

First Words

*A First Steps Communications Tool for Families
From Family to Family*

“Systems and programs change frequently. Be on the alert for information about changes to the waiver program.”

Alphabet Soup

Each month we cover abbreviations, terms or acronyms parents might hear or see while in First Steps. Here are some terms you may hear while learning more about Medicaid Waivers.

Medicaid Waivers

Under Section 1915(c) of the Social Security Act, Medicaid law authorizes the Secretary of the U.S. Department of Health and Human Services to waive certain Medicaid statutory requirements. These waivers enable States to cover a broad array of home and community-based services for targeted populations as an alternative to institutionalization.

DD = Developmental Disability

A physical or mental impairment (other than a sole diagnosis of mental illness) that originates before age 22, is expected to continue indefinitely, requires an intensive interdisciplinary plan of habilitative services leading to greater functional independence, and includes substantial limitations requiring intervention in at least three of the following areas: Selfcare; Language; Learning; Mobility; Self-direction; Capacity for independent living; Economic self-sufficiency

ICF/MR = Intermediate Care Facility for the Mentally Retarded

ICF/MRs provide diagnosis, treatment, and rehabilitation of people with DD or persons with related conditions. Such facilities provide, in a protected residential setting, ongoing evaluation, planning, twenty-four hour supervision, coordination, and integration of health or rehabilitative services to help each resident function at his or her greatest ability.

Medicaid (Home and Community-Based) Waivers

When talking with your service coordinator about financial matters or future access to services, you may have talked about the Medicaid Waiver program. There is a lot to learn about waivers, so here is some basic information we hope will help you develop a working knowledge about Medicaid waivers as it applies to children under 18. If you have further questions, please talk with your service coordinator.

What are Medicaid Waivers?

Waivers provide funding for children with disabilities to receive support and services in the home and community rather than in an institutional setting. Indiana has two types of Waiver Programs. One type, for children whose needs are primarily medical in nature, is called the Nursing Facility Level of Care Waiver and includes two Waivers – the Aged and Disabled Waiver (A&D) and the Traumatic Brain Injury Waiver (TBI). The other type, for children with developmental disabilities, is the Intermediate Care Facility for the Mentally Retarded (ICF/MR) Level of Care Waiver. There are three Indiana Medicaid Waivers requiring ICF/MR Level of Care - the Autism Waiver, the Developmental Disabilities (DD) Waiver, and the Support Services (SS) Waiver.

How is eligibility determined?

To be eligible for the A&D or TBI waiver a child must need nursing facility level of care. To be eligible for the Autism waiver a child must have a diagnosis of Autism Spectrum Disorder and a need for ICF/MR level of care. Children who have a developmental disability and a need for ICF/MR level of care are eligible for the DD waiver. Any child who is eligible for the Autism or DD waiver is eligible for the SS waiver. Family income and assets are NOT considered when determining eligibility for a child under the age of eighteen.

How do I apply for a Waiver?

If your child qualifies for the Nursing Facility Level of Care waiver you can apply by calling the local Area Agency on Aging (AAA) for an application. If your child has a developmental disability (DD) and/or a diagnosis of Autism you may apply for Waiver services by calling the local Bureau of Developmental Disabilities Services (BDDS) District Office and requesting an Application for Long-Term Care Services. See the maps in the Medicaid waiver guide (link provided in the web resource section on page two) to identify your local AAA or BDDS office. Many children are eligible for more than one type of waiver. Apply for all waivers for which your child is eligible. If you think your child may be eligible and you are turned away or not

(Continued on page 2)

For more information about Family to Family, visit our web page at <http://www.INF2F.org>. You may also call 1-800-396-7188 or email family2family@sbcglobal.net. This newsletter is written in consultation with state First Steps staff.

Medicaid (Home and Community-Based) Waivers

supported in the process of applying, ask to speak to a supervisor to seek clarification on eligibility.

How long is the waiting list?

The Nursing Level of Care waivers currently have a waiting list that is less than a year. The ICF/MR waiting lists are several years long. Waiting lists change often. If your child is in need of a waiver apply as soon as possible and inquire what date of application is currently being served.

Why should I apply now?

It is recommended for families with children who are likely to be impacted by their disabilities for a lifetime to apply as soon as possible for waivers. For some families with children who have a Nursing Level of Care, waiver services can be helpful and received relatively quickly. For families with children who have an ICF/MR level of care, applying now provides a greater likelihood that supports will be available as your child gets older. Applications can also help the state government and service systems plan for and be ready to meet needs in years to come.

Advocacy Tip Of The Month

In our last issue we wrote about the public meeting to be held in Indianapolis on June 11. At that meeting families and professionals had an opportunity to provide input on the proposed federal regulations that govern early intervention services (Part C of the Individuals with Disabilities Education Improvement Act of 2004). A nice cross section of families and professionals turned out to provide testimony, so thanks to all who took the time to be heard!

There is still time to give your input on the proposed regulations if you have thoughts to share. The deadline for input is July 23. To read and respond to the regulations:

- Go to <http://www.regulations.gov>
- Select "Department of Education" from the agency drop-down menu
- Click "Submit"
- In the Docket ID column, select ED-2007-OSERS-131 to add or view public comments
- Click on one of the "Views" icons for a pdf or html version of the Federal Register
- You may submit your comments on the proposed regulations by clicking on the "Add Comments" icon

You may also mail your comments to:
Alexa Posny , U.S. Department of Education
400 Maryland Avenue, SW., Room 4109
Potomac Center Plaza
Washington, DC 20202-2600

What do I need to do to stay on the waiting list?

You will need to update the BDDS and/or AAA office whenever your contact information, including phone or address, changes.

What is available while I am waiting?

Families waiting for an ICF/MR level of care waiver are eligible to receive a small amount of Care Giver Support Services (i.e. Respite) each year. Your local BDDS office can provide information and a listing of providers for this service. Contact them directly to find out how to access Care Giver Support funding while waiting to be targeted for a waiver slot. If you should have an **EMERGENCY** (serious illness or incapacitation of a primary care giver) while your loved one is waiting for an ICF/MR waiver you may be able to receive **Emergency Support Services**. This is not a waiver but rather an individualized package of supports created to address the needs of an individual when a primary caregiver is not able to provide care and no other supports exist. If you are in need of this type of assistance, contact your local BDDS office and ask about **Emergency Support Services**. You may need to speak to a supervisor about this.

There are other state programs that may be of help while you are waiting for waiver services. It is advisable to check to see if there are other programs for which you might be eligible. Systems and programs change frequently. Be on the alert for information about changes to the waiver program. The F2F listserv is one place many parents keep up to date. You may join the F2F listserv by sending an email to INF2FParents-subscribe@yahoogroups.com.

*Note: This article is based primarily upon information on the FSSA website and the waiver guidebook listed below. Please refer to these resources for more information.

Resources for Families

Check out these resources on Medicaid waivers:

[Indiana's Family Social Services Administration](http://www.in.gov/fssa/elderly/medicaid/index.html)
<http://www.in.gov/fssa/elderly/medicaid/index.html>

[Families USA](http://www.familiesusa.org/issues/medicaid/other/waivers/waiver-tool-box.html)
<http://www.familiesusa.org/issues/medicaid/other/waivers/waiver-tool-box.html>

[Indiana's Governor's Council for People with Disabilities, Medicaid Waiver Guidebook](http://www.in.gov/gpcpd/publications/#4)
<http://www.in.gov/gpcpd/publications/#4>