Autism Society
of North Carolina

Successor Guardian

Caring for an aging adult with autism

Successor Guardian Toolkit

This resource is for people who have taken over as the guardian for an aging adult with intellectual or developmental disabilities (I/DD), including autism. A successor guardian is someone named in a legal document to take over if the original guardian dies or can no longer act as guardian.

Although the primary emphasis of this toolkit is on older adults, the insights provided are relevant to all caregivers dealing with care transitions in complicated circumstances.

Families and caregivers gain strength when they are well-informed and receive guidance to manage the intricate changes associated with caring for aging individuals in this demographic.

This toolkit is part of a series highlighting the roles of both current and future caregivers, as well as the care recipient. It specifically focuses on providing resources and information for those who will take over caregiving responsibilities.

If you require help or have questions about any related tasks shared in this toolkit, please reach out to one of resources listed in the Support Agencies section found on page 24.

Empowering Connections

This initiative was developed by the Autism Society of North Carolina in partnership with several organizations, including NC PAL, the Whole Child Health Section of the NC Department of Health and Human Services, VAYA Health, AKALAKA, Alberta Corp, UNC, and committed family collaborators.

Introduction

This toolkit includes essential information to assist guardians in planning care for aging autistic adults.

Please review the table of contents on page 3 to help guide you in reaching your objectives. Ensure that your attention remains on person-centered planning and the principle of “nothing about me without me.”

The toolkit and the information it provides is not mandatory nor does it constitute a legally binding agreement.

Table of Contents

This toolkit is broken into different sections; you can read all of it or just choose sections that most interest you.

Part I: Quick Start

Section 1: Where to Start

The first step is obtaining the information you will need to ensure ongoing support for your care recipient. Gaining access to the email account of the former guardian/caregiver and any essential documents they managed for the individual will provide you with vital information. While having access to this information is extremely helpful, it is not a requirement. This section provides guidance on the **top five pieces** of information you need to gather and where to seek assistance.

1. Guardianship status

a. Is the person you are now supporting their own guardian or did/does someone else have guardianship of them? Can you locate the paperwork?

Legally, upon reaching the age of 18, individuals and families, Legally Responsible Persons (LRPS), are required to identify the necessary supports for engaging in supported decision-making. Supported decision-making (SDM) serves as an alternative to guardianship, allowing individuals to maintain their autonomy in decision-making while receiving assistance from trusted friends and family members of their choice. (Download our Guardianship Toolkit for more detailed information.)

2. Insurance status

a. Who is the individual's current health insurance provider?
b. Is the individual connected to a Managed Care Organization (MCO)? (See below: "Why it is important to connect to the MCO" and "How to connect to your Managed Care Organization") For more information, refer to the NCDHHS Medicaid Fact Sheet on LME/MCOs.
c. Do they have Medicaid? If so, what type of Medicaid?
d. Do they have Medicare?
e. Do you have a copy of the insurance cards?

3. Financial status

a. Are they currently benefiting from Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), or any other forms of income?
b. What existing financial resources do they have, such as a trust or ABLE account, if any?
c. Do you have contact information for extra services like food assistance or prescription medications?
These are the kinds of things to be looking for and thinking about as you gather resources and information for your care recipient.

4. What are the current need(s)?

a. What does their day look like and from where are they getting their current resources and services?

Information about supplies, schedules, routines, employment, outings, housing, food, transportation, social connections and leisure activities, therapies, hobbies, preferences, etc. will be helpful in clarifying needs and how you can support them.

5. Medical status

a. Medical documentation: Do they have an electronic medical chart? Are you able to access it?
b. Early diagnostics: You will need early diagnostic information to show the onset of autism and the Intellectual/Developmental Disability (I/DD) diagnosis up to the age of 21 to qualify for many of the state and federal funded services available for your loved one.

Why it is important to connect to the MCO

In North Carolina, Managed Care Organizations (MCOs) are responsible for managing the care of Medicaid recipients who receive services for mental health, developmental disabilities, or substance use disorders. MCOs are also known as Local Management Entities (LME). Each county in North Carolina has one MCO assigned to manage these services. MCOs are quasi-governmental entities that contract with the North Carolina Department of Health and Human Services (NCDHHS) to manage the public system of services at the community level. They are publicly funded and subject to both state law and federal managed care regulations. MCOs provide comprehensive acute care and, in some cases, long-term services and supports to Medicaid beneficiaries. They are paid a set per member per month payment for these services.

