

# The Next Step: Residential Options for Adults With Autism



Presented by:

Kerri Erb, *Chief Program Officer*  
[kerb@autismsociety-nc.org](mailto:kerb@autismsociety-nc.org)

Kim Tizzard, *Director of Family Support*  
[ktizzard@autismsociety-nc.org](mailto:ktizzard@autismsociety-nc.org)

Special Guest: Maureen Morrell, *Parent*

## Today's Objectives:

- The “Here and Now”
- The “Looming Future”
- What is YOUR plan?
- What are the options?
- Mapping out your VISION
- Resources to help



# The future arrives all too fast!

It seems one minute you are getting the diagnosis ...



# And then suddenly...

Your “child” is taller than you!



## When your child is young

- The day-to-day can be overwhelming.
- It is difficult to imagine your child as an adult.
- It is difficult to accept that you are not going to live forever.
- The future looms darkly in the distance.



## The only guarantee is...

Whether you plan for it or not,  
the future WILL arrive!!!

So, there are LOTS of questions...

- What will happen to your child with autism?
- Where will they live?
- What will they do?
- How can they be safe?





## Dealing with the emotions:

fear denial

**GUILT**

PROTECTIVENESS



inadequacy

SADNESS

## What is your plan?

- Plan A: Live forever
- OK, let's move to Plan B
- The WORST plan is NO plan at all...





## Plan B

- Siblings? Other family members?
- Where? How? Finances? Medical directives?
- What supports are needed?
- What are the most practical, optimal possibilities?  
How do we get there?



## Some initial questions to consider

- What can your child do independently?  
What level of supervision is necessary?
- What is he/she good at doing?
- What are his/her likes and dislikes?
- What type of setting would your child enjoy most?
- If your loved one can work, how much and what type of work would he/she enjoy most?
- Does he/she have medical or behavioral needs that require special consideration and/or supervision?
- Would your child prefer to live with others or in a more private setting?
- What about TRANSPORTATION?



# Planning for the future

- Although you need a plan, it doesn't need to be "in stone." Plan tentatively as things do change over time.
- INVOLVE your loved one in the process when and where you can! Every person deserves as much **SELF-DETERMINATION** as possible!
- Help your loved one to express his/her dreams for the future.
- Once you have a loose plan, start thinking about how to achieve optimal outcomes for this plan. Make some specific, measurable, attainable short-term goals.



## Once you have a plan, WHAT'S NEXT?

- If your plan involves independent or semi-independent living with supports, what life skills are needed to make this a reality? Start early in planning. (Include goals in IEPs or ISPs whenever possible.)
- Check with your MCO or local Dept. of Social Services about possible funding sources such as the NC Innovations waiver, Medicaid, Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) \*See the “Accessing Services” toolkit on our website. [www.autismsociety-nc.org/toolkits](http://www.autismsociety-nc.org/toolkits)
- TIP: Waitlists for most services can be long, so DON'T WAIT!



# What are some of the options?

Most options for individuals with IDD/ASD include community-based options with active treatment plans unique to each resident's needs

## Continuum of Housing Options

- Supervised living (supported living and alternative family living)
- DDA (Developmentally Disabled Adults) group homes
- ICF/IDD





# Homes within communities



# Active treatment & skills instruction





## Supervised living – where to start

- NETWORK: Join committees (CFAC), connect with other parents, attend trainings on adult issues, serve as a board member for residential provider agencies.
- Ensure you understand the difference between funding the living space versus the support needed for your loved one.



