The Children’s Home-Based Support Services Waiver
From the Illinois Department of Human Services
Division of Developmental Disabilities

June 18, 2007

An Interim Report Subject to Change
Compiled by The Arc of Illinois, The Family Support Network, and
The Family to Family Health Information and Education Center

What is the Children’s Home-Based Support Services Waiver?

The new Children’s Home-Based Support Services Waiver will be a new Home and Community
Based Medicaid Waiver (1915(c) for children and young adults (ages 3 - 21) with developmental
disabilities in Illinois. The waiver will provide services and supports to participating children to
enable their families to keep them at home and avoid residential placement.

The Waiver was approved by the Feds on June 6, 2007.

The current plan is for the waiver to roll out in 2 phases:

The first phase will be “conversion”. This means that children currently enrolled in the DHS/DDD
72D Program will be enrolled in the new waiver.

The second phase will be “expansion”. This means that new applications will be accepted for
children whose families have completed the PUNS form (Prioritization of Urgency of Need for
Services) with their local Independent Service Coordination agency.

When will the new waiver begin?

The start date for the new waiver is July 1, 2007.

How many children will be served?

The approved capacity set with the Feds is 600 with no more than 550 children being served at
one time.

During the first year all currently served individuals in 72D will be converted to the new
Children’s Home-Based Support Services Waiver. Within the approved capacity, 182 additional
children will begin receiving services in January of 2008.

If additional funds are appropriated for the 2008 Fiscal budget, the waiver will be amended to
increase capacity as needed. New enrollees will be selected from the Prioritization of Urgency
of Need for Services (PUNS) database.
**Who is eligible to apply for the waiver?**

Children with developmental disabilities including children with autism ages 3-21 years currently living at home with their families in Illinois and are believed to be at-risk for out-of-home placement may apply for the new waiver.

**What does “at risk of out-of-home placement” mean?**

This means that the extent of care required to maintain the child at home is so extensive - due to the severity of the developmental disability and its impact on the family - that the parents would consider residential placement for their child.

**My family is currently enrolled in 72D. How do I transition to the Children’s Program?**

The Division of DD is working very hard to get everyone in 72D transitioned to the Children’s Home-Based Support Services program by July 1st, a very tight time frame. If your family is currently receiving 72D services, your local Independent Service Coordination (ISC) agency will be contacting you to complete the appropriate paperwork. The faster they can enroll families, the more Federal Financial Participation (Medicaid Match) the state will receive. That means more families will be able to start receiving services sooner. You can identify your Independent Service Coordination (ISC) agency at [http://www.dd.illinois.gov/](http://www.dd.illinois.gov/). If you have not heard from your ISC, go ahead and call them.

You will need to identify a “service facilitator”. That may be the agency that has provided your 72D services in the past or you may choose another service facilitator with which to work. A complete list of service facilitators statewide is on the Family Support Network website homepage at [www.familysupportnetwork.org](http://www.familysupportnetwork.org). The job of the service facilitator is to help the family design a system of supports, find resources, and sign off on the plan.

If your family intends to employ personal support workers directly, you must work with Aces$ to fill out the appropriate paperwork for the personal support worker. You must have a service plan to complete the ACESS paperwork. ACESS$ is hosting enrollment sessions all around the state from June 4th through June 28. You can find specific sites and dates on their website at [http://www.acesfea.org/illinois%20Enrollment%20Sessions.htm](http://www.acesfea.org/illinois%20Enrollment%20Sessions.htm).

**My family is not currently in 72D. How do we apply for the Children’s Home-Based Support Services program?**

The first step in the application process is to schedule an appointment with your local Independent Service Coordination (ISC) agency to complete the PUNS (Prioritization of Urgency of Need for Services) form and request their assistance in applying for the new waiver. This process is most often referred to as “Pre-admission Screening” or “PAS”.

Applying for either the Adult or the Children’s Home-Based Support Services program is a process that typically will take a number of months. You will be required to provide a lot of documentation such as “proof of identity” (your child’s birth certificate) and “proof of disability”
such as medical records and psychological exams. There is other paperwork as well. Your ISC will guide you through this process. They will also create, with your help, a cover letter that describes your situation and why you need help. This is a very important part of your application and you need to be very frank about your needs. All of this will be compiled into a “packet” and submitted on your behalf by the ISC to the Department of Human Services.

Please understand that you may be eligible, but that there may not be funding available when you apply. In that case your application is usually held until more funding becomes available. Yes, it may be frustrating.

Again, you can identify your Independent Service Coordination (ISC) agency at http://www.dd.illinois.gov/.

