



IMPORTANT MEMO DDA Assessment

Revision #21 March 25, 2014

This memo is for parents who have an adult son/daughter (s/d) with developmental disabilities (D.D.) who receives in-home *Personal Care services*

To: Members of the King County Family Coalition for Developmental Disabilities and other interested persons.

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Definition and Purpose of Medicaid Personal Care (MPC) and Waiver Personal Care (WPC).

"MPC/WPC services are available to address the **unmet personal care needs** of individuals who meet functional and financial eligibility criteria." If your son/daughter is on a waiver, then this service is called Waiver Personal Care. If your son/daughter is not on a waiver, then the service is called Medicaid Personal Care. "Waiver Personal Care is available in the following waivers: Basic+, Core, and CIIBS. Both Medicaid and Waiver Personal Care (WPC) are services and governed by the same rules."

Nov 2, 2009 UPDATE

On every initial assessment, case managers must use the "directed" interview style for the Supports Intensity Scale (SIS) module of the DDA assessment. They may use a "conversational" interview style for the next two (subsequent) annual reviews of the SIS. Then for the next annual review they must revert to the "directed" interview style and the cycle begins again. So an *example* of the series would look like this

2013 – Directed
2014 – Conversational
2015 – Conversational
2016 – Directed
2017 – Conversational
2018 – Conversational
2019 – Directed

11/2/09 update continued

The “Conversational” style interview is basically a review. Every question must be dealt with but the question may be “has anything changed?” and if nothing has changed, the case resource manager may go on to the next question.

In between “directed” style interviews, if there is a significant change in the person’s circumstances and the parent requests an assessment, the CRM must use the “directed” interview style for that segment of the assessment that relates to the significant change.

THE DDA ASSESSMENT

Case Resource Managers (CRM) from DDD use an assessment to determine the Personal Care needs of the person with a developmental disability. Your CRM will come to your home to complete the DDA assessment. The initial assessment for Personal Care can take up to 3 hours to complete in a family’s home. Annual assessments thereafter generally take less time. Before you sign the assessment you may receive a paper copy. As the guardian or *Necessary Supplemental Accommodation* (NSA) representative for your s/d you should review a copy of the Service Summary, CARE Results document and the Planned Action Notice (PAN). The signature page of the Service Summary needs to be returned to the case manager. If you review your last assessment and make note of changes that have occurred, it should speed up the assessment time for you and your CRM. If your s/d receives a paid service, an Individual Support Plan (ISP) may be done on the same day.

DDA ASSESSMENT sections:

- SIS (Supports Intensity Scale) Does not generate Personal Care hours. It does affect respite hours
- SLA (Service Level Assessment) Determines Medicaid Personal Care hours. This portion is the CARE assessment.
- ISP (Individual Support Plan) Lists Services and assigns tasks and services to providers (paid and unpaid)

What you can do to prepare for the DDA assessment:

1. Have pertinent information about your s/d written down, with a paper copy for the CRM. 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 CRM arrives.
 - Name, address, phone number of s/d.
 - Contacts: family members, friends, siblings, grand parents. Role they play in s/d’s life, e.g. guardian. Name, address phone of s/d’s Medicaid Personal Care provider.
 - List of doctors. Name, address, phone number, Include primary Dr., specialists, and dentist.

- List of therapies. Name, address, phone number. List how often your s/d 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. mental retardation, autism, specific cardiac problems, seizure disorder. It is wise to schedule your s/d's yearly check up just prior to the assessment. Ask the Dr. to give you a copy of his latest chart note. *Some of the diagnosis such as "aphasia" need a written diagnosis from the physician.*
- List cognitive & psychological issues, e.g., depression, impaired judgment, obsessive behavior.
- List Dr. 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 s/d in 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.

2. If this is at least the second computerized assessment, review your last completed document and make any changes in your s/d's needs or additional diagnosis and give it to your case manager. This should speed up the process.

