A Family's Reference Guide to Services
For Youth and Young Adults with Autism

The Chapel Hill TEACCH Center
A Family's Reference Guide to Services
For Youth and Young Adults with Autism

I  Overview and Flowchart

II  Description of the Agencies

<table>
<thead>
<tr>
<th>Agency</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASNC</td>
<td><a href="http://www.autismsociety-nc.org/">http://www.autismsociety-nc.org/</a></td>
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<tr>
<td>Arc</td>
<td><a href="http://www.thearc.org/">http://www.thearc.org/</a></td>
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<tr>
<td>TEACCH</td>
<td><a href="http://www.teacch.com/">http://www.teacch.com/</a></td>
</tr>
<tr>
<td>DPI</td>
<td><a href="http://www.dpi.state.nc.us/">http://www.dpi.state.nc.us/</a></td>
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<td>MH/MR/DD/SAS</td>
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<td><a href="http://www.nasmhp.org/childdiv.htm">http://www.nasmhp.org/childdiv.htm</a></td>
</tr>
<tr>
<td>VR</td>
<td><a href="http://dvr.dhhs.state.nc.us/">http://dvr.dhhs.state.nc.us/</a></td>
</tr>
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<td>SSA</td>
<td><a href="http://www.ssa.gov/">http://www.ssa.gov/</a></td>
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Community Colleges
The Structure of the State System

III  Quick Guide to Services and Agencies

<table>
<thead>
<tr>
<th>Category</th>
</tr>
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<tbody>
<tr>
<td>Advocacy</td>
</tr>
<tr>
<td>Community Support Services</td>
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<tr>
<td>Education</td>
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<td>In-Home Care</td>
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<tr>
<td>Treatment</td>
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<tr>
<td>Transition</td>
</tr>
<tr>
<td>Summer Programs</td>
</tr>
<tr>
<td>Vocational Programs</td>
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</tbody>
</table>

IV  Helpful Hints-Step One -Diagnosis and Treatment

<table>
<thead>
<tr>
<th>Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step Two-Going Through Single Portal / Local Management Entity</td>
</tr>
<tr>
<td>Step Three-Education</td>
</tr>
<tr>
<td>Step Four-Transition</td>
</tr>
<tr>
<td>Step Five-Applying for Federal Benefits</td>
</tr>
<tr>
<td>Step Six-Residential Options</td>
</tr>
<tr>
<td>Temporary/Respite</td>
</tr>
<tr>
<td>Long-Term Residential Choices</td>
</tr>
<tr>
<td>Step Seven-Trusts, Wills, Guardianship and Other Legal Issues</td>
</tr>
</tbody>
</table>

V  Resources

VI  Attachments

VII  Appendix A – Detailed Step by Step Process for Families
I. Overview

Professionals and families often become overwhelmed when faced with the task of navigating the public service system. This reference guide is an attempt to simplify that process, while highlighting the agencies and services a family is likely to need the most. The guide will provide information about what services exist in North Carolina for individuals with disabilities, which agencies provide the different services, and how and when to access those services.

There is no magic formula that all families must follow to obtain services. However, there are some basic methods, which have proven effective for families faced with the same daunting task of understanding the system and making it work for them. Although the emphasis of the guide is on the adolescent and adult years, a family seeking services for a younger individual will also find the information useful.

Attachments and a resource list at the end of the guide will provide direction to other resources, where additional information may be found. Should you have difficulty at any stage of the process, call the Autism Society of North Carolina or your local TEACCH Center for assistance.

Information provided in this document is subject to change as the laws and procedures governing it are modified. Check this web site for updates.
DIAGNOSIS

TEACCH DEC SCHOOLS PRIVATE STATE

TREATMENT

TEACCH PRIVATE EDUCATION
Assessment OT IEP
Family Training/Support Speech
Consultation PT

SINGLE PORTAL / LOCAL MANAGEMENT ENTITY

Respite Summer Program Supported Employment
Case Management After School Program Crisis Intervention
Adult Day Program Transportation In-Home Training
Therapies CAP/DD Residential Options

TRANSITION – AGE 14-21 – CONTACT SINGLE PORTAL – LOCAL MANAGEMENT ENTITY
(If you do not have a diagnosis, you can contact agencies mentioned above.)

TEACCH ASNC FEDERAL BENEFITS Arc LEGAL ISSUES
Assessment Referrals Referrals Motor Vehicles
Support Advocacy Advocacy Military
Social Skills Support Direct Service Guardianship
Training Information Respite Trusts
Planning

FEDERAL BENEFITS
MURICAID MEDICARE SOCIAL SECURITY DISABILITY INCOME

VOCATIONAL PROGRAM RESIDENTIAL PROGRAM
(REFER TO SINGLE PORTAL / LOCAL MANAGEMENT ENTITY FOR FUNDING AND SERVICES)

VOCATIONAL REHABILITATION
IDENTIFY VOCATIONAL SERVICE PROVIDER

TEMPORARY: RESpite, IN-HOME ASSISTANCE
PERMANENT: SUPPORTED LIVING, FAMILY CARE
II. Description of the Agencies


The Autism Society of North Carolina, Inc., a non-profit organization of professionals working together with families, is committed to improving the lives of individuals and families affected by autism and related communication handicaps. They work to achieve this goal through the provision of information and referral services, advocacy and a wide range of direct services and programs including a residential summer camp. The Autism Society provides support to 37 parent support groups, or Local Units throughout North Carolina [http://www.autismsociety-nc.org/local_units.html](http://www.autismsociety-nc.org/local_units.html). ASNC also provides eleven parent advocates; located throughout North Carolina who are available to assist in accessing appropriate services for individuals with autism of all ages and their families.


