

Transition HELPBOOK



**For Families of Youth
on the Autism Spectrum
in Virginia**



2009 Revision

Dear Members of the Autism Community,

On behalf of Commonwealth Autism Service – our Board of Directors, Advisory Council and staff I welcome you to review our Transition HELPBOOK.

This tool was developed by Dottie Narodny, BA, BCaBA, Transition and Adult Services Coordinator with much cooperation from many talented people and organizations in the Virginia autism community.

Commonwealth Autism Service is pleased to make available this Transition HELPBOOK to individuals with autism, their families and their caregivers. We hope it serves to enhance the likelihood of successful transition to the wide variety of opportunities that await them. We are pleased to offer wide dissemination of this tool along with training in its use through a generous grant by ***Autism Speaks***. Their support is invaluable in making this tool both available and accessible to the autism community in the Commonwealth. We also acknowledge the original support from *The Greater Lynchburg Community Trust* for their support in the initial development of this tool.

We view this tool as a work in progress so please feel free to offer any comments and suggestions to continue to improve it.

Sincerely,

John

John A. Toscano, MSW, MBA
President & CEO

We as the author(s) of this publication hereby acknowledge *Autism Speaks Family Community Grants* as the funding agency for the project leading to this publication. The views expressed in this publication do not necessarily express or reflect the views of Autism Speaks or any other funding agency.



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Starting Out

The idea for creating this *Transition HELPBOOK* grew out of questions and experiences of youth and young adults on the autism spectrum and their family members.

Many people offered valuable input and shared their personal stories about successes and challenges as they progressed toward the end of special education services and made the transition to life after secondary school.

In offering the *HELPBOOK*, Commonwealth Autism Service hopes to provide a resource that will be useful to families in their efforts to achieve the best possible adult outcomes for their family members on the autism spectrum in Virginia.

Why a Transition HELPBOOK?

Students with disabilities receive special education services so that they can be appropriately prepared for further education, employment, and independent living.

Yet, outcome studies show that compared with their non-disabled peers, special education services have not leveled the playing field to the point where students with disabilities achieve these goals at a significant rate. Approximately half of students on the autism spectrum don't achieve any of the anticipated overall outcomes of special education.

With the passage of the Individuals with Disabilities Education Improvement Act of 2004, Transition Services requirements have been expanded with the expectation that students with disabilities will be better prepared to lead productive and independent adult lives when they leave school.

Understanding the transition process and ***starting as early as possible*** to prepare for the future is crucial to maximizing the individual's potential and quality of life.





FIND IT IN THE TRANSITION HELPBOOK

Table of Contents



Introduction & Inventory: p. 5

Inventory: p. 8

Transition Services and the Individualized Education Program (IEP): p.10

IEP Checklist: p.20

IEP Contact List: p. 25

Adulthood and Legal Competence: p. 26

Worksheet: p.29

Contact List: p. 31

Person-Centered Planning, Self-Determination and Self-Advocacy: p. 32

Worksheet: p. 35

Contact List: p. 39

Look at the Opportunities: p. 40

Worksheet: p. 45

Contact List: p. 51

Supports in the Home and Community - Medicaid Waivers: p. 53

Worksheet: p. 57

Contact List: p. 59

Social Security Administration and Disability Determination Services: p. 60

Worksheet: p. 63

Contact List: p. 65

Employment Supports/Work Incentives for Youth and Young Adults: p. 66

Worksheet: p. 69

Contact List: p. 71

Virginia Department of Rehabilitative Services: p. 72

Worksheet: p. 74

Contact List: p. 77

Appendices: pp. 78-163



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Transition and the Autism Spectrum

Though the processes and linkages of transitioning to post-school life are similar for all people, the diversity among individuals on the autism spectrum poses unique challenges for the individual, the family, and service providers.

Not the least of these is the individual's often intense need for consistent routines and environments that makes any transition experience potentially problematic.

Some of the challenges include:

- range and intensity of characteristics
- possible existence of co-existing intellectual, psychiatric, physical, and other disabilities
- diagnostic inconsistencies
- knowledge base of services providers
- expertise of transition and adults services providers
- complexity of access to adult services
- availability of adult services providers
- perspective of the individual
- concerns about disclosure of the diagnosis



Understanding Funding Streams

One of the confusing aspects of the transition process for families is the difference between eligibility for services supported by entitlement funding streams and eligibility for services that are **not** supported by entitlement funding.

When a student is found eligible for special education services, s/he then becomes “entitled”, or has the right to receive services that are funded by sources of money for the specific purpose of special education.

When the student exits school services, entitlement ends. Many advocates are working for change in this area, but at the present time, there are no guarantees once the individual leaves special education services.

At that point, the individual may be eligible for a variety of adult services, but can only access them if there is an available provider and a funding source to pay for the service.

By planning ahead, locating potential providers of adult services, and pinpointing funding streams for preferred options, individuals will be more likely to ultimately achieve their life goals.

What’s in the HELPBOOK?

- A Characteristics Inventory for you to use to create an individualized profile,
- Chapters, each with basic information on a specific topic,
- Questions to answer and a page to write in the names and contact information of people who can help you.
- Resources beyond the *HELPBOOK*
- Appendices with additional information and contacts for Commonwealth Autism Service



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Using the HELPBOOK

Begin with the Characteristics Inventory by checking the traits and writing in strengths and special interests or challenges that apply to your family member.

Then go back and mark the strengths and special interests that will be most likely to provide opportunities for further education or training, employment, and independent living. These are the important building blocks for transitioning to adult life. They will reflect the preferences and interests of the individual and the foundation for development of Transition Goals.

Then, mark the traits and challenges that are most likely to be the greatest obstacles to further education or training, employment, and independent living. These potential barriers will be your areas of focus for teaching new skills and identifying needed supports and accommodations.

The first chapter on Transition Services and the IEP will give you a better understanding of what could be included in the way of long range goals in a transition-focused IEP.

Later chapters will offer information about services and steps to take to prepare for the post-school years, as well as locations state-wide for transition and adult services providers.

Let's get started! Look over the Characteristics and Challenges Inventory on the next page and fill in the information about YOUR family member on the autism spectrum.



Individualized Characteristics and Challenges Inventory

- Identify the characteristics that are considerations for the individual on the autism spectrum.
- Add strengths, special interests, or additional potential challenges under "Other".
- Mark the traits and strengths that offer opportunities for the future.
- Mark the traits and challenges that may be obstacles for the future.

- Uses words to communicate
- Uses other ways to communicate
- Has difficulty communicating with peers
- Has difficulty communicating with adults
- Has difficulty communicating with strangers
- Is able to advocate for him/herself
- Needs others to advocate for him/herself
- Needs 1:1 support in most situations
- Has few or no same-age friends
- Has one or more same-age friends
- Can work together with another person(s)
- Has strong dietary preferences
- Needs certain kinds of sensory input

- Avoids certain kinds of sensory input
- Can calm him/herself when upset
- Has periods of behavior he/she can't control
- Has aggressive behavior toward others
- Has self-injurious behavior
- Has difficulty sleeping
- Has gastrointestinal problems
- Has a strong need for sameness and consistency
- Can make transitions with supports
- Has difficulty with large motor activities
- Has difficulty with fine motor activities
- Has attention or concentration difficulties



- Has difficulty understanding the emotions or perceptions of others
- Is able to accept directions from others
- Is able to accept suggestions from others
- Has eye-hand coordination difficulty
- Has difficulty processing auditory input
- Has difficulty processing visual input
- Has strong areas of special interest
- Has strong areas of competence
- Can self-initiate work activities
- Can complete work activities independently
- Is able to organize free time
- Can maintain a conversation with others
- Can initiate a conversation with others
- Has uneven development of cognitive skills
- Has strong cognitive skills in areas of interest
- Has mild intellectual disability
- Has moderate intellectual disability

- Has severe intellectual disability
- Has difficulty completing tasks with time limits
- Has difficulty interpreting tone of voice and body language of others
- Has been diagnosed with bi-polar disorder
- Has been diagnosed with obsessive compulsive disorder
- Has been diagnosed with an anxiety disorder
- Has been diagnosed with depression
- Has been assessed for executive dysfunction
- Other:



Transition Services and the IEP

From IDEA... to Action

No matter "where" your family member is on the autism spectrum, you probably have questions about his/her readiness for adult life. Your family member may be anxious about moving on into unknown territory. With the information and resources in the Transition HELPBOOK, you can better prepare to face the challenges involved in developing an Individualized Education Program that focuses on Transition Goals and Services.

➤ **How early can we start?**

It's never too soon to learn self-advocacy and self-determination skills. More parents are including their children in IEP meetings as early as elementary school to bring their child's perspective to the Team and to help their child become more comfortable expressing his or her needs and interests.

Student involvement in the IEP process is one of the top evidence-based secondary transition practices linked with improved outcomes after the student leaves school!

When an IEP Team meeting is held to discuss postsecondary goals or Transition Services, the student must be invited to participate.

If the student doesn't attend the meeting, the school division is required to take other steps to ensure that the student's preferences and interests are considered.

At this writing, Transition Services must be included not later than the first IEP that will be in effect when the student turns age 16. Remember, though, that Transition Services can be discussed and included in the IEP at a younger age, if the IEP Team agrees. More and more families are starting this discussion prior to transition from elementary to middle school with the realization that advance planning and information is essential to future success.



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Even before a transition focused IEP is written, families can create a vision for the future based on the needs and interests of their family member on the autism spectrum and begin looking at what opportunities are available in their home communities for the adult their child will become.

➤ **Transition Services IEP Team Members**

In addition to school staff, the student and his/her parents, representatives of any participating agency likely to be responsible for providing or paying for transition services must be invited by the school division to attend IEP Team meetings when postsecondary goals or Transition Services will be discussed, to the extent appropriate.

Notification of intent to invite outside agencies must be provided and consent must be given by the parent or student (18+) due to confidentiality issues.

As with any IEP Team meeting, the parents and student can invite others who may be of help in planning for the future and providing input into the transition process to participate.

Because there will be so much new information to absorb when the discussions begin, it's helpful to have a series of small group planning meetings before bringing everyone to the table.

➤ **Who's in the Transition Boat with You?**

The following list of some of the potential "links" to your child's future will give you an idea of the agencies and organizations who could be involved in planning for transition and postsecondary opportunities:

- Department Of Rehabilitative Services (DRS)
- Employment Services Organization (ESO)
- CWIC/WISA (SSA Benefits/Work Incentives)



- Residential Services Providers
- Transportation Services Providers
- College Disability Services Coordinator
- Center for Independent Living Representative
- Day Support Services Providers
- Community Services Board Case Manager
- DD Waiver Support Coordinator/Case Manager

More information about many of these service providers are in other chapters in the HELPBOOK.

You can also ask your school's Transition Coordinator to assist you with local contacts and details of services in your community. And school divisions may have a list of services in their communities that are usually provided with the Summary of Performance (more on this next!) when the student exits school.

Asking for this information at the beginning of the transition process will give you the opportunity to investigate what's available locally that might be of benefit to your family member in the future.

➤ **Begin with the End in Mind: The Summary of Performance**

Before getting into the specific elements of a transition-focused IEP, you should know that when a student exits school services a Summary of Performance and Achievement (SOP) must be provided. This document generally includes:

- Summary of academic achievement and functional performance
- Recommendations on how to assist the student in meeting postsecondary goals



Here are some other items that can be included and may be helpful for postsecondary services eligibility:

- Student's primary and secondary disability
- Recent assessment reports that document the student's disability or functional limitations and provide information to assist in post-school planning
- Current psychoeducational evaluation using adult norms, if the student is planning to attend a program of higher education and may need accommodations
- Intended post-school transition environments
- Academic, cognitive, and functional levels of performance
- Accommodations, modifications, and assistive technology that essential to assisting the student in achieving progress
- Recommendations for accommodations, assistive services, adaptive devices, compensatory strategies, and/or support services to enhance access in the post-school environment
- Student input and perspective

Knowing what should be included in the SOP will help you organize and plan the development of a transition-focused IEP. Linking the SOP with the IEP process and involving the student in the development of the document will maximize the usefulness of the SOP that will be given to the student when he or she exits school.

Copies of a model SOP developed by the National Transition Documentation Summit and also the SOP form available on the Virginia Department of Education website are included in the Appendices of the HELPBOOK.



➤ What are Transition Services?

Transition Services are defined in current special education law as a coordinated set of activities for a student with a disability that:

- 1 Is a results-oriented process
- 2 Is focused on improving the academic and functional achievement of the student with a disability
- 3 Facilitates the student's movement from school to post school activities, including:
 - o Post secondary education
 - o Vocational education
 - o Integrated employment (including supported employment)
 - o Continuing and adult education
 - o Adult services
 - o Independent living, or
 - o Community participation

Transition Services are all about outcomes and self sufficiency!

➤ What is a "Coordinated Set of Activities"?

- 1 Based on the individual student's needs
- 2 Takes into account the student's
 - o Strengths
 - o Interests
 - o Preferences



3 Includes

- o Specially designed instruction
- o Related services
- o Community-based experiences
- o Development of employment skills
- o Development of other post-school adult living objectives; and
- o If appropriate, acquisition of daily living skills and a functional vocational evaluation

You might wonder what is meant by “functional vocational evaluation” As the National Secondary Transition Technical Assistance Center (NSTTAC) defines it, it is: “...“an assessment process that provides information about job or career interests, aptitudes, and skills. Information may be gathered through situational assessment, observations or formal measures, and should be practical.”

➤ **The Transition-Focused IEP**

This document, updated annually, should:

- Include appropriate measurable Postsecondary Goals for each of the anticipated post-school environments/options. Postsecondary Goals specify what the youth will be doing after leaving school. So, this will be a projection into the future, rather than the usual IEP goals that should take place within the year of implementation of the IEP.

Some examples of Postsecondary Goals can be found in the Appendices, along with some resources for finding out more about how to develop Postsecondary Goals.

- Be based on age appropriate transition assessments related to:
 - o Training



- Education
- Employment, and
- Independent living skills, where appropriate

One resource for finding out about assessments that are available to help you decide which are most appropriate for your family member's needs is available on the Virginia Department of Education Training and Technical Assistance Center website. Check this out at:

<http://www.vcu.edu/ttac/transition/assessment.shtml>.

Reviewing the Characteristics and Challenges Inventory will help you determine what assessments might be needed.

- Include transition services, including courses of study, needed to assist the child in reaching those goals
- Work experiences or "community based work assessments" chosen should be based on the student's:
 - Interests and abilities
 - Placement decisions should help the student develop skills in a setting that is of personal interest to him/her

➤ **Other Things to Keep in Mind**

- Annual Goals in the transition IEP should lead to reasonable desired post-high school outcomes as stated in the Transition Goals. Transition Goals state what will happen after the student leaves school and Annual Goals in the transition IEP help the student reach the "ultimate" Transition Goals.
- Progress should be documented and measurable
- Parents and the student should request progress reports about community-based work experience



- Parents and the student should discuss with the IEP team how their child will meet post-school goals without a lapse in supports and services
- Parents and the student should maintain a portfolio and resume of their child's work experiences, progress reports, and favorable reviews from supervisors
- Seek placement settings where the student's unique abilities can be successfully utilized and improved

➤ **Failure to Meet Transition Services Requirements**

What happens if a participating outside agency fails to provide the transition services that are listed in the IEP?

If this happens, then the local school division must reconvene the IEP team to identify alternative strategies to meet the transition objectives set out in the IEP.

The participating outside agency is still responsible for any transition service they would otherwise provide an individual with a disability meeting agency eligibility criteria, assuming availability of a funding source.

This goes back to the information in the HELPBOOK regarding funding streams, and the fact that the individual can receive services only if s/he meets agency eligibility criteria and a funding stream is identified.

It will be vital for you to understand eligibility criteria for potential post-school environments your family member hopes to access.

➤ **What about College and Vocational Schools?**

In talking with families during the development of the Transition HELPBOOK, there was confusion about rights and responsibilities in postsecondary settings such as 2- and 4-year colleges, and vocational or career schools.

Special Education laws and regulations do not apply in institutions of postsecondary education and while providing a copy of the IEP and the Summary of Performance (SOP) may be helpful, it does not mean that the student will be able to access the same supports, accommodations, or services s/he received in secondary school.

Additionally, the youth will be expected to be his/her own advocate in postsecondary education and training settings. This means the prospective postsecondary education/training student will need to meet with the Disabilities Services representative at the school he or she wishes to attend to discuss what accommodations and supports will be provided. Once these are documented, the youth will need to be prepared to provide this information to professors and exercise appropriate self-advocacy skills.

Making contact with Disability Services Coordinators at institutions of postsecondary education will clarify what can and cannot be done in the way of accommodations and supports.

A copy of a recent letter from the U.S. Office of Civil Rights on this subject is included in the Appendices for more details and resources.

➤ **Testing Options, Diploma Types, Graduation**

As early as elementary school, families make decisions as part of the IEP team about which testing options will be appropriate for their child.



Decisions about testing options are closely related to graduation requirements and the type of diploma a student can receive. These decisions will influence transition status related to postsecondary goals.

Be sure to ask questions of special education service providers about the relationship of any testing choices you are considering to diplomas and diploma types. Be sure to check into Career & Technical Education courses and specialized diplomas. The Virginia Department of Education website is a good place to look to find out more on these subjects: www.doe.virginia.gov.

If your child will not meet the requirements for a standard or advanced studies diploma, the school division is required to notify you that your family member has the right to continue receiving special education services through age 21.

➤ **Before You Go to the Checklist...**

The Virginia Department of Education website (www.pen.k12.va.us) has an extensive list of additional resources and information you can access, including sample forms for Transition IEPs. You can also call and speak with a VDOE representative to get answers to questions you may have (1-800-422-2083).

For individuals on the autism spectrum and their families, it's vital that the characteristics of autism that are applicable to the individual and any other factors that will affect the individual's ability to access adult options are identified, discussed, and addressed in a timely manner.

Self-advocacy skills that enable the individual to express his/her needs as well as parental advocacy will be necessary, especially in situations where service providers are still gaining experience in working with and relating to those with autism spectrum disorders.



Checklist for the Transition-Focused IEP

	Postsecondary goal(s) for further education	Postsecondary goal(s) for further training	Postsecondary goal(s) for employment	Postsecondary goal(s) for independent living
Are there postsecondary goals in the <u>Transition Component</u> of the IEP?	<input type="checkbox"/> Yes <input type="checkbox"/> No			
Are they Measurable?	<input type="checkbox"/> Yes <input type="checkbox"/> No			
Is there an annual IEP goal(s) or short term objective(s) that will reasonably enable the student to meet this postsecondary goal(s)? (<u>Look in the Annual Goals section of the IEP</u>)	<input type="checkbox"/> Yes <input type="checkbox"/> No			
Are they Measurable?	<input type="checkbox"/> Yes <input type="checkbox"/> No			



Checklist for the Transition-Focused IEP, continued...

	Postsecondary goal(s) for further education	Postsecondary goal(s) for further training	Postsecondary goal(s) for employment	Postsecondary goal(s) for independent living
<p>Are there <u>Transition Services</u> in the IEP that focus on improving the academic and functional achievement of the student to facilitate movement from school to post-school for this postsecondary goal(s)? (<u>Look in the Transition Services/Activities section of the IEP</u>)</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Instruction <input type="checkbox"/> Related services <input type="checkbox"/> Community experience <input type="checkbox"/> Development of employment and other post-school adult living objectives <input type="checkbox"/> Acquisition of daily living skills, if appropriate <input type="checkbox"/> Functional vocational evaluation, if appropriate 	<ul style="list-style-type: none"> <input type="checkbox"/> Instruction <input type="checkbox"/> Related services <input type="checkbox"/> Community experience <input type="checkbox"/> Development of employment and other post-school adult living objectives <input type="checkbox"/> Acquisition of daily living skills, if appropriate <input type="checkbox"/> Functional vocational evaluation, if appropriate 	<ul style="list-style-type: none"> <input type="checkbox"/> Instruction <input type="checkbox"/> Related services <input type="checkbox"/> Community experience <input type="checkbox"/> Development of employment and other post-school adult living objectives <input type="checkbox"/> Acquisition of daily living skills, if appropriate <input type="checkbox"/> Functional vocational evaluation, if appropriate 	<ul style="list-style-type: none"> <input type="checkbox"/> Instruction <input type="checkbox"/> Related services <input type="checkbox"/> Community experience <input type="checkbox"/> Development of employment and other post-school adult living objectives <input type="checkbox"/> Acquisition of daily living skills, if appropriate <input type="checkbox"/> Functional vocational evaluation, if appropriate



Checklist for the Transition-Focused IEP, continued...