3. If your s/d is employed and using a job coach it is suggested that you notify the job coach as soon as you know the date and time of the assessment so they may attend. The CRM can administer the part of the assessment that relates to your s/d's work so that the job coach doesn't have to stay for the entire assessment *although questions throughout the assessment affect employment.*

Although DDD notifies the vendor of the assessment date it is wise for the family to also notify them. It is important to give the vendor as much time as possible for them to schedule someone to attend the meeting.

THINGS TO REMEMBER

1. **The Service Level Assessment (SLA) is really about hands-on assistance with some scoring for cueing. The supervision needs for the personal care tasks are "imbedded" in the score of the different tasks.**
2. **At any time during the assessment, the F1 key displays an explanation and assessment definitions for you. Request to see it!**
3. **As you proceed through the Assessment you may be asked to answer the question "have there been any changes?" "yes" or "no" on some screens. If you answer "no", the screen will gray out and you will not be able to see further options on that selection. If you answer "yes", you may see options that you did not realize would come under that heading. (Comments: We believe it is better to say "yes" and check out all the possibilities than to say "no" and miss an important part of your s/d care needs. Once you see all the options, you then may say "no".)**

Positive comments:

- Case Resource Managers (CRM) can complete the assessment without time consuming paper work. The goal is that this DDD Assessment will allow more consistency in assessing throughout the state and that there will be less variability in the way that individual CRMs administer the assessment. This is important for legislative decisions on funding, as well as for federal audits.)
- Reassessments are possible: If at any time there is a significant change in your s/d's condition or if there is a change in the status of your s/d's behavior, medical, caregiver or Activities of Daily Living (ADL's) needs, you can ask for a reassessment. You can also ask your CRM for an Exception to Rule (ETR). The CRM may apply for the ETR but will do so only if they feel it is justified.)

Concerns and Cautions:

Some parents are cautious about speaking about their s/d's deficits or diagnoses in front of them. You can do one of two things.)

- You can ask for your s/d to participate in the initial part of the assessment with the CRM. Explain that after they have finished with their part, it is now the parent part and they can be excused. Or you may phone, email or write to the CRM about issues and concerns you do NOT want to talk about in front of your s/d.
- Before the appointment, when case manager calls ask them which method of communication they would prefer.

DIAGNOSIS SECTION

One of the things you will not see on the tool is that there are two main categories for the **diagnosis section**. The two categories are **generic** and **advanced**. These are very important for you to understand. Some diagnoses, in combination with specific symptoms and/or treatments will impact the algorithm that generates personal care hours. Those diagnoses must be selected from the generic list in order for the algorithm to work.

However, not all items you list under the **generic** category will impact the algorithm. Thus, it is important for you to work with your CRM if you cannot find pertinent diagnoses on the generic list. Work with the CRM to find the proper terminology. The computerized assessment looks at diagnoses listed under the generic category in combination with its effect on the person's Activities of Daily Living (ADL). These combinations may give you increased hours. (See below for more information about ADLs.)

The **advanced** list does give the CRM a larger picture of your s/d, but it does not score any hours. (A long list of diagnoses is there to better understand the complexity of your s/d's needs). The information on the advanced list could be used as supporting information for an Exception to Rule (ETR) request by the CRM. It is important to capture all of the diagnosis and health issues for your s/d regardless of how it impacts the payment algorithm. Remember the role of the case resource manager is to complete a thorough and comprehensive assessment in order to create an appropriate support plan for your s/d.

EXCEPTION TO RULE (ETR)

If you believe that the assessment is correct but your s/d still needs additional assistance; you may request additional hours through an ETR. The case manager will discuss the request with you to obtain more information about why an ETR is needed. The regional office may send the request for the ETR to Aging and Disability Services (ADS) headquarters for review. The committee will review the request and the entire assessment for your s/d and makes the final decision. If the ETR request is denied at the regional office level and has not been sent to ADS you will receive a notice of this decision that will provide information that allows you to request an additional review of the ETR by the ADS headquarters committee. (Comment: we believe if you disagree with the number of hours in the assessment you should request the ETR. {If your case manager refuses to submit the ETR, your next step can be to call your CRM's supervisor and request the ETR on the grounds that the assessment was not an accurate reflection of your s/d's needs.})

SUGGESTIONS

During the assessment process, you may feel that your answers do not clearly show the complexity of your s/d'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 s/d, you will then be able to refer to specific areas of concern by using your notes.