Tailored Care Management | NC Medicaid (ncdhhs.gov)

North Carolina LME/MCO/TPs

Alliance Health | 800-510-9132
Counties: Cumberland, Durham, Johnston, Harnett, Mecklenburg, Orange, Wake

Partners Health Management | 877-864-1454
Counties: Burke, Cabarrus, Catawba, Cleveland, Davie, Davidson, Forsyth, Gaston, Iredell, Lincoln, Rutherford, Stanly, Surry, Union, Yadkin

Trillium Health Resources | 877-685-2415
Counties: Anson, Beaufort, Bertie, Bladen, Brunswick, Camden, Carteret, Chowan, Columbus, Craven, Currituck, Dare, Duplin, Edgecombe, Gates, Greene, Guilford, Halifax, Hertford, Hoke, Hyde, Jones, Lee, Lenoir, Martin, Montgomery, Moore, Nash, New Hanover, Northampton, Onslow, Pamlico, Pasquotank, Pender, Perquimans, Pitt, Randolph, Richmond, Robeson, Sampson, Scotland, Tyrrell, Warren, Washington, Wayne, Wilson

Vaya Health | 800-849-6127
Counties: Alamance, Alexander, Alleghany, Ashe, Avery, Buncombe, Caldwell, Caswell, Chatham, Cherokee, Clay, Franklin, Graham, Granville, Haywood, Henderson, Jackson, Macon, Madison, McDowell, Mitchell, Person, Polk, Rockingham, Rowan, Stokes, Swain, Transylvania, Vance, Watauga, Wilkes, Yancey

If you are having a behavioral health crisis and need immediate care, you can call your MCO's Crisis line:

- Alliance Health (Alliance): 877-223-4617
- Partners Health Management (Partners): 833-353-2093
- Trillium Health Resources (Trillium): 888-302-0738
- Vaya Health (Vaya): 800-849-6127

Section 2: Know Your Person

Understanding relevant information and preferences of the individual you are supporting is crucial. Please utilize this Know Your Person form and use it as a living document to update as needed.

Section 3: Know Your Team

By knowing your team and maintaining organized, clear communication, caregivers can provide more effective and coordinated care for the person they support. This Know Your Team form is a great way to list your person's circle of support.

Part II: Pathway to Support

Section 1: Social Services

What is social service? How and why a social service may be able to help.

Social services are programs and facilities that help people who are vulnerable, distressed, or disadvantaged. They are person-centered and designed to meet people's basic needs. provided by government and nongovernment/private agencies and organizations to improve the social welfare of those in need, including people with lower income, illness or disability, older adults, and children, and can include:

- **Education**: Public education
- **Welfare**: Food banks, universal health care, and public housing Infrastructure: Mail, libraries, police, and fire services
- **Social work:** Counseling, case management, and linking clients with resources other services: Childcare assistance, adoption services, and home visiting programs

Social services can refer to a broad range of social programs, including Social Security. Social Security is a federal program that is part of the Old-Age, Survivors, and Disability Insurance (OASDI) program. Social services can also include other programs, such as health, education, housing, and community development.

Adult Protective Services

With Adult Protective Services (APS), social workers provide protective services to disabled adults, 18 years of age or older, who are alleged to be abused, neglected, or exploited and in need of protection. APS social workers evaluate the reports and assess the disabled adult's capacity to consent for services. Click on this link for an APS Fact Sheet.

Section 2: Guardianship Essentials

You will want to learn all you can about the responsibilities of guardianship and if there are alternatives to guardianship that may best serve your care recipient. The Autism Society of North Carolina Guardianship Toolkit provides detailed information about guardianship and will help you understand:

- What is guardianship?
- What am I responsible for as the successor guardian based on the type of guardianship currently in place?
- What steps do I need to take as the successor guardian?

When you are named successor guardian, you will need to start the process for guardianship. The following resources can be helpful:

Managed Care Organization (MCO): Care Managers
Autism Society of North Carolina: Autism Resource Specialists
Family Support Network: Family Navigators
NC Department of Social Services
Adult Protective Services: Social Workers

Use the following links to access more detailed information about guardianship and alternatives:

ASNC/Guardianship and Alternatives Toolkit
Responsibilities of Guardians in NC or see Form AOC-SP-850
Rethinking Guardianship/ Supporting Choice and Self-Determination in North Carolina: A Guide
Rethinking Guardianship: Exploring Less Restrictive Alternatives
Flipping the Script: Guardianship 101/ARC of NC
NC Courts/Understanding Guardianship Video: Training Video

Did you know?

The Support Agencies listed on *page 24* are there to assist you in navigating resources throughout this toolkit.

Part III: Financial Guidance

Section 1: Financial Considerations

It is important to understand what your care recipient needs, how those needs are being met, and how they are being paid for. This section explore options and financial resources that may be available to help cover costs and maintain financially stability.

Housing, food, healthcare, support services, transportation, clothing, leisure activities, discretionary funds—these are all potential needs.

Some financial planning resources include:

The Arc: Future Planning Guide Financial Section is an excellent guide for taking stock of financial resources

ASNC Accessing Services Toolkit – discusses Medicaid and Social Security

ASNC Webinar: Navigating Services for Individuals with Autism – provides an overview of most common services and how they are accessed financially

A Special Needs Plan | Video Resource Library FAQ | Article Library

Section 2: Financial Resources and Funding Services

Various financial resources/funding streams are available to help pay for the needs of individuals with autism. Not everyone with autism will have access to every one of these resources or even have a need for all of them. The following information will help you understand the different financial resources that may be available

Medicaid

Medicaid is the North Carolina Department of Health and Human Services (NCDHHS) healthcare option for people with disabilities, as well as for those with low income and over age 65. Medicaid covers health, mental health, and developmental disability services for those who are eligible. The links below answer common questions about Medicaid and offer resources to help you find support.

