



# Understanding Personal Care for Children

This memo is for parents who have a child (birth to 18 years) with developmental disabilities (DD), who is eligible for Personal Care (PC).

*\*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 caregiving.*

## Background Information

In September 2004, the Aging and Disability Services Administration 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 Comprehensive Assessment Reporting Evaluation" or "CARE".

## What does the Children's Assessment Tool Formula assess?

The CARE 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" (ADL's). Hours are determined based upon the following:

- "unmet" needs, meaning support is needed beyond what is naturally available to the child.
- "extraordinary" needs, meaning needs beyond that of what a typically developing child, of the same age, would require

## What does the Children's Assessment Tool Formula assess?

Activities of Daily Living (ADL's) for children include bathing, bed mobility, body care, changing bandages or dressing wounds, eating, getting dressed, moving around a room and living environment, moving around outside of a living environment, toileting, transferring, personal hygiene and medication management. Note that questions will be asked about all of these activities and scored based on the following levels of support:

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

## What are Personal Care Services?

Personal Care, is a Medicaid service provided through a program called "Community First Choice" (CFC). CFC provides personal care services to address the unmet need for support for certain "Activities of Daily Living". Individuals must meet functional and financial eligibility criteria.

This means that a person with a disability who is eligible for the program can use government funds to hire someone to help them with tasks related to their everyday activities, like eating, bathing and toileting that they cannot do for themselves because of their disability.

## Who qualifies for Personal Care (PC)?

1. Children must be Medicaid Eligible. Medicaid is an income based program. That means the child either receives Supplemental Security Income (SSI), through Social Security Administration, or the child receives Apple Healthcare. Personal Care is also available to individuals on a Developmental Disability Administration (DDA) Medicaid waiver program. This includes the Individual and Family Services, Basic Plus, Core and Children's Intensive In-Home Behavior Support (CIIBS) Waivers. If the child is on a DDA waiver, only the child's income is considered, not the parents'. For SSI and Apple Healthcare, parent's income is used to determine the child's eligibility (before 18).

## How are hours determined?

The Children's Assessment looks at the ADL's, your child needed help with over *the last seven days before the assessment*. The assessment utilizes an algorithm to calculate the number of hours per month the government will pay for Personal Care services. Hours are based on the level of performance (what can the child do for themselves) and needs for support that occur *three or more times in the last seven day period*. The administration takes into consideration "informal supports" available to the family and reduces hours accordingly. Informal supports include family, friends, neighbors or other unpaid caregivers.

Things the algorithm takes into consideration include:

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

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

Yes, any child who has Medicaid / Apple Health Care and has an assessed unmet need for Personal Care may receive it.

## Who performs the Assessment?

Case managers from DDA provide the assessment for ALL children, whether they are DDA eligible or not. Contact your case manager if you think your child might qualify. If you do not have a DDA case manager or your child is not a DDA client, contact your local DDA office, and ask for the "Specialized Caseload".

Assessments can take up to 3 hours to complete, due to the number of questions asked and depending on the level of support your child needs. Assessments are usually done in the family home.

## What are "Informal Supports"?

Informal supports are "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 impact my child's assessment?**

The Children's Assessment Tool Formula also asks how much informal support is available to a family. Total hours can be reduced because the support needs could be considered "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, receiving child care or other activities, and the times that the parent(s) and/or other informal supports are available to care for the child.

### **Things Personal Care will not cover.**

*Child Care:* Child care is considered care provided to a child while a primary caregiver is out of the home, for work or other activities. PC may not be used specifically for "childcare" or "babysitting", however, parents are NOT required to be present at home during the provision of care. Parents are responsible to provide childcare for their children, since 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 setting, ONLY for the additional personal care assistance that allows the child to participate in the 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 child care setting must have it documented in their assessment.

*Respite:* Respite is supervision and care provided to an individual with disability, so the parent or caregiver can have a break. 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 in place of behavior support.

*Supervision:* PC hours cannot be used for general supervision that is not related to a personal care task or Activity of Daily Living. For example, supervising your child while they are playing outdoors, would not be covered.

### **What about summer time?**

During summers and other school breaks, your child may qualify for additional PC hours. Submit a written request to your DDA case manager at least 6 weeks before the school break requesting an "Exception to Rule" (ETR) for a temporary increase in hours over the school break. In the request, you will have to explain how many PC hours the child needs.

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

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.

