

Funding Adaptive Mobility Equipment for Young Children with Disabilities

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Introduction

Assistive technology (AT) can enable young children with disabilities to participate more fully in play, communication, learning and other meaningful activities. Particularly in the crucial years of early development, a child with disabilities requires AT to live as independently as possible and develop his or her full potential. Unfortunately, lack of funding deprives many children of the benefits of AT, which would enable them to lead a more inclusive life.

To help these children and their families overcome the funding-related obstacles to acquiring AT, this document summarizes basic information on funding sources for AT and how to access them. This overview for clinicians and parents includes general guidance on AT assessment and justifying the need for AT, with tips for navigating the process successfully.

Everyone has the right to a full, dignified and abundant life. Future success of infants and toddlers with disabilities depends on the development of critically important life skills. Assistive technology can help a child with a disability develop these important skills within meaningful life activities. We encourage families and caregivers to be persistent, to become knowledgeable about your child's rights, and when necessary, to pursue the help you need through advocacy.

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Definitions

Assistive technology (AT) may encompass both AT devices and AT services.

An **AT device** is any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children and adults with disabilities.

An **AT service** is any service that assists a child with a disability to select, acquire, or learn to use an AT device. These services include functional evaluations in natural environments, providing for the acquisition of AT devices including purchase and lease, customizing, adapting and maintaining AT devices, and technical assistance and training on the use of an AT device for the child with a disability, the child's family, and professionals who provide services to children with disabilities through early intervention programs.

An **assistive technology evaluation** is requested when there is reason to believe that a child can benefit from the use of AT. A good AT evaluation addresses functional activities and desired outcomes within the natural routines of the child and the family. The need for AT can be determined through the child's initial multidisciplinary evaluation, as part of a supplemental evaluation included in the child's IFSP, or through an ongoing assessment process. The evaluator must be a qualified occupational therapist, physical therapist, speech language pathologist or other credentialed professional. Any eligibility for AT services and devices typically require a recommendation signed and dated by the child's physician.

Finding Funding

This section covers generally the primary sources of funding for AT, including:

- Individuals with Disabilities Education Act (IDEA 2004)
- Medicaid
- Private Health Insurance
- Grants
- AT Networks for Used Equipment

Procedures and definitions vary by funding source and state; this guide is written in general terms but contains guidance on where to go for additional information specific to your region and situation.

Individuals with Disabilities Education Act (IDEA 2004)

IDEA Part C

The Part C Program under IDEA was established to enhance the development of infants and toddlers with disabilities; reduce educational costs by minimizing the need for special education through early intervention; maximize independent living; and enhance the capacity of families to meet the needs of their children.

Part C generally applies to children from birth until turning 3 years of age with developmental delays or who have diagnosed physical or mental conditions that may cause developmental delays. Under Part C, if AT is identified as needed in a child's IFSP (Individualized Family Services Plan), it must be provided at no cost. Regulations state that Part C programs are "payers of last resort" which means that other possible sources of funding must be exhausted before Part C funding can be used.

Each state has a unique implementation structure, but no eligible child can be denied AT or services because of a family's inability to pay for it. Depending on the state, Medicaid can be a major source of funding for Part C services. States have some discretion in determining definitions and criteria for child eligibility.

You can find your state's policy on payment for early intervention services as well as a listing of contact information for Part C Coordinators in each state at: www.nectac.org/partc/statepolicies.asp.

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IDEA Part B

Part B applies to the provision of special education and related services for children and youth ages 3-21. Under Part B of IDEA, AT must be provided at no cost to the family if it is identified as needed in a child's IEP (Individualized Education Plan.)

The U.S. Department of Education, Office of Special Education Programs' IDEA website contains comprehensive information on IDEA 2004 at: <http://idea.ed.gov/explore/home>.

Medicaid

Medicaid is a cooperative Federal-State program that provides funding for medical care, rehabilitation and other services for eligible individuals who don't have sufficient resources or income to pay for needed medical services www.cms.hhs.gov/home/medicaid.asp.

The primary goal of Medicaid is to provide assistance to persons in need and to furnish them with rehabilitation and other services to facilitate the attainment or retention of capability for independence or self care. Medicaid provides payment directly to vendors and is a major source of funding for AT.