## Supports for independent living

- Some state-funded services – individuals may have a few hours per week
- Parents may pay for ongoing help with transportation, cooking, leisure, and building natural supports
- Individual may have a part-time job, SSI, Medicaid, and rental assistance through the Key Program
- Apartment may be low-income housing designated for people with disabilities



# Supported Apartments

- Independent apartment units targeted specifically for individuals with disabilities
- Usually not licensed facilities and may only have drop-in staff
- May have project based subsidy, tenant pays 30% income
- Owned/operated by private agencies

*\*information taken from The Arc of NC material on Continuum of Housing Supports*

# Housing Choice Vouchers *(Tenant-Based Section 8)*

- Federal program administered by local Public Housing Authorities
- Participants choose their own housing unit from the **private rental market** and voucher pays a portion of rent.
- Apply for Section 8 at local Housing Authority offices

## How Much Can You Afford?

- 30% income for housing (rent/utilities)
- SSI income=750/month
- 30% of SSI =\$225 month
- **Rental subsidies** are designed to bridge the gap between income and rent

*\*information taken from The Arc of NC material Continuum of Housing and Supports*

# Housing Choice Vouchers

- Participants choose their own housing unit from the private rental market-**not limited to specific housing projects.**
- Landlord/owner must agree to rent under the program and meet price & health/safety guidelines set by the PHA.
- Tenant pays about 30% income for rent, Section 8 pays the rest.
- Once a tenant's lease is expired, the tenant can move their rental assistance to another unit.
- Average wait time varies county by county, but can be years.
- There is portability with your rental voucher

*\*Information taken from The Arc of NC Continuum of Housing and Supports*

# Federal/State Fair Housing Acts

- Prohibit discrimination in real estate transactions based on: race, color, sex, religion, national origin, familial status or **disability**.
- Applies to rentals & home ownership
- Reasonable Accommodations & Modifications
- Pets for “support” can be included in Accommodations/Modifications

*\*Information taken from The Arc of NC Continuum of Housing and Supports*

# Homeownership

- HUD
  - First time home buyer programs
- NC Housing Finance Agency
  - Down payment Assistance (forgiven after 15 yrs.)
  - NC Home Advantage program <sup>TM</sup>
- Habitat for Humanity – If you have a disability, you don't need to meet the work requirement for a Habitat Home.

*\*Information taken from The Arc of NC Continuum of Housing and Supports*



# Community-based supervised living

**24-hour residential services for 2+ adults.** Homes are licensed by DHSR. Primary aim of services and supports is goal-oriented for people who need supervision.

**Managed Care Organizations (MCO)** monitor provision of services funded through Innovations Waiver or other local funds.

Those receiving Innovations waiver services must contact their MCO Care Coordinator for list of providers.

Not receiving Innovations waiver services? Contact the area MCO and request information and assistance with housing options.

# Community-based supervised living\*

- Daily service for individuals who live in their own home without licensure – 2 to 3 people
- The house or apartment may not be owned or rented by the provider
- May include a live-in caregiver
- Provides staff and services based upon needs – daily rate
- Rental assistance not included, individuals can access affordable housing programs as eligible.
- Emphasis on self-determination



*\*Service available under Innovations Waiver-contact MCO*

# Alternative family living or AFL

- “Family setting” with skills instruction and support
- Part of a family in the community



## Alternative family living (cont.)

- When a non-related family opens their home to one or more individuals with disabilities
- Goals, choices, plans for increasing skills, and caregivers are trained
- AFL provider may provide all or some of services
- Receives reimbursement for services and is monitored by MCO
- Requires Innovations waiver or private pay



# Other community group home options

## Supported Living Homes or Developmentally disabled adult (DDA) group homes

- May have up to six people (“newer” models usually have less)
- Funding goes with person. Vacancies may be funded differently.
- Funding options include Innovations, SSI, Special Assistance (SA) and private pay



## DDA (cont.)

- Generally do NOT have overnight awake staff
- May have only one staff person on some shifts
- Generally geared toward individuals who can be at least semi-independent (without 24-hour supervision)



