Work, Assistive Technology and Transition-Aged Youth

Funding for Work-Related Assistive Technology
Through Special Education Programs, State Vocational
Rehabilitation Agencies, Medicaid, Medicare and
SSI's Plan for Achieving Self Support

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Published By:

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October 2011

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Preface

This version of the publication, *Work, Assistive Technology and Transition-Aged Youth*, is published through the National Assistive Technology (AT) Advocacy Project of Neighborhood Legal Services, Inc., as part of its Funding of AT manual series. Information about the AT Advocacy Project, and the federal grant that supports it, appears in the Publication Credits and Disclaimer on page iii, below.

This document was originally published in 2001 under the title, Funding of Assistive Technology to Make Work a Reality, to meet the needs of the two advocacy programs established through the Ticket to Work and Work Incentives Improvement Act of 1999 (see Part One, section I, below): the Benefits Planning, Assistance and Outreach (BPA&O) project, now renamed the Work Incentives Planning and Assistance (WIPA) project, and the Protection and Advocacy for Beneficiaries of Social Security (PABSS) project. Both the WIPA and PABSS projects are mandated to provide services to beneficiaries of Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) who face one or more barriers in their movement from benefits to work. with the PABSS projects authorized to represent beneficiaries in administrative appeals and litigation (other than litigation against the Social Security Administration). In fact, the original Policy and Practice Brief has been used to provide training to many attorneys and advocates employed by PABSS projects and other Protection and Advocacy programs. We targeted the 2004 version and the current version of this publication to an additional audience of attorneys and advocates who work for Protection and Advocacy for Assistive Technology (PAAT) programs and those who work for any other Protection and Advocacy (P&A) programs that might be expected to deal with these issues.

This article or manual has been built around a case scenario involving Sharon, a 17 year old with a severe physical disability who will face multiple needs for AT as she completes her special education program, attends college, and eventually moves on to her employment goal. In walking through several years of her life, she is faced with the need to access several different benefit programs as funding sources for AT, including the special education program, the state vocational rehabilitation agency, Medicaid, Medicare, and SSI's Plan for Achieving Self Support.

We purposely picked a transition-aged student with a disability for this scenario. This allows us to look at the interplay of one program, special education, which serves only children and very young adults, and another, vocational rehabilitation, that overlaps with special education in its obligation to serve young adults. It allows us to look at one health insurance program, Medicare that serves only adults, and contrast it with Medicaid, which serves both adults and children. As we plan Sharon's movement from her third year of high school, through college, and eventually law school, we can see how proactive benefits planning can help to ensure that all the pieces of the puzzle are in place (i.e., that she has the needed AT and other services) so that she can truly benefit from her high school and college education on the road to gainful employment.

One of the tricky things that face students like Sharon, her parents, and the advocates who serve them is the different funding criteria that will be used by these diverse programs for approving the various AT devices which Sharon will need. This presents a challenge to those who will assemble the paperwork to justify why a particular item is needed. While our publication does not discuss any of the funding sources exhaustively, we do point out that each program will look at funding through its own perspective or mandate. So, for example, Sharon may be able to justify funding for a laptop computer as related to her education (the special education system) or her long-term work goal (the vocational rehabilitation program, SSI's PASS), but cannot justify it as satisfying a medical need (Medicaid or Medicare). However, if we combine the laptop with a device that serves as a speech generating device, the Medicaid program may fund it.

Several of the items that Sharon will seek are expensive, like the power wheelchair and the speech generating device. Others, like the sophisticated, voice-activated computer equipment, may be on the cutting edge of technology and not familiar to some funding sources. Still other items may not even be available right now but emerge on the marketplace during the six or more years that we follow Sharon's progress. With both expensive AT and new technology, we can expect a significant number of denials through agencies like those discussed in the article.

Attorneys and advocates must be prepared to pursue administrative appeals and even litigation to address those denials. Those attorneys and advocates can come from the PAAT, the PABSS, or one or more other P&A programs. For example, since Sharon in the case scenario has a childhood diagnosis of cerebral palsy, she could be represented through the P&A for the Developmentally Disabled (PADD) program. If she faced similar needs as an adult with an age 23 spinal cord injury, she could be represented under the P&A for Individual Rights (PAIR) program. In fact, depending on the complexity of a case that goes into litigation, attorneys from two of these programs might collaborate on the case.

Publication Credits and Disclaimer

This publication, *Work, Assistive Technology and Transition-Aged Youth*, was originally developed in 2001 under the title, *Funding of Assistive Technology to Make Work a Reality*, as a Policy and Practice Brief by the Northeast Work Incentives Support Center in the Program on Employment and Disability (recently renamed the Employment and Disability Institute) at Cornell University's School of Industrial and Labor Relations. The Northeast Work Incentives Support Center was, at that time, funded under Contract Number 0600-00-51202 from the Social Security Administration, Office of Employment Support Programs to Cornell University and their subcontractors, including Neighborhood Legal Services, Inc. of Buffalo, New York. It was reprinted and republished in 2004 with the permission of these organizations. We are now reprinting and republishing this 2011 version with permission of these organizations.

The current version of this publication is published and distributed through the National Assistive Technology (AT) Advocacy Project.* That project is fully funded under contract number H224B100001 from the Rehabilitation Services Administration, U.S. Department of Education, to the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) with a subcontract to Neighborhood Legal Services, Inc..

The co-authors of this publication are James R. Sheldon, Jr., the Supervising Attorney of the National AT Advocacy Project, and Ronald M. Hager, a Senior Staff Attorney with the National Disability Rights Network. Both authors work part-time with the National AT Advocacy Project and both are national experts on the legal issues associated with the five funding sources discussed in the publication. Both authors have presented on these topics to many audiences at national conferences and throughout the country.

The original, 2001 article was reviewed for accuracy by the Social Security Administration. Since the original publication, some editing has been done to update the information, selectively expand sections of the article, and to provide more extensive citations to law and regulation. The opinions and positions expressed herein are those of the individual authors and do not necessarily reflect the position of Cornell University's Employment and Disability Institute, the Social Security Administration, the U.S. Department of Education, or any other federal agency, and no official endorsement by the Social Security Administration, the U.S. Department of Education, or any other federal agency, of the opinions and positions expressed herein should be inferred.

^{*}The National AT Advocacy Project provides technical assistance, training, and a range of other support services, nationwide, to attorneys and advocates who work at Protection and Advocacy programs and specialize in assistive technology issues. For access to our many publications, you can go to our website at www.nls.org/natmain.htm.

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A Listing of Acronyms and Abbreviations

AT Assistive Technology

BPA&O Benefits Planning, Assistance and Outreach Project

C.F.R. Code of Federal Regulations

DAC Disabled Adult Child's Benefits (referring to a form of SSDI benefits, officially

known as Child's Insurance Benefits, and also referred to as Childhood Disability

Benefits)

DME Durable Medical Equipment

IDEA Individuals with Disabilities Education Act

IEP Individualized Education Plan

IPE Individualized Plan for Employment

PABSS Protection and Advocacy for Beneficiaries of Social Security Program

POMS SSA's Program Operations Manual Systems

SSA Social Security Administration

SSDI Social Security Disability Insurance

SSI Supplemental Security Income

U.S.C. United States Code

VR Vocational Rehabilitation

WIPA Work Incentives Planning and Assistance Project

Work, Assistive Technology and Transition-Aged Youth

Funding for Work-Related Assistive Technology Through Special Education Programs, State Vocational Rehabilitation Agencies, Medicaid, Medicare and SSI's Plan for Achieving Self Support

OVERVIEW

I. The Purpose of This Article

The Ticket to Work and Work Incentives Improvement Act of 1999, in its "findings" section, recognizes the importance of assistive technology (AT)¹ in helping individuals with disabilities to work:

Coverage ... for [personal assistance services], as well as for prescription drugs, durable medical equipment, and basic health care are powerful and proven tools for individuals with significant disabilities to obtain and retain employment.²

Individuals with disabilities have greater opportunities than ever before, aided by ... innovations in assistive technology, medical treatment and rehabilitation.³

The availability of AT can make a tremendous difference in the ability of an individual to work, even when that individual has a severe disability. In the work context, AT serves several functions: it may make it possible to participate in an education or training program; it may make it possible to get prepared to leave the home for work or training; it may make it possible to travel to and from work; and in some cases, the work itself could not be done without the AT.

This article will describe how AT can assist individuals with severe disabilities to overcome barriers to gainful employment, with a focus on transition-aged youth (i.e., youth with disabilities who are moving from special education programs to training programs, college and/or work). It will also describe several key funding sources available in all states, to pay for the AT devices and services that will help individuals prepare for, get to, and succeed in employment. Specifically, we will discuss the public school special education system, state vocational rehabilitation agencies, Medicaid,

¹ A listing of the abbreviations and acronyms used in this article appears at page vi, above.

² Pub. L. No. 106-170, § 2(a)(4), 113 Stat. 1862 (emphasis added) (Congressional findings preceding 42 U.S.C. § 1320b-19). The term durable medical equipment, which is used by Medicaid, Medicare, and private insurance plans, encompasses a wide range of equipment that meets the definitions of AT referenced in this article. See, Part One, section II and notes 6 and 7.

³ Pub. L. No. 106-170, § 2(a)(7), 113 Stat. 1862.

Medicare, and the Supplemental Security Income (SSI) program's Plan for Achieving Self Support.

We originally wrote this for a primary audience of individuals who work for either a Work Incentives Planning and Assistance (WIPA) project, formerly known as the Benefits Planning, Assistance and Outreach (BPA&O) project, or a Protection and Advocacy for Beneficiaries of Social Security (PABSS) program, both of which are mandated to serve individuals with disabilities who receive either SSI or Social Security Disability Insurance (SSDI) benefits. This article, as recently edited and updated, will also be very useful for attorneys and advocates employed by Protection and Advocacy for Assistive Technology (PAAT) programs. We assume that this article will also be distributed to many SSI and SSDI beneficiaries, their families, and the agencies that serve them.

Although we are urging attorneys and advocates in the other P&A programs to get involved in the various programs summarized in this article, we have not attempted to provide a comprehensive summary of each program. Instead, we are providing enough of a summary of each funding source to provide context for looking to meet the AT-related needs of the hypothetical Sharon, a transition-aged student, whose situation is described below.

II. AT Definitions and Other Terminology

Assistive technology is a term that gained popularity after it appeared in the Technology Related Assistance for Individuals with Disabilities Act in 1988.⁴ Known by many as the Tech Act and more recently as the AT Act,⁵ this legislation provides definitions for AT devices and services:

The term "assistive technology device" means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.

* * * * *

The term "assistive technology service" means any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.⁶

The term AT service specifically includes evaluations to determine the need for a device, customizing or adapting the device for its user, repairs, maintenance, and training on how to use the device.

The popular use of the term AT is of recent vintage and only a few funding sources have adopted it to date, including the special education and the vocational

⁴ Pub. L. 100-407, 102 Stat. 1044, former 29 U.S.C. §§ 2201 et seq.