Funding for AT under Medicaid requires that the individual needing AT be eligible for Medicaid, and the device must be considered medically necessary.

If a child is not currently receiving Medicaid, service providers should refer the family to the local Medicaid office as early as possible to either become eligible for funding or to rule out Medicaid as a funding option. If a child is eligible for funding from other sources such as private insurance, those sources must be utilized before Medicaid will provide funding.

To be funded by Medicaid, AT devices must specifically address medical problems and be prescribed by a physician. AT devices that can be funded by Medicaid are generally categorized as those available to adults, and those available to children. Medically necessary AT services are covered under Federal Medicaid law, and AT devices that are

considered durable medical equipment are often covered under individual states' Medicaid regulations. **Descriptions of individual state programs are available at: www.cms.hhs.gov/MedicaidDataSourcesGenInfo/06_DescStateProg.asp**

Medicaid's Early Periodic Screening, Diagnosis and Treatment (ESDPT) Program (www.hrsa.gov/epsdt/default.htm) specifically states that medically necessary services or durable medical equipment must be provided to Medicaid beneficiaries under 21 even if not covered in the state's Medicaid program. Medical necessity must be established for Medicaid funding of AT.

Often AT is billed as Durable Medical Equipment (DME) for Medicaid and private insurers. HCPCS codes are used for identifying the DME to be purchased. Visit here for information on HCPCS codes and links to AT identifier codes www.nls.org/av/FAQ's%20HCPCS.pdf. Equipment suppliers can also help you identify the correct codes for your needs.

Private Health Insurance

Private health insurance can often be used as a source of funding for AT. Plans vary considerably in coverage and payment limits, however. Most private insurance will only fund AT that is considered medically necessary and prescribed by a physician. Individual insurance policies and procedures must be followed, and AT devices must fit within a covered category such as durable medical equipment or rehabilitation services.

Medical necessity must be determined within the definitions of the policy. The policy or plan may not refer to funding specific AT devices as such. Review the summary plan description and insurance policy carefully to determine the definitions, and how a particular AT device fits in, what benefits are covered, and what procedures must be followed to obtain AT, including assessments. Pre-authorization or pre-approval is often required, and the insurance company may require that selected or in-network vendors be used. An AT assessment should always be performed to document medical necessity as discussed later in this guide.

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Grants

Grant-awarding foundations generally exist to give grants to non-profit organizations (501 c 3). For non-profit organizations serving young children with disabilities, grants are a viable way to fund AT not of immediate medical necessity. In non-profit organizations such as public schools, grants have enabled the purchase of multiple types of AT for trial and use by children with disabilities at school or in the home and community.

Grants can provide AT for immediate use as well as provide for the ability to trial different types of devices for evaluation, simplifying justification and acquisition through other funding sources.

Grant gifts can range from a few hundred to millions of dollars. Foundations typically fund specific categories of service, such as education or public health, and many limit grants to specific geographical locations. Foundations may be looking for new programs to fund and can provide ties or collaborations with other funding sources.

Interested organizations may start the grant process based on published proposal guidelines or with a letter of inquiry depending on the individual foundation's format. A good place to begin the search for a grant is the **Foundation Center** www.fdncenter.org, which has information on grant maker websites, a foundations directory, free newsletter subscriptions, search tools, grant seeker tools, and a guide to proposal writing.

Other Organizations and Funding Sources

Many national organizations provide assistance for diagnosis-specific AT needs and/or help parents request pro-bono durable medical equipment that insurance may not cover.

- **Muscular Dystrophy Association** www.mda.org
- **Juvenile Arthritis Foundation** www.arthritis.org
- **United Cerebral Palsy** www.ucp.org
- **The National Easter Seals Society**

www.easterseals.org

- **March of Dimes** www.marchofdimes.com
- **Civitan International** www.civitan.org
- **Shriners Hospital for Children** www.shrinershq.org
- **United Way** www.liveunited.org

Local charitable foundations, community and religious organizations may also be a source for funding AT devices, often through community-based fundraising.

