



# Complex Child E-Magazine

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## How to Get a Communication Device for Your Child

by Susan Agrawal

In an ideal world, a child with a significant communication impairment would be given a communication device and begin talking on it the very next day. Unfortunately, obtaining a communication device in the real world is often very difficult, to say the least. This article will guide parents through the basic steps in acquiring a communication device.

### Preparing for the Evaluation

The most critical part of getting a communication device is the evaluation. The evaluation must be done by a highly qualified speech language pathologist with significant experience in augmentative communication, and, preferably, access to a wide variety of devices to trial. For children with motor impairments or visual impairments, it is also advisable to have an occupational therapist assist in the evaluation.

Children as young as two years old may be ready for a device. If your child has mastered cause and effect and has begun using simple switch toys or communicators, it is probably the right time. Similarly, if your child is making obvious attempts to communicate but lacks the ability, an evaluation is in order. Since many of the best centers have long waiting lists for initial evaluations, it is best to get started as early as your child begins to show signs of readiness.

In my opinion, obtaining a superior evaluation will streamline the process for getting the device and save you a substantial amount of time, effort, and possibly money. My daughter's experience in this area is telling. We were first sent to an assistive technology evaluator who had limited experience with children like my daughter. He did not even look at her in her positioning equipment or assess her directly. He simply asked for her history and said he would submit his recommendations to her early intervention program. Several weeks later, I found out he had ordered a simple direct-access device. When it arrived, I spent five minutes playing with it before putting it back in its box and returning it. My daughter cannot point and rarely makes volitional movements with her hands or fingers. This device was useless to her.

Most children are eligible to be evaluated by the public schools for assistive technology services. While this may be adequate for some children in exceptional school districts,

most families have found that an outside evaluation is critical in determining a child's needs and abilities.

How do you find a good evaluator? There are many different sources of information that may be helpful. Asking doctors, teachers, therapists, and case managers will often yield some ideas, and other parents in your area are likely to be helpful. You may want to contact your state's assistive technology program (simply Google your state and the term "assistive technology") for information. Organizations such as Easter Seals and UCP are also helpful. Finally, rehab hospitals and university level speech pathology programs may be another source.

It is common for you to need to travel quite a distance to get an appropriate evaluation. You may need to travel to a university center, a larger city, or even another state. It is well worth traveling to get a proper evaluation.

Paying for the evaluation can sometimes be difficult. Some centers only accept cash, while others may accept Medicaid, insurance, or participate in the state's early intervention program. In some cases, a school district may pay for an outside evaluation.

## **The Evaluation**

Once you find an appropriate evaluator, you need to know what to expect from an evaluation. The child's primary caregivers definitely need to be present to provide a complete history as well as their observations of the child over time. It may be helpful to bring one of your home or school therapists along for further collaboration. Make sure to bring any devices your child is currently using, such as switches or simple communicators, as well as some favorite toys. Eye glasses, hearing aids, wheelchair trays, and other similar equipment is also necessary. Expect the evaluation to take a minimum of two hours.

The evaluation itself typically begins with some basic information and assessment of your child. If your child has any motor, visual, or hearing impairments, these should be noted and assessed. Children in wheelchairs should be checked for adequate positioning since this is necessary for them to be able to access their devices. The evaluation should take place in whatever seating your child normally uses for educational activities.

Next, the child will be assessed for his ability to access a device or switch. For children without motor impairments, this step is quite simple, since directly pressing on the device usually works just fine. But children with significant motor impairments may spend quite a while in this stage, testing different switch positions, and evaluating volitional movements of the hands, head, feet, and other parts of the body.

The child's cognitive skills will also be assessed. This, of course, varies by age and abilities, but might include trials with switches, using basic communicators, playing with familiar toys or puzzles, and trying out games on the computer. For children who are

expected to use switches to access their communicators, this section of the evaluation may also include trials with a sequencer, choice-making on the computer, or basic visual and auditory scanning.