⁵ Congress re-authorized this legislation as the Assistive Technology Act of 1998 and later as the Assistive Technology Act of 2004, both codified at 29 U.S.C. §§ 3001 *et seq.*

⁶ 29 U.S.C. §§ 3002(4) & (5).

rehabilitation systems.⁷ For this reason, individuals with disabilities and the advocates who work with them need to communicate with funding sources, concerning AT, in the language that has meaning to them. When dealing with Medicaid or Medicare, the term "durable medical equipment" is used most frequently to describe traditional items like wheelchairs, speech generating devices (often called augmentative and alternative communication or AAC devices), and hospital beds. A wide range of other terms, such as prosthetic device or orthopedic appliance, will often be used to describe what we think of as AT. When AT is the term used by a program or funding source, it will usually include the variety of devices and services which will be encompassed by the many other terms.

Many persons with disabilities can benefit greatly from AT, including those with physical, visual, cognitive, and hearing impairments. The following is a list of AT devices that a person may need to benefit from an education, receive training, leave the home, travel to work, or perform work:

- Power and custom-made wheelchairs
- Speech generating devices
- Environmental control units
- Lifting devices, such as hydraulic lifts and ceiling track lifts
- Vehicle modifications, including wheelchair lifts and hand controls
- Computer equipment and adaptations, including Braille printers, voice output, touch screens, and switches which allow computer access through voluntary movements such as eye blinks or head movements
- Assistive listening devices, including hearing aids and personal FM units
- Home modifications, including ramps, lifts, and stair glides
- Work site modifications, including adapted office equipment and environmental control devices
- Classroom modifications, including adaptive seating systems

These devices and others have been obtained for persons with disabilities through a wide range of funding sources, including the special education system, the state vocational rehabilitation agency, the state's Medicaid program, Medicare, the SSI program's Plan for Achieving Self Support, and many others. Sometimes a device will only be funded following an administrative hearing or court appeal.

Low-tech AT may cost under \$50. Some devices are much more expensive, however. For example, a package of computer equipment for a computer programmer who is blind may cost several thousand dollars. Similarly, many power wheelchairs sought through Medicaid will cost more than \$10,000. As the cost escalates, the likelihood that a funding source will deny approval increases.

⁷ See definitions for AT device and AT service at 34 C.F.R. §§ 300.5 and 300.6 (special education) and §§ 361.5(b)(7) and (b)(8)(vocational rehabilitation).

III. Case Scenario to be Addressed in the Article

To give context for this article, we are providing the reader with a case scenario in which the young person with the disability needs AT to benefit from her education, receive training, leave the home, travel to work, and perform work. In order to touch on several funding sources for children and adults, we have made the individual an older teen who can be expected to have certain needs as she transitions through the last years of public schooling, through college, and eventually into paid employment. Although our hypothetical individual is a person who is expected to go on to college, AT may be equally useful to the individual who will go straight from a public school program to work or a non-college training program.

Consider Sharon, who is 17 years old and has cerebral palsy, a diagnosis she has had since birth. She is completing her junior year in high school, has above average grades, and plans to attend college to become an attorney. Sharon's 18th birthday will occur in December of her senior year in high school. Although Sharon attends all regular classes, she receives support services from a special education teacher in the classroom, as well as speech pathology, occupational therapy, and physical therapy services from her school's special education department.

Sharon resides with her mother, stepfather and a 12 year old brother who does not have a disability. Her father died when Sharon was young and she now collects \$420 in Social Security survivor's benefits on her father's Social Security record. Her parents' combined annual income is about \$60,000, which makes her ineligible for SSI at this point because both the parent's and stepparent's income is considered available to Sharon.

Sharon has already visited the School of Industrial and Labor Relations at Cornell University in Ithaca, New York and hopes to attend undergraduate school there. Her good grades and SAT scores should ensure her acceptance at the school. Her home is a 30 mile, round-trip commute from the campus, but public transportation is not available for this travel. Sharon plans to continue living at home and commute to the campus.

Sharon and her parents have identified the following AT, which is needed presently or is an expected need over the next three to five years:

- A power wheelchair. Sharon's existing lightweight wheelchair is something she can self propel on level terrain for distances up to about 200 feet. If she attends college at Cornell (the university and the village of Ithaca are extremely hilly), she will not be capable of independent mobility without a power wheelchair. Even in flat areas, the buildings on this campus (and most campuses) are spaced far enough apart that she could not propel her manual wheelchair between classes.
- A speech generating device (SGD)⁸: Sharon's speech is understandable only to familiar listeners. She currently has a seven year old device that allows her

⁸ The SGD is often referred to as either an augmentative and alternative communication (AAC) device or an augmentative communication device (ACD).

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- to speak by electronic means. This device is constantly in for repairs and it has become more difficult to find the parts to repair it.
- A laptop computer with adapted keyboard and voice input software: Sharon has extreme difficulty writing and currently has a note taker in school, funded through the special education program. She uses her family's six-year old personal computer at home, with an adapted keyboard, to do all school assignments. Despite her severe speech problems, a local university's evaluation recommends the latest in software technology to allow her to dictate notes, assignments and papers into the computer. The evaluators tell Sharon that the software program will be able to pick up her speech patterns and capture what she says with up to 90 percent accuracy. (Sharon's speech pathologist is recommending that she consider a combination laptop computer/SGD that can meet both the speech generation and personal computer functions at a fraction of the cost of the two devices combined.)
- A ceiling track lift: Currently, Sharon's parents use a traditional Hoyer lift (i.e., a hydraulic model) to get her into and out of bed, and to meet her needs in the bathroom. Her mother finds it increasingly difficult to operate the lift and her stepfather's business requires frequent out-of-town trips. The more expensive, state-of-the art ceiling track lift would allow Sharon to more safely and efficiently meet her needs in order to get out of the home to attend college.
- Access ramp at the home: Currently, Sharon and her wheelchair must go up and down stairs to enter or exit the home. The family uses a makeshift method with two long planks to allow her to move up and down the stairs. She also needs two persons to guide the wheelchair up or down. A ramp will allow Sharon to safely come and go without a second person to help her. The ramp will become particularly important when Sharon starts using the heavier power wheelchair.
- A van specifically modified for a wheelchair user: Based on a recent driver evaluation, Sharon was found capable of driving a van equipped with the various modifications that allow her to drive from her wheelchair (hydraulic lift, wheelchair lock down, hand controls, etc.). If she can obtain the van while she is in college, she will avoid the expense of a private wheelchair van service to take her to college. The van will be needed for travel to work after she leaves college.

DISCUSSION OF FUNDING SOURCES FOR ASSISTIVE TECHNOLOGY

This article will discuss the following potential funding sources for AT:

- The public schools, including their special education programs and obligations under section 504 of the federal Rehabilitation Act
- State vocational rehabilitation agencies

- Medicaid
- Medicare
- SSI's Plan for Achieving Self Support

For each funding source, we will go through the key criteria to obtain funding for AT, including:

- How one becomes eligible for the program or service
- The criteria that program follows for covering AT devices and services, and the likelihood that the program would fund the devices sought by Sharon
- Any appeal procedures for challenging a denial of funding

I. The Public Schools: Special Education Programs and Section 504 Obligations⁹

A. The Special Education System

1. Eligibility for Special Education Services

The special education rights of children and parents, as well as the responsibilities of school districts, are spelled out in a major federal law, the Individuals with Disabilities Education Act (IDEA). The IDEA guarantees, in every state, that all eligible children with disabilities receive a free appropriate public education, which is designed to meet their unique needs. It must be at no cost to the parents or student. Since there can be no income test for special education services, it does not matter, for example, that Sharon's parents have an annual income of \$60,000. The income could be half that amount or double that amount and she would be eligible for the same services.

The IDEA applies to all students aged 3 through 21, or until the student receives a regular high school diploma. ¹² To qualify for special education services, a child must have a disability, such as a speech, mobility, orthopedic, health, hearing or visual impairment, mental retardation, a learning disability, or emotional disability, because of which the child requires special education and related services. ¹³ Special education is defined as specially designed instruction to meet the unique needs of the child. ¹⁴ Related services are defined as developmental, corrective and other support services required to assist a student with a disability to benefit from an education and include

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⁹ For a more comprehensive discussion of this topic *see The Public School's Special Education System as an Assistive Technology Funding Source: The Cutting Edge*, Second Edition (April 2003), available at www.nls.org/specedat.htm.

¹⁰ 20 U.S.C. §§ 1400 et seq.; 34 C.F.R. Part 300.

¹¹ 20 U.S.C. § 1400(d)(1)(A).

¹² 34 C.F.R. §§ 300.101, 300.102.

¹³ 34 C.F.R. § 300.8.

¹⁴ 34 C.F.R. § 300.39.

occupational therapy, physical therapy, speech pathology, counseling, health services, and parent training. Sharon is eligible for special education and related services (i.e., speech pathology, occupational therapy and physical therapy), even though she attends all regular classes. This is because she needs the extra services to adequately benefit from her education.

The IDEA also requires that students receive their special education assistance in the least restrictive environment appropriate to meet their needs. ¹⁶ This means that removal from regular education classes occurs only when a student cannot be successfully educated in regular classes, even with "supplemental aids and services." ¹⁷ When a student is removed from the regular educational environment for part of the day, the student must still be educated with non-disabled peers as much as possible.

The needs of the student and the services to be provided must be designated, in writing, on an individualized education program (IEP).¹⁸ The IEP must be developed at a meeting with a group of people, including the parents and teachers. The IEP must specify all of the educational services planned for a child, including the child's placement, the special education services, and any supplementary aids or related services.¹⁹ The IEP will also indicate how often these services will be provided. The IEP Team must review the IEP at least once per year and more often if requested by a parent or teacher.²⁰

2. Eligibility for AT Through Special Education Programs

In 1990, the IDEA was amended and the definitions of AT were added.²¹ AT may be considered as special education, related services, or supplementary aids and services to ensure placement in the least restrictive environment.²² The services are to be decided upon by the IEP Team and indicated in the IEP.²³

Any request for special education services, including AT, should be made, in writing, to the IEP Team. This starts the process to determine what, if any, AT may be necessary to meet the child's educational needs. Before the IEP Team can determine a child's need for AT, it is required to obtain an appropriate evaluation.²⁴ If the parent

¹⁵ 34 C.F.R. § 300.34.

¹⁶ 20 U.S.C. § 1412(a)(5).

¹⁷ 20 U.S.C. § 1412(a)(5)(A).

¹⁸ 20 U.S.C. § 1414(d).

¹⁹ *Id*.

²⁰ 34 C.F.R. § 300.324(b)(1)(i); 64 Fed.Reg. 12592.

²¹ 34 C.F.R. §§ 300.5 & 300.6.

²² 34 C.F.R. § 300.105(a).

²³ OSEP Policy Letter to Goodman, 16 EHLR 1317 (8/10/90).

²⁴ 34 C.F.R. § 300.301.

disagrees with the findings of the school district's evaluator, the parents can request that the school pay for an independent evaluation.²⁵

The key question is whether the AT is needed to ensure that the student receives a free appropriate public education. The decision must always be made based on the individual needs of the student as determined by the participants at the IEP Team meeting. AT can be approved if it is needed to assist the child to achieve meaningful educational progress, remain in the least restrictive setting, or prepare him or her for the transition to adult life. AT should always be considered before a decision is made to place a student in a more restrictive setting.