- **The Rotary Club** www.rotary.org
- **Kiwanis Club** www.kiwanis.org
- **Lions** www.lionsclubs.org
- **Elks** www.elks.org
- **Sertoma** www.sertoma.org

The National Organization Caring for Kids also provides AT to qualified special needs children when no other means to pay is available. Visit www.nockonline.org.

Recycled, Used and Loaned Equipment

Assistive technology exchange networks are designed to make technology devices and services more available and accessible for people with disabilities. There are also many organizations that lend AT for use at no or reduced cost.

The Pass It On National AT Reuse Center has links to a number of AT exchange networks and assistive technology reuse locations in each state: <http://www.passitoncenter.org>.

A helpful directory that provides an overview of and links to many state programs is:

<http://www.usatechguide.org/links.php?catid=91>

Weblinks to state Tech Act programs can be found through RESNA at:

<http://resnaprojects.org/nattap/at/statecontacts.html>

Information on AT device loan programs can be found at: <http://www.resna.org/content/index.php?pid=144>

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Advocacy

If your funding request is denied by any of these resources, attempt to determine the reason for denial and be sure to maintain documentation of all correspondence. Protection advocates are available to help you appeal funding denials. See page 9 for a list of advocacy resources.

The Funding Process

Viewing the appropriate use of assistive technology as an investment rather than a cost can help to justify its acquisition to funding sources. The team assessment that includes goal setting and task analysis, will determine the needs for AT equipment. Preparing compelling documentation, such as the letter of medical necessity, plus the readiness to appeal denials, is emphasized throughout this section.

The Team

AT acquisition is a team activity, requiring involvement by the person with the disability and family, the physician, therapists, equipment suppliers, and others such as public school employees and benefits coordinators.

Various team members will be involved in determining the appropriateness and safety of the device, getting physician and other approvals, and interacting with the equipment supplier and related service professionals to determine the medical, educational and functional necessity of the equipment, for example:

- The family, the child's physician, and a therapist (PT/OT/SLP) or other qualified evaluator will all be involved in the initial assessment.
- Parents participate in the selection of the devices and the ongoing assessment associated with their child's use of the device.
- The physician will provide any medical restrictions or other pertinent information and will typically prescribe the AT device and verify medical necessity.

- The therapist(s) or other credentialed evaluator who assesses the child for the need for AT, will make recommendations for AT devices, review options, trial equipment if possible, and help write the letter of medical necessity.

Once the appropriate technology is acquired, therapists or other credentialed evaluators will conduct initial training and create a plan for using and tapering use of supports as new skills are acquired.

The Assessment

While there are no standardized tests to determine what kind of technology a child needs, any AT assessment should focus on the functional needs of the child. A comprehensive AT assessment will:

- Assess the child's current functional capabilities
- Establish functional goals
- Establish what type of AT will facilitate attainment of the goals
- Determine what instructional supports or prompts will be provided by the AT and how they can be eliminated as a child gains new skills
- Describe how the AT will be used to teach the child functional skills in the context of meaningful activities.

Team members should work with equipment manufacturers to understand all the AT options available.

A typical AT assessment reviews the following:

- **Functional Ability:** What are the child's current developmental and functional capabilities? AT devices should enhance the child's current functional abilities. They should address immediate needs and desired functional outcomes.
- **Needs and Goals:** What are the needs of the child and family? AT devices should facilitate inclusion into desired family activities and fit into the family's lifestyle.

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- **Capabilities and Participation:** What are the child's abilities to use AT? Will AT allow the child to respond to his or her need to make choices, respond to stimuli, and enhance participation in meaningful activities? Is the child, family and other caregivers capable of utilizing the AT device to promote independence?
- **Diagnosis and Health Benefits:** Is the child physically capable of using the AT desired? Information on diagnosis, health issues, weight bearing status, ability to be in an upright position for standing and walking, need for physical supports for functional sitting, and general health status of the child must be considered. What are the health and medical benefits of the proposed supported activities? What are the health costs of not allowing the proposed functional activities?
- **AT Features:** Can this AT device be used for a number of different tasks or activities? How useful will the technology be with other devices the child currently uses? Can the needed functional outcomes be accomplished with current equipment available or lower technology AT? If not, why not?
- **Family/Child Benefit:** Does the family (or child) like the device? Can this AT device grow with the child? Does it have supports that can be eliminated as the child gains skills?
- **Equipment Trial:** Can the device be obtained for a trial prior to requesting acquisition in order to ensure it is appropriate/optimal for the intended use?