The next step of the evaluation typically consists of showing the parent and child a variety of devices and seeing if the child responds to them and is able to use them. Depending on what is available at the center you visit, this may take quite a bit of time.

Some children will require multiple visits if they fatigue or have behavioral issues. Sometimes an evaluator will also recommend trialing some low-tech methods and then returning for a follow-up meeting. For some children, several visits may be necessary.

### **Trying Out the Device**

After the evaluation, the speech pathologist typically writes a letter with his or her recommendations. This letter usually includes a recommendation for a device, a mounting system, switches and supports to access the device, and other things such as computer software, sequencers, and environmental control units.

Many times the evaluator will recommend trying out the device at home for a month or two before it is purchased specifically for your child. Some centers will provide you with the device, while others will recommend renting it directly from the manufacturer. Most of the main manufacturers of communication devices have simple rental and loan programs. In addition, the state assistive technology programs also keep devices on hand that may be able to be borrowed. Organizations such as Lekotek, Easter Seals, UCP, schools, and local cooperatives may also have some items available for loan.

When you are trialing devices, it is important to remember that insurers typically only pay for one device every five years. You need to choose a device that is adaptable enough to be used both now and after five years of training and development.

### **Funding the Device**

Finding funding for the device is probably the largest contributor to frustration for families. While insurance and Medicaid do pay for communication devices, it is often a difficult process requiring multiple appeals.

First, determine what potential funding sources are available to you. Private insurance, Medicaid, Medicare, Early Intervention, and Medicaid Waiver Programs all may potentially reimburse for a communicator. Your school district may also purchase the device for your child.

If you hope to have insurance or Medicaid cover the device, the single most important thing you will need is a copy of the letter written after your child's evaluation. This letter

needs to include the codes for your child's underlying diagnosis as well as her specific speech impairments. It also should include a full assessment of motor abilities, cognitive abilities, and the results from trialing devices. For examples of letters, see these funding pages from Prentke Romich, a maker of communicators:

<https://funding.prentrom.com/portal/samplespeechlangeval.pdf> and  
<https://funding.prentrom.com/portal/funding.pdf>

We also found that including a medical reason for the device in the speech pathologist's report increased the likelihood of approval. Medical reasons include such things as:

- ☐ This child, who was emergently ill, was able to identify the source of her pain using her communication device, thereby allowing physicians to quickly diagnosis her condition, and saving her from multiple invasive and costly procedures.
- ☐ This child's communication device allows her to indicate how well she is breathing on a daily basis, which helps to determine if she needs her inhaler and has reduced her severe episodes of asthma dramatically. This has virtually eliminated ER visits for this child.

In addition to the speech pathologist's letter, you typically need a prescription from your doctor for a speech generating device, and copies of your insurance and/or Medicaid cards.

The best funding information probably comes from the manufacturers of communication devices. Most companies have a funding department that can submit all your paperwork for you and guide you and your therapists through the entire process. These companies deal with getting their devices approved every day and know exactly what is necessary to get your device approved.

If you decide to have your child's school district purchase the device, be forewarned that the schools are able to place restrictions on the device. Many districts require that the child return the device upon graduation or transfer to another school. Some districts, sadly enough, do not allow children to take the devices home or require that the devices be shared between multiple children. The legal issues underlying communicators purchased by schools have not been fully sorted out at this time; therefore, having the school purchase the device is definitely a last resort.

Other sources of funding may come from the private sphere. These include, but are not limited to, civic organizations such as the Elks, Lions, Variety, or Rotary Club, private charities such as National Organization Caring for Kids [<http://www.nockonline.org>], or fundraisers and benefits.

**It Does Not End Here**

Many people, and especially schools, believe that getting a device and placing it in the child's hands is the end of the road. It is, in fact, the beginning. Once the device has been obtained, training and teaching needs to begin. Programming needs to be done. Changes need to be made on an almost daily basis. Vocabulary needs to be increased. And if things are not going as planned, re-evaluation and assessment needs to be done.

But having the device in hand has opened the door to communication, and that in itself is a little bit of a miracle for so many of our children.