If your s/d loses hours from a previous assessment, or the assessment does not reflect an accurate number of hours to accommodate your s/d's unmet need for personal care, it is important to stress that you are worried about the fact that the assessment shows less of a need, rather than saying that you, as the parent/provider, are losing money. Remember the Medicaid Personal Care will never be able to pay for all of your s/d's personal care needs.

ADMINISTRATIVE HEARING (or FAIR HEARING)

Fair hearing (also known as an Administrative Hearing). If you do not agree with the assessment your next step after the ETR request is to ask for a "fair hearing" or 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 Plan of Action Notice (PAN). Read this document carefully. It will tell you what the time frame is to appeal the change in hours. If the time frame is too short, you may call or email your CRM but keep a record of this action and have them acknowledge the receipt of your message. If you appeal within the time frame the hours will not be reduced. Since May 2006, if you lose the fair hearing, you will need to "pay back" the hours of continuing benefits that you were paid during the appeal process. You will not have to repay more than 60 days worth of over payment. You have a choice in this appeal process. You may appeal by the date listed in the notice and stay at the current level of hours and risk the payback or you can accept the reduction in hours and continue the appeal process. Please note that there is no appeal to the initial decision of the CRM or the ADS ETR committee to allocate Exception to Rule hours or the number of hours the tool generates. Rather, your appeal is based on the fact that you

believe the CARE assessment does not correctly measure the level of personal care need of your s/d. You can ask for a “fair hearing” before a judge to appeal only the assessment. The judge may change the hours based on their calculations but if DDA finds that there has been a mistake in those calculations they can ask for a “Corrected Initial Order. You do not need an attorney to participate in the pre-hearing phone call with the judge and DDA. This phone call is only to see if you have spoken with DDA about a review, understand the process and know the date of the hearing. (Comment: contact The Arc of WA for free pamphlet: Representing Yourself at a Fair Hearing. 1-888-754-8798)

A signature on the service plan would in no way compromise your rights to a fair hearing. It allows the service to be delivered while the issue is being worked out. If you ask for an ETR and want a Fair Hearing, both processes can begin at the same time. If the ETR is decided before the Fair Hearing and satisfies your concerns, the Fair Hearing can be cancelled.

IMPORTANT: Keep a copy of all communications with DDA on this issue.

SERVICE LEVEL ASSESSMENT (SLA, formerly called CARE) and OTHER INFORMATION

The Service Level Assessment SLA (formerly called CARE) was developed in Oregon for elderly patients. It is a Medicaid model and was purchased by our state and modified for use on Medicaid and Waiver Personal Care recipients. It assigns level of service based on medical conditions and how those conditions impact a person’s need for help with personal care tasks.

It is important to make sure the assessment is correct. For example, a **diagnosis paired with a treatment may weigh more heavily than only a diagnosis.** As you progress through the assessment and you discover you have left out a treatment for your s/d, make sure the CRM goes back to the treatment screen and enters the activity in order for this to be scored. You must think in terms of how your s/d’s diagnosis affects them in their Activities of Daily Living (ADLs). Ask yourself: what “hands-on” care or cueing do you perform related to each diagnosis. **A diagnosis alone may not result in any change in the algorithm.**

It is very important to communicate your s/d’s needs and diagnoses to the CRM. Work with the CRM to find the proper terminology in the computer. An example: You will find that epilepsy is not on the generic list, but appears on the advanced list. However, the term seizure disorder is on the generic list. You will also need a physician’s statement for the diagnosis of Aphasia. It is best to have your s/d’s yearly physical just prior to re-assessment and to bring a copy of the exam with all diagnoses to the CRM.

The tool was modified in 2007 to better capture the needs for assistance with personal care tasks for those individuals with behavior challenges. Behaviors are weighted according to frequency, and **severity (ACUITY)** and will provide more hours for most severe behaviors. For someone with minor behavior issues, a higher ADL score may also generate more hours for personal care assistance.

The case manager will start the questions on behavior issues by asking what behaviors have been a problem in the last 5 years. They will then move to what behaviors have been present in the last week and how easily are they redirected.