Does your care recipient already have Medicaid?
Contact your local Division of Social Services (DSS) office.

How do you apply for Medicaid?
Visit the NC Department of Health and Human Services (NCDHHS) website for information and application.

What is NC Medicaid Direct and dual eligibility with Medicare?
See the NC Medicaid Direct services | NC Medicaid Managed Care (ncmedicaidplans.gov) for more information

Social Security Benefits

The Social Security Administration (SSA) provides different ways to get financial benefits. You must meet criteria to qualify. Social Security checks can be used to pay for rent, food, personal needs, etc. The two main ways to get Social Security benefits are through Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Each program has its own rules about who qualifies.

Supplemental Security Income (SSI) is a needs-based program providing a monthly stipend. It is not based on having a work history. Eligibility for SSI depends on both strict income and asset criteria.

In North Carolina, Medicaid usually comes with Social Security Disability Insurance (SSDI): an earned benefit based on work history and Social Security taxes paid. An individual with a disability may qualify for SSDI based on their own work history and other eligibility criteria, or an adult individual, with a disability that began before age 22 (Disabled Adult Child), may qualify for SSDI based on the parent's work history. The disabled adult child (DAC) may be considered for SSDI benefits even if he or she has never worked or earned enough work credits in the required time frame, to receive benefits under their own work history. SSA often refers to this type of payment as "child's" benefits. These benefit payments are made to the disabled adult child based on the parent's earning record with SSA. Note: A SSDI recipient is automatically enrolled in Medicare after 24 months.

Representative Payee

For a beneficiary of either SSI or SSDI who cannot manage their own money, a Representative Payee should be designated to oversee monthly payments. This **applies only to Social Security payment**, not other funds or resources. Being the legal/ successor guardian **does not** automatically designate someone as Representative Payee. Some Representative Payees are required to report expenses annually (www.ssa.gov/payee/form/ledger.pdf) while other Representative Payees are exempt from reporting expenses annually but must keep records of spending and savings (www.ssa.gov/payee/index.htm).

Medicare

Medicare typically is provided in coordination with some Social Security benefits. An individual may be eligible for Medicare if:

- they are receiving SSDI benefits from the individual's own work history,
- their parent is collecting SSDI due to a disability,
- their parent is retired and is collecting Social Security Retirement benefits,
- their parent is deceased and meets Social Security eligibility,
- the individual is at retirement age themselves.

Medicare Tip

Medicare becomes the primary insurance and complicates the use of Medicaid (because some providers may not accept Medicare). However, Medicare should not be refused before talking with a benefit counselor.

More Medicare information:

- Medicare.gov: What Medicare covers
- US Department of Health and Human Services: When Should I sign up for Medicare-

Achieving a Better Life Experience (ABLE) Account

An ABLE account helps people with disabilities save, invest, and spend money without losing Medicaid, Social Security benefits, or other public support. Unlike a regular bank account, money in an ABLE account does not count against financial limits that can affect eligibility for those programs.

Check the NC ABLE website for allowable annual contribution amount (as of June 2025 the amount was $19,000). You may have up to $100,000 in an ABLE account and it won't affect the SSI recipient's eligibility benefits. Any amount in the ABLE account over $100,000 would be counted by SSA as a resource. SSI benefits would then be suspended—not terminated—until the amount is under the allowable limit.

Exception for ABLE Account: If the SSI beneficiary has an ABLE account, and even others contribute to the ABLE account, distributions (payments) can be made from the ABLE account for food and housing-related expenses and there will not be a reduction in the beneficiary's SSI benefit check.

Find out more by visiting the NC ABLE website and reviewing the NC ABLE benefits webpage.

Special/Supplemental Needs Trusts (SNT)

This kind of trust helps people with disabilities stay eligible for public benefits while still getting extra financial support.

- The trust must be created with the assistance of an attorney who specializes in estate planning, trusts, and wills.
- There is no limit to how much can be deposited annually or in the life of the trust.
- For more detailed information click on this link: Special Needs Alliance Handbook on SNT for Trustees.

Bank Accounts

Your care recipient might already have different types of bank accounts, or you might want to set some up for them. These accounts can have money from person income, gifts, or benefits payments. It's important to keep an eye on the amount in the accounts to make sure they don't affect eligibility for benefits. (see Medicaid and Social Security sections above).

Joint Accounts: a bank account where multiple individuals have equal access to the funds.

Custodial Accounts: a savings account created for a child to save for them until they become an adult, (age 21 in North Carolina).

Representative Payee: bank account specifically for Social Security pay outs, managed by the individual who is the Representative Payee (see above).

Did you know?

The Support Agencies listed on *page 24* are there to assist you in navigating resources throughout this toolkit.

