



## UNDERSTANDING PERSONAL CARE FOR CHILDREN

For parents of children (birth to 18 years) with developmental disabilities who are eligible for Personal Care (PC).

**For questions about Personal Care or other disability related services contact The Arc of King County Information and Resource team at 206-829-7053 or [ask@arcokingcounty.org](mailto:ask@arcokingcounty.org)**

### Background Information

In September 2004, the Developmental Disabilities Administration (DDA) began using a new tool to assess the need for assistance with personal care tasks for children. This is a computer generated tool called “The Children’s Assessment Tool”.

### What Is Personal Care?

Personal Care, previously called Medicaid Personal Care or Waiver Personal Care, is a Medicaid program that provides personal care services to address the unmet needs of individuals who meet functional and financial eligibility criteria.

### Who qualifies for Personal Care (PC)?

1. Children must be Medicaid eligible. Medicaid is usually an *income* based program. That means the child either receives Supplemental Security Income (SSI), Apple Healthcare, or is on a Developmental Disabilities Administration (DDA) Medicaid waiver program. (This includes Individual and Family Services (IFS), Basic Plus, Core, and Children’s Intensive In-home Behavior Support (CIIBS) waivers).
2. Children with at least **3 assessed unmet** Activities of Daily Living (ADL) that require supervision that are not met by informal supports or **two ADLs** that require total, extensive, or limited help.

### Can my child receive PC if they are not a client of DDA?

Yes, any child who is Medicaid qualified and has an assessed unmet need for Personal Care may receive PC.

### Who performs the assessment?

Case Managers from DDA provide the assessment for ALL children, whether they are DDA qualified or not.

If you are already a DDA client, contact your case manager to request a PC assessment. If you don’t have a Case Manager contact the Service Request Line at 1-800-974-4428 or [DD4FSO@dshs.wa.gov](mailto:DD4FSO@dshs.wa.gov).

If your child is not a client of DDA contact Laurie Lombardo at 425-977-6521.

### What does the Children’s Assessment Tool assess?

The Children’s Assessment Tool assesses the support needed by a child who cannot complete personal care tasks by themselves. These personal care tasks are called “Activities of Daily Living” (**ADLs**) The Children’s Assessment Tool determines the “unmet” *extraordinary* needs due to the disability and developmental milestones of the child, then calculates the number of hours of paid support the child can receive.

## What are ADLs?

Activities of Daily Living (**ADLs**) include: bathing, bed mobility, body care, changing bandages or dressings when required, dressing, eating, moving around a room and living environment, moving around outside of living environment, toileting, transfers, and personal hygiene.

## How are hours determined?

The Children's Assessment Tool looks at the ADLs that you actually did for your child in the last seven days before the assessment. Scoring is based on the child's level of performance or need for assistance that occurred three or more times in the seven-day period.

DDA assigns a number of base hours to each classification group. Informal and natural supports are deducted from base hours using a numeric percentage.

Things considered in classification groups:

- Communication
- Memory
- Decision Making
- Complex Medical Conditions
- Moods and Behaviors
- Activities of Daily Living
- Memory
- Decision Making
- Complex Medical Conditions
- Moods and Behaviors
- Activities of Daily Living

Need for assistance are assessed at 5 levels:

- **Total:** The child cannot do any of the task themselves
- **Extensive:** the child needs weight-bearing help, or you fully performed the ADL
- **Limited:** Your child needs physical help, but is involved in doing part of the ADL
- **Supervision:** Your child needs monitoring, guided maneuvering, or non-weight bearing support, standby, encouragement or cueing to complete the ADL
- **Independent:** Your child can complete the ADL without help or supervision

## What are informal supports?

An informal support is a person or resource that is available to provide assistance without home and community program funding. The person or resource providing the informal support must be age 18 or older. Examples of informal supports include but are not limited to: unpaid family members, friends, neighbors, school, child-care, after school activities, adult day health, and church or community programs.

## How does informal support affect our child's assessment?

The Children's Assessment Tool asks how much *informal support* is available. Total hours could be reduced because informal support would be viewed as a "met need" or a "partially met" need. You may be asked to assist the case manager in filling out an "assistance available" schedule that shows the times that your child is in school, childcare, or other activities and the times that the parent(s) and/or other informal supports are available to care for the child.

## Personal Care is NOT:

**CHILDCARE:** PC may not be used for childcare; however, parents are NOT required to be present during the provision of care. PC cannot be used in lieu of child care. If a child is over the age of 12 and attends daycare, PC can be used in the daycare only for the additional personal care assistance that allows the child to participate in a daycare program. Parents are still responsible for the typical childcare expenses incurred. Help with personal care assistance within the daycare will need to be documented in the child's assessment. Children under the age of 12 that have documented *extraordinary* personal care needs that prevent them from attending a childcare setting must have it documented in their assessment. Working Connections, a DSHS program for low-income families, can provide assistance with daycare for eligible families. There is an additional rate for children with special needs. You may apply by calling 1-877-501-2233 or online at [Online Application for Services](#) or go to your [local Community Services Office](#)

**RESPITE:** PC is not respite. Respite is a separate service assessed by a case manager.

**SCHOOL HOURS:** PC cannot be used during the hours the child is in school. Children are expected to be in school, and the school is responsible for the needs of the child during these hours.