Early intervention programs only deal with AT that is directly relevant to the developmental needs of the child and AT devices should always be developmentally and age appropriate to justify funding. A primary goal of early intervention programs is to provide the tools necessary for a child to function at the highest level when the transition to public education takes place.

Low technology items typically rely on mechanical principles and are purchased or modified using simple tools and readily available materials. High technology devices are more

complex and sophisticated and are generally equipment items. These are selected to facilitate increased functional capabilities in specific areas such as mobility, positioning, self-help aids for daily routines, communication, computer and assistive toys, and switch access, where a lower technology device cannot be substituted.

Many AT devices are and should be used as teaching devices, with supports removed as a child learns new skills in order to facilitate maximum independence.

Establishing Justification

Justification principles are similar whether the device is paid for by private insurance, Medicaid, or via early intervention programs via an IFSP. Funding sources generally require that the least expensive item or service that is appropriate to the child's need be utilized so it is often crucial to build a strong case for more specialized and sophisticated AT devices.

Define the medical necessity appropriately for funding sources that require statements of medical need, and then also define the functional need for the device in terms of participation in life. In this way it is possible to justify a higher technology device if needed, or rule out other options based on the functioning needs of the child.

To qualify for funding, AT must meet a funding source's definitions and requirements for coverage within their policy. Justification for a needed AT device can include statements of **medical need** and/or **functional need** for the device.

Medical need

As an example, it might be medically necessary for a child to have equipment to support him or her in a standing position to facilitate weight bearing using a mobile stander, or in a supported walking assistive device like a gait trainer, due to the child's inability to stand or walk on their own. Medical necessity for standing equipment might include discussion of improved GI function, improvements in respiratory and cardiac performance, increased bone mineral density, or other health benefits derived from weight bearing. Supportive

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walking equipment can have the same type of discussion.

Functional need

In terms of educational or vocational relevance, standing and walking are isolated skills and have no context in and of themselves except for their medical benefits. Although “walking up steps” is an important skill, without context (i.e., riding the bus to and from school) it loses meaning for the child. When skills are integrated into functional activities, they become meaningful.

Functional activities are routines or events that the child will participate in on an ongoing basis that are meaningful to the child and family. Examples of routine activities occurring on a regular basis include meals, dressing, toileting, transportation, etc. Activities are defined first because they are the reason that skills are taught and determine what skills are needed. These activities can be structured to provide children with opportunities to learn new skills or practice emerging skills using the AT.

Skills are the isolated behavior components needed for participation in functional activities that will increase a child’s independence and opportunities for integration.

A collection and sequence of skills are required for each activity. Skills necessary for maximum participation in defined functional activities generally fall within the areas of:

- 1) **Communication** – understanding and using language in a variety of forms for multiple purposes.
- 2) **Motor** – processing sensory input and performing movements.
- 3) **Social** – relating to others.
- 4) **Functional Academics** – developing cognition and learning in order to use relevant information

Including these aspects regarding AT for increased function and skill learning strengthens the justification for AT to funding sources.

When choosing an AT device, it is very helpful to trial the actual device where possible, to help determine its suitability for the child with a disability. A child should have access to the AT solution that best fits his or her medical and functional needs.

Cost considerations

One of the major obstacles to funding is cost. However, the procurement of the equipment should be viewed as an investment. What are the positive outcomes in terms of the enhanced well-being of the individual? Conversely, what are the costs in terms of the negative consequences in not providing the requested AT?

AT can be an extremely cost effective approach to minimizing the need for special education services, beyond the obvious immediate benefits to the child of more independence, dignity and participation in life. This puts the initial cost of AT in perspective.