# ICF/IDD group homes

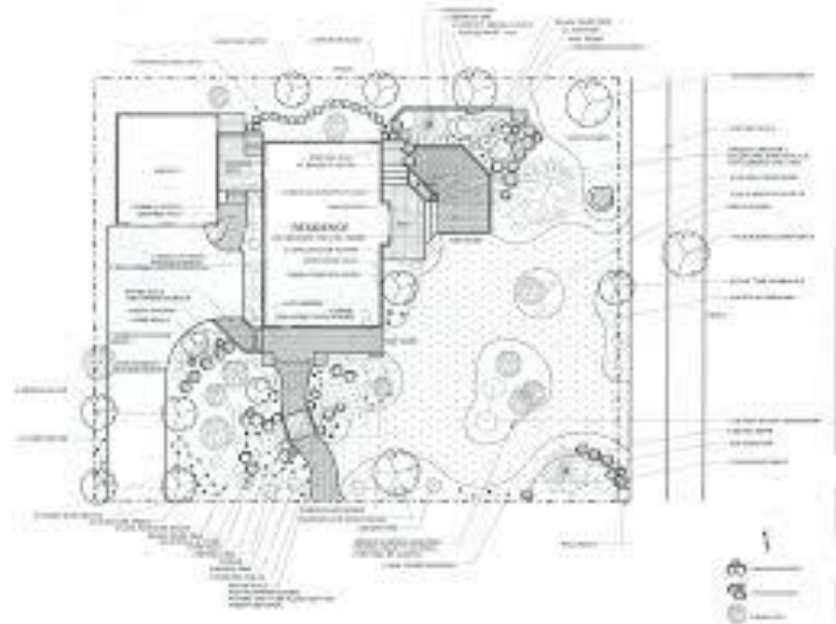
- ICF/IDD - Intermediate Care Facility for individuals with intellectual and/or developmental disabilities (highest level of supervision)
- Individuals must meet certain criteria to qualify.
- Innovations waiver recipients would qualify (lose waiver services if admitted).
- Certain number of “beds,” and funding stays with home.
- Multi-disciplinary team of consulting providers





## ICF/IDD & DDA (cont.)

- Many have waitlists; Openings can be infrequent.
- Important to go visit, ask questions (see our toolkit) and consider whether the provider and home will meet your child's needs
- Get on waitlists! You can always refuse an opening, but one may not exist when you need it!



# Group home placement

- Can be positive and open your child up to new experiences
- Can encourage greater levels of independence
- Does NOT mean you have failed as a parent
- Does NOT mean that you are no longer their parent



# Providers and homes can vary greatly

- Provider agencies vary in groups they serve and focus of services
- DDA homes generally serve people with a range of independence but not significant needs
- Level of individual goals and plans varies with each person
- Some have psychological support, dietitians, medication administration

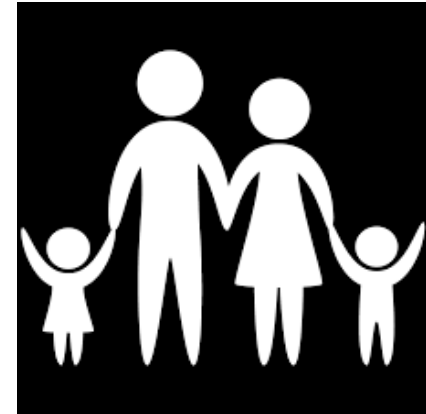


# Oversight and regulation

- Oversight, regulations, and standards are set by local and state entities
- Local – Fire Marshal, Division of Health Services
- Regional – MCOs (Managed Care Organizations)
- State – DHHS (Department of Health and Human Services) and DMA (Division of Medical Assistance) and DHSR (Division of Health Service Regulation)

## You are **STILL** their parent ....

- Residents and guardians have specific rights and participate in team meetings
- Policies and guidelines are in place to protect residents' and guardians' rights
- But your role as parent/guardian does change – not *less important*, just **different**



## Thinking outside the box .... What some parents have done

- Parents have come together to create options
- One model: Three couples with sons similar in age, interests, and level of need, made a commitment to creating an “enviable” life
- Combined their resources, purchased a house, secured a provider for services
- Worked with an attorney specializing in adult planning



*\*See article “The Young Men of Marram Place” at the back of our Residential Options toolkit*