Think about your s/d's disabilities before the assessment visit. When the CRM asks you to give the **ability level** of your s/d, **ask the CRM to specifically define the terms, for example, limited, extensive or total.** The CRM can give you definitions of these ability levels. What the CRM needs to know is what level of help your s/d received during the look-back period (usually the last 7 days before the assessment visit). Carefully listen and think. It is a good idea to ask the CRM to push F1 on the computer. At any time during the assessment, F1 can display an explanation.

Think about the decision-making skills of your s/d. This tool and program evaluates and pays for assistance for personal care tasks. Rather than your concern about the need for supervision and safety, express your s/d's needs in terms of a personal care task. (If your s/d' was unsupervised, could they make appropriate and safe choice in tasks of dressing, cooking a meal, etc.?) Compare their skills to a typical person of the same age. (Comment: We parents tend to think first of our s/d's abilities. In this instance, STOP and THINK about your s/d's disabilities. This is a deficit-based evaluation like an Individualized Education Plan (IEP) in school.) For the Supports Intensity Scale (SIS) portion of the assessment the questions are based on what the person needs to be successful in an area so you will have to change your approach to the answers.

INFORMAL (OR NATURAL) SUPPORTS

The tool also asks how much informal support is available. An example of an informal support is: any family member or friend who is not paid by DDA and is available and assists your s/d with and ADL. School is also considered an informal Total hours would be reduced if an ADL is viewed as a "met need".

Think carefully how you respond to these informal support questions. Think about how much natural support your s/d would have if you weren't there to organize it.

There will be times during the Assessment that a parent will be asked, "would you help with this task without being paid ? You must think about this. The final number of hours granted to your s/d will be influenced by the answers to these questions. When this question is asked, you may want to say. "I wish to be fully compensated for the work I am doing." Again, you must think about this carefully. It may help you to think of yourself as a provider rather than a parent.

SUPPORTS INTENSITY SCALE (SIS)

The Supports Intensity Scale (SIS) is another portion of the DDA assessment. It is a nationally normed assessment tool for people with developmental disabilities who are age 16 and above. This module also includes an assessment of caregiver needs, behavior issues, and protective supervision.

It is used to access employment support needs, create the Individual Support Plan, and determine the need for community support, and access addition supports needed for informal or community support. This portion looks at the amount of support your s/d would need to perform various activities if compared to a typical person of the same age as your s/d. You are not to answer the questions considering available funding, availability of the service or support needed to complete the task. You are to answer how much time and the level of support your s/d would need to be **successful** (remember to think of your son/daughter as if they were a typically developing person of the same age). You will receive a chart to help you answer these questions. For a video demonstrating the SIS go to <http://www.dshs.wa.gov/ddd> , click DDA assessment on the left side of the page and then go to Presentation and click Assessment Training videos to see a sample of how this portion of the assessment is done.

WHAT CAN YOU DO TO EDUCATE YOUR ELECTED OFFICIALS ABOUT PERSONAL CARE SERVICES.

During these difficult economic times, our state could choose to significantly limit personal care services. Both MPC and WPC are not “essential” services under the Medicaid State Plan. They are “optional” services *that* our state has chosen to fund.

These issues point out the importance of parents communicating with their state legislators about how important Medicaid Personal Care is to our s/ds.

1. Allowing parents to provide Medicaid/ Waiver Personal Care is a fiscally wise program for our state. The reason that we have Medicaid Personal Care is to keep individuals with I/DD out of more restrictive environments, e.g. nursing home, institution, etc.
2. Parents provide a level of care with compassion.
3. When these young people turn 18, parents could refuse to be caregivers or guardians. Instead, parents provide more care than they are paid for. They work 7 days a week.
4. It is our opinion that without the parent providers, the state would have more requests for services or for out of home placements.

(You can find your legislative district and Legislators at <http://www.leg.wa.gov>

Note: I have made every effort to research this carefully. If new information is available, please pass it along to me. I commit to making updated revisions.
~JPO,

I would like to thank the staff of DDA for their gracious cooperation and editing of this document.