By providing the appropriate AT devices at an early age, the long-term outcomes for the child can be significantly altered. For instance, one argument used to justify the need for supported standing equipment is the possibility and goal of a child learning to stand and bear their own weight, eliminating the long-term need for external assistance and related costs for toileting and other activities that typically require standing. Even if the required equipment cost several thousand dollars, when compared to the cost of providing a paid employee at a school to lift a child who has not learned to stand and bear weight, or the lifetime necessity for

mechanical transfer devices, the AT device can be viewed as a sound financial investment.

Assistive Technology and the IFSP

All children with disabilities who are eligible for early intervention services must be provided with AT, if appropriate, as part of the Individualized Family Service Plan (IFSP).

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Description of AT in an IFSP should include:

- what outcomes will be achieved, including how AT is expected to enhance the child's functional capabilities;
- what specific AT device is needed and how it is to be funded (e.g. looking at other funding sources first);
- methodology for how the device will increase the child's functional capabilities including who will be involved in assisting the child with AT use and in what activities/settings.

AT must be included in the IFSP as agreed upon by parents and other team members. AT devices and services must be related to developmental needs.

For considering inclusion of AT in a child's IFSP it should be framed within the areas of family goals, developmental needs of the child, age-appropriate meaningful activities that engage the child, what functional skills are facilitated, what problems will be solved, and will progress in participation be evident as the student masters skills (e.g. motor and communication.)

If the AT device can be included as part of the IFSP in the early intervention program, this source should be sufficient to make sure the AT is acquired, once the pursuit of all other possible sources of funding has been attempted. For all funding sources besides IDEA part C early intervention programs, a letter of medical necessity is usually needed.

Prior to initiating the process of AT assessment and acquisition, the service coordinator of early intervention programs in the local education agency (LEA) should be consulted. Many LEAs have established, state-specific procedures that can streamline the process.

Letters of Medical Necessity

Most funding sources require justification for acquisition of AT devices by way of a letter of medical necessity (LMN). This letter must be personal, be meaningful, and show that the purchase is a worthwhile investment for the payer.

It is essential to craft the letter to fit the specific service goals and definitions of each funding agency. It should encompass

medical, educational and vocational outcomes, with justification described in terms of health issues, and reduced long term health costs and societal costs.

In writing the letter of medical necessity, there are customary items that should be included, many of which can be extracted from the information collected in the comprehensive AT assessment.

- **Personal benefits:** The letter should be as personal as possible. What will this equipment do to enhance this person's life? What meaningful life activities will this person be involved in as a result of building the skills this equipment will facilitate? How does this increased participation relate to independence, choice, self determination, reduced costs for caregivers and special education, and living a full, abundant and dignified life?
- **Investment:** In addition to the health and functional benefits of the device, what are the costs of not providing the requested AT? For example, the costs to an insurer of respiratory and GI complication, osteopenia, etc. far exceed the cost of a suitable standing device for an individual who cannot yet bear weight.
- **Equipment Choice:** Why is this particular equipment the most appropriate choice to address the needs of the individual? What features make this equipment the right choice, and what features of other equipment considered preclude them from consideration? Can it adapt to the child's needs over time? For example, via removable supports of a certain type at the trunk, hips, forearms or legs. Often, having one piece of (more costly) equipment that grows and adapts with the child can often be the least expensive option over time.

Definitions of medical necessity are defined by individual insurance policies and, therefore, a claim needs to be made within the context of the definition of medical necessity by the insurer, which is found in the summary plan description and individual insurance policies. The writer must ensure that all necessary letter components, as defined by the payer (i.e. Medicaid or private insurance) are included. Using a checklist is often helpful.

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Many equipment companies also offer assistance with funding issues and writing letters of medical necessity specific to their equipment that can be accessed via their web sites.

This article and checklist on Rifton's website provides helpful guidance for writing letters of medical necessity.

<http://www.rifton.com/resources/lettersofmedicalneed/MedNecArticle.pdf>

<http://www.rifton.com/resources/lettersofmedicalneed/MedNecChecklist.pdf>

A very useful tool for clinicians to use in composing letters of medical necessity can be found at www.lmnbuilder.com, which is a free web-based service for creating HIPAA-compliant customized letters of medical necessity. The letters can be generated on your own from start to finish or you can work from a spec sheet generated for you from a Rehab Technology Supplier (RTS.) It keeps letters and justifications in a personalized database to streamline the process of writing current and future letters of medical necessity.