The Arc of North Carolina is a non-profit organization that has 45 local chapters and approximately 4500 members who advocate for educational, occupational, recreational and residential opportunities for individuals with mental retardation and other developmental disabilities. Services include Advocacy/Governmental Relations, LIFE guardianship Supports and Services, Housing Development Services, Supported Living Services, Supported Employment Services, Self Advocacy, Tre-Alliance Participant Driven Managed Supports, Citizen Monitoring, Information/Education/Referral, Prevention, Chapter Services, and Life Plan Trusts [http://www.autism-info.com/lyfplntr.htm](http://www.autism-info.com/lyfplntr.htm).


TEACCH is a Division of the University of North Carolina Medical School at Chapel Hill. TEACCH is dedicated to improving the understanding and services available for all children and adults with autism and related communication handicaps. It is a comprehensive, community-based program that includes direct services, consultation, research, and professional training. In addition to the Administration and Research Section of TEACCH, which is located at UNC-CH, there are nine regional TEACCH clinics located in Asheville, Chapel Hill, Charlotte, Fayetteville, Gastonia, Greensboro, Greenville, Raleigh, Wilmington and one vocational/residential program for adults located in Pittsboro. The clinics provide an array of services including diagnosis and treatment.
DPI - The North Carolina Department of Public Instruction - [http://www.dpi.state.nc.us/](http://www.dpi.state.nc.us/)

DPI is the Department of the State of North Carolina that is responsible for the administration of public education in North Carolina. DPI is governed by the State Board of Education. The Board of Education is composed of the Lieutenant Governor and eleven board members appointed from educational districts throughout North Carolina. DPI supervises and administers the free public school system and the funds provided by the state and federal government for its support. Funds, policies, and procedures from DPI are administered by local school districts. The districts function under the direction of a superintendent who answers to the area/county board of commissioners.

MH/MR/DD/SAS - Division of Mental Health, Mental Retardation, Developmental Disabilities and Substance Abuse Services - [http://www.dhhs.state.nc.us/mhddsas/](http://www.dhhs.state.nc.us/mhddsas/)

MH/MR/DD/SAS is one of seventeen, state level Divisions of DHHS. It is responsible for the oversight of mental health, mental retardation, developmental disabilities, and substance abuse services throughout the State of North Carolina. In addition, MH/MR/DD/SAS operates four regional psychiatric hospitals, five regional mental retardation centers, three regional educational institutions for children with serious emotional and behavioral disorders, and three alcohol and drug abuse treatment centers.

The area/county MH/MR/DD/SAS program, also referred to as the Single Portal / Local Management Entity or Mental Health, is the local branch of MH/MR/DD/SAS. Federal and state funds flow from the state to the area programs. Case managers in each area program are assigned to individuals who have applied for and been screened to receive services. The case manager establishes contracts with local agencies that are certified and licensed to provide such services. The case manager then works with the individual, family and service agencies to meet the needs established in a plan of care. Services include early intervention, in-home support, respite, recreation, transportation, residential and vocational options, and more. Again, the area Mental Health/MR/DD/SAS program is also referred to as the single portal / local management entity of services and it serves individuals of all ages who are disabled.

DSS - Division of Social Services - [http://www.dhhs.state.nc.us/dss/](http://www.dhhs.state.nc.us/dss/)

DSS is a Division of DHHS, which, in cooperation with county departments of social services, provides opportunities for individuals and families in need of basic economic support and services to become self-supporting and self-reliant. Services include rental assistance, food stamps, Medicaid, CAP-C (for children with severe medical needs) and more.
VR - Division of Vocational Rehabilitation Services - http://dvr.dhhs.state.nc.us/

VR is the state agency responsible for administering state and federal funds designated for employment services. Those services include vocational evaluation, placement, and training. The local VR unit offices are in most large cities or county seats. Vocational Rehabilitation Counselors work with business and community agencies to help them prepare their work sites to accommodate employees who have disabilities. Students with disabilities, who are interested in working, are usually referred to the VR school counselor by their senior/last year. Individuals no longer in school can be referred by to the local VR unit office by anyone including the single portal / local management entity. VR accepts referrals and provides funding for individuals with disabilities who have the potential to work in paid, supported (i.e. with specialized job placement, on the job training, and long term support) or competitive employment. Individuals accepted for supported employment services through VR are referred to vendors/agencies in the community who have a contract with VR to provide such services. The VR counselor develops a work plan for an individual and works with the individual, family, and agency to assure service delivery.

SSA - The Social Security Administration - http://www.ssa.gov/

SSA-Is the federal agency mandated to provide benefits to retirees and to individuals who are disabled and therefore unable, without intensive support, to maintain substantial gainful activity. The main office is in Baltimore, Maryland. There are local branches of the SSA in most large cities or the county seat. The SSA administers two programs for individuals with disability: SSDI (Social Security Disability Insurance) and Supplemental Security Income (SSI). An individual with an impairment can apply with SSA for financial and medical benefits upon his/her 18th birthday. Under certain conditions, including the death, retirement or disability of a parent, an individual might be eligible for benefits prior to age 18.