Government Benefits

Supplemental Nutrition Assistance Program (SNAP/EBT): This program helps people with low income get extra money to buy food. Funds are provided on an EBT (Electronic Benefits Transfer) card.

Section 8 Housing Choice Voucher Program: This program helps families with low-income, older adults and people with disabilities pay for safe and decent housing in the private market. It is funded by the federal government and is administered by the local Public Housing Authority. Generally, there is a waitlist of several years before receiving a voucher.

TANF: Temporary Assistance for Needy Families: This program gives money and support services to low-income families that have children. Use the link above for information on how grandparents and relative caregivers can access support through TANF.

Section 3: Who Covers What

What does each funding source pay for?

Medicaid

Medical Care

- Therapies: A range of therapies like psychotherapy, home health services, crisis intervention services, etc. More information about available therapies here.

- Innovations Waiver: The Innovations Waiver is Medicaid-funded Comprehensive Home and Community Based Service (HCBS). Contact your Local Management Entity/Managed Care Organization (LME/MCO) to apply or find your family member's status. To find your LME/MCO use this link.
When you apply, you are put on the Innovations Waitlist, formerly known as the Registry of Unmet Needs (RUN). For more about Innovations Waiver eligibility, click here. More about the Innovations Waiver pathway can be found here.

- 1915i Services: 1915i services are Medicaid-funded Limited Home and Community Based Services for those with Intellectual/Developmental Disabilities (I/DD). Use this link for a blog about 1915i services, eligibility, and how to apply.

Medicare

- Doctor's services
- Hospital in-patient services
- Medical Link

Social Security Benefits

- Room and Board
- ICF-IDD Group Home rent
- Social Security Benefits Link

ABLE Account

- Room and Board
- Qualified Disability Expenses (durable goods and services)
- Transportation
- ABLE Link

Supplemental Needs Trusts (SNT)

- Therapies
- Qualified Disability Expenses (durable goods and services)
- Discretionary expenses (presents for self or others, vacations)
- Room and Board (counts against SSI)

Bank Accounts (over $2,000 counts against SSI for individual)

- Room and Board (counts against SSI)
- Discretionary expenses

SNAP/EBT: Simplified Nutritional Assistance Program

SNAP provides food assistance to eligible low-income individuals/families. Other food assistance programs include:

- NC Food and Nutrition Resource Programs

- Food banks and free food pantries may offer food as well as other items depending on the specific food program. Additional items may include products for personal hygiene, cleaning, laundry, paper, etc. Some may also distribute Thanksgiving or Christmas meals.

Section 4: Additional Needs

There may be unique needs or situations that arise that require additional financial support and services. The following are some resources to assist you to ensure you and your care recipient are accessing all the available resources.

- Contact your Care Manager/Tailored Care Manager (for those with Medicaid)
- NC211 is an information and referral service of the United Way of North Carolina
- First in Families of NC offers one-time grants for specific needs in a crisis
- Free Disability Financial Planning Resources | The Arc
- The Arc's Center for Future Planning

You can also reference the "Financial Considerations" section on page 8 of this toolkit.

Crisis Financial Aid Resources

- Emergency Assistance (EA)
- Heating and cooling programs
- Work First Benefit Diversion Program: This program is "intended to be a one-time service for families and can only be provided once within a 12-month period" based on eligibility and specific crisis needs. "A caseworker must provide referrals to available agencies and community resources that will help the family avoid the need for further cash assistance in the future… Families receiving Benefit Diversion are not precluded from receiving other services such as emergency or energy assistance or one-time work-related expenses."

Part IV: Housing Choices and Residental Living

Section 1: Housing Options for Aging Adults with I/DD and Autism

One size does not fit all. There are guidelines (NCDHHS and Medicaid) that determine eligibility for those who require 24/7 oversight. The following are some resources to help you explore what is best for your care recipient.

- Residential Options Toolkit
- NCDHHS Inclusion community living guide
- Appropriate services for I/DD ASD eldercare

Did you know?

The Support Agencies listed on *page 24* are there to assist you in navigating resources throughout this toolkit.

Section 2: Funding Housing

There are a variety of ways to get help funding housing for your care recipient. Alternatives such as self–funding Supplemental Needs Trusts, Section 8 housing, roommate sharing, etc., are discussed in the Residential Options Toolkit. Here are additional resources to help you understand how to make these options work:

Arc of North Carolina: Maintains a statewide list of housing vacancies for housing with which they are affiliated.

NC211: For Section 8 housing options with link to statewide Public Housing Authority offices that manage Section 8 applications locally.

Using Supplemental Needs Trusts to pay rent: Supplemental Needs Trusts (SNT's) can be used to pay rent but they will cause a deduction from the SSI payment, up to $334/month (as of 2025). This is important to consider before using the SNT to pay rent.

Disability Rights NC: Information about housing resources.

The SSI/SSDI, Outreach, Access and Recovery (SOAR) Program: Helps disabled people who are homeless or at risk of homelessness apply for disability benefits.