Appealing a Denial

Think of any funding denial as a "not yet," rather than a "no." You are entitled to a clear explanation of the denial. Sometimes clarification or additional information is all that is needed. Try to determine the reason for denial and maintain documentation of all correspondence.

If denied, it is necessary to initiate an appeal process. Review all documentation that was submitted and get input from all team members who were part of the assessment/AT request process. Request an appeal in writing. Usually the appeal process involves an appeal referee, who will schedule a hearing with you by phone or in-person.

Advocacy

Protection advocacy for AT is available in all states if a third party denies procurement of needed equipment. Protection advocacy can help determine how to follow options for appealing funding denials, and can also serve as your advocate.

Protection advocates are available to help you appeal funding denials:

- **PAAT (Protection Advocacy for Assistive Technology)** has free resources, including attorneys, to assist persons with disabilities and their families seeking funding for AT: <http://www.nls.org/paatstat.pdf>
- Legal Services Reference: **HCFA – state and federal Medicaid contacts:** <http://www.hcfa.gov/medicaid/mcontact.htm>
- **The National Assistive Technology Advocacy Project** has information and links to many helpful AT advocacy aids: <http://www.nls.org/natmain.htm>
- Each state has a **Technology Assistance Project** listed at <http://www.ataporg.org>. These projects work to increase access to AT for people with disabilities. The purpose of the ATAP is to provide states with financial assistance that supports programs designed to enable individuals with disabilities to obtain access to assistive technology devices and services, including training and technical assistance to service providers. ATAP is the national voice of the AT programs.



Pursuing Funding for Assistive Technology (AT): Summary of Steps

I. Conduct an Assessment

- Define and document the need for assistive technology via an AT assessment provided by appropriate early intervention service providers focusing on how assistive technology is expected to enhance the child's functional capabilities.
- Determine appropriate functional goals, what type of AT will facilitate the attainment of these goals, and how AT will be used to teach functional skills in daily routines and activities.

II. Prepare the Individualized Family Services Plan (if applicable)

- Include the use of AT as part of the IFSP as agreed upon by parents and other team members. Relate what specific AT device is needed and the methodology for its use in the child's development of functional skills. (There are due process procedures available in each Local Education Agency if equipment and methodology are not agreed upon.)
- **When AT is written into the IFSP, it gives reasonable assurance that it can be obtained through Part C Programs if other sources of funding are exhausted.**
- Determine what sources of funding will be pursued prior to requesting part C funding.

III. Assemble Documentation

- Identify the specific AT device desired.
- Secure the necessary physician prescriptions and verification of medical necessity.
- Secure documentation of medical and educational necessity from professionals involved with the AT assessment.

IV. Establish Funding Source

Explore funding options in this order:

1.Private Insurance. If private insurance is available, follow

funding procedures indicated in the insurance policy. If funding is denied, follow the appeals process with the insurance company. Once appeals have been exhausted or if the child is not eligible for private insurance coverage, look next to Medicaid.

2.Medicaid. Determine eligibility for Medicaid, and if eligibility has not been established, determine eligibility through the local Medicaid office. If Medicaid is a funding option, pursue funding via the Early Periodic Screening, Diagnosis and Treatment (ESDPT) Program. Follow the funding procedure required by your state. If funding is denied, follow the appropriate documentation and appeals process. If Medicaid is not an option for funding look at other funding sources.

3.Other Funding Sources. For obtaining the needed AT device, many states have lending organizations that can be a source of AT devices. Other private funding sources can be utilized in many cases to purchase needed equipment such as foundations and service clubs.