**BEHAVIOR SUPPORT:** PC cannot be used as behavior support.

**SUPERVISION:** PC hours cannot not be used for general supervision that is not related to a personal care task.

### **What assumptions does the Children's Assessment Tool make?**

- The parent\* is the primary care provider for the child and is obligated to provide care for their child with disabilities as they would for their typical developing child. Until the child with a disability turns 18, parents are fully responsible to provide or arrange care for transportation, housework, laundry, shopping, meal preparation, wood supply, finances, pet care, foot care needs, skin care needs, telephone use and medication management. After age 18, parents are not responsible for these activities in the same way. When your child reaches his 18th birthday, contact your case manager to ask if they should schedule an interim assessment.
- Parents\* are responsible for providing or arranging for the provision of personal care needs which are age appropriate for a child. For example, a parent is responsible for changing the diapers of a 1-2 year old child; because they would do this for their typical child (i.e. the activity is "met"). Please see the "Developmental Milestones for Personal Care" chart at the end of this document. The younger the child, the more tasks that parents are expected to performed which reduces the amount of available paid support hours.
- Parents and other informal supports of children under the age of 18 are considered to be available for at least three-fourths of the time spent on activities of daily living including the extraordinary needs due to the child's disability.
- Hours for PC are based upon the support needed by a person who cannot complete personal care tasks by themselves. Hours are determined based upon the "unmet" *extraordinary* needs due to the disability of the child.

*\*Parent means the natural, step or adoptive parents, and does not apply to legal guardians or primary non-parent custodial caregivers who do not have the same legal responsibilities for care-giving. Individuals in these circumstances are scored as having their needs "unmet".*

## Are there any exceptions?

Extraordinary circumstances may be considered for an Exception To Rule (ETR). Examples of possible extraordinary circumstances are: an adolescent who needs a 2-person lift, a child who needs supervision or interventions because of significant behaviors that impact the parent's or provider's ability to assist with completion of personal care tasks, or the parent is caring for more than one individual with a disability in the family. To receive an ETR, families will need to demonstrate that the child's needs or the family's circumstances are *extraordinary*. Families may be asked to assist the case manager in filling out an "assistance available" form before an ETR can be submitted. ETRs will need to be re-submitted on an annual basis. ETRs are reviewed at the regional level and then sent to the Developmental Disabilities Administration central office in Lacey for evaluation by a committee. The case manager has the authority to apply for an ETR.

*If your family has special circumstances, particularly around the abilities of one of the parental caregivers, such as health, mental health or other issues that may prevent them from participating in the care of the child, it is important to share this information with your case manager. These things will be kept confidential. If you do not share this information the assessment assumes the child's needs are "met".*

## How can I prepare for the CARE Assessment?

Have pertinent information about your child typed up or written down, with a paper copy available for the Case Manager. This will speed up the time of the assessment. Spend some time before the assessment thinking about the following points. You may want to talk with other family members, friends, or care providers to make sure you have a complete picture before the Case Manager arrives.

- Name, address, phone number of child.
- Contacts: family members, friends, siblings, grandparents, including the role they play in child's life, (e.g. guardian)
- Name, address, phone of child's Personal Care provider. (If your child already receives PC services.)
- Name, address, phone number of all doctors. Include primary care doctors, specialists, and dentist.
- Name, address, phone number of all therapies. List how often your child attends therapies.
- List of all medications including name, dose, and reason for use. Include vitamins and over the counter drugs. State if medication is a prescription and doctor's name.
- List all diagnoses (e.g. intellectual disability, autism, specific cardiac problems, seizure disorder). It is wise to schedule your child's yearly checkup just before to the assessment. Ask the doctor to give you a copy of the latest chart notes. Some of the diagnoses such as "aphasia" need a written diagnosis from a physician.
- List cognitive & psychological issues (e.g., depression, impaired judgment, obsessive behavior)
- List doctor and dentist appointments in last year. Report emergency room and hospital visits for the last 6 months.

**TIP:** If you document your child's information electronically (i.e. in Word), keep it handy on your computer so you can make necessary changes throughout the year or just prior to your assessment. It will make it easier next time around.

**Make a list of everything YOU have done for your child in the last 7 days.** (Even list things like tying shoes and zipping jackets or advising them on the weather and what to wear.) Think of everything. (e.g. applying lotion, clipping fingernails, etc.)

If you have to done this computerized assessment before, review your last completed document and make any changes in your child's needs or additional diagnosis and give it to your case manager. This should speed up the process.