Special Needs Planning Agencies (statewide)

- A Special Needs Plan
- Mass Mutual Special Care

Special Needs Alliance

- How to leave a house or land to adult child

Housing Options and Funding Sources

Housing Option	Description	Funding Source(s)
ICF-IDD*	Needing active 24/7 care for "activities of daily living" or ADLs.	SSI, Medicaid special assistance, private pay. *Services funded by Medicaid*
DDA* Group Home	Independent with self-care but needing limited supervision.	SSI, Medicaid special assistance, private pay or SNT. *Services funded by the Innovations Waiver*
Supported Living*	Individual lives in their own home/apartment, and some services provide support.	SSI, Section 8, SNT, or private pay may pay the rent. *Services funded by the Innovations Waiver*
Independent Community Housing	Independent Community Housing	Section 8 voucher, private pay.
Continue to live with family members	Individual remains in the family home with parents and/or siblings. Can be an option for all levels of care.	Family can charge rent. This will allow the family member to collect a larger share of the Social Security benefit. *Any needed services can be funded by the Innovations Waiver.*
Alternative Family Living	Individual lives with a family other than their own. The family is certified to provide both room and board plus support services.	SSI, Medicaid special assistance and private pay or SNT. *Services funded by the Innovations Waiver.*

**Supported Living Packet: If the individual you are supporting is on the North Carolina Innovations Waiver, they are eligible for the Supported Living service. This enables people with significant disabilities the opportunity to live in their own homes.*

Part V: Employment

SECTION 1: Types of Employment Services and Access Points

EIPD or Department of Employment and Independence for Persons with Disabilities

EIPD (formerly known as Vocational Rehabilitation or VR) can help individuals find and keep a job. It offers a lower level of support and doesn't fund 1:1 care. It starts by helping people with disabilities find a job, then focuses on training. Over time, the support decreases to two check-ins per month. Contact your local office to get more information: www.ncdhhs.gov/divisions/eipd/local-office-listing

1:1 Support Services Available

1915i Services: Individual must have Medicaid to receive 1915i supports. This service can offer moderate support to full one-on-one support. It can also help someone keep or find a job, especially if they can't get EIPD/VR services. Contact your MCO to get more information about this service.

Innovations Waiver Services: Individual must have Medicaid and have been approved for a Waiver Slot to obtain the service.

Highest Level of Support: Supported Employment Programs are the most intensive alternative for people with I/DD who need help with employment but do not qualify for EIPD/VR services. Contact your local MCO for help with coordinating and funding supported employment services.

Services that can be provided within Employment Services

Vocational evaluation

- To check if someone is ready to work.
- To find out what kind of help or services a person might need to get and keep a job.
- To find out the person's strengths and skills.
- To learn what behaviors or traits might make it hard for someone to work.
- To find out what might be a good job match.
- To find out what an individual might like doing.
- To explore job skills and talents.
- To see if someone can follow directions.

Job development and obtainment

- Identifying a job goal.
- Resume development.
- Networking.
- Searching for potential job opportunities.
- Applying for jobs.
- Follow up.
- Interview preparation.
- Interview.

Job Training

- Help individuals learn the skills they need for a job.
- Teach 'soft skills' - like managing time, staying organized, communicating with supervisors, coworkers and customers.
- Help set up daily or weekly routines.
- Help create and use systems to stay focused and be successful.
- Support with transportation, such as teaching how to use the bust, Uber, Lyft, or other forms of transportation.

Job Retention

- Maximizing independence on the job.
- Long-term job retention.
- Depending on what the person needs, they might get long-term services to help them keep their job.
- Help figure out and solve problems that come up during work.
- Offer retraining if the job changes or when new tasks are added.

Employer and Coworker Training

- Encourage and help create natural supports at work, like a coworker or supervisor who can be a mentor/teacher and someone who the individual feels comfortable talking to.
- Help coworkers and supervisors learn the best way to support and communicate with the individual.
- Provide support to help everyone understand autism better.
- Help employers see the benefits of hiring people with autism.

Employment Resources

- Work Together NC Employment Toolkit
- Charting The LifeCourse Framework Interactive Employment Guide
- Ticket to Work Program
- The Arc of NC Supported Employment
- The Arc of NC Project Search
- Autism Society of North Carolina Employment Supports Program
- TEACCH Employment Services

Part VI: Elder Care Options

State Developmental Centers

State Developmental Centers (SDC's) are specialized facilities that provide comprehensive clinical care for individuals with intellectual and developmental disabilities who meet very specific criteria. Use this link to learn more.

Housing options for aging IDD/ASD adults

One size does not fit all. There are (NCDHHS and Medicaid) guidelines that determine eligibility for those who require 24/7 oversight. Please note that even with eligibility, finding housing for older adults with I/DD may be challenging because there are few resources available. Many older adults with I/DD still live with their families. However, resources for this group are gaining more attention. To learn more about residential options, review the ASNC Residential Options Toolkit.

