the facility. Many will allow you to tour even if they don't currently have an opening. It is a good idea to visit several homes/facilities while you're NOT under pressure to pick one. If you are interested, fill out an application and put it on file. Even if you're not quite ready to take that step, it's best to get applications in early, because wait lists can be very long. Remember, if an opening does occur and you are not ready, you can always decline it. It is also helpful to take along a family member or friend who can be objective. When at all possible, seek input from your child on the spectrum on what his/her desires and needs are in a residential option.

**Wait lists can be very long for group homes; do not wait to research facilities.**

**As you are choosing, here are some areas to consider:**

- How the facility is run and overseen
- Training and quality of staff
- Quality of life your child will have as far as activities, home visits, outings, etc.
- Rules and regulations of the facility
- Relationships between families and facility staff

***Visits to the homes are a key part of your research.***

*continued on next page* →



## Questions to ask

Before your visit, you may want to call the facility and find out some **background information**:

- How long has the agency been in business? Look for financial stability.
- What is the accreditation level of the group home?
- Consider the location of the home and overall supervision, as far as safety goes.
- Consider the home's distance from your residence.
- Are guardians encouraged to give input and participate in planning?
- Is there open communication between the staff and family or does all communication go through the group home manager?
- Is there an organized parent group within the agency?
- Ask a manager to tell you the group home's success stories.
- Ask the manager what the home does well and what could be improved.
- If the group home is a nonprofit with a board of directors, are there parents on the board? Are people with disabilities on the board?
- If a single room is desired, be sure to express this to the agency.

As you visit, you may want to consider these other topic areas:

### Quality of life

- Are residents' choices and preferences taken into account as far as activities, menus, schedules, staff, etc.?
- Does the provider require all the individuals to be away during the day? If so, do they provide programming for them?
- Will the individual be doing meaningful activities and will they be challenged to grow and become as independent as possible?
- Is there a set schedule or is there room to try new activities?
- What about the weekend schedule?
- If it is important to you, will roommates be close in age and have similar interests and similar "energy levels"?
- Can you bring specific items into the home to decorate the resident's room?
- Are community outings specific to individual likes or are residents grouped together for all leisure activities?
- Is the local community supportive and are residents encouraged to participate in local activities?
- How does the staff feel about drop-in visits from family and friends?
- What is the policy for home visits? Are they encouraged, and if so, do they require families to do a certain number of visits?
- How are holidays handled? Do most residents go home with family members? Is there staff available during holidays?
- How are transitions handled? Is there a process that is followed? Is it individualized and done carefully including staff from both settings?

### About the staff

- Who trains the staff, and is the training autism-specific? Are parents involved in the training?
- What is the staff-to-resident ratio? Do they have awake staff at night?
- What are the turnover rates of the staff and residents?
- How does the home handle staff mistakes?
- Does the home have a nurse to support residents with chronic medical conditions and to answer questions about medications? If so, how often do they meet with residents?



## Rules and regulations

- How is residents' money handled?
- Does the provider have health-care professionals whom they specifically use or do families need to get their own? Does the provider transport residents to their doctor's appointments?
- Can the provider follow a "special diet" if necessary?
- Is there a clients' rights committee? Who serves on it? How often do they meet? How do they handle incident reports? Ask to see the committee's manual of guidelines if there is one.
- What kind of oversight is there? Who monitors the home/agency? What is the complaint process? Ask to see it in writing.
- How does the provider handle behavioral issues with residents? What happens if residents don't get along with each other?
- What is the discharge policy? Have they ever asked a resident to leave? Under what circumstances?

## Observations during your visit

- Visit the residence three or four times, at different times of the day and on different days of the week, so you can meet more staff. The staff may have some concerns about you visiting if there are residents who are upset by visitors, but they should be flexible and understand your goal.
- Watch how the staff interacts with the residents. Do they speak to them respectfully? Do the residents seem comfortable approaching staff members or do they seem tense?
- During your visit, is the staff loose with resident information or is confidentiality well-maintained?
- Are the residents or staff active or just "hanging out"? "Hanging out" can be okay – especially when relaxing in the evening or on weekends – but if this is what you observe on every visit, then ask about the schedule.
- Is there evidence of structure or other autism supports?
- Don't be afraid to quiz the group home manager and staff. For example, if a resident has a particular medical condition, ask what they know about it. Before your loved one moves in, the staff should have at least a basic understanding of the condition so they can provide the best support possible.
- Ask staff members how long they have been with the agency or working with the home. Although turnover is inevitable, pay attention if three or four say they have been there less than six months.
- Ask to speak with a family member of one of the residents.
- Ask the staff how often they have contact with their supervisor and the QP. On average, the staff should be having contact with the group home manager almost daily and the QP at least every other week.
- In the end, trust your instincts.