For more information and/or support can be found at the Illinois Life Span Project. They can be reached through their website at http://www.illinoislifespan.org/ or by phone at 800-588-7002.

What financial resources are available to families?

Eligible children can receive supports and services valued up to $1,246 per month (two times SSI) this year. The number of dollars available is indexed to SSI assuring that the dollar amount keeps pace with inflation.

Are there any co-payments or family fees for supports in this waiver?

At this time, there are no fees or resource restrictions for the family. However, DHS is anticipating that there will be parent fees. We do not yet know what those will be.

What is covered by the new waiver?

Services are designed to be very similar to the existing Home-Based Support Services program for adults to provide a seamless transition to adult services between the age of 18 and 21.

Services to be covered by the new waiver will be determined on an individual basis by the family and their “service facilitator”.

The waiver is considered to be “the payor of last resort”. This means that the family must document their efforts to obtain needed services and supports from their child’s private insurance (if any), the school system (from the child’s IEP), and any other state funded insurance benefits such as Medicaid or All Kids.

Examples of services/supports that may be covered by the waiver include:
1. Service Facilitation/case management
2. Personal Support
3. Behavior Intervention and Treatment
4. Training and Counseling for Unpaid Caregivers
5. Home/Vehicle Modifications, Adaptive Equipment and Assistive Technology
6. Individual Service and Support Advocacy (ISSA) for each participant
Private insurance, Early Periodic Screening, Diagnosis, and Treatment (EPSDT), Medicaid, and All Kids are all possible resources for other therapies, medicines, and medical supplies. They should be aggressively explored.

For more information contact the Family to Family Health Information and Education Center at www.thearcofil.org/familytofamily, or 866-931-1110.

**Who helps families find providers and access services under the new waiver?**

Families work with a Service Facilitator to individually design a package of supports and services that will most effectively support the child and the family.

Participants currently in 72D and transitioning to the new Children’s Support Services Program may not have a Service Facilitator.

DHS is anticipating that most families will use their current 72D providers as their facilitator. They don’t have to, but, it is the easiest immediate choice. Some families have told us that their 72D provider isn’t prepared to be their service facilitator.

The Family Support Network has posted a complete current list of organizations statewide providing service facilitation on its website at www.familysupportnetwork.org.

Look for organizations that are close to you, call and ask for whoever is providing service facilitation for the Home-Based Support Services Program within that organization. Your Independent Service Coordination Agency should also be a resource as well. They may know organizations or individual service facilitators who will be particularly helpful for your situation.

**How do the Adult and Children's Home-Based Support Services Programs differ?**

Family members of **adults** in the Home-Based Support Services program **CAN** be personal support workers.

Parents of **children** in the Children’s Home-Based Support Services Program **CANNOT** be personal support workers for their own children. Medicaid feels that parents are already responsible for juvenile children, and won’t pay them for taking said responsibility.

The Children’s program is for children age 22 or below. Parents of participants age 18-22 have a choice whether to stay in the Children’s Program or switch to the Adult Program. The adult program is for persons 18 and older. Yes, there is an overlap and participants between the ages of 18 and 22 can choose which program will work best for them.

Workers in the Children’s Program require a CANTS form (child abuse history clearance) in their personal support worker enrollment packets, as they are working with children.

Participants in the Children’s program require a new 4-page Medicaid provider enrollment form in their personal support worker enrollment packets. Illinois requires all personal support workers in the Children’s and the Adult Program to be enrolled as Medicaid providers.

Adults in the Home-Based Support Services Program can access supports and services equal to up to 3 times SSI per month instead of the 2 times SSI cap allowed in the children’s program.
Participants in both the Children’s and the Adult Home-Based Support Services Program have a choice between an “agency” model and a “consumer-directed” model. They should find out what the agency will charge per hour for personal support workers so that they may make an informed decision. Participants using workers in the “agency model” are often charged a much higher hourly rate than they would pay support workers they hire themselves in the “consumer-directed” model. This can significantly affect how far a participant’s budget will “stretch”.

**How can I get more information about the new waiver?**

Families can contact the Illinois Life Span Project, [www.illinoislifespan.org](http://www.illinoislifespan.org), or 800-588-7002;

The Family to Family Health Information and Education Center, [www.thearcofil.org/familytofamily](http://www.thearcofil.org/familytofamily), or 866-931-1110.

Information updates will be posted on The Arc of Illinois website, [www.thearcofil.org](http://www.thearcofil.org) on a frequent basis.

Updates are also available on the Family Support Network website at [www.familysupportnetwork.org](http://www.familysupportnetwork.org).

Contact the The Arc Family to Family Health Information and Education Center at 866-931-1110 for more information.

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