Services for I/DD and ASD eldercare/nursing facilities

Visit the NCDHHS website for:

- Neuro-medical treatment centers for more information about Neuro-Medical Treatment Centers.
- State Psychiatric Hospitals for more information about healthcare facilities.
- Inclusion Connects: NCHHS Community Living Guide Resource Directory providing information on housing, funding, and supports for individuals with Intellectual and Developmental Disabilities (I/DD) looking to live in the community.

Healthcare advance directives/Five Wishes

Five Wishes is an advance healthcare directive, allowing individuals to express their preferences for medical care, particularly at the end of life. It focuses on more than just medical choices, encompassing personal, emotional, and spiritual aspects. This document helps individuals articulate their wishes regarding medical treatment, comfort care, how they want to be treated, and what they want their loved ones to know.

Additional resources regarding healthcare advance directives follow:

- Health Care Power of Attorney Form
- Advance Directive Overview
- How to Be a Health Care Agent
- Now What After HC POA
- Five Wishes Sample

Part VII: Crisis Management

Section 1: Procedures for Caregivers

Caregivers of adults with Intellectual and Developmental Disabilities (I/DD), including autism, face unique challenges, especially during crises. The following outlines specific procedures and actionable steps caregivers can take to prepare for and effectively manage the following emergencies.

Communication and Planning

Communication

Effective communication and thorough planning are essential components of crisis management for caregivers of adults with autism.

Discuss needs and plans: Before planning for any disaster scenarios, caregivers should discuss their care recipient's needs and emergency plans with their support network, neighbors, and other trusted individuals. This ensures everyone involved is aware of the necessary steps and can provide support when needed.

Frequent updates: Caregivers should communicate frequently with the adult in their care and their support networks to ensure they are up-to-date and are as safe as possible.

Planning

Develop a caregiving plan: Creating a detailed caregiving plan that includes your care recipient's current needs, impairments, medications, and allergies is crucial. This plan should be shared with family members, care facilities, and anyone else who might help during a crisis.

Emergency Evacuation Plan: Caregivers should think ahead about how to evacuate someone with an I/DD quickly and safely, including where to go, how to get there, and what to bring.

Crisis Form

Using a crisis management form, like the one provided below, is a helpful way to ensure that in a crisis you have all the information you need quickly and in one place.

Crisis Management Form

Crisis Management Procedures

During a crisis, specific procedures can help manage the situation effectively.

Initial Response

Contact first responders: Caregivers should contact their local police precinct or fire stations prior to requiring their assistance during a crisis. By alerting them to your care recipient's needs, you are taking a preemptive step to ensure that first responders are aware and prepared to assist them.

Provide pertinent information: During a behavioral crisis, caregivers should be prepared to communicate pertinent information to first responders using short, succinct sentences.

De-escalation and Safety

De-escalation techniques: In the case of increasing levels of agitation, caregivers should use intervention steps and procedures promoting de-escalation including remaining calm, being gentle and patient, giving space, providing clear directions, and using simple language.

Safety measures: Tools and strategies for keeping your care recipient and those around them safe in any setting (home and community) should be included in your crisis plan.

Post-Crisis Review

Review and improve: After a crisis, caregivers should review the sequence of events and identify areas for improvement. This helps refine the crisis plan and better prepare you and the person in your care for future incidents.

Steps for Caregivers During a Crisis

Contact mobile crisis services: Call the mobile crisis team serving your county for immediate assistance. Click this link to find the crisis line serving your county.

Provide necessary information: Share details about the individual's status, treatment, support, and behavioral history to help the team assess the situation effectively.

Follow crisis plan: Work with the mobile crisis team to develop and follow a crisis plan that includes short-term management and referrals for follow-up services

Utilize additional resources: Engage with programs like NC START for ongoing support and crisis prevention.

Part VIII: Beyond Today: Thriving as a New Caregiver

SECTION 1: Emotional Wellness

Grief Support

Self-care in grief

As a new caregiver, it is likely you are experiencing a loss which has put you in the position of being a new caregiver. Although the new responsibilities of caregiving can feel overwhelming, it is important to address grief and seek resources for grief support for yourself. This is an important part of self-care, and self-care is imperative to preserve your ability to be an effective caregiver.

Exploring grief support for yourself can be a great way to model and teach healthy grief expression to the person for which you now care who has most likely experienced a loss themselves. Contacting a local hospice organization can be of help. Many hospice agencies provide grief counseling in your community at no cost or on a sliding scale. Many may accept Medicaid for these services.

Support through grief

The following are some resources to help caregivers provide support as their care recipient processes grief:

ASNC Blog: Coping with Loss: Recommendations for Supporting Individuals on the Autism Spectrum through Grief

University of Hertfordshire: Managing Grief Better: People With Intellectual Disabilities

Helpful tips and reminders

- As a caregiver providing support to a bereaved person with autism, it is helpful to remember the following:
- Be honest. Include and involve the bereaved person.
- Listen. Be present there with the bereaved person.
- Actively seek out nonverbal rituals.
- Respect photos and other mementos.
- Minimize change.
- Avoid assessment of skills.
- Assist searching behavior.
- Support the observance of anniversaries.
- Seek bereavement specialists for consultation if behavioral changes persist.