## Some Parents Have:

- Held the mortgage, served as landlords, and maintained the home, letting their sons pay rent
- Taken their sons home to visit one weekend monthly so staffing is not required
- Worked in partnership to help with financial sustainability

*\*See article “The Young Men of Marram Place” at the back of our Residential Options toolkit.*



## In this scenario - the provider's responsibility

- All three young men have Innovations services.
- The provider is responsible for compliance with MCO regulations regarding service delivery, staffing, record-keeping, billing, training
- Hire, provide training, and payroll

*See article "The Young Men of Marram Place" at the back of our Residential Options toolkit*

# Finally ... What about independence? How scary is that?!

- What level of independence is possible?
- Live in their own apartment with support? How much support?
- Resources are growing to safely support people in own homes  
[www.simply-home.com](http://www.simply-home.com)
- Safety? Transportation?  
How much support is enough?



# Preparing for independent living

- Teach skills in a variety of life domains/scenarios: **Start Early!**
- Grooming/dressing
- Hygiene/health
- Planning/scheduling
- Time management
- Social skills
- Household chores
- Money/shopping
- Restaurants
- Leisure time
- Plan for emergencies



## Just remember...

- Whatever the level of support needed ....
- *“Kids should have their freedom when they need it.” – quote from a self-advocate*
- Everyone has the right to live their own life. Don’t let your fears be the main barrier to your child’s future. Self-determination leads to more successful outcomes for adults.
- Remember the focus should be on the INDIVIDUAL’s desires and needs, NOT just the family’s desires

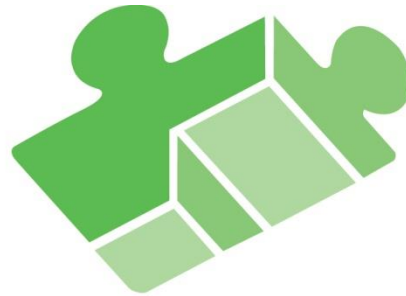


# Resources

- Residential Options toolkit [www.autismsociety-nc.org/toolkits](http://www.autismsociety-nc.org/toolkits)
- Find your local Managed Care Organization (MCO) [www.ncdhhs.gov/mhddsas/lmeonblue.htm](http://www.ncdhhs.gov/mhddsas/lmeonblue.htm)
- Division of Health Services Regulation website with list of residential providers [www.ncdhhs.gov/dhsr/reports.htm](http://www.ncdhhs.gov/dhsr/reports.htm)
- DHHS list of violations by licensed facilities in NC [www.ncdhhs.gov/dhsr/acls/adultcarepenalties.html](http://www.ncdhhs.gov/dhsr/acls/adultcarepenalties.html)
- North Carolina Housing Finance Agency [www.nchfa.com](http://www.nchfa.com)
- Autism Society of America website [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/)

## Resources (cont.)

- Financial guidance and support on future planning for needs of individuals with IDD [www.lifeplantrustnc.org](http://www.lifeplantrustnc.org)
- Arc of NC website [www.arcnc.org/file/HousingCloserLook.pdf](http://www.arcnc.org/file/HousingCloserLook.pdf)
- Financial guidance and support to plan for needs of individuals with disabilities [www.lifeplantrustnc.org](http://www.lifeplantrustnc.org)
- Simply Home agency, which provides solutions for aid in independent living [www.simply-home.com](http://www.simply-home.com)
- Guardianship Resource Guide [www.autismsociety-nc.org/wp-content/uploads/Guardianship.pdf](http://www.autismsociety-nc.org/wp-content/uploads/Guardianship.pdf)
- Developing an Individual Transition Plan [www.autismsociety-nc.org/wp-content/uploads/Developing-an-Individual-Transition-Plan-ITP-.pdf](http://www.autismsociety-nc.org/wp-content/uploads/Developing-an-Individual-Transition-Plan-ITP-.pdf)



# Autism Society *of* NORTH CAROLINA

5121 Kingdom Way, Suite 100

Raleigh, NC 27607

1-800-442-2762

[www.autismsociety-nc.org](http://www.autismsociety-nc.org)