3. Sharon's Eligibility for AT

The speech generating device is an item that special education programs have frequently funded. It would meet the definition of AT device as a supplementary aid, special education, or a related service. As her only effective means of communicating with teachers and peers, it will ensure that Sharon can effectively participate in the regular classroom. If specialized software is needed, or if training is needed to learn how to use the SGD, those items would be AT devices and services, respectively, and could also be approved by the special education system. Finally, in order to fully learn to use the device, benefit from its use, and to develop her communication abilities, Sharon should be allowed to take it home, despite any increased chances of damage to this expensive item.

The laptop computer with specialized keyboard and voice input software is an item that can be funded through a special education system. It will become important to Sharon as she and the special education system plan her "transition" from the public school system to college and eventual employment. The school may argue that she does not need the laptop to benefit from her education, as she can use the computers in the school library. Sharon may counter that the laptop is needed to meet the increased homework demands during her last two years of high school. Since the special education program has an obligation to prepare Sharon for the transition to higher education, her later need for the laptop will be an added argument for providing it while she is still in high school. Based on the limited facts we are given, it appears that Sharon will have a strong case for the computer and accessories, which may depend on how well she is able to both succeed in high school and prepare for the transition to college without them.

Since both the SGD and the laptop (or one dual purpose device) will be very important to Sharon as she enters college, it will also be important that any devices she

²⁵ 34 C.F.R. § 300.502; OSEP Policy Letter to J. Fisher, 23 IDELR 565 (12/4/95).

 $^{^{26}}$ OSEP Policy Letter to Anonymous, 29 IDELR 1089 (1/16/97).

²⁷ 34 C.F.R. § 300.105(a).

²⁸ 34 C.F.R. §§ 300.5 & 300.6.

²⁹ See 34 C.F.R. § 300.105(b) (allowing special education students to take AT devices home when that is necessary to ensure they benefit from their education).

³⁰ See 34 C.F.R. §§ 300.43, 300.320(b).

receives during high school stay with her as she leaves. This can be a problem, as most special education programs around the country will retain ownership of equipment purchased by them and the equipment will remain with the school when the student graduates. For this reason, Sharon may wish to investigate funding of these items by another entity, such as Medicaid or her state's vocational rehabilitation (VR) agency, which will allow her to retain ownership. 32

The special education program will probably not be responsible for purchasing the *ceiling track lift, the access ramp, or the modified vehicle* as they are not directly connected to whether Sharon benefits from her education. Nor are they needed, as special education or related services, to prepare her for the transition to adult life. However, a special education system will be responsible to provide Sharon with accessible transportation to and from school, including any off site programs that are part of her curriculum. Based on the facts presented, it would also not appear that the school is responsible for the *power wheelchair*, as it is not needed for Sharon to benefit from her education. Special education programs have been required to pay for mobility equipment, like wheelchairs, under limited circumstances. 34

In Sharon's case, it appears that she can propel her manual wheelchair to meet her needs in the public school. Her problem will occur when she attempts to get around in the community outside of school, goes to Cornell University, or goes to another college.

4. Appeals — What if the Parent Disagrees with the IEP Team?

Any time a parent or guardian disagrees with the services proposed on the IEP, a hearing can be requested. The parent has the right to be represented by an attorney or other advocate and can present witnesses and other evidence in support of the appeal.³⁵

The current program is to remain in place while any appeal is pending.³⁶ For example, if last year's IEP provided for use of a special computer and this year's IEP eliminated that provision, a hearing request would guarantee that the computer is provided during the course of the appeal. Additionally, if a student moves from one school district to another in the state, and the new school district refuses to recommend

³¹ 64 Fed. Reg. 12540.

³² Some states have enacted laws or policies that allow for joint purchase (i.e., by the special education program and VR agency) or transfer of ownership (i.e., purchase of used item by state VR agency) upon the student's graduation. See OSEP Policy Letter to Goodman II, 30 IDELR 611 (6/21/98) (authorizing states to arrange for the transfer of AT from the special education system to the VR system for the former student's continued use).

³³ 34 C.F.R. § 300.34(c)(16).

³⁴ See, e.g., Letter to J. Stoher, 13 EHLR 213:211 (4/20/89).

³⁵ 34 C.F.R. § 300.511.

³⁶ 34 C.F.R. § 300.518.

the computer and the parents request a hearing, the new school district must provide the computer until the case is resolved.³⁷

B. The Public Schools and Section 504

The rights of children whose disabilities do not meet the criteria for special education, but who still may need some specialized assistance, including AT, are covered by section 504 of the Rehabilitation Act of 1973 (section 504). Under section 504, schools must take reasonable steps to ensure that these students have access to the full range of programs and activities offered by the school and ensure that students receive a free appropriate public education.

To determine a student's eligibility and needs, school districts may choose to simply use the IEP Team procedures and IEP. If other procedures are used, they must include the following:

- The student must be provided with a comprehensive, individualized evaluation of his or her needs, with regular reevaluations;
- The decision about eligibility and services must be made by a group of people, including the parents, knowledgeable about the child, the evaluation information, and the placement options;
- The student's needs must be specifically identified in writing; and
- Parents have due process rights if they disagree with the district's recommendations, including the right to an impartial hearing.³⁹

The section 504 regulations do not specifically include the right to an independent evaluation at school district expense. However, the U.S. Department of Education's Office of Civil Rights (OCR) has ruled that parents have the right to request a hearing to challenge the school district's evaluation and in the case before it, the district actually paid for an independent AT evaluation. Section 504 does include the right to status quo, i.e., the continuation of existing services pending an appeal.

In the event that Sharon did not meet the criteria as a special education student, section 504 would still be available to ensure that she has full access to the school and its services. For example, to allow Sharon to move about the school, section 504 may require the installation of access ramps to allow her to enter and leave the building. It may also require the installation of an elevator to allow her to reach various locations in the school. If the school provides computers in the library to all students, section 504 would require that adaptations be provided to allow Sharon to use the computers

⁴⁰ Bradley County (TN) Sch. Dist., 134 IDELR 239 (OCR 12/15/00).

³⁷ 34 C.F.R. § 300.323(e) & (f) (new school district must provide comparable services).

^{38 29} U.S.C. § 794; 34 C.F.R. Part 104.

³⁹ 34 C.F.R. §§ 104.35 and 104.36.

⁴¹ OSEP Policy Letter to Zirkel, 22 IDELR 667 (5/15/95).

despite her severe disability. 42 Section 504 may also require the use of AT to enable the student to participate in the educational program. 43

II. State Vocational Rehabilitation Agencies

A. Eligibility for VR Services

State VR agencies can play a critical role in assisting people with disabilities to enter the work force. 44 VR services are to "empower individuals . . . to maximize employability, economic self-sufficiency, independence, inclusion and integration into . . . the work place . . . [and the community through] comprehensive and coordinated state-of-the-art programs. 45 The comments to the 2001 regulations reaffirm this "maximization" requirement. They note that states must "look beyond options in entry-level employment for VR program participants who are capable of more challenging work. 46

An eligible individual must be disabled and require VR services "to prepare for, secure, retain or regain employment." Persons must show a mental, physical or learning disability that interferes with the ability to work. It need not be so severe as to qualify the person for SSDI or SSI benefits. It need only be a substantial impediment to employment. Recipients of SSDI or SSI disability benefits are presumed to be eligible for VR services, if they intend to achieve an employment outcome. Although VR services may be denied if a person cannot benefit from them, a person is presumed capable of employment, unless the VR agency shows by clear and convincing evidence the person cannot benefit. Any service an individual is to receive from the VR system must be connected to an ultimate employment goal.

The written *individualized plan for employment (IPE)* lists the employment goal and the specific services to be provided.⁵¹ This plan is to be developed by the consumer, with assistance from the VR counselor if requested, and approved by the VR

⁴² See Colton Joint (CA) Unified Sch. Dist., 22 IDELR 895 (OCR 4/7/95).

⁴³ See, e.g., Bradley County (TN.) Sch. Dist., 34 IDELR 239 (OCR 12/15/00)(use of Alpha Smart); Kent (WA.) Sch. Dist. No. 415, 29 IDELR 978 (OCR 7/2/98) (use of a computer with a keyboarding program for written assignments).

⁴⁴ For the law and regulations governing state VR agencies, see 29 U.S.C. §§ 701 *et seq.*; 34 C.F.R. Part 361. For a more comprehensive article on this topic, with extensive citations to the law and regulations, see *Vocational Rehabilitation Services Available to Prepare Individuals with Disabilities for Work*, published by Cornell University's Northeast Work Incentives Support Center in 2001 at www.ilr.cornell.edu/ped/dep/PP_1.pdf.

⁴⁵ 29 U.S.C. § 701(b)(1)(emphasis added).

⁴⁶ 66 Fed. Reg. 4419.

⁴⁷ 29 U.S.C. § 722(a)(1).

⁴⁸ 29 U.S.C. § 705(20)(A).

⁴⁹ 29 U.S.C. § 722(a)(3).

⁵⁰ 34 C.F.R. § 361.42(a)(2), (e).

⁵¹ 29 U.S.C. § 722(b).

agency.⁵² Prior to developing the IPE there must be a comprehensive assessment, to the extent necessary to determine the employment outcome, objectives and nature and scope of VR services.⁵³ It may also include a referral for the provision of rehabilitation technology services, "to assess and develop the capacities of the individual to perform in a work environment."⁵⁴

The VR agency must ensure that all necessary services are provided to equip the individual for employment. It cannot choose to provide only some services to eligible individuals to save costs. The "severity of an individual's disability or the cost of services can have no bearing on the scope of services the individual receives." ⁵⁵

The services available from the VR system are incredibly broad and varied. The following are representative VR services under which AT could be funded: (1) an assessment by someone skilled in rehabilitation technology (i.e., AT); (2) services needed for the diagnosis and treatment of physical or mental impairments, including prosthetic and orthotic devices, eyeglasses and visual services; (3) transportation, including the purchase and repair of vehicles, including vans; (4) interpreter services, readers, rehabilitation teaching, and orientation and mobility services; (5) AT, including vehicular modification, telecommunications, sensory, and other technological aids and devices; (6) transition services for students with disabilities; (7) other goods and services determined necessary to achieve an employment outcome; and (8) postemployment services necessary to assist an individual to retain, regain, or advance in employment.⁵⁶

States may but are not required to follow a financial needs test when providing VR services.⁵⁷ However, any financial needs test must take into account the individual's disability-related expenses.⁵⁸ If the VR agency's policy requires that some individuals share the cost for services with the state agency, the individual's level of financial contribution must not be so high as to "effectively deny the individual a necessary service." SSI and SSDI recipients are totally exempt from any financial needs test. 60

The following services must be provided without regard to financial need: (1) diagnostic services; (2) counseling, guidance and referral services; (3) job placement; (4) personal assistance services; and (5) "any auxiliary aid or service," such as interpreter or reader services, that the individual needs to participate in the VR program

 $^{^{52}}$ 29 U.S.C. §§ 722(b)(1)(A) & 722(b)(2)(C).

⁵³ 34 C.F.R. § 361.45(b).

⁵⁴ 34 C.F.R. § 361.5(b)(6)(iii).

⁵⁵ 66 Fed. Reg. 4426.

⁵⁶ 29 U.S.C. § 723(a); 34 C.F.R. § 361.48.

⁵⁷ 34 C.F.R. § 361.54(a), (b)(1).