Managing and Creating Boundaries

As a new caregiver, learning to manage and create boundaries is not just about following rules, it is a foundational practice that enhances the emotional wellness, autonomy, and development of the person with I/DD, while also protecting your own mental health and sustainability. By prioritizing boundary education and reinforcement, you can provide compassionate, high-quality care without sacrificing your own well-being. Below are some helpful resources for creating boundaries.

Resources for Creating Boundaries

ASNC Blog: On Empowerment: Where to Begin When Building Self-Advocacy Skills and How to Be a Better Ally
giv.care Blog: Teaching Boundaries to Adults with Developmental Disabilities
Heart to Heart: Empowering Independence: Strategies for Adults with IDD to Thrive
Community Mainstreaming: Helpful Tips for Teaching Social Boundaries to Adults with Developmental Disabilities
Guilde for Human Services: Crisis Care for Individuals with Intellectual and Developmental Disabilities

Decision-making and self-determination

Many individuals with I/DD do not get the chance to make decisions about fundamental parts of their day-to-day lives. Often, their parents, support workers or case-managers make decisions about where they live and the activities, they feel the individual would like best without allowing the individual to play an active role in their lives. As a caregiver, these kinds of decisions may also fall to you and may at times feel overwhelming.

It is important to remember that the person in your care has a right to self-determination and can participate in making choices, setting goals, and taking responsibility. Self- determination allows for building skills like choice-making, decision-making, problem-solving, and self-advocacy.

It can be challenging to think "outside the box" when supporting someone with I/DD and allowing the care recipient more self-determination and supported decision-making is an important way to give care and support.

Here are some resources you can use to help promote self-determination:

- Opportunity Village: 6 Ways to Foster Independence...
- Relias: The 6 Building Blocks of Empowerment in IDD
- Neuro Nav Blog: Person-Centered Planning Resources for Adults with IDDs

Section 2: Support Systems

Building a Support Network for Your Person

A circle of advisors/friends

PATH, MAPS, and Circles of Support were developed to assist individuals, families, and their support networks to plan positive and positive futures.

Circles came first with Judith Snow and helped her to discover who was in her life and how to work to build an exciting and robust future. **Making Action Plans (MAPS)** had its origins in schools, replacing the medicalized files with stories that children and adults could use to discover the potential and direction for inclusion and friendship for all. **Planning Alternative Tomorrows with Hope (PATH)** followed by reversing the planning process, beginning with a North Star imagination of dreams and highest purpose, and then a vision of possibility, working backwards into steps in an action plan to implement a better life. Here are some PATH, MAPS, and Circles of Support resources.

- Person-Centered Planning
- Circles Template
- Charting Our Circles of Support
- MAPS Workbook

Family-to-family support and support groups

Feelings of grief, anxiety about the future, guilt, or social isolation are very common. Finding community support and connection with other parents/caregivers facing similar challenges is extremely beneficial. Family-to-family and/or support groups allow sharing personal experiences, tips, and advice with an understanding audience. It helps alleviate feelings of loneliness as well as foster hope when you interact with others further along in their journey. Family-to-family support and/or support groups also provide a safe space to talk through the range of emotions that come with caregiving for a child with a disability. There are many avenues to connect with other families. The following list of resources can help you get started:

Autism Society of North Carolina (ASNC) Support Groups: ASNC has Support Groups across the state. Click here to find one in your area.

Family Support Network of NC provides caring connections and support to families of individuals with disabilities, mental health challenges, special healthcare needs, and their community. For information about regional programs, click here.

Parent Support Map by Legal Aid NC breaks down resources statewide and by region and by general support and general special needs for children with specific disabilities like autism, ADHD, etc. If you cannot find caregiver support resources in a specific region or county, look at the statewide resources to find assistance.

NC Division of Aging Family Caregiver Support Program offers a range of services to support family and caregivers supporting loved ones at home.

easterseals PORT Health's IDD Family Peer Support promotes group services for parents and caregivers of people with I/DD and mental health diagnoses. The program connects families/caregivers with resources and helps them make connections with their peers in local communities throughout North Carolina.

Alliance of Disability Advocates is a peer support program that links individuals experiencing a disability with each other to share their personal lived experience.

First in Families NC helps families with family members who have a developmental disability/delay or traumatic brain injury with items or services not covered by insurance or Medicaid.

NC Guardianship Association (NCGA) trains and supports court-appointed guardians and works to ensure guardianship is carried out in such a way as to support self-determination and the rights and dignity of those individuals with guardians.

Self-Care for the New Caregiver

Being a caregiver can be very stressful for you and your relationships. Feeling overwhelmed and stressed is natural. These feelings are real and valid. They are not wrong or unusual for caregivers and should be addressed, which is why doctors sometimes refer to caregivers as "hidden patients."