	Postsecondary goal(s) for further education	Postsecondary goal(s) for further training	Postsecondary goal(s) for employment	Postsecondary goal(s) for independent living
Are the postsecondary goals based on one or more age-appropriate transition assessment(s)? (<u>Look in the IEP or in the student's file</u>)	<input type="checkbox"/> Yes <input type="checkbox"/> No			
Did the transition assessments take into account the student's needs, strengths, preferences, and interests for each postsecondary goal(s)?	<input type="checkbox"/> Yes <input type="checkbox"/> No			



Checklist for the Transition-Focused IEP, continued...

	Postsecondary goal(s) for further education	Postsecondary goal(s) for further training	Postsecondary goal(s) for employment	Postsecondary goal(s) for independent living
Do the Transition Services include courses of study (coursework) that focus on improving the functional achievement of the student that are aligned with the postsecondary goals? (<u>Look in the IEP</u>)	<input type="checkbox"/> Yes <input type="checkbox"/> No			
Is the coursework a multi-year description of coursework from the student's <u>current year</u> to the anticipated <u>exit year</u> designed to help achieve the student's desired post-school goals?	<input type="checkbox"/> Yes <input type="checkbox"/> No			



Checklist for the Transition-Focused IEP, continued...

	Postsecondary goal(s) for further education	Postsecondary goal(s) for further training	Postsecondary goal(s) for employment	Postsecondary goal(s) for independent living
For Transition Services that are likely to be provided or paid for by other agencies, with parent or child consent (age 18+), is there evidence that representatives of the agencies were invited to the IEP meeting? (Look in the IEP)	<input type="checkbox"/> Yes <input type="checkbox"/> No			
What agency(ies) will be providing or paying for services?				





Contact List for the Transition-Focused IEP



IEP Case Manager:

Name _____ Contact info _____

Transition Coordinator:

Name _____ Contact info _____

Vocational Rehabilitation Counselor:

Name _____ Contact info _____

Employment Services Organization Representative:

Name _____ Contact info _____

Center for Independent Living:

Name _____ Contact info _____

Medicaid Waiver Assistance:

Name _____ Contact info _____

Assistive Technology Resource:

Name _____ Contact info _____

Social Security Administration Work Incentives Counselor:

Name _____ Contact info _____

On the back of this page, add additional contact information for others who can help with each of the postsecondary goals and services identified in the Transition-Focused IEP



Adulthood

Legal Competence...All or Nothing?

Legal adulthood in Virginia arrives at age 18 and certain rights and responsibilities are automatically conferred upon the youth. Among the legal rights that arise on one's 18th birthday include the right to vote and to make one's own financial, medical, and educational decisions. In addition, re-determination for some benefits, such as those received through Social Security Administration programs, will be made based on adult criteria.

➤ **Conditions for Determining Competence**

Like most high school students and young adults, youth on the autism spectrum will continue to want and/or need support and advice from family members as they move toward postsecondary life and independence.

It's helpful to understand that legal involvement in the life of an adult child is not necessarily "all or nothing".

For a family member on the autism spectrum, overall competence may be affected by social and communication deficits and difficulties with understanding the perspective of others.

Legal involvement of parents in their adult child's life can be set up and changed over time to reflect the individual's growth toward self-sufficiency and independence as well as changes in individual and/or family circumstances.

This may mean that some families will need to seek full guardianship or may decide to pursue other less restrictive options prior to the youth turning age 18.

The legal processes can be confusing and complex. Seeking advice early from an attorney or advocacy organization representatives with experience in selecting and developing legal options for youth on the autism spectrum and their families is critical.



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➤ Tools

Power of attorney, guardianship, conservatorship, wills, trusts, and advance medical directives (living will and healthcare power of attorney) are the primary legal tools used to assist families and individuals with delegating or retaining control over major life decisions to the extent appropriate.

Letters of Intent are also beneficial and provide guidance for courts and others involved in making legal decisions that affect your family member.

The legal processes can be confusing and complex. Seeking the advice of an attorney or advocacy organization representatives with experience in selecting and developing legal options for youth on the autism spectrum and their families is critical.

More detailed information, including alternatives to guardianship, can be found in the Appendices under the heading *Legal Tools for Families*.

➤ Thinking Points

When a youth or young adult does not have a passport or driver's license, another form of official photo identification will be needed. The Virginia Department of Motor Vehicles offers secure photo IDs. Check with your local DMV office or the DMV website for more information.

One question on the application for a photo ID for young men is whether or not he has registered for the Selective Service. Men with disabilities that would disqualify them from military service still must register with the Selective Service. Check to see if your family member's High School has a Selective Service Registrar who can help him register.

For youth receiving Social Security Administration benefits, designation of a representative payee will need to



be reviewed prior to age 18.

For youth receiving special education services, all of the legal rights of parents are transferred to the student at age 18. Parents and students must be notified at least one year prior to the student's 18th birthday about the transfer of rights.

The next section explains what steps parents can take if their family member needs assistance with the special education process.

➤ **Educational Decision-Making**

As with all legal involvement options that come when children reach the age of 18, responsibility for educational decision making is not necessarily an all or nothing situation.

The Virginia Department of Education (VDOE) has developed a resource document explaining the three options that schools recognize related to the determination of an adult student's ability to make educational decisions. These options allow a parent, family member, or other person to be appointed to make educational decisions on behalf of an adult student, if appropriate.

A student capable of giving informed consent can designate an adult to be the student's agent to receive notices of IEP meetings and to be involved in all other aspects of the IEP process through a specific Power of Attorney. Power of Attorney may be revoked or terminated by the student.

For youth who are not capable of giving informed consent, there are two options. The first is being appointed as a Guardian through court proceedings. The second is by getting certification from certain professionals that the student is incapable of giving informed consent. More information and sample forms for certification and Power of Attorney are in the Appendices of the HELPBOOK.



The following section offers some questions to consider as you seek to identify options with your family member about the changes that come with adulthood.

BECOMING AN ADULT

1. What legal rights and responsibilities will I be ready for when I turn 18?
 - Voting?
 - Taking care of my own finances?
 - Making my own medical decisions?
 - Making my own educational decisions?
 - Having my own insurance?

2. If I need advice about my legal rights and responsibilities, who will help me?

3. If I receive benefits from the Social Security Administration, have I contacted them about re-determination as an adult? Will I still need a representative payee when I turn 18?

4. Do I have an official photo identification card? If not, who can help me get one?

5. What kinds of support and assistance will I need from family members and others when I am an adult?

6. Who will give me the supports and assistance I need?



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7. Do I need a guardian or conservator to help me make decisions and manage my finances? If so, who will be my guardian or my conservator?
8. Do I have an advance medical directive?
9. Do I attend my IEP meetings at school? If not, who can help me get involved and be a leader at my IEP meetings?
10. Has my school told me about being responsible for my own educational decisions when I turn 18? If not, who can help me learn about this?





Contact List for Adulthood



Voter registration information:

Name _____ Contact info _____

Medical, dental, pharmacy, psychological, counseling, etc.:

Name _____ Contact info _____

Social Security Administration:

Name _____ Contact info _____

Guardian, conservator, attorney:

Name _____ Contact info _____

Department of Motor Vehicles:

Name _____ Contact info _____

Other people who can help:

Name _____ Contact info _____

Name _____ Contact info _____



*On the back of
this page, add
additional
contact
information for
others who can
help with the
transition to
legal adulthood
at age 18*



Person-Centered Planning

Hear my voice...Honor my choice

Person-centered planning is a useful process for individuals, their families, and service providers as they talk together and plan for the individual's future. The focus is on the youth or young adult and the development of partnerships to build an adult lifestyle that reflects personal choice and self-determination.

➤ Starting out

To begin the process, sit down with people who understand the individual's way of communicating, what makes him/her most comfortable in his/her environment(s), and who can best help the individual think about and express his/her hopes and plans for the future.

If discussions about an adult future haven't taken place previously, start by talking about what the individual wants to do tomorrow, next week, next month, next year, or any point on that continuum that is comfortable for him/her.

For some youth on the autism spectrum, thinking about the future and growing up can bring about feelings of strong anxiety.

Discussions about the eventual death of family members or other major life transitions are not the best way to start planning for the future with the individual.

Rather, taking small steps during discussions about the future can lessen the potential for anxiety.

Focus on the positive aspects of planning for the future, even if the first discussion begins with planning for the next day!



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➤ Considerations during the process

It may be challenging at times to detect the individual's preferences and needs from his/her perspective, even for those closest to the individual.

The individual may have difficulty conceptualizing and articulating his/her preferences and needs, even when expressive communication skills are well-developed.

Frequent consistent opportunities for discussion will best serve the individual and everyone involved in the transition process.

Keeping the futures planning discussion going over time can help counter feelings of confusion and frustration that sometimes can occur during transition to middle and high school and the even greater challenges of transition to adulthood and postsecondary life.

Although adult options for individuals on the autism spectrum are increasing, many gaps remain in understanding specific needs of individuals on the spectrum. Pragmatic communication, social skills, executive functions and sensory needs are generally those areas that are least understood by people who have not had previous close association with someone on the autism spectrum.

The purpose of person-centered planning is not to try to fit individuals to available options; rather it is about real choices, independence, and access to services and supports that are proactive and responsive to individual strengths and preferences.

For youth and young adults on the autism spectrum, finding, or in many cases, creating the "right" option requires major advocacy efforts.

Families often will be called on to share their expertise and may need to “interpret” to others who do not know the individual or do not fully understand how features of autism affect his/her communication, behavior, social interaction, and learning style.

Be prepared to provide information during the transition process even as you continue to expand your child’s self-advocacy skills.

➤ **Adolescence and beyond...**

As individuals on the autism spectrum enter adolescence, new issues often arise along with the typical features of adolescence.

For some, a specific diagnosis may not occur until middle or high school, leaving families scrambling for information and appropriate services.

For others depression, psychiatric disorders, increasing social phobia, anxiety, and other concerns may emerge or intensify.

The individual and his or her family may also be concerned about the effects of disclosure of an autism spectrum diagnosis to others.

Family members may be in varying stages of crisis due to stressors both related and unrelated to the features of autism spectrum disorder manifested by the individual.

These are all factors that can be taken into account during the process of person-centered planning and will influence the steps taken to overcome obstacles and capitalize on the preferences, strengths, and special interests of the individual which are the most likely sources of future success.



The extent and intensity of assistance needed and received by the individual and his/her family unit during the transition process is related to the probability of success and achievement of desired post-school outcomes.

Seeking effective ways for the individual, regardless of age or ability, to communicate with others, request accommodations, and express other needs as well as dreams for the future will be his/her foundation for a self-determined life.

The following list of questions will help you work toward achieving life goals by developing a list of special interests, preferences, dislikes, optimal environmental conditions, etc., as well as ideas about what the individual would like to do in the future.

My Life....My Plan

➤ What do I like best?

- About being at home:
- About being at school:
- About being in the community:

➤ What are the things I do best?

- At home:
- At school:
- In the community:



➤ What things are hardest for me to do?

- At home:
- At school:
- In the community:

➤ The places I most like to be:

- At home:
- At school:
- In the community:

➤ The people I like best:

- At home:
- At school:
- In the community:



➤ Things I don't like:

- At home:
- At school:
- In the community:

➤ The best way for me to talk with people is:

➤ When I meet new people, I feel:

➤ When I go someplace I've never been before, I feel:

➤ I feel happy when:

➤ I feel sad when:

➤ I feel angry when:

➤ The kinds of foods I like are:

➤ The kind of sound I like is:



- The kind of light I like is:

- My favorite activities are:

- What I like best about a friend:

- When I'm with a friend, I like to:





Contact List for Person-Centered Planning



People who will participate in the person centered planning meeting(s):

Name _____ Contact info _____
 Name _____ Contact info _____
 Name _____ Contact info _____
 Name _____ Contact info _____

Parent Resource Center (books and resource materials):

Name _____ Contact info _____

Trained person centered planning facilitator:

Name _____ Contact info _____

Family/Caregiver Training provider (DD Waiver):

Name _____ Contact info _____



*On the back of
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 contact
 information for
 others who can
 help with
 Person-
 Centered
 Planning*



Look at the Opportunities!

Living...Learning...Working

*Everyone needs opportunities and supports to live a self-determined life. Connecting interests and preferences with choices and options that are available in or near your community is a good first step. It's never too early to reach out and make these connections! For many individuals, it may be necessary or beneficial to look beyond what is available locally for models in other areas that can be used to help **create** the kinds of opportunities and supports that work for the individual.*

➤ **What's in your community?**

If desired options for the individual are not known to you or are not yet available in your community, you can be an advocate and a resource for service providers to replicate programs that exist elsewhere or to develop new programs and supports.

A Transition Council may be meeting near you and your participation is one way to meet and work with others to develop awareness and locate services to meet your family member's individual needs.

Information about existing Transition Councils is included in the Appendices.

➤ **Where are the opportunities/supports?**

Supports evolve from working together, having fun, and offering motivational opportunities specific to the individual's special interests and preferences.

The closest and easiest opportunities and supports for individuals on the autism spectrum are the natural ones found within families.



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Earning/spending money, participating in family routines, and giving input into family decisions are natural ways to learn functional skills necessary to adult survival at whatever level is appropriate for the individual.

➤ **Expanding beyond home**

Natural opportunities and supports are also typically found among friends, neighbors, co-workers, and community groups.

If communication, social, and/or behavior differences are not understood and accepted by those outside the immediate family, then it will be necessary to increase understanding and acceptance by others through personal advocacy.

Work to find ways for the individual to develop self-advocacy skills that will help overcome barriers to understanding and acceptance by others. Self-determination and self-advocacy skills development can be incorporated into the IEP. Many excellent assessments, tools, and curricula that schools and families can use to develop these skills can be found at www.imdetermined.org.

Talking with friends, neighbors, co-workers, and members of community groups about the special interests and strengths of the individual may lead to participation in activities related to shared special interests.

Opportunities include volunteer work, part-time jobs after school, during holidays, and in the summer, mentoring or being mentored, job shadowing, and spending time away from home in safe environments.

All of these have the potential to increase capacity to interact and feel comfortable with life as part of the larger community.

Networking with other individuals on the autism spectrum and their families is often an effective way to find opportunities and supports of which you may not have been aware.



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There are numerous informal groups and organizations meeting around Virginia that offer occasions for parents, siblings, and individuals on the spectrum to network, exchange ideas and information, help one other, and just have fun together.

A list of many of these groups and organizations can be found in the Appendices.

➤ **Making a fresh start**

In some cases, the individual and family may have had negative experiences when venturing out beyond home or school environments and feel anxious about deviating from comfortable routines.

When behavior has been misinterpreted by others or actions of the individual have led to consequences such as involvement with the juvenile justice system, special efforts by everyone involved will be needed to identify steps to enable the individual and family to move beyond past history. This may require assistance from an experienced counselor and in-home supports as well as community-based supports.

Counseling and behavioral support services can often be accessed through Community Services Boards/Behavioral Health Agencies, Medicaid and Medicaid Waivers and university-based autism centers. Information about where to access these supports is included in Transition HELPBOOK chapters and in the Appendices.

Seeking out environments that support gradually increased opportunities to learn and practice public behavior and social interaction may seem difficult, but finding the right fit is worth the effort.

When the individual reaches adulthood and he/she will need to be able to cope with decreased levels of shelter and protection by familiar adults and engage in increased interaction with unfamiliar peers and authority figures regardless of the adult environments that are accessed.



It will be helpful in the long term to seek ways to move beyond any history of negative experiences and take concrete steps that will build a new history of positive, motivating experiences.

➤ **Opportunities in school settings**

Keep criteria for supportive environments in mind when you are working on developing Individualized Education Programs leading up to postsecondary transition.

With an increasing number of students on the spectrum receiving special education services, many schools have put programs into place that not only include peer supports in classrooms, but extend to extracurricular activities.

If these programs are not yet in place in your child's school, seek out models elsewhere and work with the IEP Team to bring them into your child's school environment.

Look for experienced professionals in the school or in the community who can be contracted to train or assist school staff to learn how to facilitate social interactions with peers and authority figures.

Postsecondary options such as 2 and 4 year college programs for individuals on the autism spectrum, including those with learning challenges, are increasing every year. Learning the social and functional skills necessary for preparing the individual to be successful in new environments can be incorporated into the IEP.

Identifying and defining essential supports and accommodations are also important elements to include in any IEP. And once the essential supports and accommodations are in place and proving to be effective, collaborative efforts to scale back supports and accommodations over time as the student matures and is ready to become more independent is a helpful step toward transitioning to adult environments.



➤ **Support providers in the community**

System supports are available through public and private service agencies and as you go through the HELPBOOK, you will learn more about specific system supports available prior to and during the transition process and preparation for adult life.

You will be able to identify specific individuals within agencies who will become primary contacts for information and access to services.

Remember, once the individual exits the system of mandated special education services, different criteria for service eligibility are applied and generally, services are NOT mandated.

Points of entry into various service systems may initially be confusing and service provision and responsibility among agencies may overlap, change, and be affected by economic and geographic considerations.

Just as you once learned (and are probably still learning) the “language” of special education services, you will be learning multiple new languages and terminology related to transition and adult services and options!

Be sure to ask the Transition Coordinator about opportunities for work experiences, internships, mentoring, job shadowing and other community-based pre-employment prospects.

The questions in the next section will help you identify areas of interest to your family member as well as identify possible supplementary experiences.