Community College/Universities

College and University systems provide knowledge and skills that can enhance one’s ability to live satisfactorily. However, community college and university programs are not required to provide the same level of accommodation for students with disabilities that is required in the public school system. It is important to assess the demands of an advanced degree program and the complexity of job positions to which such a degree leads. The technical/community college system in North Carolina offers a variety of career development programs that emphasize concrete skills in various trades. Many community college and university programs offer tutoring, counseling, and organizational support to individuals with disabilities. However, careful investigation of the resources of the specific colleges/universities is recommended.
## III. Quick Guide to Services and Agencies

<table>
<thead>
<tr>
<th>Service</th>
<th>Agency</th>
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<tbody>
<tr>
<td>Advocacy</td>
<td>ASNC, Arc, TEACCH</td>
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<tr>
<td>Community Support Services</td>
<td>MH/MR/DD/SAS</td>
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<tr>
<td>Diagnosis</td>
<td>TEACCH, DEC (Developmental Evaluation Clinic)</td>
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<td>Education</td>
<td>DPI</td>
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<td>N.C. Life Plan Trust</td>
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<td>Functional Assessment</td>
<td>DPI/TEACCH</td>
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<td>DHR/MR/DD</td>
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<td>Medical Care</td>
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<td>Summer Programs</td>
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<td>Vocational Services</td>
<td>VR, MH/MR/DD/SAS</td>
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</table>
IV. Helpful Hints: A Step-by-Step Process  
(See Appendix A for detailed information about each of these steps)

Step One - Diagnosis and Treatment  
_____ Obtain a diagnosis that is documented in writing.

For an individual in North Carolina for whom the diagnosis of autism or a related developmental disability is being considered, a referral to Division TEACCH should be considered. A diagnosis by TEACCH or a Developmental Evaluation Clinic, school psychologist, or private clinician typically provides documentation of a disability. Documentation of a disability is necessary to access the services provided by public agencies for individuals with disabilities.

Step Two - Going Through Single Portal / Local Management Entity  
_____ Contact the Area Program / Single Portal Agency / Local Management Entity and complete the application process.
_____ Get written documentation that your application has been processed.

"Going through single portal / local management entity" is a phrase developed by the State of North Carolina and it refers to the Division of Mental Health/Mental Retardation/Developmental Disabilities and Substance Abuse Services (i.e. the Single Portal / Local Management Entity of entry for services for individuals with disabilities.) This Division is a branch of the NC State Department of Health and Human Resources (DHHR). The Single Portal / Local Management Entity process is designed to track consumers' needs and, whether those are being met. It should prevent families in need of services from "falling through the cracks" between the agencies that exist.

Step Three - Education  
_____ Obtain a functional, educational assessment during the early adolescent years.
_____ Assure that the results of this assessment are integrated into goals of the IEP.
_____ Assure the IEP includes experiential, community based goals.
_____ Assure there is an annual evaluation of progress made on all goals.

All students need to prepare themselves for the opportunities and challenges of adulthood. Such preparation is critical for adolescents with autism because it is the key to a happy and productive life. There is no legal precedent that guarantees services for them like the one for children (i.e. Public Law 94-142 that guarantees a free and appropriate education for all school-aged children). Therefore, individuals with disabilities must maximize their abilities and opportunities in preparation for satisfactory
occupation during their adult years. One of the most important components of satisfactory occupation is the ability to function independently. An essential step in the process of achieving such independence for the student with autism is to obtain a functional, educational assessment. That is, educational assessment should measure the student’s ability to function independently in areas essential to daily living as an adult (e.g. communication, social, self care, independence, etc.). Teaching goals derived from the assessment should be included in the IEP and progress on those should be reviewed annually.

Step Four - Transition

_____ Assure a written ITP (Individualized Transition Plan) is in place at age 16.

_____ Assure a referral to VR has been made at age 16 or older if a work capability assessment is desired.

_____ Assure a referral to the Single Portal Agency / Local Management Entity has been made by the beginning of the final year of school unless your relative with autism is able to function independently.

_____ If the VR assessment or Transition Plan includes any form of employment, assure a referral is made back to the Single Portal / Area Program / Local Management Entity for Long-Term Supported Employment.

_____ Keep a log in which all correspondence to and from agencies is documented.

By the age of 14 the student with autism should have the above mentioned assessment and it should be reviewed annually to measure progress toward appropriate assessment-based goals. At the age of 16 a written Individualized Transition Plan, like the IEP, should be developed in conjunction with the family and reviewed annually until the transition from school to a future setting occurs. The process of transitioning to the next setting should include a referral back to the Single Portal Agency / Local Management Entity by the beginning of the final year of education, if not sooner unless the student can function well without assistance. As part of the referral, all future needs should be listed, (e.g. vocational, recreational, residential, transportation, etc.) even if they are not needed immediately.

Step Five - Applying for Federal Benefits

_____ Keep a log of all correspondence to and from agencies.

_____ For Individuals 17 and under with autism - If financially eligible and benefits are desired, apply to the SSA for SSI (includes Medicaid application) for a child with a disability.

_____ For Individuals 18 and older with autism - If benefits are desired, apply to the
SSA for SSDI, SSI, Medicaid, and Medicare.

Individuals with disabilities are entitled to governmental benefits. These might include:

- **SSI** - Supplemental Security Income  
- **SSDI** - Social Security Disability  
- **Medicaid**  
  [http://www.dhhs.state.nc.us/dma](http://www.dhhs.state.nc.us/dma)
- **Medicare**  

Adolescents under the age of 18 years must apply for SSI based on their parents’ incomes. Individuals who are 18 years and over can apply as their own, sole provider unless they live with their family. Program incentives exist for those who are working with disabilities. These allow one to keep part or all of their benefits while receiving a salary.