⁵⁸ 34 C.F.R. § 361.54(b)(2).

⁵⁹ 34 C.F.R. § 361.54(b)(2)(iv)(C).

⁶⁰ 34 C.F.R. § 361.54(b)(3)(ii).

and which would be mandated under section 504 of the Rehabilitation Act or the Americans with Disabilities Act. ⁶¹

VR agencies will not pay for a service if a comparable benefit is available through another provider. For example, if an applicant qualifies for personal assistance services through Medicaid, the VR agency will not provide them. But, loans, which must be repaid, are not similar benefits. The SSI Program's Plan for Achieving Self Support (PASS) is not a comparable benefit. Additionally, AT is exempt from the comparable benefit requirement.

B. Sharon's Eligibility for AT

Most of the items listed in the Sharon scenario, above, can potentially be funded through a state VR agency if she can establish: i) that she needs the item to reach her vocational goal; and ii) that she meets the VR agency's financial need criteria, if any. ⁶⁸ Generally, she would also need to show that she has exhausted any comparable benefits that may be available to pay for the item. However, since each of the items sought should meet the definition of an AT device or service, their funding is exempt from the comparable benefit requirement. ⁶⁹

More than likely, the VR agency will refer Sharon to either Medicaid or Medicare (if she is eligible for those programs) to fund *the power wheelchair and speech generating device*, even though those items are exempt from the comparable benefit requirements. To Both Medicaid and Medicare will routinely fund those items when they are medically necessary. Sharon should be encouraged to foster good will with the VR agency by first seeking Medicaid or Medicare funding for these items.

The *laptop computer, with accessories, and the access ramp* are items that are likely to be funded through the VR agency if Sharon can show they are necessary for the success of her vocational plan. It is less likely that Medicaid or Medicare will be willing to fund these items, but as explained in part III we believe Medicaid should fund

⁶¹ 34 C.F.R. § 361.54(b)(3)(i)(A)-(G).

^{62 29} U.S.C. § 721(a)(8).

⁶³ See Rehabilitation Services Administration, Policy Directive, RSA-PD-92-02 (11/21/91), available at www.ed.gov/policy/speced/guid/rsa/pd-92-02.pdf.

⁶⁴ *Id*.

⁶⁵ See part V, below.

⁶⁶ 66 Fed. Reg. 4419.

^{67 34} C.F.R. § 361.53(b)(5).

⁶⁸ The reader should keep in mind that SSI and SSDI recipients are exempt from the VR agency's financial needs test, if it has one. Based on the assumed facts, Sharon will become eligible for SSI at age 18 (see section III.C, below), making her exempt from any financial needs test.

^{69 34} C.F.R. § 361.54(b)(3)(i)(G).

⁷⁰ As discussed in section III, below, a dual purpose laptop computer/speech generating device can be funded by most state Medicaid programs. Under a 2001 Medicare policy (see section IV.), the dual purpose device can be funded when the personal computer function, which is not related to speech production, has been disabled prior to sale.

the access ramp. Sharon need not exhaust SSI's PASS as a potential funding source as that is not considered a comparable benefit.

The *ceiling track lift* is a more difficult argument. A VR agency can fund home modifications, under the category of rehabilitation technology, when necessary to allow a person to leave the house to attend a training program, set up a home business, or go to work. Although the ceiling track lift, which is typically used to get a person to and from the bed or bathroom, may be viewed more like a personal hygiene aid, personal assistance is a service that can be covered by the VR program. Sharon's best approach is to argue that the ceiling track lift, like the access ramp and the van modifications, is necessary to get her out of the house and to school.

In a few states, the VR agency will fund a *vehicle lease or purchase* if needed to participate in a VR program. It is clear that the federal VR regulations permit a state to fund vehicles, but less clear whether it would require that they do so in all cases.⁷¹ Under the facts presented, however, one should argue that since the purchase or lease of a vehicle would be less expensive than a private transportation service to and from college for four years, a vehicle should be purchased or leased for Sharon. In all states, the agency should pay for the modifications to allow Sharon to get into the van and drive it from her wheelchair.

C. Hearing and Appeal Rights

Anyone dissatisfied with a decision by the VR agency has the right to appeal. Appeals can be pursued through mediation or an administrative hearing before an impartial hearing officer. The Client Assistance Program (CAP) is available in every state to assist individuals who have questions or who are appealing a VR decision.

At a hearing, the individual has the right to be represented by an attorney or other advocate. The individual can present evidence and cross-examine witnesses. The hearing decision is final and must be implemented, unless appealed.⁷⁴ Either party may appeal a final administrative decision to court.⁷⁵ However, pending review in court, the final administrative decision must be implemented.⁷⁶

⁷¹ Under 2001 federal regulations, a state VR agency is authorized to purchase a vehicle as a means of transportation. 34 C.F.R. § 361.5(b)(57)(i), Ex. 2. To date, however, very few state VR agencies will purchase or lease a vehicle.

⁷² 34 C.F.R. §§ 361.57(b)(1)(i) & (ii).

⁷³ 34 C.F.R. § 361.57(b)(1)(v).

⁷⁴ 34 C.F.R. § 361.57(e)(4) & (h).

⁷⁵ 34 C.F.R. § 361.57(i).

⁷⁶ 34 C.F.R. § 361.57(h).

III. Medicaid

A. Eligibility for Medicaid⁷⁷

Medicaid, also known as Medical Assistance, is a cooperative federal-state program authorized by Title XIX of the Social Security Act. ⁷⁸ It is a health insurance program, designed to serve persons with limited income and resources. Although every state has the option of whether or not to have a Medicaid program, every state has exercised that option and has a Medicaid program. Administration of Medicaid will occur at the state level, with the state Medicaid agency often delegating decision making to other state agencies, to county or local Medicaid units, or to managed care organizations. Medicaid can pay for a wide range of health-related costs for both children and adults with disabilities, including many of the items sought by Sharon.

Medicaid is typically the only or primary health insurance plan for persons with disabilities who have limited income. Additionally, an increasing number of individuals with disabilities are looking to Medicaid as their primary health insurance plan, notwithstanding higher levels of income. Medicaid may be available to those individuals through state-specific Medicaid waivers, through optional Medicaid buy-in programs (for working individuals), or through the section 1619(b) provisions.

Medicaid eligibility will vary somewhat from state to state. Generally, the majority of persons with severe disabilities will become Medicaid-eligible in one of two ways: through the SSI program or through the medically needy program. In 39 states, the District of Columbia, and the Northern Mariana Islands, an individual eligible for SSI is automatically eligible for Medicaid. If the SSI check is as little as \$1, Medicaid eligibility is guaranteed. In most of these states, an SSI application is also a Medicaid application and no additional action is needed to ensure Medicaid eligibility. However, the following states require a separate Medicaid application: Alaska, Idaho, Kansas, Nebraska, Nevada, Oregon, Utah, and the Northern Mariana Islands.

In 11 states, known as section 209(b) states, Medicaid eligibility is not automatic for SSI recipients. These states use their own Medicaid eligibility criteria which is different from SSI eligibility criteria. The states which exercise the 209(b) option are: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North

⁷⁷ As this is updated in September 2011 the federal health care reform legislation, the Patient Protection and Affordable Health Care Act of 2010, is now a law with its provisions to be phased in over several years. The new law will eventually mandate some Medicaid eligibility standards, with implementation scheduled for 2014. However, there appears to be no immediate, federally-mandated changes in Medicaid eligibility standards that would affect the discussion in this section. Good sources of information on implementation of this new law are the websites of the National Health Law Program (www.healthlaw.org) and the Kaiser Family Foundation (www.kff.org).

⁷⁸ 42 U.S.C. §§ 1396-1 et seq.

^{79 42} U.S.C. § 1396a(a)(10)(A)(i).

^{80 42} U.S.C. § 1396a(f).

Dakota, Ohio, Oklahoma, and Virginia.⁸¹ Four separate categories of former SSI recipients can retain automatic Medicaid eligibility as if they were still receiving SSI. These include:

- Recipients of Social Security Widow's/Widower's Benefits. If a person, age 50 to 54, loses SSI when he or she becomes entitled to widow's or widower's benefits under Social Security, the person will remain automatically eligible for Medicaid if SSI eligibility would continue in the absence of the widow's or widower's benefits. Eligibility continues only for so long as the person remains ineligible for Medicare, a period of 24 months following the first month of Social Security eligibility.⁸²
- Recipients of Social Security Childhood Disability Benefits. Recipients of Social Security Child's Insurance Benefits, often referred to as either Childhood Disability Benefits (CDB) or Disabled Adult Child's (DAC) benefits, can continue eligibility for automatic Medicaid if, after July 1, 1987, the person lost SSI due to entitlement to or an increase in CDB benefits.⁸³
- The Pickle Amendment. This protects certain persons who lost SSI because
 of cost of living increases in Social Security benefits. Automatic eligibility
 continues if the person would be eligible for SSI under present eligibility
 standards if Social Security cost of living increases since the last month the
 person received both SSI and Social Security benefits are disregarded.
- The Section 1619(b) Program. This provides Medicaid for individuals who lose SSI benefits because earnings become too high to continue receiving cash benefits. Under 1619(b) criteria, automatic Medicaid will continue if the person would continue to be eligible for SSI if the wages were ignored and if annual income is less than a specified income threshold.⁸⁵ The 1619(b) eligibility thresholds, ranging in 2011 from a high of \$56,502 in Connecticut to a low of \$24,438 in Alabama, will usually change each year and will vary state by state.⁸⁶

The *Medically Needy Program*, often referred to as a spend down,⁸⁷ is an option exercised by approximately two thirds of the states. Medically needy individuals

⁸¹ SSA Program Operations Manual System (POMS) SI 01715.020.

^{82 42} U.S.C. § 1383c(d).

⁸³ 42 U.S.C. § 1383c(c). For an excellent reference on this issue, see Munger, J., Categorical Medicaid Eligibility for Recipients of Disabled Adult Child Social Security Disability Benefits, 29 CLEARINGHOUSE REV. 1044 (March 1996).

⁸⁴ 42 U.S.C. § 1396a(note); 42 C.F.R. § 435.135. For a more detailed explanation of the Pickle Amendment, see Bonnyman, G. *Medicaid Eligibility in a Time Warp*, 22 CLEARINGHOUSE REV. 120 (June 1988) and *Screening for Medicaid Eligibility Under the Pickle Amendment*, updated annually and published in Clearinghouse Review and on various websites.

^{85 42} U.S.C. § 1382h; 20 C.F.R. § 416.264 - .269; POMS SI 02302.010 C.

⁸⁶ See POMS SI 02302.200 N.

^{87 42} U.S.C. § 1396a(a)(17).

are those who would qualify for Medicaid, including individuals who are disabled, but have income or resources above limits set by their state. Since Medicaid eligibility workers often do not explain the spend down program to applicants or recipients, it is important that you find out if your state offers this option and take steps to educate yourself on how it works. At a minimum, you should keep up to date on your state's medically needy income eligibility levels for various sized families.

How does the spend down work? Each state will set its own medically needy income level based on family size. All individuals meeting the federal (i.e., SSI) definition of disability, who have income and resources below their state's medically needy level, automatically qualify for Medicaid.