Opportunities to Move Forward

➤ **Learning: 2 or 4 year college**

1. I can learn more about my special interests best at college.
 - a. Yes
 - b. No
2. College is not what I want or need.
 - a. Yes
 - b. No
3. I need to know more about college options before I can decide.
 - a. Yes
 - b. No

➤ **Learning: Community College Campus-based transition programs for students 18-21**

1. There is a program like this for students in my area and I am planning to attend.
 - a. Yes
 - b. No
2. I would like to find out if there is a program like this for students in my area.
 - a. Yes
 - b. No
3. I'm planning to go to a 2 or 4 year college, get a job, or be in a day support program, so I am not interested in a program like this.
 - a. Yes
 - b. No



➤ **Learning: Career and vocational training programs**

1. I plan on entering a career or vocational training program.
 - a. Yes
 - b. No
2. I need to find out more about career or vocational training programs I can attend.
 - a. Yes
 - b. No
3. I'm planning to go to a 2 or 4 year college, get a job, or be in a day support program, so I am not interested in career or vocational training programs now.
 - a. Yes
 - b. No

➤ **Working: Career exploration**

1. I have participated in career exploration activities such as internships, job shadowing, or job sampling.
 - a. Yes
 - b. No
2. I have not participated in any career exploration activities yet.
 - a. Yes
 - b. No
3. I would like to find out how I can participate in career exploration activities.
 - a. Yes
 - b. No



➤ **Working: Vocational preparation**

1. I have completed a functional vocational assessment.
 - a. Yes
 - b. No
2. I have not completed any kind of vocational assessment yet.
 - a. Yes
 - b. No
3. I would like to find out how I can get a vocational assessment.
 - a. Yes
 - b. No
4. I have heard about Woodrow Wilson Rehabilitation Center and their vocational assessment programs.
 - a. Yes
 - b. No
5. I would like to find out more about Woodrow Wilson Rehabilitation Center and their vocational assessment and other programs.
 - a. Yes
 - b. No
6. My school has vocational preparation programs and I am taking vocational preparation classes.
 - a. Yes
 - b. No
7. I would like to find out more about vocational preparation programs at my school.
 - a. Yes
 - b. No



➤ **Working: Experience**

1. I have had work experience as an unpaid volunteer in my community.
 - a. Yes
 - b. No
2. I have earned money working for family and neighbors.
 - a. Yes
 - b. No
3. I have worked part-time earning money after school and during the summers.
 - a. Yes
 - b. No
4. I have had other kinds of work experiences and they are:

5. I have never had any work experience, including regular jobs or responsibilities in my home.
 - a. Yes
 - b. No
6. I need help finding ways to get work experience.
 - a. Yes
 - b. No

➤ **Living: Independence skills**

1. I can be independent in my daily life with minimal or no supports.
 - a. Yes
 - b. No



2. I can be independent away from my family or familiar environments.
 - a. Yes
 - b. No
3. I need to learn more independence skills.
 - a. Yes
 - b. No
4. I have lived away from my home and family for a week or longer.
 - a. Yes
 - b. No
5. I have lived away from my home and family for more than a night.
 - a. Yes
 - b. No
6. I would like to try staying overnight or longer away from my home and family.
 - a. Yes
 - b. No

➤ **Living: Money**

1. I can manage my money with little or no help.
 - a. Yes
 - b. No
2. I need to know more about how I can manage my money.
 - a. Yes
 - b. No
3. I have a savings account where I save money for things I want or need.
 - a. Yes
 - b. No



➤ **Living: Transportation**

1. I have a driver's license.
 - a. Yes
 - b. No
2. I would like to get a driver's license in the future.
 - a. Yes
 - b. No
3. I ride public transportation.
 - a. Yes
 - b. No
4. I would like to try riding public transportation.
 - a. Yes
 - b. No

➤ **Some other things I would like to know about or do are:**





Contact List for Moving Forward



School transition coordinator:

Name _____ Contact info _____

People I have worked for:

Name _____ Contact info _____

Name _____ Contact info _____

Name _____ Contact info _____

People I would like to work with:

Name _____ Contact info _____

Name _____ Contact info _____

Places where I would like to work:

Name _____ Contact info _____

Name _____ Contact info _____

Name _____ Contact info _____

Department of Rehabilitative Services Counselor:



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Name _____ Contact info _____

Center for Independent Living:

Name _____ Contact info _____

Work Incentives Specialist:

Name _____ Contact info _____

Assistance with access to Medicaid Waivers:

Name _____ Contact info _____

Disabilities Services Coordinator at a College or Technical School:

Name _____ Contact info _____

Employment Services Organization:

Name _____ Contact info _____



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Supports in the Home and Community

Toward Independence...With Help!

Helping youth on the autism spectrum increase independence and self-advocacy skills are goals families and service providers strive for. But without opportunities to practice and generalize newly acquired skills across environments and people, those skills may be lost or insufficiently developed. Further, transitions and change pose significant challenges to even the most competent person with autism. Home and community-based supports and services can help you meet the challenge.

➤ Medicaid Waivers

The Medicaid program is an enormously important source of money to pay for services and supports for people with developmental disabilities. About \$3 of every \$4 that states spend for developmental disabilities services comes by way of Medicaid. Once, Medicaid dollars only paid for institutional services. Today, Medicaid allows more diverse services and supports for individuals in the community, by "waiving" the need to get those same services in an institution.

Medicaid Waiver funding help individuals with disabilities access integrated community settings appropriate to their individual support requirements and preferences, exercise meaningful choices, and obtain quality services.

Families caregivers do not always have the time and resources to provide opportunities to help their family member on the autism spectrum access a variety of environments and interact with diverse people due to the demands of work, household responsibilities, and the needs of other family members.

For many families, Medicaid Waiver Services can offer much-needed supports and assistance across environments and reduce some of the pressure to "do it all".



Access to Medicaid Waiver Services can help individuals remain in the community rather than going to a residential placement. For others, it may increase independence so that support intensity during adulthood is decreased.

Often, families express confusion about the different Waivers that are available and how to access them.

Finding people to help you understand the Waivers and guide you through the application makes the process easier.

➤ **Downside...Upside**

Yes, Waivers are accessed through more than one agency. Yes, there are waiting lists (urgent and non-urgent), which may be long. Yes, you may not see the need for Waiver services when your child is young.

However, going through the application process and determining eligibility for a Waiver of great value. At least two of the Medicaid Waivers provide opportunities for prevocational services and supported employment, in addition to other types of services and supports.

Some of the services and supports of various Medicaid Waivers include:

- 1 access to assistive technology
- 2 assistance with activities of daily living
- 3 day support
- 4 work related personal assistance
- 5 environmental maintenance so the individual can remain in his/her home and community
- 6 transportation to and from training sites
- 7 prevocational activities



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- 8 environmental modifications
- 9 training, education, and counseling services to families and non-paid caregivers
- 10 in-home and other residential supports
- 11 assistance with adapting behavior in the community
- 12 therapeutic consultation in the fields of psychology, social work, behavioral analysis, speech therapy, occupational therapy, therapeutic recreation, and physical therapy
- 13 supported employment
- 14 training in intellectual, sensory, motor, and affective social skills development

However, at this time, even when someone qualifies for Waiver Services, it may be difficult to find a provider for the services due to lack of availability and/or low reimbursement rates.

If you encounter difficulties in this area, contact DMAS and your representative to the General Assembly to make them aware of your experience. In the Appendices, there is a list of current Medicaid Waiver Mentors in Virginia whom you can contact for more information.

➤ **Waiver Flavors**

Each Medicaid Waiver has specific eligibility criteria and services, and is accessed in different ways.

Medicaid Waivers that are most frequently utilized by individuals on the autism spectrum are the DD Waiver (Individual and Family Developmental Disabilities Support Waiver) and the MR Waiver (Mental Retardation Waiver).

It is possible for someone who is eligible for the DD Waiver or the MR Waiver to also be eligible for one of the other Waivers, even while on a waiting list for the DD or MR Waiver.

Medicaid Waiver rules and access requirements are complex and change periodically, so the most up-to-date information should be sought from the agencies that have oversight responsibility for each Waiver.



An excellent resource that explains the various Waivers and how to access them is available through The Endependence Center at www.endependence.org.

Medicaid Waiver Mentors and Support Coordinators are also a resource for families and are located throughout Virginia. They may work in local agencies or may be independent providers. Contact The Endependence Center for information about Mentors and Support Coordinators in your area.

Others who can help you are located at Centers for Independent Living, Community Services Boards/Behavioral Health Agencies, Departments of Social Services, and the Virginia Department of Behavioral Health and Developmental Services (BHDS – formerly DMHMRSAS).

Your answers to questions on the next two pages will help you decide which Waiver might be appropriate for your family member.



Is there a Medicaid Waiver for Me?

- Do I have a diagnosis of Mental Retardation (Intellectual Disability)? **If not, I might be eligible for the Developmental Disabilities (IFDDS) Waiver.**
- Has someone in my family completed a Request for Screening Form (see Appendices) and submitted it to the nearest Child Development Center to see if I am eligible for the **Developmental Disabilities (IFDDS) Waiver**?
- Which services and supports in my home and/ or community might be right for me?

<ul style="list-style-type: none"> <input type="checkbox"/> Day Support <input type="checkbox"/> Companion Services <input type="checkbox"/> Supported Employment <input type="checkbox"/> In-home Residential Support <input type="checkbox"/> Therapeutic Consultation <input type="checkbox"/> Personal Care Services <input type="checkbox"/> Respite Care <input type="checkbox"/> Supported Employment <input type="checkbox"/> Attendant Services 	<ul style="list-style-type: none"> <input type="checkbox"/> Family and Caregiver Training <input type="checkbox"/> Crisis Supervision <input type="checkbox"/> Environmental Modifications <input type="checkbox"/> Assistive Technology <input type="checkbox"/> Personal Emergency <input type="checkbox"/> Response System (PERS) <input type="checkbox"/> Support Coordination <input type="checkbox"/> Prevocational Services <input type="checkbox"/> Assistive technology
---	---



- Do I have a diagnosis of Mental Retardation (MR) or Intellectual Disability (ID)? **If so, I might be eligible for the Mental Retardation Waiver.**
- Has someone in my family contacted the nearest Community Services Board or Behavioral Health Authority to apply?
- Which services and supports in my home and/ or community might be right for me?
 - Residential Support Services
 - Day support
 - Supported employment
 - Prevocational services
 - Personal assistance
 - Respite care
 - Companion
 - Assistive technology
 - Environmental modifications
 - Skilled nursing services
 - Therapeutic consultation
 - Crisis stabilization
 - Personal emergency response systems
 - Assistive technology
 - Attendant care
 - In-home residential support





Contact List for Waiver Services



Child Development Center (DD Waiver):

Name _____ Contact info _____

Community Services Board/Behavioral Health Authority (MR Waiver):

Name _____ Contact info _____

Waiver Mentor:

Name _____ Contact info _____

Center for Independent Living:

Name _____ Contact info _____

Case Manager/Support Coordinator:

Name _____ Contact info _____

Name _____ Contact info _____



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Disability Determination Services

Opening the Door to Social Security Administration Disability Benefits

Accessing Social Security Administration (SSA) disability benefits programs starts with an application to the SSA, followed by the Disability Determination process. Two SSA benefits programs for individuals with disabilities are Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Basic medical criteria for eligibility are the same for both SSI and SSDI. Recipients of benefits under these programs may also be eligible for Medicaid or Medicare benefits.

➤ **SSA applications overview**

Take a look at the SSA's descriptions in the HELPBOOK Appendices for child and adult criteria for autistic and other pervasive developmental disorders to see the basic medical eligibility criteria, and how, exactly, the SSA defines disability.

Eligibility criteria are NOT necessarily the same as eligibility for special education services.

At age 18, adult criteria apply.

If an individual has been diagnosed with co-existing conditions, such as ADHD, anxiety disorder, vision, hearing, speech, or balance disorders, chronic bowel disorders, seizures, mental retardation, mood and affective disorders, the documentation of these conditions will also be considered during the disability determination process.

It will be up to you to make all the relevant information available.



➤ What's the first step?

Begin by completing an initial application for disability benefits to the SSA.

Get the free SSA Disability Starter Kit and copies of SSA forms to help you prepare.

Advocates generally recommend contacting your local SSA Field Office to set up an appointment to meet face-to face to apply for disability benefits.

Once you have completed the initial application for disability benefits and have submitted the application and required documentation to the SSA Field Office, your application will then be sent to a Disability Determination Services office.

Disability Determination Services (DDS) is a division of the Virginia Department of Rehabilitative Services (DRS) with many regional offices around the state.

Applications for disability benefits are assigned to a skilled case worker who will collect and access the applicant's medical records according to specific SSA guidelines. The case worker will be working in conjunction with a licensed clinical psychologist and a physician.

For many people, the application process seems overwhelming. Advance preparation, including gathering all the necessary records and information will help you speed up the application and disability determination process.

Keep a log that includes:

- date(s) you made contact with SSA and/or DDS representatives,
- phone number(s) you called
- name of the person(s) you spoke with



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- ❑ brief notes of your conversation(s)
- ❑ follow-up steps and timelines

If you receive any correspondence by mail from SSA/DDS, a prompt response should be made. Note the date you responded in your log, and if necessary, make a copy of the correspondence for your files.

➤ **Understanding SSA benefits**

Once your family member is found eligible for benefits through the Disability Determination process, then the types of benefits will be determined.

Did you know that a child with a disability or a “disabled adult child” can receive cash benefits under the work record of a parent (and sometimes a grandparent) who is retired, deceased, or disabled?

Eligibility for SSA benefits will also open the door for eligibility for Employment Supports/Work Incentives, as well as Medicaid or Medicare.

There are many rules and contingencies (if this...then that) for these benefits and seeking expert help is always a good idea! In addition to SSA and DDS staff, there are others who can help you with the application and disability determination process. If you meet the financial eligibility criteria, Legal Aid services may be available.

Others who may be able to offer assistance include employees of Centers for Independent Living, CSBs, the Virginia Office of Protection and Advocacy, and the Department of Rehabilitative Services.

Advocates recommend that if the first application is denied, get help in understanding the reasons for the denial and then try again by way of an appeal.

Two things to remember: complete documentation and timely responses are essential.



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Answering the questions below with the help of the information in the Appendices will get you started.

Opening the SSA Benefits Door

- Do I meet the basic medical criteria for Social Security disability benefits as a child or an adult with autism or other pervasive developmental disorders?**
- Do I have other co-existing conditions that I need to let SSA and DDS know about?**
- Have I gotten a copy of the free SSA Disability Starter Kit?**
- Have I contacted my local SSA Field Office to ask any questions I may have and to let them know I want to file an application for disability benefits?**
- Do I know where the closest SSA Field Office and Disability Determination Services Office are located?**
- Do I have all my medical and psychological evaluations and other disability-related information available and organized so I can access the information and answer questions?**
- Do I have a log or notebook where I can write down:**
 - date(s) I made contact with SSA and/or DDS representatives,
 - phone number(s) I called
 - name of the person(s) I spoke with
 - brief notes of my conversation(s)
 - follow-up steps and timelines



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- Do I have a safe and accessible place to keep all mail I receive from the SSA and DDS offices?**
- Have I contacted others who can help me understand and complete the process of applying for disability benefits?**
- If my first application was denied, did I seek help in understanding the reason(s) why?**
- If my first application was denied did I appeal the denial?**





Contact List for SSA Benefits



Social Security Administration Field Office closest to me:

Location:

Name _____ Contact info _____

Disability Determination Services Office closest to me:

Location:

Name _____ Contact info _____

Medical and psychological records I need from:

Name _____ Contact info _____

Name _____ Contact info _____

Name _____ Contact info _____

Center for Independent Living:

Name _____ Contact info _____



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help with
accessing Social
Security
Administration
Benefits*



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Employment Supports/Work Incentives (ES/WI)

Uncle Sam Wants Everyone.....to Work!

Social Security Administration (SSA) Employment Supports/Work Incentives make it possible for individuals with disabilities to work and still receive monthly benefits payments. The goal of the SSA supports is to enable youth and adults with a disability to become self-supporting and achieve whatever level of financial independence is possible for the individual. Continued access to health benefits through Medicaid and/or Medicare is possible even after the point of becoming self-supporting.

➤ **The importance of employment**

Unfortunately, youth and young adults on the autism spectrum have one of the lowest rates of paid employment among all disability categories (National Longitudinal Transition Study-2). Recent data show that 98% of adults with an autism diagnosis are unemployed and 88% of individuals with a diagnosis of Asperger Syndrome are unemployed.

Frequently youth on the autism spectrum report that they have not had any work experience, paid or un-paid, including chores at home, volunteer work, working for neighbors and family friends, job-shadowing, internships, or part-time work after school or during the summer.

The reasons for these deficiencies in experience are as varied as the characteristics of the individuals, but the impact on success in postsecondary environments is significant.

Helping your family member by investigating potential supports that will allow him/her to move toward economic independence and access the community through employment is an important part of planning for the future.

Adults on the autism spectrum often come to feel that work offers them opportunities beyond financial independence.

If they are working in an area of special interest, it is easier to relate to others in their workplace who share those interests and they are able, through their work, to achieve success and balance in their lives.



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As Temple Grandin puts it: *“Work is such a big part of the human experience that it’s important for all to hold a job, no matter how big or small. We learn so much from working that it would be a shame to miss out on those experiences.”*

For families and service providers, ways to access work experience opportunities include:

- ❑ Creating opportunities for the individual to take responsibility for jobs around the home, school, and community, and then generalize skills learned to other supportive, natural environments.
- ❑ Modeling task orientation and completion skills for jobs around the home and elsewhere.
- ❑ Motivating the individual to participate in work experiences as early as possible by capitalizing on the individual’s strengths and special interests.
- ❑ Incorporating extrinsic motivators as a part of new work experiences and/or difficult tasks.
- ❑ Providing information about the characteristics and preferences of the individual to potential employment providers.
- ❑ Using visual supports such as sequenced task schedules, video-modeling for tasks and social interactions, reminder cards, maps to locate items needed for tasks, IPODS and PDAs as well as other assistive technology.
- ❑ Including career exploration and related activities in the IEP as early as possible

Making sure that youth on the autism spectrum have access to work experiences will help everyone involved identify what the specific barriers may be for that individual and will drive evidence-based efforts to help the individual overcome those barriers.

SSA Work Incentives are a valuable resource for overcoming barriers to success.



➤ Understanding SSA Work Incentives

Once the individual has gone through the application process for disability benefits and is approved to receive SSI and/or SSDI payments, applying for applicable Employment Supports or Work Incentives can help the individual:

- ❑ enter,
- ❑ re-enter,
- ❑ stay in the workforce, and
- ❑ protect eligibility for SSA cash payments and health care

Employment supports can be accessed as early as 7th grade! And some employment supports allow the individual to test his/her ability to work over a period of 9 years or more.

Because of the range of opportunities and complexity of the rules for ES/WI, seeking assistance in understanding and accessing these supports is vital!

Descriptions of some of the SSA Work Incentives are included in the Appendices of the HELPBOOK.

A user-friendly resource for gaining an understanding of the various Employment Supports/Work Incentives can be found at www.workworld.org.

SSA offers many brochures and resource guides, including their “Red Book”, which is available at no cost, and explains the various employment supports available under SSI/SSDI.

The Department of Rehabilitative Services, Centers for Independent Living, and Work Incentives Specialists can also provide guidance and information.

The following pages are a way for you to gather information, plan work experiences with your family member, and think about the possibility of accessing SSA Benefits and Work Incentives.



Lifework Planning

- **Would I like to work and earn money while I am a student?**
- **Three types of work I am most interested in are:**

- **Some of the things that make it difficult for me to find or keep work are:**
 - Lack of experience
 - Lack of opportunity
 - Supports on the job are not available
 - Accommodations I need are not available
 - I don't have transportation
 - Other:
- **Have I had career exploration opportunities at school?**
- **The careers that I liked were:**

- **I have NOT had career exploration opportunities at school. Who can help me explore careers at school?**



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- **I haven't applied for SSA benefits yet, but I'd like to find out if I am eligible. Who can help me?**

- **I receive SSA benefits and I'd like to find out if I can use Employment Supports and still keep my benefits. Who can help me?**

- **I do some work for my family and neighbors after school, on the weekends, and during school holidays. The kinds of work I like best are:**

- **When I work for my family and neighbors, I earn money that I can spend. Some of the things I spend my money on are:**

- **I save some of my money for the future. I'm saving the money so I can:**





Contact List for Work Experience and SSA Work Incentives



Transition Services Coordinator:

Name _____ Contact info _____

Potential employers:

Name _____ Contact info _____

Name _____ Contact info _____

Name _____ Contact info _____

Social Security Administration:

Name _____ Contact info _____

Community Work Incentives Coordinator:

Name _____ Contact info _____

Work Incentives Specialist:

Name _____ Contact info _____



On the back of this page, add additional contact information for others who can help with accessing work experience and Social Security Administration Work Incentives



Virginia Department of Rehabilitative Services (DRS)

What's on the Menu?

www.vadrs.org

DRS is the comprehensive source for information and assistance in helping your family member with an autism spectrum disorder become more independent and self-sufficient in the area of employment. Knowing something about the multitude of services DRS offers will help you prepare for the transition IEP.

➤ **DRS: What's it good for?**

Accessing DRS services and involving a Vocational Rehabilitation Counselor in the transition planning process helps everyone involved have a clearer picture about assessments, training, work experiences, and employment opportunities that may be available for your family member as s/he leads up to the transition from school to adult life.

DRS services that may be available at no cost to qualified individuals include:

- Diagnostics, Evaluation, Assessment
- Disability awareness counseling
- Vocational and career path counseling
- Job seeking and job retention counseling
- Access to Employment Resource Centers – job searching and finding employment leads
- Job Placement
- Driver Evaluation
- On-the-job Training
- Follow along services after job placement



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DRS also offers information about community based services across Virginia. These services include Assistive Technology, Personal Assistance Services, Centers for Independent Living, Employment Services Organizations and Community Rehabilitation Case Management Services.