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 typically developing child. Parents are considered fully responsible to provide or arrange provision for many activities/supports until the child turns 18. These activities/supports include transportation, housework, laundry, shopping, meal preparation, wood supply, finances, pet care, foot care needs, skin care needs, telephone use and medication management. These are considered "met" needs because parents must provide it to the child. After age 18., some of these activities may be considered "partially met", "unmet", or "met". When your child reaches 18, contact your DDA case manager to ask if they should schedule an interim assessment.

Other activities measure the difference between what is expected in typical development compared to the support needs of the child with a disability. For example, a parent is responsible for changing the diapers of a 1-2 year old child (i.e. the activity is "met"). However, because typically developing children age 15 do not need help changing diapers, if a 15 year old child needed help with that task, it would be considered "unmet" or "partially met". Please see the "Age guidelines for personal care" chart at the end of this document for more information. The younger the child, the more tasks that parents are expected to perform which reduces the amount of available paid hours.

The Personal Care algorithm assumes that parents will provide three quarters of the support required for Activities of Daily Living, including extraordinary needs of the child.

### 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 the ETR can be submitted. ETR's will need to be re-submitted on an annual basis. ETR's 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 but may not always agree to request one.

### How can I prepare for The Children's Assessment?

1. Have pertinent information on 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. Role they play in child's life, e.g. guardian, babysitter, etc.
- Name, address, phone of child's Personal Care provider\*. (\*If your child already receives PC services.)
- List of doctors. Name, address, phone number. Include primary Dr., specialists, and dentist.
- List of therapies. Name, address, phone number. List how often your child attends therapies.
- List of all medications. Name, dose, reason. Include vitamins and Over the Counter drugs. State if medication is a prescription and Dr. 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 prior to the assessment. Ask the doctor to give you a copy of his latest chart notes. Some of the diagnoses such as "aphasia" need a written diagnosis from the 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.
- Make a list of everything YOU have done for your child in the last 7 days. (Even list things like tying shoes, zipping jackets, advising them what to wear based on weather, applying lotion, clipping toenails, etc.) *Think of everything.*

2. If this is at least the second computerized assessment, 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.

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 need will be always assumed to be "met".

*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 the next time around!*

### Are there any other suggestions?

- 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, ask them to specifically explain what they mean by terms they use, for example, limited, extensive or total. The Case Manager can give you definitions of these terms. They need to know 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 in these categories. 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, Medicaid 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 if I don't agree with the outcomes of the assessment?**

If you do not agree with the assessment, discuss your concerns with your case manager, and their supervisor if needed. If you are unable to come to a resolution, your next step is to ask for a "fair hearing" or "administrative hearing". This is essentially an appeal of the assessment. If there is a reduction in hours from a previous assessment, you will be notified in writing. This notification document is called a "Planned Action Notice" (PAN). Read this document carefully. If you appeal within the right time frame, you will be able to keep your hours until a decision is made at the hearing. Keep in mind if you lose your appeal, you will have to pay back up to 60 days of the back payment.

*TIP: As parents, we tend to think 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.*

*TIP: 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, including: fastening any item of clothing, orthotics, shoes; whipping 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!*

### **My child has Personal Care Hours! Now what?**

Once your child's hours have been determined, you have to hire a Personal Care Provider. There are two ways to hire a provider:

1. Through a Home Care Agency
2. By hiring an Individual Provider (IP)

A Home Care Agency is an organization that facilitates finding a caregiver for you or your loved one's individual personal care needs. DDA will send over the assessed personal care hours and the agency will work with you to create a schedule. Many families chose to work with an agency, so they do not need to go through the added burden of searching for a caregiver and hiring and firing processes. The downside is that you will not personally know the caregiver, which means it may take awhile for a relationship to form.

An Individual Provider (IP) is someone you hire to provide services. You can hire anyone you'd like, and they can become contracted after having a background check and required training. Most people have the best success finding someone from their personal networks (family, friends or neighbor). You can also have the person you hire sign up with a home care agency, if they prefer. An advantage to utilizing an IP over a Home Care Agency, is that you will know the person providing care to your loved one. Unfortunately, however, if the IP leaves or quits, the responsibility falls on the family to find someone new.

Ask your case manager for a list of homecare agencies and for information about contracting to become a personal care provider.

### **Can I be my child's Personal Care provider?**

No. Parents cannot be the provider for children under the age of 18. Once the child turns 18, parents can become their child's Personal Care provider.

**For questions or further resources, please contact The Arc of King County Information and Family Support Team at 206-829-7053 or Ask@arcofkingcounty.org .**