Individuals with income above the medically needy level do not automatically qualify for Medicaid. They must first meet a "spend down" or "share of cost" test. The spend down is the amount by which the individual's income exceeds the medically needy level after subtracting allowable deductions. Consider this example: In New York, which has a 2011 one-person medically needy level of \$767 per month, a single adult with a disability receives a monthly SSDI check of \$887. Since this exceeds the state's medically needy level of \$767, the Medicaid agency will disregard the first \$20 as an unearned income exclusion and the individual will face a \$100 spend down (i.e., their countable income exceeds the medically needy level by \$100). The spend down acts like a deductible or insurance premium that must be paid or incurred before the insurance program, i.e., Medicaid, begins coverage.

The optional *Medicaid Buy-In for Working Individuals Program*⁸⁹ is an important way for individuals with disabilities to obtain or retain Medicaid coverage when they are working. It is designed to provide health insurance to working people with disabilities who, because of relatively high earnings, cannot qualify for Medicaid under another provision. The buy-in was originally made available as part of the federal Balanced Budget Act of 1997. The enhancements to this optional program have been touted as some of the more important provisions of the Ticket to Work and Work Incentives Improvement Act of 1999.90 The following 43 states had adopted and were implementing a buy-in program as of September 2011: Alaska, Arizona, Arkansas, California, Connecticut, Delaware, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Louisiana, Maine, Maryland, Massachusetts (section 1115 Medicaid waiver), Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming. 91 You may wish to check the status of the buy-in program in your state.

⁸⁸ 42 U.S.C. § 1396a(a)(10)(C).

⁸⁹ See 42 C.F.R. §§ 407.40 – 407.50.

^{90 42} U.S.C. §§ 1396a(a)(10)(A)(ii)(XV) & (XVI) and 1396o.

⁹¹ See "State Medicaid Buy-In Programs: Implementation Status, Enrollment and Program Design Features" (April 2010), prepared by Allen Jensen, Work Incentives Project, George Washington University.

The buy-in program is most important to those individuals with disabilities who have significant health care needs that cannot be met through employer-sponsored health benefits plans and have no ability to obtain or retain Medicaid under traditional rules, when working for significant wages. Most often, the group that will benefit most will be recipients of SSDI, who were not simultaneously eligible for SSI and, thus, cannot qualify for Medicaid under the section 1619(b) program. Many of these individuals currently receive Medicaid through medically needy programs and could not afford to work if it meant giving up Medicaid as the source of payment for expensive items like prescription drugs, personal assistance services, and durable medical equipment (i.e., AT). In those states that have implemented buy-in programs, eligibility for Medicaid can continue in many cases at annual wage levels exceeding \$50,000. In a few of the states, Medicaid eligibility can continue at annual wage levels exceeding \$70,000.

Subject to federal criteria, a state can choose to structure the buy-in as it sees fit. Largely due to fears of rising Medicaid costs, only five or six states had initiated buy-in programs when the Ticket to Work and Work Incentives Improvement Act (TWWIIA) was signed into law in December 1999. TWWIIA sought to make the program more attractive to states. Key federal eligibility criteria for the original, 1997 buy-in include:

- Eligible individuals must be in a family whose net income is less than 250 percent of the federal poverty level. A single individual is in a family of one.
- Except for the individual's earnings, the person with a disability would be considered eligible for SSI benefits. This includes the definition of disability.
- Each state determines its own definition of a "family."
- All SSI exclusions apply to the determination of family income, including the earned income exclusions.
- Individuals are not required to have been on SSI to be eligible for this buy-in provision.
- The State must make a disability determination if an individual was not an SSI recipient.
- Substantial gainful activity (i.e., in 2011 earnings in excess of \$1,000 monthly, or \$1,640 for the statutorily blind) is not an eligibility consideration.
- States can increase the resource limits to as high as \$14,000.
- States can charge premiums or other cost-sharing charges.

The 1999 TWWIIA legislation builds on the 1997 legislation, adding provisions that make it more attractive to states:

- It allows states to offer a Medicaid buy-in to persons with disabilities who work and have earnings between 250 and 450 percent of the federal poverty level.
- Participating states are allowed to set income limits and require cost-sharing and premiums, based on income, on a sliding scale. A state could require

- some individuals to pay the full premium as long as the premiums do not exceed 7.5 percent of the individual's total income.
- States must require a 100 percent premium payment for individuals with adjusted gross incomes greater than \$75,000 unless states choose to subsidize the premium using their own funds.

В. **Eligibility for AT Through Medicaid**

The categories of service covered by Medicaid will vary greatly from state to state. This is because the majority of Medicaid service categories are optional. A state must cover all "required" categories of service, such as inpatient hospital care and home health care services for persons entitled to skilled nursing services. 92 A state may choose which of approximately 30 "optional" categories of service to cover.

Typically, state Medicaid programs have covered AT through one or more of the following coverage categories: home health care (which includes medical supplies and equipment, commonly referred to as "durable medical equipment"), physical therapy (PT), occupational therapy (OT), speech therapy, prosthetic devices, and rehabilitative services. 93 With the exception of home health care, all of these categories are optional for adults, meaning that some states will cover them and some will not.

Children under age 21 are covered under a special mandatory program, known as the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. 94 Under federal Medicaid law, a state is required through its EPSDT program to cover all of the required and optional services for Medicaid-eligible children under age 21 even if some of those optional categories are not covered for adults. 95 The statutory language governing EPSDT would seem to support a very expansive view of when a child will receive AT under the EPSDT program. A service must be covered for a child if it is among the required and optional services and is "necessary ... to correct or ameliorate defects and physical and mental illnesses and conditions ... "96

In addition to fitting within a Medicaid coverage category (required or optional), an AT device will not be approved by a state Medicaid agency unless it is medically necessary. Medical necessity is not defined by the federal Medicaid law or regulations. But, any state definition of medical necessity must be consistent with the broad purposes of the Medicaid program. The federal law states that the primary goal of Medicaid is to provide medical assistance to persons in need and to furnish them with

^{92 42} C.F.R. §§ 440.70(b)(3), 440.220(a)(3).

⁹³ See 42 C.F.R. §§ 440.70(b)(3) (home health care), 440.110 (PT, OT and speech), 440.120 (prosthetic devices), and 440.130 (rehabilitation). The optional PT, OT and speech categories are important because the federal regulations define these categories as including any necessary supplies and equipment.

^{94 42} U.S.C. § 1396d(a)(4)(B); 42 C.F.R. § 440.40(b).

^{95 42} U.S.C. § 1396d(r)(5).

⁹⁶ Id. For a very detailed discussion of EPSDT, see Medicaid, AT and Kids: How Medicaid's EPSDT Program Expands the Availability of Assistive Technology for Children Under 21 in All States (AT Advocate newsletter, Spring 2008), available at http://www.nls.org/av/winter08.pdf.

rehabilitation and other services to help them "attain or retain the capability for independence or self-care." ⁹⁷

C. Sharon's Eligibility for AT

Sharon will become eligible for SSI disability benefits at age 18. Her parents' income and resources will no longer be counted against her and her SSI payment will be based on her own income and resources. She will then become Medicaid-eligible in those states in which Medicaid is automatic for SSI recipients. In other states, she may be eligible under the medically needy program, with or without a spend down. If Sharon is in one of the 43 states which have a Medicaid buy-in program for working individuals with disabilities, she might be eligible for the Medicaid buy-in (in most states after age 18) even if she is only working a few hours each month. Once eligibility is established, she will be eligible through EPSDT (up to age 21) for coverage under all of the required and optional service categories. This will provide the maximum possibilities for coverage of the AT-related items she is seeking.

Every state's Medicaid program should cover the *power wheelchair* and *speech generating device* if Sharon can show that they are medically necessary. Typically, these items would be covered as durable medical equipment. The SGD has also been covered in some states as a prosthetic device⁹⁸ or under the equipment clause of the speech, hearing and language disorders category.⁹⁹ Some Medicaid decision makers will balk at approving the power wheelchair, claiming that Sharon can get around in most environments with her lightweight, manual wheelchair. In some states, Sharon may need to appeal (see below) to establish that the power wheelchair is needed to meet all of her mobility needs, particularly as she begins spending time on a college campus within a hilly community.

The *ceiling track lift* could also be covered under Medicaid's durable medical equipment category. The controversy here will not focus on whether a lifting device is needed; instead, some Medicaid programs may argue that a less costly, stationary lifting device can meet her needs. Again, Sharon may need to appeal to establish her right to the preferred ceiling track lift. In any case in which a Medicaid agency seeks to limit the person to the less expensive device, it will be critical to have the supporting documents from doctors and other health professionals address why the lesser item falls short of meeting the person's needs (e.g., Sharon's mother is incapable of operating the stationary lift without subjecting herself to serious injury). If a Medicaid-funded personal care aide is needed to operate the stationary lift, but is not needed to operate the ceiling track lift, this may help show that the stationary lift is actually a more expensive alternative in the long run.

The *access ramp for the home* is an item that many Medicaid programs will balk at funding. A typical response will be to say that it is not primarily medical in nature or is a matter of convenience rather than a medical necessity. The authors are aware of

98 42 C.F.R. § 440.120.

⁹⁷ 42 U.S.C. § 1396-1.

⁹⁹ 42 C.F.R. § 440.110(c).

several cases, in different states, in which access ramps or stair glides within the home have been approved following a hearing, or as a settlement following the commencement of litigation. In some states, a separate Medicaid waiver program may cover a range of home modifications as an exception to general rules for those who qualify for the waiver. We believe that in Sharon's case the access ramp should be approved by her Medicaid program as it is specifically designed to meet the mobility needs of a person with a disability and will allow Sharon to safely come and go from the home.

A Medicaid program would not be expected to pay for a *laptop computer, its accessories, or the van*. These are not items one thinks of as meeting a medical purpose or as being medically necessary. Keep in mind, however, that there are several dual purpose SGDs on the market that double as laptop computers. Often, these are no more expensive and sometimes less expensive than dedicated SGDs that meet the same communication needs. Unlike Medicare, many state Medicaid programs will pay for dual purpose devices, especially when they are the least costly alternative for meeting the individual's communication needs. We can also expect state Medicaid programs to balk at paying for the *van modifications*. However, we are aware of two hearing decisions from New York and an unreported court decision from Colorado in which vehicle modifications were approved to meet the needs of either a driver or a passenger with a disability.

Medicaid Waivers Can Fund AT. Individuals with disabilities and their advocates should not be too quick to rule out potential funding of items which appear to fall outside the scope of Medicaid. Every state will have one or more special waiver programs, typically referred to as Home and Community Based Services Waivers. These waivers, which are optional, will vary greatly from state to state. When approved by the federal Centers for Medicare and Medicaid Services (CMS), a state is permitted under a waiver to provide a range of services to special populations that are not available to Medicaid recipients generally. 102

Many states, through Medicaid waivers, will provide a range of very expensive services if they are necessary to keep a person in the community and out of an institution. These typically include a range of home modifications, including ramps, lifts, stair glides, and other items, that are a challenge to obtain through the standard Medicaid program. One of New York's waiver programs will, under limited circumstances, pay for van modifications if they are needed for the transport of a child with a disability in a van owned by the parent or parents. Since no two states will

¹⁰¹ 42 U.S.C. § 1396n(c). For a more detailed summary on Home and Community Based Services waivers, see the Summer-Fall issue of our *AT Advocate* newsletter and its feature article, "HCBS Waivers as a Funding Source for AT," available at www.nls.org/av/fall07.pdf.