➤ **What a DRS Counselor can do**

A DRS counselor can help you find out how to access appropriate evaluations and assessments, including career screening assessments, career exploration, interest and aptitude testing, hands-on work sample exploration, situational assessment, and community based work exploration.

Knowledge gained from these assessments and experiences will guide the transition services and courses of study needed to assist your child in reaching appropriate, measurable postsecondary goals.

In addition to assessments conducted locally, students may be able to access services at Woodrow Wilson Rehabilitation Center (WWRC) in Fishersville.

For more information about this and other programs, including the Postsecondary Education Rehabilitation Transition (PERT) Program, talk to your child's Vocational Rehabilitation Counselor.

Another area of value to you and your family member might be DRS Business Services.

Included in this area are accommodations and supports in the workplace, matching business needs to work skills and training of individuals with disabilities, corporate disability awareness training, and financial incentives available to businesses that hire and/or accommodate individuals with disabilities in their workplace.

The Mission Statement of DRS is:

In partnership with people with disabilities and their families, the Virginia Department of Rehabilitative Services collaborates with the public and private sectors to provide and advocate for the highest quality services that empower individuals with disabilities to maximize their employment, independence, and full inclusion into society.



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Menu for the Future

What do you want on YOUR plate?

The DRS counselor who works with students at my school is:

When will the DRS counselor who works with students at my school come to an IEP meeting?:

I have already had one or more vocational assessments. The assessment(s) I had were:

- Career screening assessment
- Career exploration
- Interest and aptitude testing
- Work sample exploration
- Situational assessment
- Community-based job or career exploration
- Other



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Three things I learned from the vocational assessments are:

- 1 _____
- 2 _____
- 3 _____

I have not had any vocational assessments yet. Who can help me access vocational assessments?

I would like to find out about visiting Woodrow Wilson Rehabilitation Center. Who can help me?

Employment Services Organizations in my area are:

Three things an Employment Services Organization can help me do are:

- 1 _____
- 2 _____
- 3 _____

I am planning to go to a 2 year or 4 year college. What can DRS do to help me while I'm in college?

I would like to learn how to drive. Is there a program at Woodrow Wilson Rehabilitation Center that can help me learn?



It is not easy for me to talk to people. I use picture cards or writing to let people know what I want. Is there an assistive technology device that could help me communicate more easily and with more choices?

How can DRS counselor me after I leave high school?

What services from DRS are free and what services would I have to pay for?





Contact List for DRS Assistance



DRS Counselor:

Name _____ Contact info _____

Vocational Assessments:

Name _____ Contact info _____

Woodrow Wilson Rehabilitation Center:

Name _____ Contact info _____

Employment Services Organizations:

Name _____ Contact info _____

Assistive Technology Resource:

Name _____ Contact info _____



On the back of this page, add additional contact information for others who can help with accessing transition assessments, work experiences and the Department of Rehabilitative Services




FIND IT IN THE APPENDICES


- A Person Centered Planning Page 79**
- B Disclosure and Self-Advocacy Page 81**
- C Family Stress Page 83**
- D Transition Councils and Training and Technical Assistance Centers in Virginia Page 85**
- E Autism Action and Support Groups Page 88**
- F Legal Tools for the Age of Majority Page 99**
- G Transfer of Parental Special Education Rights at Age 18 Page 103**
- H Social Security Administration Disability Eligibility Criteria (Adult) Page 108**
- I Social Security Administration Disability Eligibility Criteria (Child) Page 109**
- J Social Security Administration Disability Determination Starter Kit Information Page 110**
- K Disability Determination Services Field Offices Page 111**
- L SSI and SSDI Benefits for Children and Adults Page 112**
- M Centers for Independent Living Page 114**
- N Three SSA Work Incentives for Youth and Young Adults with Disabilities Pages 116**
- O SSA Work Incentives for SSI and SSDI Beneficiaries Page 119**
- P Work Incentives Specialists Advocate Contact Information Page 123**
- Q Medicaid Waivers, CSBs/BHAs, Child Development Centers Page 125**
- R Department of Rehabilitative Services Page 138**
- S Summary of Performance Page 141**
- T Institutions of Higher Education – Office of Civil Rights Information Page 154**
- U Medicaid Waiver Mentors in Virginia Page 159**
- V Examples of Postsecondary Goals Page 160**
- W Community Work Incentives Specialists Contact Information Page 162**

Contact Information for Commonwealth Autism Service Page 163



Appendix A – Person Centered Planning

“The goal is to have a beautiful life, not a beautiful plan.”
 ~ Michael Smull

The importance of Person Centered Planning as a tool to envision the future and create an effective transition IEP cannot be underestimated. It may look complicated at the outset, but there are many resources available to help you to map future options and to systematically overcome obstacles that may be in the way.

Here are three guides for creating a person centered plan:

- **ELP (Essential Life Style Planning)**
 - Michael Smull
 Support Development Associates
 3245 Harness Creek Road
 Annapolis, Maryland 21403
 (410)626-2707 * FAX 626-2708
 Email mwsmull@cs.com

- **MAPS and PATH (Planning Alternative Tomorrows with Hope)**
 - Jack Pearpoint
 24 Thome Crescent
 Toronto, ONT M6H2S5 Canada
 (416) 658-5363
www.inclusion.com



- **Personal Futures Planning**

- Dr. Beth Mount
Graphic Futures
25 West 81st Street #16B
New York, NY 10024
(212)362-9492*FAX (212) 769-2969
www.capacityworks.com

For assistance in locating a facilitator for person centered planning in Virginia:
Partnership for People with Disabilities – Tera Yoder: tyoder@vcu.edu

Also, check with your school division’s guidance counselors or Parent Resource Center, The Arc, Community Services Board, and Behavioral Health Center for books and additional resources.

Web-based resources on Person-Centered Planning are numerous, including those with self-study courses, downloadable resources, and great ideas for engaging your family and others in the community in developing a person-centered plan. Here are four sites to check out:

<http://www.ilr.cornell.edu/edi/pcp/>

<http://www.ttac.odu.edu/Articles/person.html>

<http://www.ncset.org/publications/viewdesc.asp?id=1431>

<http://www.pacer.org/tatra/resources/personal.asp>



Appendix B – Disclosure and Self-Advocacy

"Self-advocacy and disclosure are inexorably linked because the need for self-advocacy begins when a person's needs are not being met in a given situation. Part of self-advocacy involves educating others of one's needs, and that usually includes reasons why; hence disclosure."

~Stephen Shore

How much disclosure is needed in any given situation is as varied as the characteristics of each individual on the spectrum.

Family members are generally the primary determiners of the level of disclosure that is necessary or appropriate when their children are young.

As the individual enters adolescence and moves toward adulthood, s/he will often be the primary person who decides what is necessary or appropriate.

As for any individual with a disability, this can be a source of conflict within the family and confusion for the individual. Discussions within the family and with trusted "outsiders" can go a long way toward helping resolve the issues and answer some of the questions about disclosure.

Because disclosure is often situational and has the potential to be beneficial or damaging, it is rarely possible to determine in advance what is best for each individual on the spectrum. As Stephen Shore points out, self-advocacy often involves some level of disclosure.

In situations involving law enforcement and the juvenile or criminal justice system, for example, disclosure can make the difference between disaster and safety. Two excellent resources for information are: Davis, B and Schunick W.G. (2002). *Dangerous Encounters: Avoiding Perilous Situations with Autism*. (London: Jessica Kingsley Publishers), and Dennis Debbault's website: www.autismriskmanagement.com.



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Setting up potential disclosure scenarios and practicing ways to handle them will help develop self-advocacy skills across environments.

Some models for doing this as well as much other helpful information and guidance can be found in *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum* (Shawnee Mission, KS: Autism Asperger Publishing Co.). Chapters written by six individuals on the autism spectrum cover a broad range of disclosure and self-advocacy issues and include practical strategies, including how to use the IEP to build self-advocacy skills.

Speaking with adults on the spectrum as well as their siblings and parents can offer insights about how people deal with self-advocacy and disclosure and what the outcomes were for them.

Books and websites maintained by individuals on the spectrum also offer a variety of perspectives and experiences related to disclosure and self-advocacy. Among these are:

- Prince-Hughes, D. (2002). *Aquamarine blue 5: Personal stories of college students with autism*. Athens, OH: Ohio University Press.
- Shore, S. (2003). *Beyond the wall: Personal experiences with autism and asperger syndrome*, second edition. Shawnee Mission, KS: Autism Asperger Publishing Co.
- Stillman, W. (2003). *Demystifying the autistic experience: A humanistic introduction for parents, caregivers, and educators*. London: Jessica Kingsley Publishers.



Appendix C – Family Stress

“When a family has a child diagnosed with autism, unique stressors are added.”
 ~ *Adrienne Horowitz*

Individuals on the autism spectrum and their families often report that they feel as though the stress in their lives never lets up.

Finding a diagnosis, trying to understand the implications of the diagnosis, finding services, making sure the services are effective, advocating for their family member’s needs, teaching self-advocacy skills, fostering special interests and community participation, being chronically sleep deprived...the list goes on.

Families may feel that the individual on the spectrum is not able to participate in family and community life without a trusted adult or sibling to help “interpret” the community and actively facilitate involvement.

For adolescents with autism spectrum disorders, transitioning away from the relative safety and familiarity of elementary school to middle and high school comes with environmental, academic, communication, and social challenges, including sexual development, that they are often not well-prepared for.

For youth and their families, the arrival of adulthood and postsecondary life brings additional concerns about safety, independence, finances, living arrangements, confusion about adult service options and systems, and much more.

Siblings, too, may feel embarrassment, jealousy, and frustration beyond what is felt by their peers with “neurotypical” siblings. In some cases, they may take on roles in care-giving beyond age-appropriate emotional capabilities. They may also be concerned about their roles as care-givers upon the loss of a parent or parents.



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Families, including youth on the spectrum and siblings, report feelings of isolation from neighbors, relatives, and the community in general. Divorce rates have been reported to be as high as 80% among families who have a child with an autism spectrum disorder.

What resources and strategies are available to help overcome feelings of isolation and relieve some of the stress?

- Networking with others through autism support groups either locally or on-line has been of value to many families. (*See Appendix E*)
- Counseling is often helpful but may be difficult to access in some locations.
- The Autism Society of America (www.autism-society.org) offers strategies for families.
- Accessing in-home and community-based supports through Medicaid Waiver services can be of benefit.
- Community respite programs and “sibshops” are available in some areas.

The positive news is that with every passing day, more awareness and expertise is becoming available to improve outcomes and increase support for individuals on the spectrum and their families.



Appendix D – Transition Councils in Virginia

Transition Councils exist across Virginia and provide opportunities for learning more about local and statewide options as well as offering conferences and workshops, networking with other families and service providers, and information-sharing about the transition and postsecondary needs of youth and adults on the autism spectrum.

New Councils are being created, so check with your local school division’s transition coordinator to find out if there is a group meeting in your area. The Virginia Department of Education’s Regional Training and Technical Assistance Centers may also have information on Transition Councils meeting or being developed in your area.

Check with your local Virginia Department of Education Training and Technical Assistance Center (www.ttaonline.org) to find out how you can get involved in a Transition Council near you.

Central Virginia Transition Council

Lynchburg, Bedford, Amherst, Campbell

Disability Coalition

Harrisonburg, Rockingham

Greater Richmond Interagency Transition Council

Richmond, Goochland, Henrico, Chesterfield, Colonial Hts., Hopewell

Greater Roanoke Valley Transition Council

Roanoke, Botetourt, Craig, Franklin, Salem

Jefferson Area Transition Council (JATC)

Albemarle, Charlottesville, Greene, Fluvanna, Nelson, Louisa



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Rockbridge Area Transition Council (RATC)

Buena Vista, Lexington, Rockbridge

Southside VA Intercommunity Transition Council

Appomattox, Prince Edward, Cumberland, Amelia, Lunenburg, Nottoway

Transition Advisory Council

Augusta, Staunton, Waynesboro, Bath, Highland

Region IV Transition Council

Northern Virginia and Surrounding Counties

Virginia Interagency Transition Council

Statewide agency and organization participation

Meets quarterly in Richmond

Contact: Marianne Moore, Virginia Department of Education

804.225.2700 or Marianne.Moore@doe.virginia.gov



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Virginia Department of Education Regional Training and Technical Assistance Centers

Regions 1 and 8: Virginia Commonwealth University, Richmond, VA

Phone (800) 426-1595 Visit: <http://www.vcu.edu/ttac/>

Regions 2 and 3: Old Dominion University, Norfolk, VA

Phone (888) 249-5529 Visit: <http://www.ttac.odu.edu/>

The College of William and Mary, Williamsburg, VA

Phone (800) 323-4489 Visit: <http://www.wm.edu/TTAC/>

Region 4: George Mason University, Fairfax, VA

Phone (703) 993-3670 Visit: <http://ttac.gmu.edu>

Region 5: James Madison University, Harrisonburg, VA

Phone (888)205-4824 Visit: <http://ttac.cisat.jmu.edu>

Regions 6 and 7: Virginia Polytechnic Institute and State University, Blacksburg, VA

Phone (800) 848-2714 Visit: <http://www.ttac.vt.edu>

Radford University, Radford, VA

Phone (877) 544-1918 Visit: <http://ru-portal.radford.edu/ttac>



Appendix E – Autism Action and Support Groups in Virginia

Autism Society of America – VA Chapters

Central Virginia Chapter – serving the areas of Amelia, Chesterfield, Charles City, Richmond, Colonial Heights, Goochland, Hanover, Henrico, Louisa, Petersburg, Powhatan

President: Jennifer Vest, jennifervest@comcast.net

Mailing Address: P.O. Box 29364, Richmond, VA 23242-0364

Information and Referral: Bradford Hulcher, (804) 257-0192, fax (804) 290-0286 or asacv@aol.com

Website: www.asacv.org

Autism Society of America – Central VA Chapter - Teen Youth Group

The **ASA-CVC** will have a teen youth group meeting *in conjunction* with our regularly scheduled monthly meetings. **When you come to our meetings**, please consider bringing your teen with autism (approximately 12-18 year old) and their teen siblings for a social get-together. If your child is able to attend, please RSVP to 257-0192 or asacv@aol.com. If you have any questions, please feel free to call Pat Weaver at 965-0332 or email her at pmarie88@comcast.net. (As always, free childcare for younger children is available by reserving a spot a week prior to the meeting by contacting ASACV at 257-0192.)

Northern Virginia Chapter – serving the areas of Alexandria, Fairfax, Fauquier, Loudoun, & Prince William counties

President: Beka Martinez, president@asanv.org

Mailing Address: P.O. Box 1334, Vienna, VA 22183

Information and Referral: Andrea Kramer at andreakramer_su@yahoo.com or 703-495-8444
info@asanv.org

Website: www.asanv.org



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Peninsula Chapter – serving the counties of Gloucester, James City, Matthews, New Kent, Surry and York, and the cities of Hampton, Newport News, Poquoson, Portsmouth, Suffolk, West Point and Williamsburg

President: Linda Pinkus, Danlin87@aol.com

Mailing Address: 109 Panther Paw Path, Williamsburg, VA 23185-5773

Information and Referral: Cindy Favret, (757) 565-6367, Petrus66@verizon.net

Website: www.peninsulautism.org

***The Peninsula Autism Society Williamsburg Support Group** has changed its meeting location to King's Way Church at 5100 John Tyler Highway (Rte. 5). Free childcare is now available, with advance reservations. Please provide at least four day's notice for reservations (contact Susan Reese at spreese@cox.net or 220-1137). This group will meet on the last Thursday evening of each month from 7-9 p.m., in the downstairs fellowship hall of the church.

***The Peninsula Autism Society Newport News Group** meets on the second Monday of the month (except for August) at the Christ United Methodist Church in Newport News (133 Deep Creek Road, off Warwick Blvd.), 7:00pm-9:00pm. Autism-friendly childcare is provided at all meetings by experienced providers. Please contact Mike Langille at 757-722-1207 by the Friday before the meeting if you require childcare services.

Tidewater Chapter – serving the cities of Norfolk, Portsmouth, Virginia Beach, Chesapeake and Suffolk

President: Joanna Bryant, 757-461-4474

Mailing Address: Endependence Center Bldg, 6300 E. Virginia Beach Blvd., Norfolk, VA 23502

Information and Referral: Joanna Bryant, (757) 461-4474, tidewaterasa@verizon.net

Website: www.tidewaterasa.org



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Other Resources for Individuals and Families

Fredericksburg Area

Autism Outreach, Inc. is now offering a support group in the Fredericksburg area. The first meeting will be on **Thursday, February 15 at 7pm at the the Disability Resource Center at 409 Progress Street.**

Please contact Crystal Peterson CrystalPAO@aol.com or visit www.autismoutreach.org for more information or to register.

Lynchburg Area

Central Virginia Autism Action Group and Parent Support Group

Contact: Didi Zaryczny, Dzaryczny@autismva.org or (540) 587-8990, ext. 108.

Danville Area

Piedmont Autism Action Group

Contact: Didi Zaryczny, Dzaryczny@autismva.org or (540) 587-8990, ext. 108.

Blacksburg Area

New River Valley Autism Action Group

Contact: Didi Zaryczny, Dzaryczny@autismva.org or (540) 587-8990, ext. 108.

Roanoke Area

Greater Roanoke Valley Autism Action Group

Contact: Didi Zaryczny, Dzaryczny@autismva.org or (540) 587-8990, ext. 108.

Cumberland Area

Heart of Virginia Autism Action Group

Contact: Didi Zaryczny, Dzaryczny@autismva.org or (540) 587-8990, ext. 108.



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*Marion Area***Southwest Virginia Autism Action Group**

Contact: Didi Zaryczny, Dzaryczny@autismva.org or (540) 587-8990, ext. 108.

Family Members of Children with Asperger Syndrome

St. Joseph's Villa, 8000 Brook Road, Richmond, VA

Family Support Group will be held the second Thursday of each month, 4:00pm-5:00pm, at Brook Road Academy, St. Joseph's Villa. Contact: Nancy Toscano, 804-553-3267, ntoscano@sjvmail.net

Parents with Special Needs Children Support Group

Meets 2nd and 4th Thursdays from 6pm – 7:30pm at Discover United Methodist Church – 1300 Gayton Road. Anita Harrison, MS, LCSW, ACSW and Robyn Mosley, MA, Counselors with Christian Counseling Associates, a division of Resource Guidance Service, Inc. lead this group. Call Robyn at (804) 257-9700 for more information.

A Voice for GAP Kids

Contact Info: (804) 749-3895 or MooreLM@juno.com

S.N.A.P. – Supporting the Needs of Autistic's Parents – Chesterfield County, VA

website: <http://groups.yahoo.com/group/SNAP-chesterfield>

email: SNAP-chesterfield@yahoogroups.com

Support group meetings are held at the Clover Hill Library, Hull Street Road, Midlothian, VA 23112 Contact: Joe Maciejczyk, 804-748-2070, jmaciejczyk@comcast.net

Eagle's Nest

A faith-based support group for parents of children with special needs

Sponsored by: Woolridge Road Church, Moseley, VA

Contact: Tammy Burns, tcburns@woolridgeroad.com, 804-639-4777



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Free Respite Offered through Local Church Ministry, Chesterfield, VA

Gift of Time is the Through the Roof Ministry's respite care program designed especially for families with children of special needs and their siblings. Parents can enjoy a "Gift of Time," while their children spend an evening of fun with Through the Roof. This program is free and open to the public, but you must register your children in advance. Respite will be offered the 4th Friday of each month in 2006. For more information or to register contact Tammy Burns at 639-4777 or tburns@woolridgeroad.org for a registration form. Through the Roof Ministry is a ministry of Woolridge Road Church.

GRACE – Greater Richmond Autism Coalition for Equality, Richmond, VA

Committed to advancing the interests of children and youth with Autism. For more information on GRACE, membership and volunteer services, call (804) 257-9007.