**Step Six - Residential Options**

**Temporary Respite**

_____ If respite is desired, apply through the Single Portal Agency / Local Management Entity.

Respite is a service that allows families to receive in-home or center-based assistance with the supervision and care of their family member with autism. This means that either a staff person comes into the home to supervise the individual while the family or parents leave or that the individual with autism goes to a respite center, for brief periods of time (i.e. hours, days, up to a month at center based regional centers). Again, the Single Portal Agency / Local Management Entity is the first place to apply for such services.

**Long-Term Residential Choices**

_____ Consider a plan for the future needs/living arrangements you prefer for your relative with autism, which can be carried out in your absence.

_____ If residential living is desired, complete an application through the Single Portal Agency / Local Management Entity.

If a family decides to seek residential services outside of their home for their family member with autism, there are several different options. Those include group home living, family-care homes, boarding homes, nursing homes, a regional state facility or (individual) supported living in any setting. Application for these programs can be made through the area, Single Portal Agency / Local Management Entity. Though group homes and other group living models were at one time the only residential programs available for individuals with autism, more emphasis is being placed now on individual, community based placements such as apartments/ houses, etc. with staff support provided. If you are not ready for placement but think you might want it in the future, tell Single Portal / Local Management Entity staff to note residential placement as a future need.
Step Seven - Trusts, Wills, Guardianship, and other Legal Issues

_____Register all males for the draft at age 18.

_____Consider the pros and cons of guardianship for your relative with autism.

_____Assure the conditions of all trusts, involving your relative with autism, are measured against the pros and cons of leaving funds or property to that individual.

Once an individual with autism reaches the age of eighteen years, he or she becomes an adult in the eyes of the law. This means the parent no longer has a legal right to make legal decisions on behalf of that child unless the parent or someone else such as another family member has filed with the courts for the right of guardianship over that individual. Becoming a guardian for someone means the court has granted you the right to make some or all decisions on another’s behalf.

Trusts and wills that leave assets to individuals with autism will affect eligibility status for local, state, and federally funded programs. Guidelines for developing life plan instruments can be obtained from the Autism Society, the Arc, N.C. Life Plan Trust, http://www.autism-info.com/lyfplntr.htm and/or an attorney.

V. Resources
(available at Chapel Hill TEACCH Center)

Making Your Way - Opening Doors to Employment and Other Opportunities for Adults with Autism (Prepared under the auspices of the Vocational Committee of the Autism Society of NC)
By Elizabeth Thompson, Parent Advocate October 1996

The Triangle Resource Guide

The Durham County Area Program Single Portal Plan and Summary of Services
*(Example)*

How to Access CAP-MR/DD – from the NC Council on Developmental Disabilities –
http://www.nc-ddc.org/

*Contact your local Area Program to obtain a copy of the Single Portal Plan for your county.*
VI. Attachments

THE STRUCTURE OF THE STATE SYSTEM

Community College System

\[\text{Regional Campuses} \quad \text{← State Legislature } \quad \text{→ University System} \]

Regional Campuses

Departments of State

including

Departments of (Corrections, Health and Human Services, Transportation, etc.)

The Department of Health and Human Services

DHHR

Divisions*

(including)

(In Raleigh)

MH/MR/DD/SAS

VR

DSS

DMA

MH/MR/DD/SAS Area Program

Single Portal Agency

Local Management Entity

(In your county)

*DIVISIONS-Social Services-DSS, Mental Health, Developmental Disabilities & Substance Abuse-
MH/MR/DD/SAS, Vocational Rehabilitation-VR, Medical Assistance-DMA, Facility Services, Aging,
Services for the Blind, Child Development, Community Health, Epidemiology, Information Resource
Management, Women's and Children's Health, Public Health, Economic Opportunity, Citizen Services,
Services for the Deaf and hard of Hearing, Rural Health and Resource Development.
## VI. Attachments

### Chapel Hill TEACCH Center
Area MH/DD/SAS Programs

<table>
<thead>
<tr>
<th>County</th>
<th>Area Program</th>
<th>Address</th>
<th>Phone Numbers</th>
<th>FAX Numbers</th>
<th>Single Portal</th>
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<td>Caswell County</td>
<td></td>
<td>Burlington, NC 27215</td>
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<tr>
<td>Orange County –</td>
<td>O-P-C Area Program</td>
<td>100 Europa Drive, Suite 490</td>
<td>(919) 913-4000, (919) 913-4003 FAX</td>
<td>*So.Orange/Chatham Single Portal: 913-4344</td>
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<tr>
<td>Person County</td>
<td></td>
<td>Chapel Hill, NC 27517</td>
<td>(919) 913-4000, (919) 913-4003 FAX</td>
<td>*No.Orange/Person Single Portal: 644-6590</td>
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<tr>
<td>Durham County -</td>
<td>The Durham Center</td>
<td>Carmichael Building, 2\textsuperscript{nd} Floor</td>
<td>(919) 560-7200, (919) 560-7216</td>
<td>Single Portal: 560-7487</td>
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<td>300 N. Duke St.</td>
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<tr>
<td>Franklin County –</td>
<td>V-G-F-W Area Program</td>
<td>134 S. Garnett Street</td>
<td>(252) 430-1330, (252) 430-0909 FAX</td>
<td>Single Portal: 430-1330</td>
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<tr>
<td>Vance County</td>
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<td>Granville County</td>
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<td>Warren County</td>
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<tr>
<td>Johnston County -</td>
<td>Johnston Area Program</td>
<td>PO Box 411</td>
<td>(919) 989-5500, (919) 989-5532 FAX</td>
<td>Single Portal: 989-5500</td>
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<td>Smithfield, NC 2757</td>
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<tr>
<td>Wake County -</td>
<td>Wake Area Program</td>
<td>220 Swinburne Street, Suite 2010</td>
<td>(919) 212-7199, (919) 212-7285 FAX</td>
<td>Single Portal: 857-9110</td>
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<tr>
<td></td>
<td></td>
<td>Raleigh, NC 27620</td>
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Appendix A