**Visit the residence three or four times, at different times of the day and on different days of the week, so you can meet more staff.**

Remember that ALL parents of both neuro-typical as well as children with disabilities desire for their children to live healthy, happy, and productive lives. We tend to celebrate neuro-typical children's successes when leave the nest at 18, yet we tend to be overprotective with our children with autism or other disabilities. While this is perfectly understandable in many ways, we need to realize that individuals with ASD also have a right to their freedom, independence, and self-determination to the greatest extent that is possible. When we begin to plan for our children's futures, we have begun to give them the wings to take flight without us.

# Additional Resources:

**ASNC's Autism Resource Specialists** are available to help families learn about residential options. Find the Autism Resource Specialist in your area at <http://bit.ly/AutismResourceSpecialists>. ASNC also offers several workshops that might be helpful on topics such as guardianship, transitioning to adulthood, and residential options; check the workshop schedule to see whether one is upcoming, <http://bit.ly/ASNCWorkshopCalendar>, or ask your Autism Resource Specialist.

## Books

All of these titles are available in the ASNC Bookstore. Shop online at [www.autismbookstore.com](http://www.autismbookstore.com) to benefit ASNC.

**Special Needs Planning Guide** - *John W. Nadworny CFP and Cynthia R. Haddad*

**Preparing For Life** - *Dr. Jed Baker*

**Moving Out: A Family Guide to Residential Planning for Adults with Disabilities** - *Dafna Krouk-Gordon and Barbara D. Jackins*

**Life Skills 101: A Practical Guide** - *Tina Pestalozzi*

**Living Well on the Spectrum** - *Valerie L. Gaus*

**Living Independently on the Autism Spectrum** - *Lynne Soraya*

**Life and Love: Positive Strategies for Autistic Adults** - *Zosia Zaks*

## Websites

North Carolina Department of Health and Human Services (NCDHHS) - [www.ncdhhs.gov](http://www.ncdhhs.gov)

North Carolina Division of Medical Assistance (DMA) - <http://www.ncdhhs.gov/dma/medicaid/>

Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) - <http://www.ncdhhs.gov/mhddsas/>

Glossary of terms and acronyms - [www.ncdhhs.gov/mhddsas/glossary.htm](http://www.ncdhhs.gov/mhddsas/glossary.htm)

Consumer-directed supports page - <http://www.ncdhhs.gov/consumerdirectedsupports/index.htm>

Listing of facilities by type/category - <http://www.ncdhhs.gov/dhsr/reports.htm>

"Everything from A to Z" - <http://www.ncdhhs.gov/familiesandadults/index.htm>

North Carolina Client Assistance Program - <http://cap.state.nc.us>

Guardianship and alternatives to guardianship - [http://www.ncdhhs.gov/aging/adultsvcs/afs\\_guard.htm](http://www.ncdhhs.gov/aging/adultsvcs/afs_guard.htm)

Information on Medicaid - <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Population/People-with-Disabilities/Individuals-with-Disabilities.html>

Life Plan Trust of North Carolina - [www.lifeplantrustnc.org](http://www.lifeplantrustnc.org)

SSI/Medicaid and Medicare and Special Assistance - <http://lifeplantrustnc.org/handouts/>. You can order a free comprehensive information packet on future care and estate planning for individuals with disabilities at this link.

North Carolina Housing Finance Agency - [www.nchfa.com](http://www.nchfa.com)

Simply Home: Innovative Solutions for Independent Living - [www.simply-home.com](http://www.simply-home.com)

The Arc of NC - [www.arcnc.org/file/HousingCloserLook.pdf](http://www.arcnc.org/file/HousingCloserLook.pdf)

Autism Society of America - [www.autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/residentialhousing/](http://www.autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/residentialhousing/)

The Council on Quality and Leadership (CQL) - <http://www.thecouncil.org/resources/index.aspx?id=86>

# Glossary

**AFL** - Alternative Family Living is an out-of-home setting in which the participant receives 24-hour care and lives in a private home environment with a family (or individual). Services are provided to address the care and habilitation needs of the participant.

**DDA** - Supervised Living/Residential Setting for Developmentally Disabled Adults is a group home that provides 24-hour personal care and habilitation for adults with intellectual/developmental disabilities to help them develop self-help skills, gain work experience, and participate in community activities.

**ICF/IDD** - An Intermediate Care Facility for Individuals with Developmental Disabilities is an optional Medicaid benefit that enables states to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence. Although it is an optional benefit, all states offer it, if only as an alternative to home and community-based services waivers for individuals at the ICF/IDD level of care. (Formerly known as ICF/MR.)