Ways to make time for self-care:

- Practice saying "no."
- Take breaks (respite care).
- Incorporate your care recipient into your self-care activities.

Seven pillars of self-care and self-care activities

1. Mental: Reading, yoga, brain dump.
2. Emotional: Meditation, journaling, counseling/therapy.
3. Physical: Napping, exercising/gym, walking, hydration, being in/on water, bathing, yoga.
4. Environmental: Keep your space clean/tidy, open windows for fresh air, brighten up space with plants.
5. Spiritual: Religious/Worship, prayer, meditation.
6. Recreational: Board games, painting, drawing.
7. Social: Find your "people" and make time for them.

Additional Self-Care Resources

- Mayo Clinic: Tips to manage caregiving, self-care
- Harvard Health: Self-care for the caregiver
- Family Caregiver Alliance: Taking Care of YOU: Self-Care for Family Caregivers
- Daily Caring: 8 Types of Self-Care for Caregivers: Which Help Most? – DailyCaring

Part IX: Looking Ahead

As a successor guardian, it is important that you plan for your care recipient's future should you no longer be available. The following are some things to consider as part of that planning:

Pre-burial/Funeral Planning | Pre-need Planning | Life Insurance Assignment | Estate Planning

Pre-need planning may be done with funeral homes. Payments may be paid monthly, in full, or may have a life insurance policy attached (life insurance policies should be assigned to the funeral home and should be irrevocable).

Purchasing life insurance for individuals with a diagnosis of I/DD, ASD may sometimes be difficult. Special Considerations information below will provide coverage.

Estate planning considerations should be made so ongoing care may be covered. If an individual is a Medicaid recipient, receiving inheritance dollars or estate dollars may provide a disruption in Medicaid coverage, so careful planning should be done with the Medicaid provider.

Successor guardian needs the following to help ensure as smooth a transition as possible:

Assurance that all the above needs have been addressed: financial planning, living arrangements, medical coverage (insurance), end-of-life decisions and planning.

Careful planning of a "Person-centered Treatment Plan" to outline desired outcomes for an individual. Plan should address specific needs to keep the individual safe, healthy, and thriving, including what the individual may desire in daily care (style of communication, type of clothing, vocation, hobbies, food preferences, hygiene routine, bedtime preferences, friends and family connections, etc.).

All things person-centered that may be pre-planned will be helpful for a successor guardian and will be most helpful for the individual, especially if there are difficulties with communication.

Support Agencies

These agencies provide information and services for caregivers supporting individuals who have developmental delays/ disabilities or autism spectrum disorder. Their staff can answer your questions and provide guidance and assistance.

Autism Spectrum Disorder diagnosis, services, and resource navigation.
Autism Society of North Carolina | Phone: 800-422-2762

Education, Resource Advocacy, and Parent Information Center for children with special needs.
Exceptional Children's Assistance Center (ECAC) | Phone: 800-962-6817

Government benefits and services for children with disabilities.
Children and Youth with Special Healthcare Needs Helpline | 800-737-3028

Intellectual/Developmental Disabilities (I/DD) services and resources.
The Arc of North Carolina | Phone: 800-662-8706

Resource navigation, information, and emotional support for families of children with disabilities.
Family Support Network TM of North Carolina | Phone: 800-852-0042

Glossary of Terminology

Service Plans

Adult Day Programs: Programs offering social skills training, vocational training, supported employment, community outreach, volunteerism, and creative expression through art.

Behavioral Supports: Licensed clinicians provide help including assessment, consultations, creation and use of structured systems and visual supports, instructional strategies, functional communication training, and development of formal Behavior Support Programs.

Comprehensive Intervention Programs: Treatment plans developed and delivered by psychologists and other licensed professionals trained in evidence-based practices (e.g. ABA) to promote appropriate skills and behaviors.

Employment Support: Assistance and instruction in developing job-ready skills and finding, maintaining, and thriving in a job.

Family Consultation: Collaboration with the family to provide specific recommendations for appropriate home supports, opportunities for community participation, and coping strategies.

Recreational Opportunities: Social skills groups or camps that provide opportunities for participants to bond over common interests, practice social skills, and try new activities. Staff are trained to understand their needs and help them reach new goals.

Residential Homes: These homes allow adults with autism to experience community living while receiving support and supervision in their daily activities.

Respite: Care for the individual with autism so caregivers receive a break and are better able to care for their child.

Skill Building and Support: One-to-one tutoring or group training to teach or increase the following skills: communication, social skills, daily living and personal care/hygiene skills, and fostering community relationships and integration.

Terms

APS: Adult Protective Servcies (see page 6)

I/DD: Intelectual Development Disability

LME: Local Management Entities (see page 5)

LRPS: Legally responsible person

MCO: Managed Care Organization (see page 5)

SDM: Supported decision-making

SSDI: Social Security Disability Insurance

SSI: Supplemental Security Income

Glossary of Resources

Support Groups & Programs / Family-to-Family Support

AARP Resources for Caregivers and their Families

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VOX How to Care for People in Your Life with Intellectual Disabilities