Detailed Step-by-Step Process for Families

Step One - Diagnosis and Treatment

For an individual in North Carolina for whom the diagnosis of autism or a related developmental disability is being considered, a referral to Division TEACCH should be considered. A diagnosis by TEACCH or a Developmental Evaluation Clinic, school psychologist, or private clinician typically provides documentation of a disability. Documentation of a disability is necessary to access the services provided by public agencies for individuals with disabilities. Whether or not a family is receiving active treatment through TEACCH or services through the Autism Society, they can always contact staff there to discuss their needs related to their family member with autism. The Social Security Administration does not recognize Asperger’s as a disability.

Step Two - Going Through Single Portal / Local Management Entity

"Going through single portal" is a phrase developed by the State of North Carolina and it refers to the Division of Mental Health/Mental Retardation/Developmental Disabilities and Substance Abuse Services (i.e. the Single Portal / Local Management Entity of entry for services for individuals with disabilities.) This Division is a branch of the NC State Department of Health and Human Resources (DHHR). The Single Portal / Local Management Entity process is designed to track consumers' needs and whether those are being met. It should prevent families in need of services from "getting lost in the system" between the agencies that exist. That is, if you apply for services and are referred to an agency, you should receive a response from that agency indicating the status of your application. You should not get lost in the system because one agency referred you to another agency, after which you never heard from anyone again. The Single Portal / Local Management Entity process puts the responsibility on the Single Portal Agency / Local Management Entity (i.e. the local office of MH/MR/DD/SAS) to track those who have completed an application for services and prevent them from "falling through the cracks." The Single Portal Agency / Local Management Entity typically maintains lists of consumers waiting for services. These are referred to as the Single Portal / Local Management Entity waiting lists.

As encouraging as such a Single Portal / Local Management Entity philosophy is, the best way to assure that your family member does not fall through the cracks is to keep their name and needs active with the Single Portal Agency / Local Management Entity. The best way to do this is to contact the agency in your area often (i.e. at least once or twice a year and more often, if those needs are urgent and unmet.) There is a Single Portal Agency / Local Management Entity office in your county or, depending on the population of the area in which you live, in the next county nearby. The mental health office is often listed in the phone book under county or city offices. In addition, the area Single Portal Agencies / Local Management Entities and phone numbers are listed at the end of this guide. When you are ready to obtain services for your family member, call...
the area mental health office in your area and ask what you need to do to apply for
services for your family member who has a developmental disability.

You do not have to go to the Single Portal Agency / Local Management Entity to obtain
services from TEACCH or the Autism Society. However, as soon as you are comfortable
approaching the Single Portal Agency / Local Management Entity to present your needs,
it is a good idea to do so. This is important because the Single Portal / Local
Management Entity staffs maintain a waiting list for services and there could be a long
wait. The sooner you get the name of your family member on the list, the better off he or
she will be when the selections for services are made. The lists of families in need,
which are kept by the area offices, are what the state uses to determine which services
need to be funded in each area. If families do not identify their needs, officials will
explain that they have no justification to provide funding for future services. If your
family member is chosen to receive a service before you are ready to accept that service,
you can always turn it down and ask that your name be returned to the waiting list.
Though you might not need a service in the immediate future, getting on the list, if you
think you will need it in the future, is an important step to consider. If you do not
complete an application for services through the Single Portal Agency / Local
Management Entity, your family member’s needs will not be tracked.

Not all area offices handle the application process in the same way. Some area programs
have reported to parents that they do not have an actual application form. Do not let such
a statement stop you from pursuing some concrete (i.e. preferably written in the form of
an application or letter) assurance that your needs have been documented and that those
will be considered if services become available. Application for services is an important
step and it is a place in the process of acquiring services where the process will often
break down. If you are able to get an appointment with a staff member during which you
can make your needs known and to which you can take your family member with a
disability, that is usually the best approach. Such face to face contact can provide staff an
opportunity to attach a face with a name and to understand more clearly how autism
affects your family member and you. Do not let the agency drop the ball during the
application process. Pursue the application process until you are satisfied that a staff
person has documented your name, address, and needs and that they plan to respond to
your request.

Keep a copy of all correspondence and a simple log of all phone contact between you and
the agencies with which you deal. You might need such documentation in the future.
However, in many instances it can be helpful, if for no other reason than it can help you
remember names and services. If you are in need of immediate services do not hesitate to
explain that and the reason why, to the staff person. If you consider yourself and/or your
family to be in a crisis, say so (i.e. make sure they understand it). If you are told your
needs can best be met by a particular program such as the Community Alternatives
Program, but staff add that they have no available CAP monies, ask if they have any
other funds, state or local, that your family might obtain to meet your needs. The
application process should go smoothly. Just be prepared to pursue it vigorously if it
does not. If you have any difficulty and/or you feel your are facing an emergency, enlist
the advice of staff at the Autism Society or TEACCH.