**Innovations Waiver** - The NC Innovations Waiver is designed to provide an array of community-based services and supports to individuals with intellectual and/or developmental disabilities. These services provide a community-based alternative to institutional care for individuals who require an ICF-IDD level of care and meet additional eligibility criteria for this waiver. Under normal Medicaid requirements, the income and resources of a parent can be considered in determining Medicaid eligibility for a person residing in the family household. With the Innovations Waiver, those normal requirements are waived and only the income and resources of the individual with a disability are considered to deem eligibility for services.

**MCO** - Managed Care Organizations were formerly known as Local Management Entities or LMEs in North Carolina. The MCO is the “gatekeeper” or manager for the continuum of Medicaid and other managed-care services for individuals with disabilities in the state of North Carolina as administered through the NC Division of Health and Human Services.

**SA** - Special Assistance is a federal program that can provide stipends/financial assistance to individuals who are either 65 or older, blind, or disabled.

**SSI** - Supplemental Security Income is a federal program that provides stipends to low-income people who are either 65 or older, blind, or disabled.

# Appendix: The Young Men of Marram Place

*By Diana Armatage Johnston*

*Reprinted from March 2010 Exceptional Parent Magazine*

Bucky is 29 years old. Jesse is 27 years old. Paul is 23 years old. They have lived together at Marram Place<sup>1</sup>, a four-bedroom house, for over a year and have become best friends. Each works 20 hours per week in the community for his own spending money. After work, the guys walk, swim, work on computers, help with the housework, deliver a disabled neighbor's mail to her door, and paint. These artists are city guys who like living close to the center of town.

## Life is Good

Making life good for three young men who require 24/7 support with their social, communication, and daily living skills is the main goal of Marram Place. This article is the short version of how six involved parents put together an independent housing plan for their adult sons with autism and the lessons they learned that may be of use to other families.

## Finding the Right House

First, find out all the legal requirements for a supportive living home in your state and town. Then find an affordable house of the right size that has the potential to meet those rules. The parents worked long and hard to obtain local zoning, building, fire, and health department approvals. With assistance from their non-profit partner<sup>2</sup>, they obtained approvals for statewide governmental housing and community support programs – subsidies that were essential to make the project work.

Programs and property rules will differ by state, county, town, and even district. Knowing the rules before putting hard cash down on a house is important. Finding one-stop technical or legal help will be hard because the wide range of expertise required is rarely found in one law firm or non-profit organization. It may be that pioneers are the best source of advice for each other and that families who have learned to work together while developing a supportive housing plan for their children have the best chance of making that plan work in the long run.

## Putting the Package Together

In 2002, the average monthly rent in the US exceeded the maximum monthly SSI payment. This fact is not news to anyone who has ever tried to live on SSI alone. For an SSI recipient who needs assistance to live independently – as well as a place to live – the gap between income and the cost of very basic needs is huge. Bridging that gap takes energy, persistence, a lot of cooperation, and a creative combination of private, non-profit, and public funds. Here is how Marram Place manages to stay in the black:

- Each resident receives waiver program support for in-home care and employment assistance.
- Each resident's social security payment is pooled.

- Each resident receives Special Assistance, a North Carolina Medicaid program that helps pay the costs of assisted living facilities for eligible residents of an eligible facility. (In other circumstances, Section 8 or another federal or state housing subsidy program might help.)
- The parents of each resident pooled their private resources to buy Marram Place as tenants-in-common. The parents maintain the property, insure it, and pay the mortgage.

The non-profit partner and the parents negotiated an agreement for the non-profit to manage Marram Place. The non-profit rents the house, acts as representative payee for all those subsidy streams, and hires the six skilled people who provide 24/7 care.

Every second weekend the young men go to their parents' homes and the house closes from 6:00 p.m. on Friday to 6:00 p.m. Sunday.

## Lessons Learned

The parents who are making Marram Place work for their sons have learned that bricks and mortar and subsidy streams matter, but cooperation and trust matter more. Here is what they have to say to those parents trying to make independent living a reality for their adult children with autism.

**First** – look for other parents with realistic and similar goals for their children. Local autism professionals helped put the right mix of families together for Marram Place. Over time, the nuclear families are becoming one big family.

**Second** – build trust through shared financial commitment and effort. All the parents were veteran advocates for their sons and knew each other personally or by reputation through work with local autism groups. They have made the same financial contributions.

**Third** – divide the work. One parent is a skilled carpenter. Another is a skilled electrician. Another parent was the lead advocate with zoning, building, fire, and health department bureaucrats. Another is the prime contact with the non-profit partner. All worked hard and supported each other.