ROCK – Raising Our Celiac Kids

Contact: Kathi Rogers, 804-364-2339, RogersKathl@aol.com

Our Daughters with Autism Network – Networking group thru email. To contact the group: e-mail Cindygwinn2004@yahoo.com, or visit www.gwinnandassociates.org for additional information.

The Shenandoah Valley Autism Partnership

Where Parents and Professionals Come Together for Positive Change

An affiliate of the Arc of Harrisonburg/Rockingham

Mailing Address: 7437 Goods Mill Road Harrisonburg, VA 22801

The Shenandoah Valley Autism Partnership (SVAP) provides a forum for families and professionals that support individuals with Autism Spectrum Disorders in the Shenandoah Valley. For more information, Contact: Fonda Watson (Information), 540-289-9206, svap@valleyautism.org; Sally Chappel (Co-Chair), 540-568-8095, chappesl@jmu.edu; Sheryl Shenk (Co-Chair), 540-438-8880, shenksl@aol.com



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MANOS – Moms Autism Network of Shenandoah – An email network serving the counties of Shenandoah, Page and Clarke, and the cities of Winchester and Frederick

Contact: Kathy Wakeman, Medicaid Waiver Mentor, Community Resource Specialist for Shenandoah Valley Case Management, 540-984-8657, kwmentor@shentel.net or Ana Maria Echaniz, 2hearts@shentel.net

Winchester Support Group – serving the Winchester area

Contact: Kathi L. Adams, 540-535-0777, otkidskills@yahoo.com

BattleAutism List Serve: Fredericksburg Area

BATTLEAUTISM@yahoogroups.com

Join the list serve to post questions or make comments.

Autism Support Group of Fredericksburg ASGF

www.autismsgf.org

Contact: Nancy Masannat, 540-371-2594, rmasannat@aol.com or Kathleen Bufalari, 540-741-1542

Autism Support Group – The VA Institute of Autism, VIA, 1416 Westwood Road, **Charlottesville, VA** hosts this monthly parent support group that is open to the community on the first Tuesday of every month at 7:00pm. Call 434-923-8252 for additional information.

HFA/Asperger's Support Group – The VA Institute of Autism, VIA, in **Charlottesville, VA** hosts this monthly parent support group that is open to the community on the third Wednesday of every month at 7:30pm. Contact Gina Yoder at 434-923-8252 or yodergl@earthlink.net for additional information.

Just For Kicks Soccer Program for Kids with Disabilities

Saturday February 3rd

Slaughter Recreation Center, *505 Edgemont Rd, Charlottesville*

10:00 – 11:15am (Ages 3-8)

11:30am – 1:00pm (Ages 9-18)



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FREE

Contact: Thomas E. Moran, Just For Kicks/SKILLSnDRILLS Program Director
540-383-5896 mobile
888-202-7545 toll-free
tom@skillsndrills.com

Asperger Syndrome and High Functioning Autism Parent Support Group

Fairfax, Virginia area

Meetings are held the 3rd Wednesday of the month at 7:30pm

Contact Barry Loss at (703) 704-7010 or e-mail bloss@erols.com for meeting location.

Prince William County Support Group for Parents of Children Diagnosed with Autism Spectrum Disorders

Contact: Christine Hoch, 703-754-8973, choch@comcast.net.

Meetings are held the 2nd Thursday of the month at 7:00 pm in room 22 of 8730 Sudley Road, Manassas, VA.

Parents of Autistic Children – Northern Virginia (POAC-NoVA)

POAC is an international organization dedicated to improving the public education of special needs students by providing opportunities for scientifically-based training to parents, teachers and related personnel that provide direct services to children with autism and other developmental disabilities.

Contact: Scott Campbell, scott.alan.campbell@atec.army.mil, 703-391-2251
www.POAC-NoVA.org

Eddie's Club

Eddie's Club, Inc. is a non-profit organization geared towards giving youngsters, boys and girls ages 4 – 21 that have any form of disability, an opportunity to participate in a supervised, volunteered based, activity and recreational program.



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Eddie's Club offers multiple activities to kids and teens with special needs. Our Club serves not only as an activity program for the kids but also a respite and informational program for the families. P.O. Box 523493 Springfield, VA 22152 Phone (703) 551-0652

Military Support Group – go to <http://groups.yahoo.com/group/NavyFamilieswithSpecialNeeds>

STOMP - <http://www.stompproject.org> – Specialized Training of Military Parents is a federally funded Parent Training Information Center established to assist military families who have children with special education or health needs. Begun in 1985, it a project of Washington PAVE, and is funded through a grant from the U.S. Dept. of Education.

Jewish Social Services Agency of Metropolitan Washington (JSSA) offers many social skill support groups for children, adolescents AND adults with ADHD, Asperger Syndrome, PDD, peer relationship difficulties, etc..., as well as a summer social skills camp and a NEW Support Group for parents of adults with Asperger's Syndrome and related disorders. Call 703-204-9100 (VA) or 301-816-2633 (MD) for more information.

Asperger Adults of Greater Washington

District of Columbia, Northern Virginia, and Maryland

This is a social and support group for adults with Asperger Syndrome and High Functioning Autism. We meet on Sunday of each month in downtown Washington for lunch. We welcome new members to our group and also invite them to join our listserv: <http://health.groups.yahoo.com/group/dcaspie/>
Contact: Phone 703-516-9265, E-mail: info@aagw.net

Parents of Allergic Children (PAC) – Virginia

Richmond, Virginia

Meetings are held the 1st Friday of the month at 10:30am
at St. Marks United Methodist Church, 11551 Lucks Lane, Midlothian, VA 23114
Contact Paula Bush- President and founder at 804-739-1495
or visit their website at www.parentsofallergicchildren.org



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Parents for Autistic Children's Education – P.A.C.E.

Parents for Autistic Children's Education (PACE)™ is a membership organization and independent voice for parents that is open to parents and guardians of children with autism or similar disorders and discusses a wide range of issues related to the special needs of these children. Fairfax, VA. Contact information: Tom Urban, President, 703-861-5235; e-mail: tfuii@yahoo.com

Parent to Parent

Matches a parent just learning of their child's diagnosis with a volunteer veteran parent of a child with a similar diagnosis. Veteran parents are specially trained to provide informational and emotional support. **ARC of VA** at (toll free)1-888-604-2677, ext. 5

Parent to Parent and Family Voices of Virginia are proud to announce the new Family to Family Health Information and Education Center of Virginia called the **Virginia Integrated Network of Family Organizations – The VA-INFO Center.**

The VA-INFO coalition meets monthly in the Richmond, VA area, bringing together youth and families who have children with special needs, representatives from state agencies, community-based organizations and disability specific support groups from across the Commonwealth. To join the VA-INFO coalition, learn more about the VA-INFO Center, or to get information, assistance or support, call toll-free 877-264-8366, 804-264-8428 or visit the website www.va-info.org.

VA Department of Education, Special Education and Student Services – Parent Resource Center

Listing http://www.pen.k12.va.us/VDOE/Instruction/Sped/prc_list.pdf Local Special Education Advisory Committees (SEAC's) in Virginia advise school divisions on the needs of students with disabilities and the improvement of special education services and student outcomes. The Partnership for People with Disabilities and the Virginia Department of Education are pleased to announce a website for building and maintaining effective SEAC's. www.vcu.edu/partnership/seac.



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Asperger's Support Group of the National Capital Area, in the Reston/Sterling/Dulles area, meets the 2nd Tuesday of each month. For additional information, contact Pam Escobar at 703.430.3519, aspergers_nca@hotmail.com.

MUMS: National Parent-to-Parent Network

MUMS is a national Parent-to-Parent organization for parents or care providers of a child with any disability, disorder, chromosomal abnormality or health condition. Its main purpose is to provide support to parents in the form of a networking system that matches them with other parents whose children have the same or similar condition. Through a database of over 8000 families covering over 1600 disorders, very rare syndromes or conditions can be matched. Parents can then exchange valuable medical information, as well as, the names of doctors, clinics and medical resources or research programs. MUMS also connects parents with support groups dealing with their child's specific disability or assists them in forming a group. Parents Only: 1-877-336-5333

Email: mums@netnet.net

Prince William County Support Group for Parents of Children with Autism

Meetings held on the last Wednesday of the month from 7:00 – 9:45 in the multi-purpose room of the Muriel Humphrey Respite Center 13505 Hillendale Drive, Dale City. For childcare call one week ahead. For information contact Stephanie Hoversten, at (ph) 703-490-8913, (email) hoversten@earthlink.net or Anne Marie Auffant at (ph)703-492-8842, (email) tootsdc@aol.com

Community Opportunities (Co-Op), Inc.

Helps individuals set-up and maintain Micro-Boards. A Micro Board assists individuals in living an independent life, yet have a support system in place when they need it.

P.O. Box 11204

Blacksburg, VA 24062-1204

540-961-7346

MicroboardsNRV@aol.com



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Autism Network for Hearing & Visually Impaired Persons

This is a data bank project to establish a network for those with autism combined with a hearing or visual disability, and encourage the development of centers to diagnose and evaluate individuals with these disorders. This is a totally parent run network.

Contact: Dolores and Alan Bartel 7510 Ocean Front Avenue Virginia Beach, VA 23451
(757)428-9036 fax (757)428-0019

Commonwealth Catholic Charities – The Counseling Center at Commonwealth Catholic Charities provides professional counseling services to individuals, children and families who are experiencing emotional difficulties. Individual/family counseling is offered in Richmond, Charlottesville, Hopewell, Staunton, and Roanoke. Examples of Counseling Issues include:

- Anxiety
- Children/ Adolescent Behavior Problems
- Depression
- Marriage Conflicts
- Panic Attacks
- Phobias
- Adjustment Problems
- Past Abuse Issues
- Parent-Child conflicts

Talk Autism – Talk Autism is a communication shared by many organizations who access a common database of resource directories, distance learning library, and special message boards. By sharing a central yet customized communications platform, users can find resources here or virtually, within our partners' websites. www.talkautism.com



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Appendix F – Legal Tools for Families: Age of Majority

Each state has its own definitions and legal requirements for guardianship and conservatorship proceedings as well as about other legal tools to assist individuals with disabilities and their families.

These may change over time, so it is important to consult with experienced legal practitioners to be sure that your arrangements are set up according to current law and then revised as needed.

The Code of Virginia defines a “Guardian” as a person appointed by the court who is responsible for the personal affairs of an incapacitated person, including responsibility for making decisions regarding the person’s support, care, health, safety, habilitation, education, therapeutic treatment, and, if not inconsistent with an order of involuntary admission, residence. Where the context plainly indicates, the term includes a “limited guardian” or a “temporary guardian.”

The Code of Virginia defines a “Conservator” as a person appointed by the court who is responsible for managing the estate (including both real and personal property) and financial affairs of an incapacitated person and, where the context plainly indicates, includes a “limited conservator” or a “temporary conservator.”

The Code of Virginia defines an “Incapacitated Person” as an individual who has been found by a court to be incapable of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that the individual lacks the capacity to:

- meet the essential requirements for his health, care, safety, or therapeutic needs without the assistance or protection of a guardian or
- manage property or financial affairs or provide for his support or for the support of his legal dependents without the assistance or protection of a conservator. A finding that the individual displays poor judgment alone shall not be considered sufficient evidence that the individual is an incapacitated person within the meaning of this definition.



In addition to forms of Guardianship and Conservatorship, other tools including Special Needs Trusts, Advance Medical Directives and Powers of Attorney, are available to help individuals and families “customize” their plans for the future.

Setting up a plan that will maximize the individual’s opportunity to retain public benefits for which he/she may be eligible, including cash payments through SSA, health care, vocational rehabilitation, supported employment, subsidized housing, personal attendant care, etc., require expert advice.

A Letter of Intent is also a tool that is strongly recommended by experts. A Letter of Intent can be written today and then updated as needed. This document describes the individual’s history, current status, and hopes for the future. Involving your child and siblings in the writing of the Letter of Intent ensures that your child and his/her siblings’ views and wishes are represented.

The Letter of Intent is then made available to those who will be directly involved in your child’s life in the event of your illness, incapacitation, or death. Even though the Letter of Intent is not a legal document, it is information upon which courts can rely in any decision-making processes in which they may be involved.

ASA chapters and other parent support and advocacy groups often offer workshops on these topics and provide opportunities for families to learn more, network, and gain information based on the experiences of others.

The following information is excerpted from the Autism Society of America website page on “Planning for the Future”:

Here are 10 steps you can follow to help you create a directive or Letter of Intent that addresses the lifestyle and care needs of your family member. The information recorded depends on the type and severity of the disability.



- Prepare a life plan.** Decide what you want regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements.
- Write informational and instructional directives.** Put your hopes and desires and those of your family member in a written document. Include information regarding care providers and assistants, attending physicians, dentists, medicine, functioning abilities, types of activities enjoyed, daily living skills, and rights and values. Make a videotape during daily activities such as bathing, dressing, eating, and recreation. A commentary accompanying the video is also useful.
- Decide on a type of supervision.** Guardianship and conservatorship are legal appointments requiring court-ordered mandates. Individuals or institutions manage the estate of people judged incapable (not necessarily incompetent) of caring for their own affairs. Guardians and conservators are also responsible for the care and decisions made on behalf of people who are unable to care for themselves. In some states, guardians assist people and conservators manage the estate of individuals. Many parents who have kids with disabilities do not realize that when their children reach 18, adults may no longer have legal authority. Choose conservators/guardians for today and tomorrow. Select capable individuals in the even you become unable to make decisions in the future.
- Determine the cost.** Make a list of current and anticipated monthly expenses. When you have established this amount, decide on a reasonable return on your investments, and calculate how much will be needed to provide enough funds to support his or her lifestyle. Don't forget to include disability income, Social Security, etc.
- Find resources.** Possible resources to fund your plan include government benefits, family assistance, inheritances, savings, life insurance, and investments.
- Prepare legal documents.** Choose a qualified attorney to assist in preparing wills, trusts, power of attorney, guardianship, living will, etc.



- Consider a “Special Needs Trust.”** A Special Needs Trust holds assets for the benefit of people with disabilities and uses the income to provide for their supplemental needs. If drafted properly, assets are not considered income, so people do not jeopardize their Supplemental Security Income or Medicaid. And, too, they don’t have to repay Medicaid for services received. Appoint a trustee and successor trustees (individuals or corporate entities, such as banks). **Use a life-plan binder.** Place all documents in a single binder and notify caregivers/family where they can find it.
- Hold a meeting.** Give copies of relevant documents and instructions to family/caregivers. Review everyone’s responsibilities.
- Review your plan.** At least once a year, review and update the plan. Modify legal documents as necessary.

Once you have decided to prepare a plan, find someone to help you or hire a professional planner. In Virginia, the Commonwealth Community Trust (not-for profit charitable organization) offers families several options for creating trusts that protect benefits and can be coordinated with other family estate plans. Call: 888.241.6039 for more information and assistance.

Referral sources are available through governmental agencies, organizations, or local support groups. “Who will care when you are no longer there?” is an overwhelming concern people with disabilities and their families must address. Solutions are available. The next step is up to you.

Note: The previous section was developed by Barton Y. Stevens, ChLAP, Founder and Executive Director of Life Planning Services in Phoenix, AZ. See: www.autism-society.org

Appendix G - Age of Majority Transfer of Rights of Students with Disabilities Virginia Department of Education

The following information is excerpted from the VDOE Resource Document (2004) for schools, students, parents, and families about the transfer of parental rights in special education that occurs when a student with a disability reaches the age of majority at age eighteen. Always seek competent legal advice before taking any action!

The Virginia Department of Education recognizes three ways for a parent, family member, or other person to be appointed to make educational decisions on behalf of an adult student.

A student who has reached the age of 18 years is presumed to be a competent adult, and thus all rights under the Individuals with Disabilities Education Act shall transfer to from the parent to the adult student unless one of the following actions has been taken :

1. The parent requests being a court-appointed guardian and is given authority to make educational decisions at a guardianship hearing before a judge;
2. The parent assists the adult student to appoint or designate, in writing, a competent adult of his or her choice to make educational decisions through a power of attorney, signed and executed by the adult student and a Notary Public. (See the sample Power of Attorney form);
3. The parent or other competent adult pursues certification that the adult special education student is unable or incapable of providing informed consent in making educational decisions and is considered by the school division to be the "educational representative" to make educational decisions for the student. (See the sample Certification Form of the Inability of a Student to Provide Informed Consent for Education Decisions).



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Sample Specific Power of Attorney for Educational Decisions Made Under the Individuals with Disabilities Education Act

KNOW ALL PERSONS BY THESE PRESENTS:

That I, _____ (full name), residing at _____
 _____ (full address), and born on _____ (month, date, year),
 hereby make, constitute, and appoint _____ (full name) of
 _____ (full address), as my lawful attorney-in-fact
 to act in my name, place and stead, make all educational decision on my behalf, act and legally bind me to any
 and all educational decisions and/or programs, including, but not limited to, the following hereinafter
 described:

(initial)___ receive notice of all meetings and actions proposed or refused pertinent to my special education
 program

(initial)___ participate in all meetings pertinent to my special education program

(initial)___ request legal due process proceedings if a disagreement regarding my special education program
 arises

(initial)___ represent my interests in mediation to resolve disputes with the local school division

(initial)___ agree or disagree with proposed Individualized Education Programs and special education
 placements

(initial)___ Other _____

as I would, might or could do if acting personally. I hereby ratify and confirm all lawful acts done by said
 attorney-in-fact in accordance with this specific power of attorney. This specific power of attorney shall not
 terminate upon me becoming disabled, incompetent, or incapacitated, and all power and authority granted
 hereunder to said attorney-in-fact shall continue and be exercisable by said attorney-in-fact notwithstanding
 that I may subsequently become disabled, incompetent, or incapacitated, and all acts done by said attorney-in-
 fact pursuant to this specific power of attorney during the period of any such disability, incompetence, or
 incapacity, shall have in all respects the same effect and shall inure to the benefits and bind me and my estate
 as fully as if I were not subject to such disability, incompetence, or incapacity, and all power and authority



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granted hereunder shall remain in full force and effect until such time as such power and authority granted hereunder shall be revoked by me in writing.

Plural shall be substituted for the singular and singular for the plural wherever the context hereof so requires.

WITNESS the following signatures on this _____ day of _____, _____.

Student

COMMONWEALTH OF VIRGINIA }

} To Wit:

CITY/COUNTY OF _____ }

I, the undersigned, a Notary Public in and for the jurisdiction aforesaid, in the Commonwealth of Virginia, do hereby certify that _____ (student), whose name is signed to the foregoing Specific Power of Attorney, has acknowledged the same before me in the jurisdiction aforesaid.

Given under my hand this _____ day of _____, _____-/

(Notary Public)

My Commission expires: _____



Sample Certification Form of the Inability of a Student to Provide Informed Consent for Educational Decisions made under the Individuals with Disabilities Education Act

Please provide the following information:

1. Name of the student being evaluated: _____;
2. Name of the competency evaluator personally evaluating the Student: _____;
3. Professional degree or license that entitles the competency evaluator to make this determination: (Circle One - See attached *Transfer of Rights to Students Who Reach the Age of Majority*, for additional information and requirement of specific professionals)
 - Medical Doctor Physician's Assistant Certified Nurse Practitioner
 - Licensed Clinical Psychologist Licensed Clinical Social Worker
 - Guardian Ad Litem for the Adult Student Court Appointed Special Advocate
4. Has the competency evaluator, in the course of his/her professional duties, personally evaluated the person whose capacity is in question (the student)?
5. The student suffers from the following debilitating illness and/or conditions:
6. Due to the above-stated debilitating illness and/or conditions and related limitations of the student, it is my professional opinion that the student **IS CAPABLE / IS NOT CAPABLE** of providing informed consent for educational decisions made under the Individuals with Disabilities Education Act; and
7. Due to the nature of the student's debilitating illness and/or conditions as stated in this document, it is my opinion that the ability of this student to provide informed consent for educational decisions should be reviewed on _____ (date) and thereafter every _____ years. (Fill in the blank with a number not exceeding three years. Re-evaluation should occur annually unless the condition that makes the student incapable of providing informed consent is either degenerative, irreversible or perpetual given the present state of medical science, as known by the Competency Evaluator)

I have read and understand all parts of the document, *Transfer of Rights to Students Who Reach the Age of Majority*, pertaining to informed consent for educational decisions made under the Individuals with Disabilities Education Act. I understand them and I have completed this evaluation form based on the guidelines set forth in the Procedure.