***As parents, we tend to think first of our child's abilities. In this instance, STOP and THINK about your child's disabilities. This is a deficit-based evaluation like an Individualized Education Plan (IEP) in school.***

### **Are there any other suggestions?**

*Because of the way the computer codes the assessment, it is very important for you as the parent to think about EVERY LITTLE THING you have done in the last 7 – 30 days for your child and discuss it during the assessment. (Little things: fastening any item of clothing, orthotics, shoes; wiping face; lending an arm or hand while standing, walking, tucking into bed; health, safety or personal care reminders, etc.) Break down each task step-by-step and tell them in detail!*

Think about your child's disabilities before the assessment visit. When the Case Manager asks you to discuss what actually occurred during the look-back period, (usually the last 7 days before the assessment visit), ask them to specifically define the terms. For example, the Case Manager will use works like "limited", "extensive" or "total". Make sure you know exactly what each term means so that the Case Manager fully understands the care that your child needs. The Case Manager can give you definitions of these terms. . What they need to know is what level of help your child actually received during the look-back period (usually the last 7 days before the assessment visit).

During the assessment process, you may feel that your answers do not clearly show the complexity of your child's needs. Take careful notes. If you feel that the final assessed hours do not accurately reflect the personal care needs for your child, you will then be able to refer to specific areas of concern by using your notes.

If your child loses hours from a previous assessment, or the assessment does not reflect an accurate number of hours to accommodate your child's unmet need for personal care, it is important to review the assessment for accuracy. You may let them know that you are concerned that the assessment shows less of a need. Remember, Personal Care hours will never be able to pay for all of your child's personal care needs.

*Sit beside the Case Manager where you can see the computer screen. Carefully listen and think. It is a good idea to ask them to push F1 on the computer. At any time during the assessment, F1 can display an explanation.*

## **What happens after the assessment?**

After your assessment the Case Manager will calculate the total number of paid hours of PC your child can receive per month. The case manager will mail you a Plan of Action Notice (PAN) which lists the exact number of monthly hours.

For children under the age of 18, parents cannot be paid to provide PC to their own child. You must find another person to become the paid provider. There are several ways to find a provider:

- Friends or family over age 18 who are legal to work can become an “Individual Provider”. Talk to your Case Manager to set up a contract and training.
- Different agencies recruit, train, and connect providers with families. Talk to your Case Manager for a list of agencies near you. You can also find a list of agencies on The Arc’s on-line resource guide here: <http://www.arcokkingcounty.org/what-we-offer/resource-guide/care-respite-resources>
- The Home Care Referral Registry maintains a list of “Individual Providers” who want to Personal Care services. You can find more information here: [hcrr.wa.gov/HCRR/king.html](http://hcrr.wa.gov/HCRR/king.html)

## **What happens if I don't agree with the assessment?**

If you do not agree with the assessment, discuss your concerns with your case manager. If you are unable to come to a resolution, your next step is to ask for a “Fair Hearing” or “Administrative Hearing” – basically an appeal of the assessment. Read the Plan of Action Notice (PAN) document carefully. It will tell you what the time frame is to appeal the change in hours.

***If you appeal within the right time frame, you will be able to keep your hours until a decision is made at hearing. Keep in mind if you lose your appeal, you will have to pay up to 60 days of back payment.***

*Beginning November 16, 2011, the DSHS/DDA amended long-term care services rules, including WAC 388-106-0130, to revise the assessment process for allocating personal care hours. This revision was necessitated by the Washington State Supreme Court's decision in Samantha A. v. Department of Social and Health Services. The department will consider developmental milestones for children as defined in WAC 388-106-0130.*

*Note: We have made every effort to research this carefully. If new information is available, please pass it along to us. We commit to making updated revisions. Please contact The Arc of King County Information and Resource team at 206-829-7053 or [ask@arcokkingcounty.org](mailto:ask@arcokkingcounty.org)*

Developmental Milestones for Activities of Daily Living (ADLs)		
ADL	Self-Performance	Developmental Age Range
Medication Management	Independent Self-Directed Assistance Required	Child under 18 years of age
	Must Be Administered	Child under 12 years of age
Locomotion in Room	Independent Supervision Limited Extensive	Child under 4 years of age
	Total	Child under 13 months of age
Locomotion Outside Room	Independent Supervision	Child under 6 years of age
	Limited Extensive	Child under 4 years of age
	Total	Child under 25 months of age
Walk in Room	Independent Supervision Limited Extensive	Child under 4 years of age
	Total	Child under 19 months of age
Bed Mobility	Independent Supervision Limited	Child under 37 months of age
	Extensive	Child under 25 months of age
	Total	Child under 19 months of age
Transfers	Independent Supervision Limited Extensive	Child under 3 years of age
	Total	Child under 19 months of age

Toilet Use	Independent Supervision Limited Extensive	Child under 7 years of age
	Total	Child under 37 months of age
Eating	Independent Supervision Limited Extensive	Child under 3 years of age
	Total	Child under 13 months of age
Bathing	Independent Supervision	Child under 12 years of age
	Physical help/Transfer Only	Child under 5 years of age
	Physical help/part of bathing	Child under 6 years of age
	Total	Child under 37 months of age
Dressing	Independent Supervision	Child under 12 years of age
	Limited	Child under 8 years of age
	Extensive	Child under 7 years of age
	Total	Child under 25 months of age
Personal Hygiene	Independent Supervision	Child under 12 years of age
	Limited Extensive	Child under 7 years of age
	Total	Child under 37 months of age