¹⁰⁰ See section IV, below.

¹⁰² By approving the waiver, CMS would typically be waiving the federal requirements that all Medicaid rules be applied statewide and that all similarly situated Medicaid recipients receive comparable services.

¹⁰³ See N.Y. State Department of Health, Administrative Directive, Transmittal # 00 OMM/ADM-4 (May 22, 2000), explaining the criteria for approving home adaptations and vehicle modifications under the state's Care at Home I and Care at Home II waiver programs, available at www.wnylc.net/pdf/2000-adms/00ommadm4.pdf.

operate identical waiver programs, the individual or their advocate must investigate to determine what waivers are available in their state.

D. Appealing Medicaid Decisions

Requests for funding of AT will typically go through a prior approval process. If the request for funding is denied, federal law requires that the Medicaid recipient be given a written notice that details the reasons for the denial and informs the recipient of his or her right to a fair hearing.¹⁰⁴ A fair hearing must be available to any individual whose prior approval request is denied or not acted upon in a reasonably prompt manner. An individual who is denied AT through a Medicaid waiver program is also entitled to a written notice of the decision and the right to a hearing to challenge that decision.

State Medicaid agencies must inform recipients of the method to obtain a hearing and the ability to be represented by an attorney or other representative. Since the time limits for requesting a hearing will vary from state to state, it is critical to read the denial notice for an explanation of these time limits. The Medicaid recipient has the right to be represented by an attorney or advocate, or can proceed without a representative. As with all the administrative hearings described in this article, the individual has the right to call witnesses, present written evidence, and confront and cross-examine adverse witnesses. The federal regulations require that the hearing decision be issued within 90 days of the request for hearing.

IV. Medicare

A. Eligibility for Medicare

Medicare is the nation's largest health services funding program. This federal health insurance program covers three primary classes of persons:

- Persons age 65 or older;
-)ersons receiving SSDI payments (including many adults with developmental disabilities who receive SSDI on the earnings record of a parent, and many who receive SSDI as widows or widowers) or railroad retirement benefits based on disability; and
- Persons with end stage renal disease.¹⁰⁵

There is also a class of Medicare-Qualified Federal Employees who can qualify for benefits. 106

SSDI recipients who have exhausted their nine-month trial work period can continue to qualify for Medicare, even if they cease eligibility for SSDI cash benefits,

¹⁰⁴ The federal regulations governing fair hearings are found at 42 C.F.R. §§ 431.200-250.

¹⁰⁵ 42 U.S.C. § 1395c.

¹⁰⁶ POMS HI 00801.400 et sea.

during a 93-month extended period of Medicare coverage. During the extended coverage period, the individual can receive Medicare under the same terms as described below (i.e., cost-free Part A coverage; optional Part B and Part D coverage, with a premium and out-of-pocket expenses). After the end of the extended coverage period, the individual can pay for coverage under the Premium-Hospital Insurance for the Working Disabled program. ¹⁰⁸

Medicare is divided into three parts, known as Part A, Part B, and Part D. *Medicare Part A*, known as hospital insurance, covers among other things inpatient care, nursing home care, hospice care, home health services, and durable medical equipment. For most Medicare beneficiaries, there is no premium required to obtain Part A coverage. *Medicare Part B*, known as supplemental medical insurance, covers various outpatient services, including physician services, durable medical equipment, prosthetic and orthotic devices, and home health services. To enroll in Part B, a Medicare beneficiary must pay a monthly premium (\$96.40 for most individuals in 2011, but \$110.50 if newly eligible in 2010 or \$115.40 if newly eligible in 2011). State Medicaid programs may pay the Part B premiums for persons with low income. This usually is done through the Medicare Savings Programs known as the Qualified Medicare Beneficiaries (QMB), Specified Low-Income Medicare Beneficiary (SLMB), or Qualified Individual (QI-1) programs. Medicare Part D, known as the prescription drug benefit, has been a part of the program since 2006. Part D is beyond the scope of this publication and will not be discussed further.

Most Medicare recipients receive benefits through the "traditional" Medicare program. A minority of Medicare recipients receives benefits through a "managed care" option, now referred to as the Medicare Advantage program. The managed care option exists in most parts of the country and is run through any number of local or regional health maintenance organizations. The managed care option, as it relates to claims for durable medical equipment coverage, is subject to a prior approval process.

The facts indicate that Sharon, at age 17, receives Social Security survivor's benefits on her deceased father's Social Security record. Moving forward in time, we can assume that Sharon will cease to be eligible for survivor's benefits when she graduates from high school as an 18 year old. At that time, based on her severe physical disability, she should qualify for SSDI benefits as a Disabled Adult Child (typically referred to as Childhood Disability Benefits by the Social Security Administration). After 24 months of eligibility for SSDI, she will then become eligible for Medicare.

¹⁰⁷ 42 U.S.C. § 426(b), as amended by section 202 of the Ticket to Work and Work Incentives Improvement Act of 1999 (increasing the period from 39 to 93 months). In some cases, extended Medicare can continue for more than 93 months after the trial work period.

¹⁰⁸ POMS HI 00801.170 (Part A), 00805.005 A.1 (Part B).

¹⁰⁹ POMS HI 00601.001 et seq.

¹¹⁰ POMS HI 00610.001 et seg.

¹¹¹ POMS SI 01715.005 A.5 & 6.

¹¹² POMS HI 00208.066.

B. Sharon's Eligibility for AT Through Medicare

Medicare, through its Part B benefit, will cover AT devices, such as the power wheelchair or speech generating device sought by Sharon, under its durable medical equipment (DME) coverage category. Medicare has a four-part definition for DME. It is defined as equipment which:

- Can withstand repeated use;
- Is primarily and customarily used to serve a medical purpose;
- Generally is not useful to a person in the absence of an illness or injury; and
- Is appropriate for use in the home. 113

When Medicare covers DME, it pays for 80 percent of a Medicare approved rate. The 20 percent co-payment would be Sharon's obligation, but it could be covered through Medicaid if she is also eligible for that program. The co-payment could also be covered by a private insurance program. If Sharon is eligible for the Medicare Savings Program know as the Qualified Medicare Beneficiaries Program (QMB), her local Medicaid agency will probably pay for her co-payments. The Medicare approved rate is sometimes less than what the vendor traditionally charges for a piece of DME. If the DME vendor agrees to accept the lower approved rate, then the individual will owe 20 percent of the approved rate. However, if the vendor refuses to accept that rate, then the individual could owe far more than 20 percent of the purchase price.

The DME vendor should be familiar with Medicare's process for approving payment. In traditional Medicare (the majority of cases), one of four Durable Medical Equipment-Medicare Administrative Contractors (DME-MACs) will be responsible for claims. Unlike Medicaid, with traditional Medicare there is no prior approval process. Instead, the claims process starts when the individual takes delivery of an item from the DME vendor, with the vendor processing the claim with or without taking assignment (i.e., by taking assignment the vendor agrees to accept the rate which Medicare has set, even if that rate is \$0). If the vendor is not confident that the DME-MAC will ultimately agree that DME is available for payment, the vendor will rarely accept assignment, meaning that the individual must agree to pay for the item subject to Medicare reimbursement. In the optional managed care or Medicare Advantage program, all claims will be subject to a prior approval process with claims submitted to the managed care agency or HMO through which the individual is enrolled.

The federal Medicare agency maintains a *National Coverage Determinations* (NCD) Manual and within the NCD Manual it maintains a *Durable Medical Equipment Reference List*. The list contains the names of more than 100 pieces of DME and then indicates 1) that the item is "covered," and under what circumstances it can be

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¹¹³ 42 C.F.R §§ 410.38(a), 414.202 (also includes definitions for prosthetic and orthotic devices).

¹¹⁴ See POMS SI 01715.005 A.5.

¹¹⁵ See NCD Manual § 280.1. This is available on the CMS website. Go to the "Medicare Coverage Center "at www.cms.hhs.gov/center/coverage.asp and follow the links for NCDs, then Durable Medical Equipment Reference List.

approved; or 2) that the item must be "denied"; or 3) that the coverage criteria exists someplace else within the NCD Manual. For example, the reference list provides that *power wheelchairs* are covered if the clinical criteria for the Mobility Assistive Equipment (MAE) NCD are met. 116 Under the 2005 NCD or policy governing the approval of wheelchairs and scooters (i.e., MAE), Sharon would have to establish that she needs the power wheelchair in her home in order to meet one or more mobility-related activities of daily living. Under this very controversial but enforceable criteria, Sharon might be denied funding through Medicare because, for example, she can move about in her home in the existing manual wheelchair to take care of hygienic needs in her bedroom and bathroom. However, if the power wheelchair is approved under the MAE criteria, she would be permitted to use the wheelchair for activities outside the home. 117 In Sharon's case, if the power wheelchair is not available for funding through Medicare, she should be able to get it funded through Medicaid. Medicaid is not bound by the Medicare criteria and should look at Sharon's need for independent mobility outside the home.

As of 2001, a **speech generating device** is covered by Medicare. Under the NCD covering speech generating devices, Sharon should be eligible for Medicare funding of the SGD because she cannot effectively communicate without one. 118

Readers should note that the binding effect of NCDs on various Medicare decision makers is spelled out in the federal Medicare regulations. An NCD is binding on all Durable Medical Equipment-Medicare Administrative Contractors (DME-MACs), HMOs, and Administrative Law Judges (ALJs). Many of the old ALJ decisions in which the ALJ was able to ignore an existing NCD are probably no longer valid statements of the current law.

There will be AT devices which appear to meet Medicare's DME definition and do not appear on the DME Reference List. In those cases, the decision maker is authorized to approve funding on a case-by-case basis taking into account: the Medicare Claims Processing Manual, Chapter 20, "Durable Medical Equipment, Prosthetics and Orthotics, and Supplies (DMEPOS)"; whether the item has been approved for marketing by the Food and Drug Administration and is otherwise generally considered to be safe and effective for the purpose intended; and whether the item is reasonable and necessary for the individual patient. 120

As noted above, the approval of Medicare-funded DME is overseen in traditional, i.e., non-managed care Medicare by four regional DME-MACs. Those MACs enforce the NCDs and also develop and enforce *Local Coverage Determinations (LCDs)*. LCDs

¹¹⁷ The existing criteria is based on the statutory provision which states that DME "includes ... wheelchairs ... used in the ... home." 42 U.S.C. § 1396x(n).

¹¹⁶ See NCD Manual § 280.3.

¹¹⁸ See NCD Manual § 50.1. We note that Medicare's 2001 policy, approving coverage for SGDs, states that only "dedicated" devices will be approved. It will not pay for dual purpose devices that can double as a personal computer unless the personal computer functions have been disabled.

¹¹⁹ 42 C.F.R. § 405.1060.

¹²⁰ See Durable Medical Equipment Reference List, NCD Manual § 280.1, note 115, above.

are policies which govern claims within a DME-MAC's region of the country. Even though typically developed by one of the four regional DME-MACs, Medicare policy requires that LCDs must be uniform throughout the country, ¹²¹ meaning that each of the four DME-MACs will have identical LCDs that govern decisions in their respective regions. LCDs are binding on the HMOs implementing Medicare Advantage Plans.