The types of services available through the Single Portal Agency / Local Management Entity include: short-term respite, summer programs, after school programs, day programs for adults, residential programs, vocational programs, crisis intervention, case management, in-home assistance, special equipment, special transportation services, physical therapy, occupational therapy, speech services, and more. Some of the services listed here are provided through federally funded programs such as the CAP/MR/DD Program (Community Alternatives Program).
http://www.dhhs.state.nc.us/dma/1999commalt.html

The CAP/MR/DD program is designed to prevent institutionalization of at-risk individuals with medically documented disabilities such as autism. Additional information, documentation, and/or applications might be necessary to access these services. If you are told that all the slots for a given program have been allocated already to others, ask what other services are available to you until more allocations can be made. Again, enlist the assistance of staff of the Autism Society or TEACCH if you need assistance completing these applications.

**Step Three - Education**

All students need to prepare themselves for the opportunities and challenges of adulthood. Such preparation is critical for adolescents with autism because it is the key to a happy and productive life. There is no legal precedent that guarantees services for them like the one for children (i.e. Public Law 94-142 that guarantees a free and appropriate education for all school-aged children). Therefore, individuals with disabilities must maximize their abilities and opportunities in preparation for satisfactory occupation during their adult years. One of the most important components of satisfactory occupation is the ability to function independently. An essential step in the process of achieving such independence for the student with autism is to obtain a functional, educational assessment. The teacher should be able to determine from such an assessment, a student's current level of achievement in all areas of daily living.

Once a student's level of functioning in each area of daily living has been established, educational goals should be developed as the focus of future instruction for that student. All areas of daily living, not just academics, must be included in the evaluation and its recommendations because the disability of autism affects all areas. Therefore, the Individualized Educational Plan (i.e. IEP) should contain educational goals that address all areas of daily functioning, including the following: Self-Help, Independent Functioning, Communication (receptive and expressive), Leisure, Social Interaction, and Vocational skills. As the student progresses through middle and upper school settings, success in each area should be assessed continually and goals should be adjusted to reflect progress and future educational direction. A student's teacher or resource
specialist should be able to explain by the end of each school year, specifically, how the student has progressed on the previously assessed skill areas and where instruction in those same areas should begin for the next term.

The goal then, of an appropriate education for an adolescent with autism, is to impart knowledge to the student that will assist him or her to function successfully in the world outside of the educational setting. Without the ability to apply the skills learned, the student with autism will face tremendous odds when seeking and maintaining successful occupation in their adult life. Therefore, experiential/community based learning is essential. It provides the student with the opportunity to generalize skills learned in school to the community and it provides the opportunity to identify new skill areas that might not present themselves in the restricted environment of the school.

An example of an IEP designed according to the above mentioned process can be obtained from a regional TEACCH classroom consultant. In addition, teachers interested in learning about the above mentioned, assessment based educational programming and structured teaching techniques, can obtain information and training information from the regional TEACCH center staff.

**Step Four - Transition**

By the age of 14 the student with autism should have the above mentioned assessment and it should be reviewed annually to measure progress toward appropriate assessment-based goals. At the age of 16 a written Individualized Transition Plan, like the IEP, should be developed in conjunction with the family and reviewed annually until the transition from school to a future setting occurs. The process of transitioning to the next setting should include a referral back to the Single Portal Agency / Local Management Entity by the beginning of the final year of education, if not sooner. This referral is particularly important if no appropriate setting is available. The teacher or resource specialist also should make a referral to Vocational Rehabilitation Services, if the family and/or student age 16 or older wishes to have an assessment made of the student's work potential.

If the VR Counselor finds the student has the potential, with specialized assistance, to function adequately in a competitive work environment (i.e. earning minimum wage), VR funds might be allocated during the final year of school to provide a supplemental evaluation of the student's work skills and training needs. Funds also can be accessed to provide a job coach from a local VR service vendor (e.g. TEACCH, local Adult Developmental Vocational Program). A job coach utilizes the supplemental evaluation, job placement, and on-the-job training services along with limited Long-Term Support (LTS) of two visits per month to the job site.

By the end of the next to the last year of a student's education, it should be clear to the teacher, the student, and the family where the student is headed after graduation. Activities characteristic of that setting, whatever that setting might be (e.g. the
community college, adult day program, workshop, university, supported or competitive employment, creative living, etc.), should be simulated first in the school setting. After the student masters those skills in the school setting, teaching should move gradually into the community.

The student should be ready to transition gradually during their last year of public school into a new setting that is appropriate to their skills and choice of adult occupation. Again, experiential/community based learning is a key component to successful and effective transition planning for the student with autism. It can assure that what is taught is functional and valuable to the student as he or she progresses into adulthood.

Some students, based on the above assessment, can work, but only if they have more intensive Long Term Support (LTS) such as daily visits from a job coach or access at all times to a job coach located in the same building to function successfully on a job. A student who needs such intensive LTS services should be referred to the Single Portal Agency / Local Management Entity to apply for intensive LTS services. If and when LTS funding is obtained from that agency or any other source, an individual can return to VR and apply for funding of job placement and on-the-job training services.

Many students with autism demonstrate skills and interests that blend better with non-competitive occupational settings than with competitive employment settings. For instance, many individuals with autism are unable to sustain a steady rate of performance as required by an employer for more than a few minutes at a time. New alternatives to standard employment settings are being developed for individuals with autism who would benefit from such a program. If families are interested in exploring these alternatives, they should contact the Autism Society of North Carolina for information on these programs and how to develop one in their area.