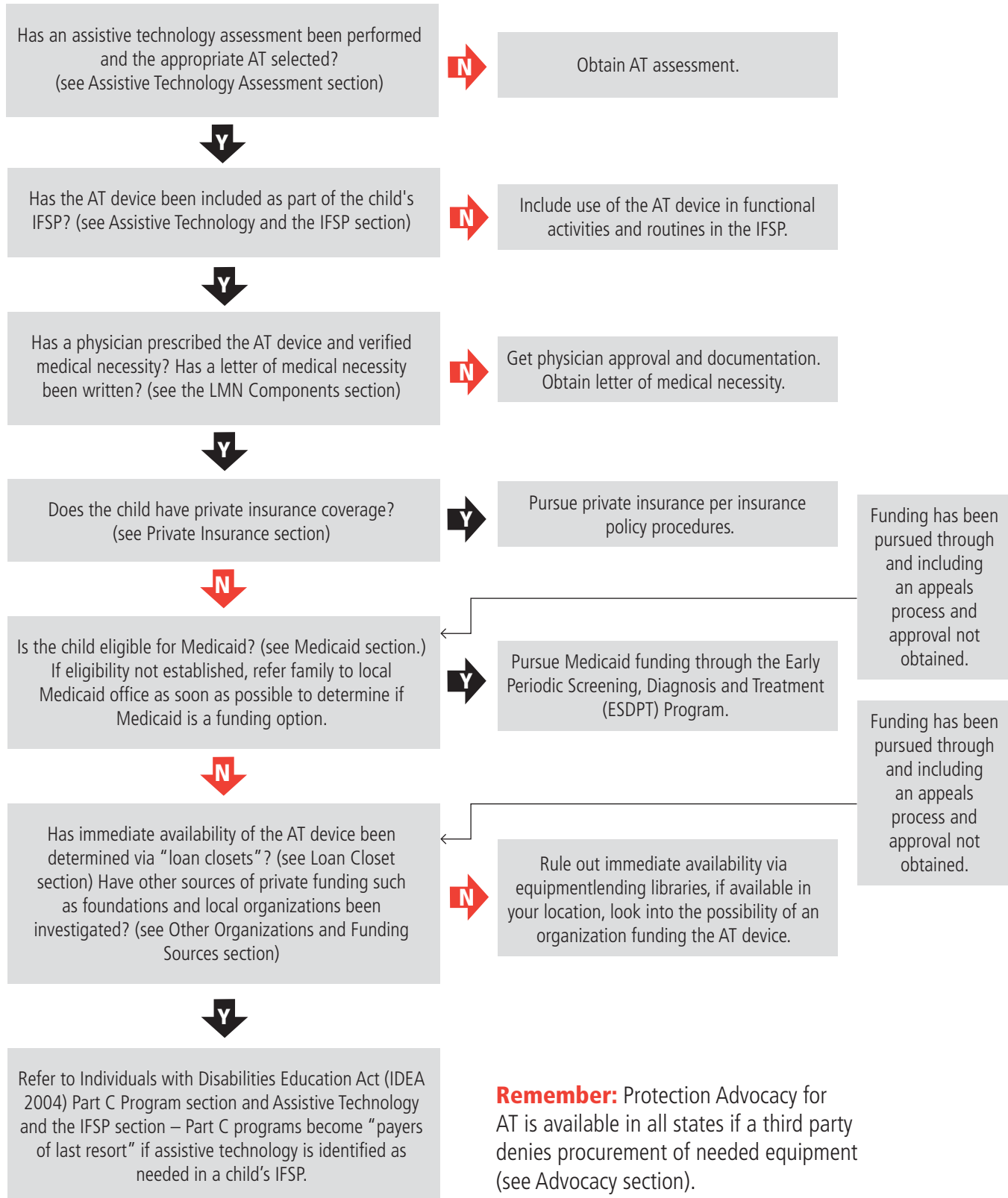
4.Part C. If no other source of funding is available, Part C Programs become "payers of last resort" if the assistive technology is identified as needed in a child's IFSP.

V. General Advice

- Utilize the many online tools available, such as LMN Builder and other resources with links in this guide.
- Take advantage of the expertise and guidance of assistive technology suppliers. Most AT suppliers have resources to help with the process of funding equipment and are most helpful in navigating paperwork and complex procedures.
- Consider everyone involved in the process as a team member, including companies, agencies, and funding sources, knowing that everyone is working to enhance the lives of children with disabilities. Treating all involved with a positive and respectful attitude will work to your advantage now and in future requests.
- Don't give up too soon. Remember that protection advocacy is available.

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AT Funding Algorithm





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