When we wrote our original publication of 2001 and edited publication of 2004, there was no NCD governing *ceiling track lifts*. At that time, we urged the reader that the NCD 280-1, the DME Reference List, would have required an individual decision for coverage based on the criteria spelled out above. However, we later learned through working on an actual case, that the DME-MAC for the region including New York State, NHIC Corp., had an LCD in place that precluded funding of ceiling track lifts. ¹²² The legality of that LCD was challenged through the "LCD Review" process ¹²³ initiated by New York's PAAT project in 2007. Thereafter, following significant discovery, briefing, and an ALJ decision, ordering further discovery, briefing, and an administrative hearing, NHIC voluntarily retired the existing LCD and replaced it with a new LCD for Patient Lifts, L5064, which now provides for coverage of ceiling track lifts, effective January 1, 2009. ¹²⁴ Identical patient lift LCDs have now been published by the three other DME-MACs. ¹²⁵

The new LCD would allow Sharon to obtain coverage of the ceiling track lift, if "transfer between bed and chair, wheelchair, or commode is required and, without the use of the lift, [she] would be bed confined." We would need to further explore the facts to establish whether Sharon meets the criteria. Given that she has been using a manual Hoyer lift, it would appear that she meets the basic criteria and the only question would be whether the more expensive ceiling track lift is required rather than the less expensive manual lift.

It is clear that Medicare will not cover the *laptop computer, the van or the van modifications*. The laptop computer does not meet that part of the DME definition that requires that the item be "primarily and customarily" used to serve a medical purpose. Regarding the van and modifications, since part of the definition of DME requires that an item be "appropriate for use in the home," even the van modifications (which, arguably, are medical equipment) cannot be covered under Medicare's DME category.

The new LCD appears on the NHIC website at www.medicarenhic.com/dme (use the links for LCD/Medical policies). Our Spring/Summer issue of AT Advocate contains a lead article that describe the procedures for the LCD review and explains the review that resulted in this new LCD (available at www.nls.org/av/summer09.pdf).

¹²¹ See, e.g., Medicare Program Integrity Manual, Part 13.1.14.

¹²² See former LCD for Patient Lifts, L5064.

¹²³ See 42 C.F.R. Part 426.

¹²⁵ See National Government Services (<u>www.ngsmedicare.com</u>), covering Jurisdiction B (see LCD L27218); CGS Administrators (<u>www.cgsmedicare.com</u>), covering Jurisdiction C (see LCD L11562); and Noridian (<u>www.noridianmedicare.com</u>), covering Jurisdiction D (see LCD L11577). Follow the search function on each site to view the new LCD.

A better argument can be made for Medicare to cover the *access ramps*, but Medicare has traditionally not covered items like ramps, and stairway elevators specifically appear on the DME Reference List as non-covered convenience items that are not considered medical in nature. Sharon could be encouraged to seek funding for the ramp in an appeal. Keep in mind, however, that to the extent that the NCD exclusion for stairway elevators was to apply (arguably, it would not apply to an access ramp), the Medicare regulations would make that NCD binding on administrative law judges.

C. Appealing Medicare Decisions

The appeals system governing Medicare denials for DME coverage will vary slightly, depending on whether an individual is covered through the traditional program or through the managed care option. The time periods for requesting appeals will also vary depending on the level at which the most recent decision was made. In the discussion that follows, we used information available on the CMS website, rather than the regulations, for updated information on whether a specific monetary threshold is required at various levels of appeal. Beneficiaries and their advocates should always carefully read the most recent notice of denial for appeal rights and deadlines.

1. Appeals in the Traditional Medicare System

The great majority of individuals seeking DME will receive Medicare benefits through the traditional program as administered by the DME-MACs. Readers should keep in mind that some of the time limits for requesting review and the necessary amounts in controversy have changed in recent years.¹²⁷

The *initial decision*, denying benefits, must be in writing. The written notice shall inform the party of the right to have such determination reviewed. The first level of appeal, known as the *redetermination*, will be conducted by the DME-MAC. The beneficiary has 120 days from the date of the adverse initial decision to request this review. There is no minimum monetary threshold required for the redetermination.

If the review decision goes against the beneficiary, he or she has a right to **reconsideration** before a Qualified Independent Contractor (QIC). Here again, there is no minimum monetary threshold. The beneficiary has 180 days from the date of the redetermination to request the reconsideration.

If the reconsideration goes against the beneficiary, the next level of appeal is the *administrative law judge hearing*. At the ALJ hearing, the amount in controversy must be at least \$130. The beneficiary has 60 days from the date of the adverse QIC decision to request an ALJ hearing.

Following an adverse ALJ decision, the beneficiary has the right to request review by the *Medicare Appeals Council*. At this stage, there is no threshold for an amount in controversy. The beneficiary has 60 days from the date of the adverse ALJ hearing decision to request this review. If the Appeals Council rules against the

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¹²⁶ See The Medicare Appeals Process (Medicare Learning Network, January 2011), available at www.cms.gov/MLNProducts/downloads/MedicareAppealsprocess.pdf.

¹²⁷ The regulations governing traditional Medicare appeals, in DME cases, are located at 42 C.F.R. §§ 405.801- 405.857. *See also The Medicare Appeals Process*, note 126, above.

beneficiary, review may be sought within 60 days in the *United States District Court*. The amount in controversy must be at least \$1,300.

2. Appeals in the Medicare Advantage System

Again, this appeals process is somewhat different from that followed in the traditional Medicare program. Readers should note the changes, compared to the traditional program, in times for requesting the appeal, the party handling the appeal, and the amount in controversy at various appeal levels.¹²⁸

The initial decision must be in writing. When the initial decision goes against the beneficiary, the regulations refer to this as an *adverse organization determination*.

The beneficiary has 60 days from the date of the organization determination to request a *reconsideration*. If the reconsideration decision is not entirely favorable to the beneficiary, the appeal will automatically be forwarded to an independent contractor for a further reconsideration.

If the reconsideration is adverse to the beneficiary, he or she has 60 days to request an *administrative law judge hearing*. The amount in controversy must be at least \$130 to pursue this appeal.

Following an adverse ALJ decision, the beneficiary has the right to request review by the *Medicare Appeals Council*. At this level, the beneficiary has 60 days from the date of the adverse ALJ hearing decision to request this review.

If the Appeals Council rules against the beneficiary, review may be sought within 60 days in the *United States District Court*. Like the rules governing appeals in the traditional system, the amount in controversy must be at least \$1,300, with that amount being annually adjusted based on the medical care component of the Consumer Price Index.

V. SSI's Plan for Achieving Self Support 129

A. Eligibility for a PASS

SSI is a needs-based program. An SSI recipient must have limited income and limited resources. The PASS allows a person with a disability to exclude income and/or resources, which would otherwise be countable under SSI, when the excluded

¹²⁸ The regulations governing the Medicare Advantage Program appeals (or "grievances") are located at 42 C.F.R. §§ 422.564-422.612.

The Plan for Achieving Self-Support (PASS) is discussed in greater detail in other publications. See Sheldon, J. & Lopez-Soto, E., Plan for Achieving Self-Support: An SSI Work Incentive and Approach to Self-Directing Vocational Rehabilitation to Support a Range of Work Goals, available at: www.ilr.cornell.edu/edi/nymakesworkpay/docs/PASS-1.3.pdf; BENEFITS MANAGEMENT FOR WORKING PEOPLE WITH DISABILITIES: AN ADVOCATE'S MANUAL, ch. 4 (Empire Justice Center, 2009)(containing up-to-date citations and forms).

¹³⁰ See 20 C.F.R. §§ 416.1100 et seq. (income) and 416.1201 et seq. (resources).

money is to be used for some occupational objective. 131 By doing so, the person retains SSI, becomes eligible for more SSI, or becomes eligible for SSI as a new applicant.

The PASS enables an individual to achieve an occupational objective, i.e., self-support, through use of this excluded income and resources. For example, the PASS may enable a person to secure education or training needed to become self-supporting, to make the transition into employment, or to set up a business. In a case like Sharon's, the PASS can be used to purchase items like the van or laptop computer if those items will help pave the way to her vocational goals.

The proposed PASS must be submitted to SSA in writing, preferably using SSA Form 545. That Chances for approval are enhanced if great care is taken to document fully, on SSA's form, the person's needs and the viability of the proposal as a means of attaining self-support. Anyone, including the SSI applicant or recipient, can write a PASS. The authors recommend involvement of an advocate or other trained specialist in writing the PASS.

A number of items must be contained in the written PASS, including: 133

- A designated occupational objective;
- Specific savings/planned disbursement goals directly related to the objective;
- A list of items or activities requiring savings or payments and anticipated amounts;
- · A specific period of time for achieving the objective;
- Identification and segregation of any money or other resources being accumulated and conserved; and
- A detailed business plan when self-employment is a goal.

In the past, a PASS could only be approved for up to 48 months. The regulations, as revised in 2006, no longer impose a strict time limit on an approved PASS. The regulations now require that the PASS proposal contain a beginning date and reasonable ending date to meet the individual's employment goal. ¹³⁴ If Sharon will need the PASS to support both her college and law school attendance, on the way to attaining her goal to become a lawyer, the PASS could be approved for a period of seven years or longer if she can justify the need for this time frame.

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¹³¹ 42 U.S.C. §§ 1382a(b)(4)(A)(iii) and (B)(iv), 1382b(a)(4); 20 C.F.R. §§ 416.1180 *et seq.*; POMS SI 00870.001 *et seq.*

¹³² 20 C.F.R. § 416.1181. SSA's form 545, although not mandatory, should be used by individuals and their advocates to submit PASS proposals. This form is available at www.ssa.gov/online/ssa-545.pdf.

¹³³ 20 C.F.R. § 416.1181; POMS SI 00870.006.

¹³⁴ 20 C.F.R. § 416.1181.

B. Using a PASS to Fund AT

The money set aside under a PASS can be used for anything that can be specifically tied to achieving an occupational objective. ¹³⁵ Just as there are limitless ways that people make money, there is no real limit on the types of proposals that can be approved.

In recent years, there has been an increase in the uses of technology, including AT, and other creative approaches to allow persons with disabilities to achieve self-support. Advocates should not be shy about encouraging individuals to use the PASS for funding creative approaches to self-support, including the use of cutting edge technology. Legislative history to the 1972 Social Security Act amendments indicates that the provision in the law for the PASS should be liberally construed if necessary to accomplish the self-support objective. 136

The following is a nonexclusive list of uses for the income or resources set aside under the PASS. Any of these items can be funded if reasonable and necessary to achieve the individual's vocational goal: 137

- Attendant care
- Basic living skills training related to the work goal
- Child care
- Costs for room and board when attending educational, training, employment, trade, or business activities
- Dues and subscriptions for publications for academic or professional purposes
- Equipment, supplies, operating capital and inventory required to establish and carry on a trade or business
- Equipment/tools either specific to the individual's condition or designed for general use
- Meals consumed during work hours
- Operational or access modifications to buildings, vehicles, etc., to accommodate disabilities
- Tuition, books, supplies and all fees and costs imposed by or in connection with an educational or occupational training facility including tutoring, testing, counseling, etc.