All students with autism who are unable to function independently (i.e. without any staff assistance) should apply for services through the Single Portal Agency / Local Management Entity by the beginning of their last year in school. That is, both students who can work with additional assistance and students who need non-competitive occupational settings with staff assistance must apply for those services through the Single Portal Agency / Local Management Entity.

Individuals with autism for whom higher education is appropriate must apply to those programs using the procedures established by the college or university of their choice. Specialized services including tutoring might be available through the counseling office of each school. VR also considers applications for special assistance in the area of higher education, unique skill training (e.g. computer training, piano tuning, etc.), and with the development of small business opportunities. VR also offers assistance with unique, short term, independent living needs.

During transition periods some families have found “Circle of Friends” a helpful support. The Exceptional Children's Assistance Center (ECAC) [http://www.ECAC-parentcenter.org/](http://www.ECAC-parentcenter.org/) Is a resource of information on this concept of supporting individuals with disabilities by
involving members of their community. Family members can plan ahead for the transition process by obtaining an Individualized Transition Plan (ITP) packet from the ECAC.

**Step Five - Applying for Federal Benefits**

Individuals with disabilities are entitled to governmental benefits. These might include Supplemental Security Income (SSI), Social Security Disability (SSDI), and Medicaid or Medicare. Adolescents under the age of 18 years must apply for SSI based on their parents’ incomes. Individuals who are 18 years and over can apply as their own, sole provider unless they live with their family. If an individual lives with their family and receives monetary support or in-kind support (i.e. food, housing, etc) from them, that support will be counted as income and affect/reduce one type of benefit (e.g. SSI). In such a case, it is best to show how (i.e. by providing cancelled checks) that individual does or will need to contribute part of that income toward the household expenses. Always keep records of any correspondence with the Social Security Administration, including copies of applications and a log of dated phone contacts with the names of people with whom you have spoken and the basics of what they said.

A family member or other representative who has a written release of information, signed by the individual with autism or his guardian, can file an application for benefits through the Social Security Administration on behalf of that individual. The application can be made over the phone, especially if it is difficult for the individual and/or the family member to attend an appointment. In either case, after calling 1-800-772-1213, an appointment time will be offered and an application packet will be sent. At that appointment time you must be present to receive the call and have the information listed in the packet, which you will need to report to the interviewer. You will be asked to provide the interviewer with the name, address, and phone number of a licensed psychologist or physician/psychiatrist, who is knowledgeable about the individual with autism and their disability.

Two things must be verified through the information that is provided to the Social Security Administration. One is documentation of the disability written by a licensed psychologist or physician. The other is an explanation that the individual is unable to engage in Substantial-Gainful Activity (SGA). SGA is defined by the Social Security Administration as the capacity to work and earn over an average of $700.00 per month. If an individual can work but requires VR services to obtain and maintain a job or if they must pay for special, job related expenses, they can qualify to receive a monthly benefit while working to earn more than the SGA (i.e. $700 per month) level. If the individual does not need such assistance, they will not qualify for benefits or they will not continue to receive an existing benefit once the trial work period ends (i.e. trial work period=nine non-consecutive months of work at a salary above the level of Substantial Gainful Activity/$700).
Once the SSA has all the initial information, an application will be filed first requesting Supplemental Security Income (SSI) benefits. That will either succeed or fail and only then, will the application for Social Security Disability Income (SSDI) be filed. Getting approved for SSDI is not contingent on being approved for SSI; one is not dependent on the other. Adults with autism sometimes do not receive SSI but do receive SSDI and vice versa. Some adults qualify for both SSI and SSDI. Others receive benefits based on a parent's disability or based on a deceased parent's work history.

If an individual is approved for SSI in North Carolina, they will automatically be referred for and receive Medicaid (i.e. medical insurance). If an individual goes to work and loses their eligibility for SSI, they will be offered the opportunity to pay a minimal amount each month to maintain their Medicaid eligibility. **Eligibility for benefits that have been lost because of earnings, in most cases, can be re-established if an individual loses their job.**

If an individual is approved for SSDI, they must wait five months from the date of the application before the first monthly benefit will begin. When the benefit does begin, it usually will include a back payment for those five months. After two years of receiving SSDI an individual becomes eligible for Medicare (Medical Insurance). An individual approved for SSI usually starts receiving monthly benefits within a month of being approved. Again, always document SSA correspondence (i.e. dates of phone calls, staff names, what you were told) and save all letters from and to the SSA. Also assure that records (e.g. pay stubs reflecting income) are kept. If you are told that the Social Security Administration has over-paid your family member and that the member must pay back money, remember that you have the option to ask for a waiver of that payback. That is, if the individual receiving the benefit does not have sufficient funds in the bank and/or if they use all their income on living expenses each month, a waiver of the payback might be granted. There is a form for this waiver, which you can ask to be completed on your family member's behalf. If you need assistance in completing this process call the Autism Society of North Carolina or the Regional TEACCH center.

**Step Six - Residential Options**

**Temporary Respite**

Respite is a service that allows families to receive in-home or center-based assistance with the supervision and care of their family member with autism. This means that either a staff person comes into the home to supervise the individual while the family or parents leave or that the individual with autism goes to a respite center, for brief periods of time (i.e. hours, days, up to a month at center based regional centers). Again, the Single Portal Agency / Local Management Entity is the first place to apply for such services. Summer camp programs, before and after-school programs, and year round recreational services also can serve as respite services for families. Some families make arrangements with other families to provide respite services for each other.
Health care agencies that provide nursing assistant and companion care for the elderly or medically impaired have become a valuable resource for care providers. Look in the phone book under in-home nursing care to find these resources. If you request services from such an agency, make sure they understand the nature of your family member's disability. The CNA/Certified Nursing Assistant or Companion Sitter is the appropriate level of staff to request from such agencies. These agencies charge by the hour. If staff request training or consultation on how to work with an individual with autism, refer them to the Autism Society or TEACCH.