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Signature of Competency Evaluator Date

Title of Competency Evaluator

Address of Competency Evaluator

Witness

Address of Witness

**The entire resource document can be found on the Virginia Department of Education website at:
http://www.pen.k12.va.us/VDOE/Instruction/Sped/transfer_rights.pdf**



Appendix H - SSA Disability Determination Criteria Autistic and Other Pervasive Developmental Disorders Adult

12.10 Autistic disorder and other pervasive developmental disorders: Characterized by qualitative deficits in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activity. Often, there is a markedly restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of the following:

1. For autistic disorder, all of the following:

- a. Qualitative deficits in reciprocal social interaction; and
- b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity; and
- c. Markedly restricted repertoire of activities and interests;

OR

2. For other pervasive developmental disorders, both of the following:

- a. Qualitative deficits in reciprocal social interaction; and
- b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity;

AND

B. Resulting in at least two of the following:

- 1. Marked restriction of activities of daily living; or
- 2. Marked difficulties in maintaining social functioning; or
- 3. Marked difficulties in maintaining concentration, persistence, or pace; or
- 4. Repeated episodes of decompensation, each of extended duration.



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Appendix I - SSA Disability Determination Criteria Autistic and Other Pervasive Developmental Disorders Childhood (Under 18)

112.10 Autistic Disorder and Other Pervasive Developmental Disorders: Characterized by qualitative deficits in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activity. Often, there is a markedly restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of the following:

1. For autistic disorder, all of the following:

- a. Qualitative deficits in the development of reciprocal social interaction;
- b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity; and
- c. Markedly restricted repertoire of activities and interests;

or

2. For other pervasive developmental disorders, both of the following:

- a. Qualitative deficits in the development of reciprocal social interaction;
- b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity;

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraphs B2 of 112.02.



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Appendix J - SSA Disability Determination Disability Starter Kit Information

The Disability Starter Kit will help you get ready for your disability interview or help you complete the online application. Kits are available in English and Spanish for adults and for children under age 18.

The starter kit provides information about the specific documents and the information that SSA will request from you.

SSA will ask for more details during the disability interview or when you complete the online Child or Adult Disability Report Form.

The kits also provide general information about the disability programs and our decision-making process that can help take some of the mystery out of applying for disability benefits.

Each Disability Starter Kit contains a:

- Factsheet that answers questions most people ask about applying for disability benefits,
- Checklist of documents and information SSA will request, and
- Worksheet to help you gather and organize the information you will need for your disability interview or to complete the online forms.

http://www.socialsecurity.gov/disability/disability_starter_kits.htm



Appendix K - Virginia Disability Determination Services Offices

CENTRAL REGIONAL OFFICE
 5211 W. Broad St., Suite 201
 Richmond, VA 23220
 Telephone: (800) 523-5007
 (804) 662-9300

TIDEWATER REGIONAL OFFICE
 5700 Thurston Ave., Suite 107
 Virginia Beach, VA 23455
 Telephone: (800) 379-4403
 (757) 363-3800

NORTHERN REGIONAL OFFICE
 11150 Fairfax Blvd. Suite 200
 Fairfax, VA 22030-5066
 Telephone: (800) 379-9548
 (703) 934-7400

SOUTHWEST REGIONAL OFFICE
 111 Franklin Rd., S.E., Suite 250
 Roanoke, VA 24011
 Telephone: (800) 627-1288
 (540) 857-7748

ADMINISTRATIVE OFFICE:
 8004 Franklin Farms Drive
 Richmond, Virginia 23229-5019
 Telephone: (804) 662-7625



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Appendix L - SSI and SSDI Benefits for Children and Adults

Supplemental Security Income (SSI) – Children

- Children under age 18 (or under 22 for a student still in school) who are not married or heads of households and who meet the disability criteria during the Disability Determination process may be eligible for SSI.
- If the child lives at home and the parents do not receive SSI benefits, then some portion of the parents' income and resources may be considered in deciding if the child is eligible and if so, how much the monthly benefit will be.
- The number of parents, other children living in the household, and the sources of income are taken into consideration.
- Children living overseas with parents who are in military service may also be eligible for SSI.
- Be sure to take a look at *Appendix O* for more information about SSA Employment Supports/Work Incentives for SSI and SSDI beneficiaries.

Supplemental Security Income (**SSI**) – Adults

- Adult individuals who meet the disability criteria during the Disability Determination process and who are unable to work to the performance and monetary level of what the SSA calls “substantial gainful activity” (SGA) may be found eligible for SSI cash benefits.
- The dollar amount of SGA changes each year and other income and resources may be taken into consideration. Be sure to see the sections on Employment Supports/Work Incentives and Adult Options (guardianships, trusts, etc.), since there is information that may also be relevant to SSI benefits.

Social Security Disability Insurance (**SSDI**) – Children

- Children under the age of 18 or who are between 18 and 19 and still attending school may be eligible for payments from the Social Security Administration if they have a parent who is receiving SSA disability benefits, has retired, or is deceased. Adoptive children may also be eligible.

Social Security Disability Insurance (**SSDI**) – Adults

- The SSDI program pays benefits to adults who have a disability that began before they became 22 years old.
- These benefits are based on a parent’s Social Security earnings record. Additionally, the adult with a disability that began before age 22 may be eligible for employment supports for work expenses, rehabilitation, and training.

Appendix M - Centers for Independent Living in Virginia

Centers for Independent Living (CILs) offer a wide variety of resources and assistance to individuals with disabilities, their families and caregivers, and the community.

Among the types of services CILs offer include: information and referral, peer counseling, independent living skills training, individual and systems change advocacy, disability awareness, technical assistance regarding accessibility and legal issues, as well as general disability related information.

Staff located at some CILs can assist with information and access to Medicaid Waivers, Work Incentives benefits, and general benefits planning strategies. Even in there is not a CIL in your county/town/city, CILs generally serve the areas surrounding their main offices.

The following is a list with contact information for CILs around Virginia:

<u>Location:</u>	<u>Address:</u>	<u>Name:</u>	<u>Contact:</u>
Abingdon	230 Charwood Dr.	Appalachian Independence Center	276 628 2979
Arlington	3100 Clarendon Blvd.	Independence Center of NV	703 525 3268
Charlottesville	815 Cherry Ave.	Independence Resource Center	434 971 9629
Christiansburg	215 Roanoke St.	New River Valley Satellite (Blue Ridge ILC)	540 381 8829
Danville	1045 Main St.	Piedmont Independent Living Center	434 797 2530



Exmore	4364 Lankford Highway	Eastern Shore Center for Independent Living	888 7872033 276 935
Grundy	Rt. 460 East	Clinch Independent Living Services	6088
Hampton	2021-A Cunningham Dr.	Peninsula Center for Independent Living	757 827 0275
Harrisonburg	205 B South Liberty St.	Valley Associates for Independent Living	540 433 6513
Lynchburg	500 Alleghany Ave.	Lynchburg Area Center for Independent Living	434 528 4971
Manassas	9001 Diggs Rd.	Independence Empowerment Center	703 257 5400
Norfolk	6300 Virginia Beach Blvd.	Endeppence Center	757 461 8007
Norton	147 Plaza Rd.	Junction Center for Independent Living	276 679 5988
Petersburg	1845 Fort Mahone St.	Crater District CIL Satellite	804 892 9338
Richmond	4009 Fitzhugh Ave.	Resources for Independent Living	804 353 6503
Roanoke	1502-B Williamson Rd.	Blue Ridge Independent Living Center	540 342 1231
Winchester	403 B South Loudon St.	Access Independence	800 8352716



Appendix N - Three Employment Supports/Work Incentives for Youth

Student Earned Income Exclusion – SSI recipients

For students who are under age 22 and who are receiving SSI benefits, the Student Earned Income Exclusion (SEIE) allows the individual to earn up to \$ 1,510 per month up to a total of \$6,100 per calendar year in 2007 while regularly attending school without having the earnings decrease the individual's SSI cash benefits.

The purpose of the SEIE is to encourage the student to work during the summer months or participate in work experiences/programs during the school year and still receive SSI benefits.

“Regularly attending school” means that the individual:

- takes one or more courses of study and attends classes, and
- is in grades 7-12 for at least 8 hours per week,
- is in a college or university for at least 8 hours a week,
- is in a training course to prepare for employment at least 12 hours a week (15 hours/week if shop practice is involved), or
- is attending for less time than indicated above for reasons beyond student's control, such as illness.

If the student is being taught at home, he/she may still be considered to be “regularly attending school” if he/she:

- is studying a course/courses given by a school (grades 7-12), college, university or government agency, and
- is receiving services from a home visitor or tutor who directs the study.

Plan for Achieving Self Support – SSI recipients (and some SSDI recipients)

A Plan for Achieving Self-Support (PASS) allows the individual, to spend or save for later, income (other than SSI income) and/or resources for employability investments such as training, education, transportation, equipment, software, etc. and certain other expenses that SSA agrees will help him/her move toward a realistic occupational goal and increase capacity for self-support.

Individuals age 15 and up are most likely to be considered for a PASS. A PASS can be developed with the assistance of a Vocational Rehabilitation Counselor, Benefits Specialist, the Virginia Office for Protection and Advocacy, Employment Network, Work Incentives Specialist, and/or the Social Security Administration.

In some cases, an individual who is NOT receiving SSI benefits but who IS receiving SSDI benefits can spend or set aside some of his/her SSDI benefit toward a PASS and then become eligible for SSI and Medicaid.

Subsidies and Special Conditions – SSI (during initial eligibility only)/SSDI recipients

"Subsidies" and "Special Conditions" include supports an individual receives on the job that may result in him/her receiving more pay than the actual value of the services performed.

These supports are of particular value to individuals who those display more significant limitations or characteristics that indicate a greater need for support, at least initially, in coping with work environments and work task demands.

Commonly it is thought that individuals with severe cognitive and physical/sensory disabilities are more likely to be targeted for supported employment. However, there are individuals who are categorized as having "high functioning autism" and Asperger Syndrome who also may need the options available through supported employment services.



This could include any individual on the autism spectrum who has not been able to access competitive employment or when competitive employment has been interrupted or intermittent due to the manifestation of his/her disability.

Supported employment options include:

- specialized job training
- job coaches
- assistive technology
- specialized supervision
- reduced duties
- transportation
- mentoring
- socialization with other employees
- job re-structuring/creation/development, and
- many other options as appropriate to the individual



APPENDIX O - SSA Partial List of Work Incentives for SSI/SSDI Beneficiaries

(Employment Supports/Work Incentives available through both SSI/SSDI are in **bold italics**.)

All work activity must be reported by SSI/SSDI beneficiaries to SSA in order to determine the potential effect on benefits.

Seek expert advice in advance!

SSI – Supplemental Security Income

1. 1619 A Allows a working SSI recipient to earn a certain level of income while receiving SSI payment and Medicaid at no cost.
2. 1619B Allows Medicaid eligibility to be retained at no cost when the level of income eliminates the SSI payment under certain conditions.
3. ***Expedited Reinstatement/Benefits Under certain conditions, if benefits have ended due to the level of earnings from work, reinstatement of benefits, including Medicare and Medicaid, can be requested without filing a new application to SSA.***
4. ***Impairment Related Work Expense IRWE allows certain out of pocket disability-related expenses that an individual needs in order to work to be deducted from the income reported to SSI for a reduced income calculation.***



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5. **Plan for Achieving Self Support PASS allows the individual to set aside income and/or resources for an occupational objective and helps the individual increase or maintain the level of SSI payment.**
6. Property Essential for Self Support Certain resources, including property, equipment, and a vehicle that are needed for an individual to be self-supporting may be excluded from the resource test for eligibility for SSI.
7. **Section 301 If a person is determined to be no longer disabled by SSA and is participating in a vocational rehabilitation program, cash benefits may continue until the program ends.**
8. Student Earned Income Exclusion SEIE allows individuals under the age of 22 who are participating in educational or training programs to exclude income from benefits calculations and continue to receive cash benefits under certain conditions.
9. **Subsidies and Special Conditions Applicable to SSI only during initial determination process.**
10. **Ticket to Work Available for individuals ages 18-64 to assist beneficiaries to obtain employment with sufficient wages to eliminate SSI cash payments.**



SSDI – Social Security Disability Insurance

1. Expedited Reinstatement/Benefits

Under certain conditions, if benefits have ended due to the level of earnings from work, reinstatement of benefits, including Medicare and Medicaid, can be requested without filing a new application to SSA.

2. Extended Period of Eligibility

Allows the individual to continue receiving Medicare even though they may be earning above a certain level of income and also allows the individual to access reinstated benefits without re-application under certain conditions.

3. Impairment Related Work Expense

IRWE allows certain out of pocket disability-related expenses that an individual needs in order to work to be deducted from the income reported to SSI for a reduced income calculation.

4. Plan for Achieving Self Support

PASS allows the individual to set aside SSDI income for an occupational objective and may also help the individual be eligible for SSI payment.

5. Section 301

If a person is determined to be no longer disabled by SSA and is participating in a vocational rehabilitation program, cash benefits may continue until the program ends.

6. Subsidies and Special Conditions

The value of subsidies is excluded when counting earnings for benefits amount under certain conditions.

7. Ticket to Work

Available for individuals ages 18-64 to assist beneficiaries to obtain employment with sufficient wages to eliminate SSDI cash payments.

8. Trial Work Period

TWP enables an individual to test work skills with full benefits checks for 9 months (non-consecutive) over a 60 month period when medical recovery from disability is not an issue. Free Medicare Part A coverage can continue after the TWP for an extended period of time under certain conditions.

Appendix P - Certified Work Incentives Specialists in Virginia

Location:	Name:	Affiliation:	Contact:
Abingdon	Melissa Meade	Appalachian Independence Center	276 628 2979
Alexandria	Jeffrey Brown	LMEC	703 461 3886
Annandale	Carolyn Price	St. John's Community Services	703 914 2755
Arlington	Edward McEntee	ENCV	703 525 3288
Bedford	Dorothy Narodny	Commonwealth Autism Service	1-800 649 8481
Bumpass	Emma Brault	Rappahannock CSB	540 373 7737
Charlottesville	Sherri Grupp	Individual	434 989 7619
Charlottesville	Robins Rudacil	WorkSource Enterprises	434 972 1730
Chester	Sharon Van Pelt	Chester House	804 748 6787
Farmville	Ryan Follett	STEPS	434 392 5649
Farmville	Diana Messer	Crossroads CSB	434 392 1403
Fredericksburg	Kim Baker	disAbility Resource Center	540 373 2559
Harrisonburg	Kent Stoneburner	Friendship Industries	540 434 9134
Leesburg	Sara McInturff	Loudon Co. CSB	703 777 0522
Lexington	Ashley Crutchfield	Rockbridge CSB	540 463 3141
Lynchburg	Shelley Reichard	Commonwealth Supportive Services	434 239 0536
Lynchburg	Heather Sweitzer	Lynchburg Area CIL	434 528 4971
Norton	Sandra Spivey	Junction CIL	276 679 5988
Radford	Cindy Vinkemulder	Goodwill of the Valleys	540 639 9027
Red Oak	Hazel Bowman Smith	Individual	434 547 5186
Richmond	Sharon Bungler	RSVP	804 288 6272
Richmond	Jonathan Coleman	The New Y-CAPP	804 301 6356
Richmond	Susan Farmer	Richmond DSS	804 648 7154



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Richmond	Sherman Gifford	The Choice Group	804 278 9151
Richmond	David Leon	Hermitage/Henrico CSB	804 232 5259
Richmond	Corey Martin	Richmond ARC	804 358 1874
Richmond	Carolann Pacer-Ramsey	Families First	804 649 0773
Richmond	Kathi Shiff	Individual	804 4678757
Richmond	Kathi Shiff	Richmond Behavioral Health Authority	804 819 4000
Roanoke	Susan Klein	Blue Ridge Independent Living Center	540 342 1231
Roanoke	Terri Preston	Career Support Systems	540 815 6722
Springfield	Barbara Moskowitz	MVLE	703 569 3990
Winchester	Sara McInturff	Individual	540 533 5611



Appendix Q - Overview of Two Medicaid Waivers in Virginia

Developmental Disabilities Waiver (IFDDS)

Who is eligible? Individuals 6 years of age and older with a condition related to mental retardation, but who do not have a diagnosis of mental retardation

Who starts the process? Individual, parent, or representative completes a Request for Screening Form and submits it to the nearest Child Development Center (See **Appendix R** for list).

What services/supports are included in the DD Waiver?

- Day Support
- Companion Services (Agency or Consumer Directed)
- Supported Employment
- In-home Residential Support
- Therapeutic Consultation
- Personal Care Services
- Respite Care (Agency or Consumer Directed)
- **Supported Employment**
- Skilled Nursing Services
- Attendant Services
- Family and Caregiver Training
- Crisis Supervision
- Environmental Modifications
- Assistive Technology
- Personal Emergency Response System (PERS)
- Support Coordination
- **Prevocational Services**



**REQUEST FOR SCREENING
FOR
INDIVIDUAL AND FAMILY DEVELOPMENTAL DISABILITIES SUPPORT WAIVER
(DD WAIVER)**

***This is a request to be screened for the Individual and Family Developmental Disabilities Support Waiver. Submission of this request form does not guarantee admission into the waiver, nor does it guarantee Medicaid eligibility. Fill the request form, print, sign, and mail to the Child Development Clinic closest to your area.*

Name of person to be screened: _____
Last
First
SS#

Address (include city, state, zip): _____

County: _____ Phone Number (include area code): (____) _____

*Date of Birth: _____
Individuals must be 6 years of age or older and cannot have a diagnosis of Mental Retardation to be eligible for this waiver.

Are you currently Medicaid eligible? Yes ____ No ____

- If yes, provide 12-digit Medicaid identification number: _____
- What services are you currently receiving under Medicaid: _____

Signature of Person Making Request for Screening: _____
 Date: _____

Completed applications must be submitted to your local Child Development Clinic. Forms sent to DMAS will not be processed.