**Fourth** – review the new construction vs. existing building issue carefully at the outset. New green buildings are cheaper to maintain in the long run and it is hard to find an existing house that fits both the many rules and residents' needs. Houses with enough separate bedrooms to sleep three men and an overnight caregiver tend to have a lot of expensive space that is not needed. The Marram Place parents bought an existing house that complied with all the rules, only after making renovations.

**Fifth** – find a location in a safe and welcoming neighborhood that fits residents' lifestyles and provides easy access for staff, for residents' jobs, and for parents.

**Sixth** – go for the smallest group of residents whose pooled resources make the deal financially workable. Timing is also key. Autism professionals advised the parents that moving out of the family home into a group setting works better if done in their sons' twenties.

**Seventh** – finding the right non-profit to manage the home is as important as finding the right house. The Marram Place non-profit partner has hired experienced caregivers with a career commitment to the provision of in-home care. These career people have benefits, salary increases, and the full trust and active involvement of all the parents, who know the importance of staff stability.

**Eight** – review the situation regularly. Currently, the parents are taking a second look at the tenants-in-common property ownership structure of Marram Place and considering how best to handle ownership of the house in their individual estate planning documents.

**Finally** – know that it is well worth the hard work, frustration, and substantial financial commitments to see your adult children established in an independent living arrangement that they love – one that is designed to nurture them in the long run. After years of struggle, relief and pure joy are very satisfying emotions.

*This article was based on interviews with the parents who have made Marram Place a reality for their sons and was written by Diana Armatage Johnston, at the time a member of the Special Needs Alliance and a lawyer with the Van Winkle Law Firm in Hendersonville, NC.*

1. *The house is real but the name was changed to ensure privacy.*
2. *The Autism Society of North Carolina serves as the "non-profit partner" for this home.*

# About Autism

Autism Spectrum Disorder (ASD) refers to a group of developmental disabilities – including classic autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger’s Syndrome – that affect a person’s ability to understand what they see, hear, and otherwise sense. It is a brain disorder that affects communication, social interaction, and behavior.

Individuals with ASD typically have difficulty understanding verbal and nonverbal communication and learning appropriate ways of relating to other people, objects, and events. No two people with ASD are the same. As its name implies, ASD is a spectrum disorder that affects individuals differently and with varying degrees of severity. Additionally, ASD is often found in combination with other disabilities.

It is estimated that up to 1 out of every 68 children has some form of ASD. Evidence suggests that the prevalence rate in North Carolina is even higher than the national average, at 1 in 58. More than 60,000 individuals live with ASD in North Carolina.

The overall incidence of ASD is consistent around the globe, but it is five times more prevalent in boys than in girls. ASD knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of occurrence. While ASD is typically diagnosed in children, it is a lifelong disorder that affects individuals of all ages.

## What Causes ASD?

Although it was first identified in 1943, to this day no one knows exactly what causes ASD. However, research to discover its cause is ongoing. Many researchers believe that there is a strong genetic component. Some research suggests a physical problem that affects the parts of the brain that process language and information; other research points to an imbalance of brain chemicals. A variety of possible external or environmental triggers are also being studied. It is possible that ASD is caused by a combination of several factors.

## Signs and Symptoms

People with ASD may have problems with social, behavioral, and communication skills. They might repeat behaviors and might not understand change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things.

### A person with ASD might:

- have severe language deficits or differences
- talk about or show interest in a restricted range of topics
- not point at objects to show interest, such as an airplane flying over
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people’s feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- laugh, cry, or show distress for no apparent reason
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- be oversensitive or under-sensitive to pain
- lose skills they once had (for instance, stop saying words they were once using)





## Autism Society of NORTH CAROLINA

The Autism Society of North Carolina is the leading statewide resource organization serving people across the autism spectrum throughout their lifespans. We understand the challenges of the autism community because we work with individuals with Autism Spectrum Disorder (ASD) every day.

ASNC works to directly improve the lives of individuals and families affected by autism through advocacy, training and education, and direct services.

**Advocacy:** We are the only autism-specific advocacy organization in North Carolina, and it is the heart of what we do. We find resources for families, assist with school issues, educate families through workshops, help individuals navigate the services system, and host local support groups. We also give those with autism a voice in public policy by maintaining relationships at the state legislature and other policy-making entities.

**Training & Education:** We focus on evidence-based best practices that empower self-advocates, families, and professionals. We also work to increase understanding and acceptance of people with ASD in the community.

**Services:** ASNC is a direct care service provider, and a recipient of the highest level of accreditation by the Council on Quality Leadership for exemplary service provision. Individuals with ASD receive a variety of residential, recreational, vocational, and community-based services that are designed to meet their needs, interests, and strengths.

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