¹³⁵ 20 C.F.R. § 416.1181(f); POMS SI 00870.025 B.5.

¹³⁶ Pub. L. No. 92-603, 1972 U.S. CODE CONG. & ADMIN. NEWS 4989, 5138; POMS SI 00870.001 A.

¹³⁷ POMS SI 00870.025 B.5.g.

- Uniforms, specialized clothing, safety equipment and appropriate attire (e.g., suits and dresses) for job interviews or working in an office or professional setting
- Maintenance costs for any of the above items
- Transportation costs, including: lease, rental or purchase of vehicle, subject to the limitations on installment payments, ¹³⁸ public transportation and common carriers, fuel costs, registration fees and initial cost of insurance premiums
- Job coaching/counseling services
- Job search or relocation services
- Preparation fees for developing a PASS (but fees for monitoring a PASS are not allowed)
- Taxes and government-imposed user fees (e.g., permits, licenses) connected with obtaining any of the above
- Finance and service charges connected with obtaining any of the above

It should be emphasized that most of the items listed as fundable through the PASS are potentially fundable through other means. Much of what is listed can be funded through a state VR agency. Much of what is medically related can be funded through Medicaid or Medicare. Availability of various other educational grants should also be explored. The person should be advised to look to the PASS as a source of supplemental funding for these items, or as the source of funding for items that generally cannot be funded through other means. A PASS should be viewed as an alternative to a loan which must be repaid.

C. Using the PASS for Sharon

The easiest way to understand how the PASS works is to look at Sharon's case. Since the income of Sharon's parents, including her stepparent, will count until her 18th birthday, ¹⁴¹ we should consider the PASS to take effect on or after her 18th birthday (i.e., December of her senior year). If the facts do not change, Sharon may be eligible for an SSI check to supplement her \$420 SSDI check (e.g., a \$274 SSI check in a state that does not supplement the 2011 federal benefit rate of \$674 per month).

Sharon's need for *a specially modified van* could be funded under a PASS in order to pursue her career goal of becoming a lawyer. In fact, all of the needed items could potentially be funded under a PASS if Sharon can show that they are necessary to achieve her vocational goal. The vehicle purchase, however, is the one item for which

¹⁴⁰ See sections III. and IV, above.

¹³⁸ See SSA's 1997 Emergency Instructions, EM-97-191, providing that a PASS provision for installment payments can be approved if the expense is necessary to achieve the vocational goal and cannot be met out of current income.

¹³⁹ See section II, above.

¹⁴¹ Under SSI rules, Sharon will be considered an adult at age 18. Her parents' income will no longer be counted in determining her eligibility.

she may have to rely on the PASS. If she buys a van, the VR agency will most likely pay for most, if not all, of the special modifications needed. 142

Sharon decides to set up a PASS to help fund the purchase of a van, proposing, as of her 18th birthday, to deposit \$400 of her monthly SSDI check into a specially designated account. As noted above, under SSI regulations and policy, Sharon can save money under an approved PASS for whatever period of time is reasonably needed to achieve her goal. In this case, Sharon chooses a provisional period of 48 months for the PASS (knowing she can amend the end date later if necessary). She will then use the money toward purchase of a van, in order to pursue her occupational objective. Under SSI regulations, the money in the special bank account will not be considered a countable resource and will not count toward SSI's \$2,000 resource limit. 143 In addition, the \$400 of her SSDI that is set aside will not be countable income for SSI purposes. Therefore, her SSI payment will be increased to \$674. Thus, in 48 months' time, without affecting the amount of her disposable income for monthly living expenses, Sharon will be able to accumulate \$19,200 plus interest, nearly enough to pay for the van.

In a state that pays the 2011 SSI federal benefit rate (FBR), with no state supplement, this is how Sharon's SSI check would be calculated:

Total Income:

Total Expenses for PASS:

\$420 Unearned

\$400 per month

\$ 0 Earned

SSI Calculation:

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Total countable income = $0
($420 - 400 \text{ PASS expense} = $20 - 20 \text{ unearned income exclusion} = $0)
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New SSI payment amount = \$674 (\$674 SSI FBR – 0 countable income after PASS exclusions = \$674)

In the above example, the PASS will enable Sharon to achieve a number of things:

- Accumulation of more than \$19,000 toward the purchase of a vehicle;
- The leveraging of \$20,000 or more from her state VR agency to pay for van modifications;
- Maintenance of monthly income, for living expenses, at or near the same level:144

¹⁴² See section II.B, above.

¹⁴³ 20 C.F.R. § 416.1180.

¹⁴⁴ Before the PASS was approved, Sharon's monthly income available for living expenses was \$694, i.e., \$420 in SSDI and \$274 in SSI benefits. After the PASS is approved, her monthly income available for living expenses remains at \$694, i.e., \$20 of SSDI not set aside for PASS and \$674 in SSI benefits.

- Retaining automatic eligibility for Medicaid in most states (ensuring a continued funding source for AT and many other items); and
- Under various public and subsidized housing programs and the food stamp program, ability to disregard income set aside under a PASS.¹⁴⁵

D. Using "Deemed Income" to Fund a Vocational Objective: PASSes for Spouses and Children

If the income of a spouse or parent is high enough, a part of that income will be considered available to the SSI applicant or recipient. In determining the SSI eligibility of a married person, part of the income of an ineligible spouse is, if high enough, deemed available to and considered as income of that married person. Similarly, part of the income of an ineligible parent or stepparent is, if high enough, deemed available to and considered as income of a child under 18 years old. In Sharon's case, a part of her parents' \$60,000 in annual wages would be deemed available to her and make her ineligible for SSI. Like any other form of income that is considered available to an SSI recipient, deemed income can be used to fund items in a PASS.

Let's change the facts in Sharon's case. Assume she will be 16 years old next month and lives with her mother and 12-year-old brother. There is no other parent in the household. She was getting a full \$674 SSI check and automatic Medicaid (based on her state's rules) until her mother went to work. The countable deemed income is now \$50 over the monthly limit for SSI — i.e., the deemed income is \$724 per month in a state that pays the 2011 federal benefit rate of \$674 per month. Accordingly, Sharon will no longer be eligible for SSI. 147

A PASS is proposed to put \$724 of the mother's monthly wage into an account to save for the van to allow Sharon to attend college to prepare to become a lawyer. When the PASS is approved, SSI will no longer count the deemed income and Sharon will qualify once again for a \$674 SSI check. She will also remain qualified for Medicaid. If Sharon saves this money for two full years, or until deeming stops on her eighteenth birthday, she will be able to save nearly \$17,376 in her PASS fund. She may also wish to put into the PASS account any lump sum she received for retroactive eligibility if she was recently approved for SSI following an appeal.

In Sharon's case, the PASS can also be used to fund any number of other items which specifically relate to her long-term vocational goal. For example, she may wish to

¹⁴⁵ See, e.g., 24 C.F.R. §§ 5.609(c)(8)(ii), 813.106(c)(8)(ii), 913.106(c)(8)(ii)(providing that money set aside in an approved PASS will not be counted as income in calculating the tenant's rent contribution). See 7 U.S.C. §§ 2014(d)(16) and (g)(providing a similar exemption in the food stamp program).

¹⁴⁶ See 20 C.F.R. §§ 416.1160(a)(1)(deeming of income from ineligible spouse) and (a)(2)(deeming of income from ineligible parent).

¹⁴⁷ Under SSI's complicated deeming formula, if Sharon, her brother and her mother are the only three persons in their household, the mother would have to earn \$3,258 per month (\$39,091 per year) in 2011 for \$724 to be deemed available to Sharon.

¹⁴⁸ 20 C.F.R. § 416.1165.

save money toward the specially adapted computer equipment or a specially designed computer desk and seating system.

Unfortunately, the PASS has been ignored as a way to use deemed income to fund items related to a person's vocational goal. For example, based on statistics compiled by SSA, as of December 2010, there was only one PASS in existence, nationwide, for a child under age 18. It is unclear if those PASSes involved the use of deemed income to fund the child's vocational goal. Hopefully, that number will go up dramatically as we all look to the PASS as an option for children under age 18.

E. Appeals - What if a PASS Proposal is Denied?

The denial of a PASS proposal, or any part of the proposal, is considered a decision affecting the right to SSI benefits and is subject to the SSI appeals process. This involves three potential appeals before the SSA (reconsideration, administrative law judge hearing and Appeals Council) and a potential appeal to the federal district court. Following any adverse decision (i.e., denial of the proposal, or the denial following a reconsideration or hearing), the PASS applicant is allowed 60 days from receipt of that decision to request an appeal or review of the most recent decision.

The first level of appeal, reconsideration, is before a person at SSA who played no part in the initial denial. That appeal can be on papers only or it can be through a face-to-face meeting. The hearing level appeal is before an administrative law judge who is independent of the decision makers who previously denied the PASS proposal. At the hearing, the judge will accept written documents, and testimony of the PASS applicant and any witnesses. The Appeals Council level of appeal is a paper review typically based on the hearing decision, any evidence and testimony from the hearing, and any written arguments submitted on behalf of the person appealing. ¹⁵⁰

VI. CONCLUSION

This article has provided numerous examples of how AT can help a person overcome the effects of a disability on the road to work. We have also discussed five key, federally-sponsored programs that are potential funding sources for the AT devices and services that Sharon, in the hypothetical, would need to take all the steps necessary to achieve her final vocational goal. The five funding sources discussed will exist in every state and, with the exception of the options for states under Medicaid, the federal requirements governing the programs will be the same in every state. ¹⁵¹

There are many other potential funding sources for AT not discussed in this article. These include private health insurance plans, the federally-sponsored State Children's Health Insurance Program, state specific programs, and charities. There are

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¹⁴⁹ See SSI Annual Statistical Report, 2010, p. 110.

¹⁵⁰ The regulations governing appeals in the SSI program are found at 20 C.F.R. §§ 416.1402-.416.1499.

¹⁵¹ In special education and state VR programs, a state or local agency could offer more, but not less than the federal law and regulations mandate. With Medicare, some managed care agencies or HMOs will offer more, under managed care plans, than federal Medicare law would require. SSI's PASS will operate under the same rules, nationwide.

also SSI work incentives, in addition to the PASS, that could be used to help fund AT devices like those sought by Sharon. These include both impairment related work expenses and blind work expenses as exclusions from earned income. ¹⁵² Enforcement of anti-discrimination laws, such as the Americans with Disabilities Act or section 504 of the Rehabilitation Act, can also help to overcome the barriers that often exist for persons with disabilities in public transportation systems, colleges, and places of employment. Specifically, enforcing those laws can establish the right to AT-related interventions to enable persons with disabilities to move into the world of work.

Individuals who work for a WIPA project or a Protection and Advocacy program, such as the PABSS or PAAT programs can play a critical role in helping SSI or SSDI recipients to identify potential AT funding sources that will help them overcome barriers to employment. If the AT funding request is denied, they can advise the individual on appeal procedures and direct them to an attorney or advocate who can represent them in the appeal. Some PABSS programs may decide to represent individuals in these appeals when the AT in question will help the person overcome a barrier to work. Other PABSS programs and WIPA projects may wish to refer the individual to one of the other P&A programs, such as the PAAT program.

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¹⁵² See 20 C.F.R. §§ 416.976 and 416.1112(c)(8).