**Long-Term Residential Choices**

Many families come to the realization that moving away from home is just as appropriate and natural for an adult with autism as it is for an adult without autism. Others find it natural for their family to remain together indefinitely. Each family needs to decide what is best for them and take steps to ensure the success of that plan. Families, who choose to continue to provide for their family member at home, can access programs that offer in-home respite or more continuous/daily in-home care. Both of these options would involve a staff person who would come into the home to provide supervision, care, recreation, social, and daily living skills training. Families who choose such options need to make future contingency plans for the member with autism and for themselves. Such plans should make it clear how the family, upon their death or infirmity, wants to continue the care of the member with autism. Such plans might include having someone else (e.g. another family member) move into their home. Or it might include arranging for the individual with autism to move in with someone else, where his or her current care could be continued.

If a family decides to seek residential services outside of their home for their family member with autism, there are several different options. Those include group home living, family-care homes, boarding home, a nursing home, or (individual) supported living in an apartment, a regional state facility. Application for these programs can be made through the area, Single Portal Agency / Local Management Entity. Though group homes and other group living models were at one time the only residential programs available for individuals with autism, more emphasis is being placed now on individual, community based placements such as apartments/ houses, etc. with staff support provided. Such living arrangements can be funded through the Single Portal Agency / Local Management Entity and families should go there to apply. A family can always apply directly to a private residential program, but many area Single Portal / Local Management Entity programs require that all service programs certified in their area of jurisdiction only take referrals through the Single Portal / Local Management Entity Office. Contact the Autism Society of North Carolina for more information about residential services for people with autism throughout the state.
Step Seven - Trusts, Wills, Guardianship, and other Legal Issues

Information on each of these topics can be obtained from the Autism Society of North Carolina or from the Arc. Once an individual with autism reaches the age of eighteen years, he or she becomes an adult in the eyes of the law. This means the parent no longer has a legal right to make legal decisions on behalf of that child unless the parent or someone else, such as another family member, has filed with the courts for the right of guardianship over that individual. Becoming a guardian for someone means the courts have granted you the right to make decisions on their behalf. There are different types or levels of guardianship (i.e. limited guardianship) that provide for guardianship in specific areas only, such as in the case of medical or financial decisions. Some types of publicly funded programs such as CAP/MR/DD (i.e. Medicaid) require that guardianship be established. Again, for more in-depth information about guardianship and its implications, contact the Autism Society of North Carolina, the Arc, and/or an attorney experienced in these matters.

Trusts and wills that leave assets to individuals with autism will affect eligibility status for local, state, and federally funded programs. Guidelines for developing a life plan instruments can be obtained from the Autism Society, the Arc, N.C. Life Plan Trust http://www.autism-info.com/lyfplntr.htm and/or an attorney. If you contact an attorney without the assistance of these organizations, be sure to explain the following information. The individual with autism can have no direct say or control over any monetary benefits provided for them through a trust while, at the same time, they are receiving certain types of public/governmental monies (i.e. SSDI or SSI).

In addition to issues regarding wills and trusts, families need to remember to register males for the military draft at age eighteen. Questions regarding a specific individual's capability to engage in the military can be addressed by staff at the local TEACCH center or at the Autism Society of North Carolina.

Information provided in this document is subject to change as the laws and procedures governing it are modified. Check the ASNC http://www.autismsociety-nc.org/ or TEACCH web sites http://www.teacch.com/ for updates.
HELPFUL STEPS CHECKLIST

_____ Obtain a diagnosis which is documented in writing.

_____ Contact the Area Program / Single Portal Agency / Local Management Entity and complete the application process.

_____ Get confirmation that your application has been processed.

_____ Obtain a functional, educational assessment during the early adolescent years.

_____ Assure that the results of this assessment are integrated into goals of the IEP.

_____ Assure the IEP includes experiential, community based goals.

_____ Assure there is an annual evaluation of progress made on all goals.

_____ Assure a written transition plan (ITP) is in place at age 16.

_____ Assure a referral to VR has been made at age 16 or older if a work capability assessment is desired.

_____ Assure a referral to the Single Portal Agency / Local Management Entity has been made by the beginning of the final year of school unless your relative with autism is able to function independently.

_____ If the VR assessment or Transition Plan includes any form of employment, assure a referral is made back to the Single Portal / Area Program / Local Management Entity for Long-Term, Supported Employment.

_____ Keep a log in which all correspondence to and from agencies is documented.

_____ For individuals 17 and under with autism - If financially eligible and benefits are desired, apply to the SSA for SSI (includes Medicaid application).

_____ For individuals 18 and older with autism - If benefits are desired, apply to SSA for SSDI / Medicare and SSI/Medicaid.

_____ If respite is desired, apply through the Single Portal Agency / Local Management Entity.

_____ Consider a plan for the future needs/living arrangements you prefer for your relative with autism, which can be cared out in your absence.
_____ If residential living is desired, complete an application through the Single Portal Agency / Local Management Entity.

_____ Register all males for the draft at age 18.

_____ Consider the pros and cons of guardianship for your relative with autism.

_____ Assure the conditions of all trusts, involving your relative with autism, are measured against the pros and cons of leaving funds or property to that individual.