FOR SCREENING TEAM USE ONLY

Date Application Received: ___/___/___
 Signature of Receiver: _____
 Date(s) Contact Made With Applicant: _____
 Date Screening Performed: ___/___/___
 Service Approved?: If Approved, which service? ICF/MR DD Waiver
 Service Not Approved?: If Not Approved, Reason: _____
 Date Applicant Notified: ___/___/___ (Attach copy of letter to this request)



Child Development Clinics in Virginia

Submit the Request for Screening Form for the DD Waiver to the Child Development Center in your area

HARRISONBURG: *Serving the counties of Augusta, Bath, Greene, Highland, Rockbridge, and Rockingham; Cities of Buena Vista, Harrisonburg, Lexington, Staunton, and Waynesboro.*

Shenandoah Valley Child Development Clinic

James Madison University

MSC 9011

Harrisonburg, VA 22807 Phone: 540-568-7956

LYNCHBURG: *Serving the counties of Albemarle, Amelia, Amherst, Appomattox, Bedford, Campbell, Buckingham, Charlotte, Cumberland, Lunenburg, Nelson, Nottoway, and Prince Edward; Cities of Bedford, Charlottesville, and Lynchburg.*

Central Virginia Child Development Clinic

P.O. Box 2279

Lynchburg, VA 24501 Phone: (434) 947-2030

WINCHESTER: *Serving the counties of Clarke, Fauquier, Frederick, Loudoun, Madison, Page, Rappahannock, Shenandoah, and Warren; Sterling, City of Winchester*

Child Development Clinic of Northwest Virginia

158 Front Royal Pike, Suite 100

Winchester, VA 22602 Phone: (540) 722-3484

ARLINGTON: *Serving the cities and counties of Arlington, Fairfax, Alexandria, Falls Church, and McLean*

Northern Virginia Diagnostic and Evaluation Clinic

Arlington Department of Human Services

3033 Wilson Boulevard, Suite 600B - 24

Arlington, VA 22201 Phone: (703) 228-1621



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FREDERICKSBURG: *Serving the counties of Caroline, Essex, Hanover, King and Queen, King George, Lancaster, Northumberland, Prince William, Richmond, Spotsylvania, Stafford, and Westmoreland; cities of Fredericksburg, Manassas, and Manassas Park, Culpepper and Orange.*

Rappahannock Area Child Development Center
810 Westwood Office Park
Fredericksburg, VA 22401 Phone: (540) 899-4025

PETERSBURG: *Serving the counties of Chesterfield, Dinwiddie, Fluvana, Greensville, Henrico, Powhatan, Prince George, Surry, Sussex, Goochland, and Louisa; Cities of Colonial Heights, Emporia, Hopewell, Petersburg, and Richmond.*

Crater Child Development Clinic
2002 Wakefield Street
Petersburg, VA 23805 Phone: (804) 862-6186

NEWPORT NEWS: *Serving the counties of Charles City, Gloucester, Isle of Wight, James City, King William, Mathews, Middlesex, New Kent, Southampton, and York; Cities of Hampton, Newport News, Poquoson, and Williamsburg*

Peninsula Child Development Clinic
416 J. Clyde Morris Boulevard
Newport News, VA 23601 Phone: (757) 594-7319

NORFOLK: *Serving the counties of Accomack and Northampton; Cities of Chesapeake, Franklin, Norfolk, Portsmouth, Suffolk, and Virginia Beach.*

Tidewater Child Development Clinic
830 Southampton Avenue
Norfolk, VA 23510 Phone: (757) 683-8770



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DANVILLE: *Serving the counties of Brunswick, Halifax, Henry, Patrick, Pittsylvania, and Mecklenburg; Cities of Danville, Martinsville, and South Boston.*

Child Development Clinic- Southside
Public Health Center- Suite G-41
326 Taylor Drive
Danville, VA 24541 Phone: (434) 797-1040

GATE CITY: *Serving the counties of Bland, Buchanan, Dickenson, Grayson, Lee, Russell, Scott, Smyth, Tazewell, Washington, Wise, and Wythe; Cities of Bristol and Norton.*

Southwest Virginia Child Development Clinic
112 Beech Street, Suite 1
Gate City, VA 24251 Phone: (276) 386-3803

ROANOKE: *Serving the counties of Allegheny, Botetourt, Carroll, Craig, Floyd, Franklin, Giles, Montgomery, Pulaski, and Roanoke; Cities of Clifton Forge, Covington, Radford, Roanoke, and Salem.*

Roanoke City Health Department
VA Medical Center
1970 Boulevard Building 76-1
Salem, VA 24153 Phone: (540) 983-1089



Mental Retardation Waiver (MR Waiver)

Who is eligible? Individuals six years of age or older who have a diagnosis of mental retardation and Individuals under age six who have a diagnosis of mental retardation or are at developmental risk.

Who starts the process? Individual, parent, or representative contacts the local Community Service Board or Behavioral Health Authority (See **Appendix S** for list) to request services.

What services/supports are included in the MR Waiver?

- Residential Support Services
- Day support
- Supported employment
- Prevocational services
- Personal assistance
- Respite
- Companion
- Assistive technology
- Environmental modifications
- Skilled nursing services
- Therapeutic consultation
- Crisis stabilization
- Personal emergency response systems



Community Services Boards and Behavioral Health Services Offices in Virginia

Contact the Office nearest you to apply for the MR Waiver

Alexandria CSB: *Serving the City of Alexandria*

720 North Saint Asaph St 4th Floor Alexandria, VA 22314-1941

Main Phone: (703) 838-4455 Fax: (703) 838-5070 TDD: (703) 838-5054

Alleghany Highlands CSB: *Serving the County of Alleghany and the Cities of Clifton Forge and Covington*

601 Main Street Clifton Forge, VA 24422

Main Phone: (540) 863-1609 Fax: (540) 863-1612 TDD: (540) 962-3939

Arlington CSB: *Serving the County of Arlington*

1801 North George Mason Drive Arlington, VA 22205

Main Phone: (703) 228-5000 Fax: (703) 228-5234 TDD: (703) 228-5269

Blue Ridge Behavioral Health Care: *Serving the Counties of Botetourt, Craig and Roanoke and the Cities of Roanoke and Salem*

301 Elm Avenue SW Roanoke, VA 240164001

Main Phone: (540) 345-9841 Fax: (540) 342-6891 TDD: (540) 345-0690

Central Virginia CSB: *Serving the Counties of Amherst, Appomattox, Bedford and Campbell and the Cities of Bedford and Lynchburg*

2241 Langhorne Rd Lynchburg, VA 24501

Main Phone: (804) 847-8050 Fax: (804) 847-6099 TDD: (804) 847-8062

Chesapeake CSB : *Serving the City of Chesapeake*

PO Box 1647 1417 N Battlefield Blvd Suite 350 Chesapeake, VA 23327 Main Phone: (757) 547-9334

Fax: (757) 547-3595 TDD: (757) 547-0534



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Chesterfield CSB: *Serving the County of Chesterfield*

PO Box 92

6801 Lucy Corr Court Chesterfield,VA 23832-0092

Main Phone: (804) 768-7220 Fax: (804) 768-9205 TDD: (804) 768-7200

Colonial CSB : *Serving the Counties of James City and York and the Cities of Poquoson and Williamsburg*

1657 Merrimac Trail Williamsburg,VA 23185

Main Phone: (757) 220-3200 Fax: (757) 228-7173 TDD: (757) 872-6650

Crossroads CSB: *Serving the Counties of Amelia, Buckingham, Charlotte, Cumberland, Lunenburg, Nottoway and Prince Edward*

PO Drawer 248

60 Bush River Drive Farmville,VA 23901-0248

Main Phone: (804) 392-7049 Fax: (804) 392-4013 TDD: (800) 828-1120

Cumberland Mountain CSB: *Serving the Counties of Buchanan, Russell and Tazewell*

PO Box 810 Cedar Bluff,VA 24609-0810

Main Phone: (540) 964-6702 Fax: (540) 964-5669 TDD: (540) 964-7013

Danville-Pittsylvania CSB: *Serving the County of Pittsylvania and the City of Danville*

245 Hairston Street Danville,VA 24540

Main Phone: (434) 799-0456 Fax: (434) 793-4201 TDD: (434) 799-0198

Dickenson County CSB: *Serving the County of Dickenson*

PO Box 309

McClure Avenue Clintwood,VA 24228

Main Phone: (540) 926-1682 Fax: (540) 926-8134 TDD: (540) 926-6691



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Dickenson County CSB: *Serving the County of Dickenson*

PO Box 309

McClure Avenue Clintwood,VA 24228

Main Phone: (540) 926-1682 Fax: (540) 926-8134 TDD: (540) 926-6691

District 19 CSB: *Serving the Counties of Dinwiddie, Greensville, Prince George, Surry and Sussex and the Cities of Colonial Heights, Emporia, Hopewell and Petersburg*

20 West Bank Street Suite 2 Petersburg,VA 23803

Main Phone: (804) 862-8054 Fax: (804) 862-8064 TDD: (804) 862-8063

Eastern Shore CSB: *Serving the Counties of Accomack and Northhampton*

PO Box 453 Nassawadox,VA 23413

Main Phone: (757) 442-3636 Fax: (757) 442-2319 TDD: (757) 442-2880

Fairfax-Falls Church CSB: *Serving the County of Fairfax and the Cities of Fairfax and Falls Church*

12011 Government Center PKWY Suite 836 Fairfax,VA 22035-1105

Main Phone: (703) 324-7000 Fax: (703) 803-9687 TDD: (703) 324-4495

Goochland-Powhatan CSB: *Serving the Counties of Goochland and Powhatan*

PO Box 189

3058 River Road West Goochland,VA 23063

Main Phone: (804) 556-5400 Fax: (804) 556-5428 TDD: (804) 556-5422

Hampton-Newport News CSB : *Serving the Cities of Hampton and Newport News*

2501 Washington Ave 2nd Floor Newport News,VA 23607

Main Phone: (757) 245-0217 Fax: (757) 245-0218 TDD: (757) 245-4812



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Hanover County CSB: *Serving the County of Hanover*
 12300 Washington Highway Ashland,VA 23005-7646
 Main Phone: (804) 752-4275 Fax: (804) 752-4252 TDD: (804) 752-4184

Harrisonburg-Rockingham CSB: *Serving the County of Rockingham and the City of Harrisonburg*
 1241 North Main Street Harrisonburg,VA 22802
 Main Phone: (540) 434-1941 Fax: (540) 434-1791 TDD: (540) 434-1941

Henrico Area CSB: *Serving the Counties of Charles City, Henrico and New Kent*
 10299 Woodman Road Glen Allen,VA 23060-2798
 Main Phone: (804) 261-8500 Fax: (804) 261-8580 TDD: (804) 261-8484

Highlands CSB: *Serving the County of Washington and the City of Bristol*
 510 Cumberland Street 4th Floor Bristol,VA 24201
 Main Phone: (540) 669-3179 Fax: (540) 669-9093 TDD: (540) 628-9504

Loudoun County CSB: *Serving the County of Loudoun*
 102 Heritage Way NE Suite 305 Leesburg,VA 20176
 Main Phone: (703) 777-0377 Fax: (703) 771-5367 TDD: (703) 771-0377

Middle Peninsula-Northern Neck CSB: *Serving the Counties of Essex, Gloucester, King & Queen, King William, Lancaster, Mathews, Middlesex, Northumberland, Richmond and Westmoreland*
 PO Box 40 Saluda,VA 23149
 Main Phone: (804) 758-5314 Fax: (804) 758-3418

Mount Rogers CSB: *Serving the Counties of Bland, Carroll, Grayson, Smyth and Wythe and the City of Galax*
 770 West Ridge Road Wytheville,VA 24382
 Main Phone: (540) 223-3200 Fax: (540) 223-3250 TDD: (540) 223-1721



New River Valley CSB: *Serving the Counties of Floyd, Giles, Montgomery and Pulaski and the City of Radford*
 700 University City Boulevard Blacksburg,VA 24060
 Main Phone: (540) 961-8300 Business Fax: (540) 961-8466 TDD: (540) 961-8400

Norfolk CSB : *Serving the City of Norfolk*
 248 West Bute Street Norfolk,VA 23510-1404
 Main Phone: (757) 441-5300 Fax: (757) 441-1153 TDD: (757) 441-1701

Northwestern CSB: *Serving the Counties of Clarke, Frederick, Page, Shenandoah and Warren and the City of Winchester*
 209 W. Criser Road Suite 300 Front Royal,VA 22630
 Main Phone: (540) 636-4250 Fax: (540) 636-7171 TDD: (540) 828-1120

Piedmont CSB: *Serving the Counties of Franklin, Henry and Patrick and the City of Martinsville*
 24 Clay Street Martinsville,VA 24112
 Main Phone: (540) 632-7128 Fax: (540) 632-9998 TDD: (540) 632-4669

Planning District 1 Behavioral Health Services: *Serving the Counties of Lee, Scott and Wise and the City of Norton*
 PO Box 537 Cloverleaf Square Bldg E Suite 5 Big Stone Gap, VA 24219
 Main Phone: (540) 523-2562 Fax: (540) 523-6133 TDD: (540) 523-2562

Portsmouth Dept. of Behavioral Healthcare Services : *Serving the City of Portsmouth*
 600 Dinwiddie Street, Suite 200 Portsmouth,VA 23704-3844
 Main Phone: (757) 393-8618 Fax: (757) 393-5226



Prince William County CSB: *Serving the County of Prince William and the Cities of Manassas and Manassas Park*

8033 Ashton Avenue Suite 107 Manassas,VA 20109-2892

Main Phone: (703) 792-7700 Fax: (703) 792-7704

Rappahannock Area CSB: *Serving the Counties of Caroline, King George, Spotsylvania and Stafford and the City of Fredericksburg*

600 Jackson Street Fredricksburg,VA 22401

Main Phone: (540) 899-4370 Fax: (540) 371-3753 TDD: (540) 373-3223

Rappahannock-Rapidan CSB : *Serving the Counties of Culpeper, Fauquier, Madison, Orange and Rappahannock*

PO Box 1568

15361 Bradford Road Culpeper,VA 22701-4238

Main Phone: (540) 825-3100 Fax: (540) 825-6245 TDD: (540) 825-7391

Region Ten CSB: *Serving the Counties of Albemarle, Fluvanna, Greene, Louisa and Nelson and the City of Charlottesville* 800 Preston Avenue Charlottesville,VA 22903-4420

Main Phone: (804) 972-1800 Fax: (804) 970-2198 TDD: (804) 972-1715

Richmond Behavioral Health Authority: *Serving the City of Richmond*

107 South 5th Street Richmond,VA 23219

Main Phone: (804) 819-4000 Fax: (804) 819-4081 TDD: (804) 819-4145

Rockbridge Area CSB: *Serving the Counties of Bath and Rockbridge and the Cities of Buena Vista and Lexington* 241 Greenhouse Ave. Lexington,VA 24450

Main Phone: (540) 464-8560 Fax: (540) 464-8562 TDD: (540) 463-3141



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Southside CSB : *Serving the Counties of Brunswick, Halifax and Mecklenburg and the City of South Boston*
 PO Box 488 424 Hamilton Boulevard South Boston,VA 24592
 Main Phone: (804) 572-6916 Fax: (804) 572-4881 TDD: (804) 572-2103

Valley CSB: *Serving the Counties of Augusta and Highland and the Cities of Staunton and Waynesboro*
 110 West Johnson Street Staunton,VA 24401
 Main Phone: (540) 887-3200 Fax: (540) 887-3245 TDD: (540) 887-3246

Virginia Beach CSB: *Serving the City of Virginia Beach*
 3432 Virginia Beach Blvd. Virginia Beach,VA 23462
 Main Phone: (757) 437-5760 Fax: (757) 490-5736 TDD: (757) 437-6157

Western Tidewater CSB: *Serving the Counties of Isle of Wight and Southampton and the Cities of Franklin and Suffolk*
 2480 Pruden Blvd. Suffolk,VA 23434
 Main Phone: (757) 925-2224 Fax: (757) 925-1537 TDD: (757) 925-3404



Appendix R - Virginia Department of Rehabilitative Services Field Offices

City	Phone	E-Mail
Abingdon	(276) 676-5565	Larry.Overbay@drs.virginia.gov
Alexandria	(703) 960-3411	Teri.Bertsch@drs.virginia.gov
Charlottesville	(434) 296-5621	Naomi.Aitken@drs.virginia.gov
Richmond	(804) 674-2369	Lynn.Harris@drs.virginia.gov
Christiansburg	(540) 381-7122	Toni.Hamilton@drs.virginia.gov
Culpeper	(540) 829-7360	Bob.Canaday@drs.virginia.gov
Danville	(434) 791-5257	Doriane.Mills@drs.virginia.gov
Belle Haven	(757) 787-5992	Paul.Hughes@drs.virginia.gov
Fairfax	(703) 359-1124	Jane.Bennett@drs.virginia.gov
Farmville	(434) 392-8189	Roxanne.Slaughter@drs.virginia.gov
Fishersville	(540) 332-7700	George.Drummond@drs.virginia.gov
Franklin	(757) 562-6151	marie.Gibson@drs.virginia.gov
Fredericksburg	(540) 899-4161	Bob.Canaday@drs.virginia.gov



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Hampton	(757) 865-4863	Roger.McDaniels@drs.virginia.gov
Harrisonburg	(540) 434-5981	George.Drummond@drs.virginia.gov
Richmond	(804) 662-7123	Mark.Peterson@drs.virginia.gov
Leesburg	(703) 771-4775	Jim.Hall@drs.virginia.gov
Lynchburg	(434) 947-6721	Roxanne.Slaughter@drs.virginia.gov
Manassas	(703) 335-5550	Bob.Canaday@drs.virginia.gov
Marion	(276) 781-7466	Mike.Rouse@drs.virginia.gov
Martinsville	(276) 632-7161	Doriane.Mills@drs.virginia.gov
Richmond	(804) 662-9222	Susan.Prousalis@ssa.gov
Norfolk	(757) 455-0831	marie.Gibson@drs.virginia.gov
Petersburg	(804) 863-1625	Lynn.Harris@drs.virginia.gov
Portsmouth	(757) 686-5004	Lynn.Kushner@drs.virginia.gov
Richlands	(276) 963-1028	Mike.Rouse@drs.virginia.gov
Richmond	(804) 367-0175	Antoinette.Smith@drs.virginia.gov
Roanoke	(540) 776-2731	Toni.Hamilton@drs.virginia.gov



South Boston	(434) 575-7949	Doriane.Mills@drs.virginia.gov
St. Paul	(276) 762-5561	Larry.Overbay@drs.virginia.gov
Charlottesville	(434) 924-8329	Naomi.Aitken@drs.virginia.gov
Virginia Beach	(757) 683-8440	Paul.Hughes@drs.virginia.gov
Warsaw	(804) 333-4386	Mark.Peterson@drs.virginia.gov
Williamsburg	(757) 253-4817	Roger.McDaniels@drs.virginia.gov
Winchester	(540) 722-3453	Jim.Hall@drs.virginia.gov
Wytheville	(276) 228-2108	Mike.Rouse@drs.virginia.gov

Appendix S – Summary of Performance Samples/Info

Sample

SUMMARY of PERFORMANCE

Student's Name: _____ Student ID # _____
 Disability: _____
 Student's Address: _____
 Phone Number: _____

School/Address: _____
 Phone Number: _____
 Person/Position completing this report: _____
 Date: _____

Post-secondary Goals:
 Employment: _____

Education/Training: _____

Independent Living/Community Participation: _____

Current Academic Achievement: (include courses of study)

Current Functional Performance:

Recommendations for achieving post-secondary goals:

Attached is a resource directory of community and adult service agencies.
 To obtain a copy of transcripts, contact the school guidance office.
 To obtain copies of Special Education documentation, contact the Office of Special Education, School Board Office.



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NATIONALLY RATIFIED SUMMARY OF PERFORMANCE MODEL TEMPLATE

This template was developed by the National Transition Documentation Summit © 2005 based on the initial work of Stan Shaw, Carol Kochhar-Bryant, Margo Izzo, Ken Benedict, and David Parker. It reflects the contributions and suggestions of numerous stakeholders in professional organizations, school districts and universities particularly the Connecticut Interagency Transition Task Force. It is available to be freely copied or adapted for educational purposes. The model template has been formally ratified by the Council for Exceptional Children's Division on Career Development and Transition (DCDT), Division on Learning Disabilities (DLD), and Council on Educational Diagnostic Services (CEDs), Learning Disability Association (LDA), the Higher Education Consortium for Special Education (HECSE), and the Council for Learning Disabilities (CLD).

Purpose: The Summary of Performance (SOP) is required under the reauthorization of the Individuals with Disabilities Education Act of 2004. The language as stated in IDEA 2004 regarding the SOP is as follows:

For a child whose eligibility under special education terminates due to graduation with a regular diploma, or due to exceeding the age of eligibility, the local education agency "shall provide the child with a summary of the child's academic achievement and functional performance, which shall include recommendations on how to assist the child in meeting the child's postsecondary goals" §Sec. 300.305(e)(3).

The Summary of Performance, with the accompanying documentation, is important to assist the student in the transition from high school to higher education, training and/or employment. This information is necessary under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act to help establish a student's eligibility for reasonable accommodations and supports in *postsecondary* settings. It is also useful for the Vocational Rehabilitation Comprehensive Assessment process. The information about students' current level of functioning is intended to help postsecondary institutions consider accommodations for access. *These recommendations should **not** imply that any individual who qualified for special education in high school will*



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automatically qualify for services in the postsecondary education or the employment setting. Postsecondary settings will continue to make eligibility decisions on a case-by-case basis.

The SOP is most useful when linked with the IEP process and the student has the opportunity to actively participate in the development of this document.

The SOP **must** be completed during the final year of a student's high school education. The timing of completion of the SOP may vary depending on the student's postsecondary goals. If a student is transitioning to higher education, the SOP, with additional documentation, may be necessary as the student applies to a college or university. Likewise, this information may be necessary as a student applies for services from state agencies such as vocational rehabilitation. In some instances, it may be most appropriate to wait until the spring of a student's final year to provide an agency or employer the most updated information on the performance of the student.

- Part 1: Background Information** – Complete this section as specified. Please note this section also requests that you attach copies of the **most recent** formal and informal assessment reports that document the student's disability or functional limitations and provide information to assist in post-high school planning.
- Part 2: Student's Postsecondary Goals** – These goals should indicate the post-school environment(s) the student intends to transition to upon completion of high school.
- Part 3: Summary of Performance** – This section includes three critical areas: Academic, Cognitive and Functional levels of performance. Next to each specified area, please complete the student's present level of performance and the accommodations, modifications and assistive technology that were **essential** in high school to assist the student in achieving progress. Please leave blank any section that is not applicable.

An **Accommodation** is defined as a support or service that is provided to help a student fully access the general education curriculum or subject matter. Students with impaired spelling or handwriting skills, for example, may be accommodated by a note-taker or permission to take class notes on a laptop computer. An accommodation *does not change the content* of what is being taught or the expectation that the student meet a performance standard applied for all students. A **Modification** is defined as a change to the general education curriculum or other material being taught, which alters the standards or expectations for students with disabilities. Instruction can be modified so that the material is presented differently and/or the expectations of what the student will master are changed. Modifications are not allowed in most postsecondary education environments. **Assistive Technology** is defined as any device that helps a student with a disability function in a given environment, but does not limit the device to expensive or “high-tech” options. Assistive technology can also include simple devices such as laminated pictures for communication, removable highlighter tapes, velcro and other “low-tech” devices.

The completion of this section may require the input from a number of school personnel including the special education teacher, regular education teacher, school psychologist or related services personnel. It is recommended, however, that one individual from the IEP Team be responsible for gathering and organizing the information required on the SOP.

- Part 4: Recommendations to assist the student in meeting postsecondary goals** – This section should present suggestions for accommodations, adaptive devices, assistive services, compensatory strategies, and/or collateral support services, to enhance access in a post-high school environment, including higher education, training, employment, independent living and/or community participation.
- Part 5: Student Input (Highly Recommended).** It is highly recommended that this section be completed and that the student provide information related to this Summary of Performance. The student’s contribution can help (a) secondary professionals complete the summary, (b) the student to better understand the impact of his/her disability on academic and functional performance in the

postsecondary setting, (c) postsecondary personnel to more clearly understand the student's strengths and the impact of the disability on this student. This section may be filled out independently by the student or completed with the student through an interview.

Part 1: Background Information

Student Name: _____ **Date of Birth:** _____

Year of Graduation/Exit: _____

Address:

_____ (Street) _____ (Town, state) _____ (Zip code)

Telephone Number: _____ **Primary Language:** _____

Current School: _____ **City:** _____

Student's primary disability (Diagnosis): _____

Student's secondary disability (Diagnosis), if applicable: _____

When was the student's disability (or disabilities) formally diagnosed? _____

If English is not the student's primary language, what services were provided for this student as an English language learner?



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Date of most recent IEP or most recent 504 plan: _____

Date this Summary was completed: _____

This form was completed by: Name: _____ **Title:** _____

School: _____ **E-mail:** _____

Telephone Number: _____

Please check and include the most recent copy of assessment reports that you are attaching that diagnose and clearly identify the student's disability or functional limitations and/or that will assist in postsecondary planning:

- | | |
|--|--|
| <input type="checkbox"/> Psychological/cognitive | <input type="checkbox"/> Response to Intervention (RTI) |
| <input type="checkbox"/> Neuropsychological | <input type="checkbox"/> Language proficiency assessments |
| <input type="checkbox"/> Medical/physical | <input type="checkbox"/> Reading assessments |
| <input type="checkbox"/> Achievement/academics | <input type="checkbox"/> Communication |
| <input type="checkbox"/> Adaptive behavior | <input type="checkbox"/> Behavioral analysis |
| <input type="checkbox"/> Social/interpersonal skills | <input type="checkbox"/> Classroom observations (or in other settings) |
| <input type="checkbox"/> Community-based assessment | <input type="checkbox"/> Career/vocational or transition assessment |
| <input type="checkbox"/> Self-determination | <input type="checkbox"/> Assistive technology |
| <input type="checkbox"/> Informal assessment: | |
| <input type="checkbox"/> Informal assessment: | |
| <input type="checkbox"/> Other: | |



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Part 2 – Student’s Postsecondary Goal(s)

1.

2.

3.

If employment is the primary goal, the top three job interests:

1.

2.

3.



Part 3 – Summary of Performance (Complete all that are relevant to the student).

ACADEMIC CONTENT AREA	Present Level of Performance (grade level, standard scores, strengths, needs)	Essential accommodations, assistive technology, or modifications utilized in high school, and why needed.
Reading (Basic reading/decoding; reading comprehension; reading speed)		
Math (Calculation skills, algebraic problem solving; quantitative reasoning)		
Language (written expression, speaking, spelling)		
Learning Skills (class participation, note taking, keyboarding, organization, homework management, time management, study skills, test-taking skills)		



COGNITIVE AREAS	Present Level of Performance (Grade level, standard scores, strengths, needs)	Essential accommodations, modifications and/or assistive technology utilized in high school and why needed.
General Ability and Problem Solving (reasoning/processing)		
Attention and Executive Functioning (energy level, sustained attention, memory functions, processing speed, impulse control, activity level)		
Communication (speech/language, assisted communication)		



FUNCTIONAL AREAS	Present Level of Performance (strengths and needs)	Essential accommodations/ modifications and/or assistive technology utilized in high school and why needed.
Social Skills and Behavior (Interactions with teachers/peers, level of initiation in asking for assistance, responsiveness to services and accommodations, degree of involvement in extra-curricular activities, confidence and persistence as a learner,)		
Independent Living Skills (Self-care, leisure skills, personal safety, transportation, banking, budgeting)		
Environmental Access/Mobility (assistive technology, mobility, transportation)		
Self-Determination /Self-Advocacy Skills (Ability to identify and articulate postsecondary goals, learning strengths and needs;		



<p>Career-Vocational/Transition/Employment (Career interests, career exploration, job training, employment experiences and supports)</p>		
<p>Additional important considerations that can assist in making decisions about disability determination and needed accommodations (e.g., medical problems, family concerns, sleep disturbance)</p>		



Part 4 – Recommendations to assist the student in meeting postsecondary goals

Suggestions for accommodations, adaptive devices, assistive services, compensatory strategies, and/or collateral support services, to enhance access in the following post-high school environments (only complete those relevant to the student’s postsecondary goals).

Higher Education or Career-Technical Education:	
Employment:	
Independent living:	
Community participation:	

Part 5 – Student Input (Highly Recommended)

SUMMARY OF PERFORMANCE: STUDENT PERSPECTIVE

- A. How does your disability affect your schoolwork and school activities (such as grades, relationships, assignments, projects, communication, time on tests, mobility, extra-curricular activities)?
- B. In the past, what supports have been tried by teachers or by you to help you succeed in school (aids, adaptive equipment, physical accommodations, other services)?
- C. Which of these accommodations and supports has worked best for you?
- D. Which of these accommodations and supports have not worked?
- E. What strengths and needs should professionals know about you as you enter the postsecondary education or work environment?

I have reviewed and agree with the content of this Summary of Performance.

Student Signature: _____

OFFICE OF THE ASSISTANT SECRETARY



Appendix T – Institutions of Postsecondary Education

Information from the Office of Civil Rights
U.S. Department of Education

March 16, 2007

Dear Parent:

I am Stephanie Monroe, the assistant secretary for civil rights in the United States Department of Education in Washington, D.C., where I direct the work of the Office for Civil Rights (OCR). The Department's mission is to ensure equal access to education and to promote educational excellence throughout the nation. OCR contributes to the success of this mission through vigorous enforcement of civil rights laws.

I am reaching out to you to help raise awareness of issues and to share information about legal rights and responsibilities that will affect students with disabilities as they transition from high school to institutions of postsecondary education.

Increasingly, after completing high school, students with disabilities continue their education at institutions such as two- and four-year colleges and universities and at vocational and career schools. Institutions of postsecondary education are responsible for providing disability-related services to students with disabilities. OCR's experience as a law enforcement agency, however, and other data, indicate that some students have reported that they need disability-related services and accommodations but do not receive them.

OCR enforces Section 504 of the *Rehabilitation Act of 1973* (Section 504) and Title II of the *Americans with Disabilities Act* (Title II), which prohibit discrimination on the basis of disability. Every school district and nearly every institution of postsecondary education in the United States is subject to Section 504 or Title II. Entities covered by these civil rights laws have an obligation to comply with legal requirements and to carry out their programs and activities in a manner that does not discriminate on the basis of disability.



Through the Office of Special Education and Rehabilitative Services (OSERS), the Department of Education administers the *Individuals with Disabilities Education Act (IDEA)*, which provides funds to states to assist in making a free appropriate public education (FAPE) available to eligible children with disabilities. *IDEA* requirements apply to state education agencies, school districts and other public agencies that serve *IDEA*-eligible children. Institutions of postsecondary education have no legal obligations under *IDEA*. OSERS also administers the state Vocational Rehabilitation (VR) Services program, a formula grant program that provides funds to state VR agencies to assist eligible individuals with disabilities to obtain employment, including the provision of services designed to facilitate the transition of eligible students with disabilities from school to post-school activities.

OCR strongly encourages students with disabilities to know their rights and responsibilities and the responsibilities of institutions of postsecondary education under Section 504 and the *Americans with Disabilities Act*. This information will help to facilitate equal access to postsecondary education programs and activities for students with disabilities. This information may also help students successfully make the transition from a secondary school system in which parents and school staff have typically advocated on their behalf to a postsecondary system in which they will be expected to advocate for themselves.

Institutions of postsecondary education have significantly different responsibilities from those of elementary and secondary school districts. The unique relationship between postsecondary institutions and students with disabilities is apparent in the application and pre- and post-admission processes. For example:

Prior to Admission

- Institutions of postsecondary education may not make inquiries about prospective students' disabilities prior to admitting them. Prospective students may choose to provide an institution with information about disabilities, but any disclosure of disability is voluntary.
- Institutions of postsecondary education may inquire about whether prospective students can meet the academic and technical standards that are required for admission, provided that such inquiries are not designed to reveal the existence of disabilities.



- Prospective postsecondary students may obtain changes in standardized testing conditions in the administration of entrance examinations if they can provide documentation from a qualified professional that supports the existence of a disability and the need for the specific change.

Following Admission

- Institutions of postsecondary education do not have a legal duty to identify students with disabilities. These institutions' obligations are different from those of school districts, which must identify elementary and secondary school students with disabilities.
- After admission, institutions of postsecondary education may make confidential inquiries of students about disabilities that may require accommodation. A postsecondary student does not have to disclose that he or she has a disability. To obtain academic adjustments, however, students must identify themselves to institutions of postsecondary education as having disabilities and must make a request for an academic adjustment. A student may request an academic adjustment at any time, but advising the institution as soon as possible of the need for an academic adjustment can help to ensure that the institution has adequate time to review the request and provide an appropriate academic adjustment.
- Section 504 and *IDEA* require school districts to conduct an evaluation of a student suspected of having a disability at no cost to the student or his or her parents to determine whether the student has a disability and, because of that disability, needs special education and-or related services. Institutions of postsecondary education, however, are not required to pay for such evaluations. Therefore, if funding from other sources, such as the state VR agency, is not available to a postsecondary student, the student may have to pay for the evaluation.
- To comply with the requirements of *IDEA*, a school district or other public agency must have in effect an individualized education program (IEP) for children with disabilities. School districts may also create a plan or another document describing the evaluation and placement decisions they make for elementary and secondary school students pursuant to Section 504. Institutions of postsecondary education have no obligation to create these documents.
- Institutions of postsecondary education must provide appropriate academic adjustments based on students' disabilities and individual needs when necessary to avoid discrimination. In providing an academic adjustment, a



postsecondary institution does not have to eliminate or lower essential requirements, or make modifications that would result in a fundamental alteration of the programs or activities being offered or impose an undue burden on the institution.

- Institutions of postsecondary education may establish reasonable procedures for requesting academic adjustments and students are responsible for knowing these procedures and following them. Postsecondary institutions may require students who request academic adjustments to provide documentation of their current disabilities and the need for academic adjustments. The institutions must inform students of the documentation they require. Elementary and secondary school IEPs generally will not be sufficient documentation, due to the different contexts and requirements of postsecondary education. However, existing assessment reports and a summary of the student's academic achievement provided in compliance with *IDEA* may meet some documentation requirements.
- Institutions of postsecondary education may not require students with disabilities to pay part or all of the costs of academic adjustments. Postsecondary institutions may not condition their provision of academic adjustments on the availability of funds, refuse to spend more than a certain amount to provide academic adjustments, or refuse to provide academic adjustments because they believe other providers of such services exist.

These are just a few examples of the changes students with disabilities may encounter as they make the transition from high school to postsecondary education. To provide further information, OCR has prepared a pamphlet entitled *Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities* and a guide entitled *Transition of Students with Disabilities to Postsecondary Education: A Guide for High School Educators*. The pamphlet and guide explain the legal requirements of Section 504 and Title II in the postsecondary education context.

Please help us to continue to increase the participation of students with disabilities in postsecondary education by using these documents and by sharing them with other parents, students, educators and interested persons. You may obtain the pamphlet electronically at <http://www.ed.gov/ocr/transition.html> and the guide electronically at <http://www.ed.gov/ocr/transitionguide.html>. Additional copies of the pamphlet are available by writing to ED Pubs, Education Publications Center, P.O. Box 1398, Jessup, MD 20794-1398; by faxing to 301-470-1244; by e-mailing to edpubs@inet.ed.gov; by calling 1-877-433-7827 or 1-800-872-5327; by TDD and



TTY at 1-877-576-7734; or by ordering online at www.edpubs.org. Both the pamphlet and the guide are available in alternative formats, such as Braille, large print or computer diskette by calling

202-260-0852 or 202-260-0818. The pamphlet is also available in Spanish. (See <http://www.ed.gov/about/offices/list/ocr/transition-sp.html>).

For more information and assistance, you may contact OCR's Enforcement Office for your state. Contact information for these offices is at <http://wdcrobcolp01.ed.gov/CFAPPS/OCR/contactus.cfm>.

Thank you for helping OCR to increase awareness of this important issue.

Sincerely yours,

Stephanie Monroe
Assistant Secretary for Civil Rights



Appendix U

Medicaid Waiver Mentors in Virginia

Mentors are people in your community who have received training on Medicaid Waivers and are available to provide community workshops and information on an individual basis to people who are using or trying to access Waiver services.

Misty Buccolo
Commonwealth Autism Service
Richmond
804-355-0300 mbuccolo@autismva.org

Lucy Cantrell
Hanover Arc
Hanover
804-798-2400 lucy@hanoverarc.org

Bill Duncan
Appalachian Independence Center
Wytheville
276-228-8765 aic.galax@embarqmail.com

Tennie Gratz
disAbility Resource Center
Fredericksburg
540-373-2559 tgratz@cildrc.org

Kimball Gray
Endeppence Center of NOVA
Arlington
703-525-3268 kimballg@ecnv.org
Barbara Greenberg
Parent Resource Center

Christiansburg
540-381-6175 bgreenbe@bev.net

Samantha Gregg
Endeppence Center
Norfolk
757-351-1588 sgregg@endeppence.org

Linda Gurley
Peninsula Center for Independent Living
Hampton
827-0275 gurleyl@iepcil.org

Sandy Hermann
Children's Hospital of the King's Daughters
Norfolk
757-668-8519 Sandra.Hermann@chkd.org

Bradford Hulcher
Autism Society of Central Virginia
Glen Allen
804-290-0284 bradhul@aol.com

Dana Jackson
Blue Ridge Independent Living Center
Roanoke

540-342-1231 djackson@brilc.org

Abra Jacobs
Eastern Shore Center for Independent Living
Exmore
757-414-0100 jacaw2003@yahoo.com

Andrea King
Valley Associates for Independent Living
Harrisonburg
540-433-6513 andrea@govail.org

Roberta McEachern
Independence Empowerment Center
Manassas
703-257-5400 rmceachern@ieccil.org

Sheila Roop
Intellectual Disabilities Agency New River Valley
Christiansburg
540-381-0310 sheila@idaofthenrv.org

Didi Zaryczyny
disAbilities Resource Network
Bedford
434-851-1648 DidiZautism@aol.com



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APPENDIX V

Examples of Postsecondary Goals

These examples are excerpted from the HEATH Resource Center Parents' Guide to Transition (<http://www.heath.gwu.edu/index.php/200902041093/Modules/Parents-Guide-to-Transition.html>)

Education/Training:

Goal: Following graduation, I will attend State University and major in architecture. This is postsecondary (following graduation) and it is measurable (will attend).

Goal: Following completion of school, I will receive on-the-job training at Home Depot. This is both measurable and postsecondary. Your child will receive specific training at a specific business, or for a specific career choice.

Goal: Following graduation of school, I will audit a course on sign language at Northern Community College. Following completion of school, I will attend college part-time. Both of these are postsecondary and measurable goals for the student planning to continue learning on a college/university campus.

Employment:

Goal: Following graduation, I will work as a design engineer or someone who works with creating products, roads, or designing buildings.

Goal: Following graduation (or following completion of school), I will work in my neighborhood at a bakery. This goal is both measurable and postsecondary.

Goal: Following completion of school, I will audition for commercials or movies. This measurable goal is postsecondary and reflects the individual's passion for the stage and screen.



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Goal: **Following completion of school, I will volunteer or work as an assistant to the city park’s grounds keeper.** This is both measurable and postsecondary.

Independent Living:

Goal: **Following graduation, I will live in the dorm while attending college.** This is postsecondary (following graduation) and it is measurable (will live in the dorm).

Goal: **Following completion of school, I will live in a home with friends or roommates and receive support from the Community Adult Agency.** This is measurable and postsecondary.

Practice writing some Transition Goals:

(when) _____

(who will) _____

(what will you do) _____

(where or what) _____



APPENDIX W

Benefits Specialists/Community Work Incentives Coordinators

Greater Fredericksburg Area

Kim Baker - 540-373-2559 **E-mail:** kbaker@cildrc.org

Shenandoah Valley

Hilda Lifsey - 804-895-1837 **E-mail:** Hlifsey@gmail.com

Roanoke/Southwest Virginia **Terri Preston** - 540-815-6722 **E-mail:**
tpreston@careersupport.net

Richmond, Petersburg & Central Virginia

Steve Waldron - mobile 804-370-7037 **E-mail:** skwjcw@hotmail.com

Monroe Spencer - mobile: 804-731-0130 **E-mail:** monroe@careersupport.net

Far Southwest Virginia

Sandra Spivey - 276-431-1195 or 276-679-5988 **E-mail:** sandra@junctioncenter.org

Northern Virginia

Marilyn Morrison - (571) 339-1305 **E-mail:** mmorrison@vaaccses.org



COMMONWEALTH AUTISM SERVICE CONTACT INFORMATION:

1 800 649 8481

2100 West Broad St.

Richmond, VA 23220

information@autismva.org

www.autismva.org

Please contact us with any suggestions or comments related to the Transition HELPBOOK.

If you need further assistance, please do not hesitate to contact Commonwealth Autism Service.

Thank you, Autism Speaks, for your support for Transition Training for families in Virginia.

