The Arc of King County

IMPORTANT MEMO DDD Assessment

Revision #18 **October 12, 2010**

This memo is for parents who have an adult son/daughter (s/d) with developmental disabilities (D.D.) who receives Medicaid or Waiver Personal Care (MPC or WPC).

To: Members of the King Co. Parent Coalition for Developmental Disabilities and other interested persons.

From: Joanne O'Neill, Parent Training Coordinator, 425.746.2178, jponeill@arcofkingcounty.org
(call or email Joanne with questions.)

~Thanks to Margaret-Lee Thompson for help in editing.

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 DDD 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 the series would look like this

2009 – Directed
2010 – Conversational
2011 – Conversational
2012 – Directed
2013 – Conversational
2014 – Conversational
2015 – Directed
Etc.

The "Conversational" style interview is basically a review. Every question must be dealt with but the question may be "has anything change?" 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 the significant change.

IMPORTANT: DATED INFORMATION:
As of July 1, 2009, the Medicaid Personal Care (MPC) and Waiver Personal Care (WPC) hours were reduced by up to 3.5%.

IMPORTANT: DATED INFORMATION:
As of July 1, 2010 your son's/daughter's in-home hours may have changed based on the most recent individualized CARE assessment.
The changes include:
* A reduction associated with meal preparation and/or housework when you adhere to a special diet or are incontinent and have identified informal supports assisting you.
* A partial restoration of the hours reduced July 1, 2009

You should have received a letter that is a Planned Action Notice (PAN) which informed you of the change. (If you did not receive a letter there was no change to the assessment hours.)
This change is a result of legislative action responding to the need of the state to cut the state's expenditures in order to pass a balanced budget.

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 personal care is called Waiver Personal Care. If your son/daughter is not on a waiver, then their personal care is called Medicaid Personal Care. "In 2004, when DDD implemented its four new Home and Community Based Waivers, personal care services were included in three of them as a waiver service. These Waiver Personal Care (WPC) services are governed by the same rules as MPC." (quotes from MPC Program Summary, August 2009, DDD)

THE DDD ASSESSMENT

Case Resource Managers (CRM) from DDD use an assessment to determine Personal Care needs of the person with a developmental disability. Your CRM comes to your home. Before you sign the assessment you should review a paper copy. The initial assessment for Personal Care can take up to 3 hours to complete in a family's home. Annual assessments thereafter are taking less time. As the (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 your s/d's CRM. You'll also receive a copy of the assessment details if you are the paid provider. 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.

DDD ASSESSMENT sections:

- SIS (Supports Intensity Scale) — Does not generate hours.
- SLA (Service Level Assessment) — Determines Personal Care Hours. This was previously called CARE.
- ISP (Individual Support Plan) — Lists Services and assigns tasks and services to providers (paid and unpaid).

What you can do to prepare for the DDD assessment:

1. Have pertinent information on 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. Many 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 <u>employed and using a job</u> 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. DDD attempts to notify the vendor of the assessment date and time.

<u>THINGS TO REMEMBER</u>

1. **The Service Level Assessment (SLA) is really about hands-on assistance with some scoring for cueing. The supervision needs 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. <u>If you answer "yes", you may see options that you did not realize would come under that heading.</u> (<u>Comments:</u> 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".)**

<u>Positive comments:</u>

- 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.)
- <u>Reassessments are possible</u>: 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. <u>You can also ask your CRM for</u>

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 par and they can be excused. Or you may phone, email or write to the CRM about issues and concerns you do NOT with 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 increased hours to your s/d. (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)

The **ETR** process works in the following way: You convey to the CRM that you are concerned the assessment does not capture your s/d's needs for assistance with personal care tasks. Ask the CRM if s/he feels that there is enough evidence to as for an ETR. This should be done when you receive the assessment with the hours attached. The CRM decides if ETR request is appropriate. If so, the CRM then submits the request to a committee in ADSA Headquarters after it is reviewed by regional management. The committee reviews the request and the entire assessment for your s/d and makes the final decision. Your s/d's current hours are not reduced until there is a ruling on ETR. (Comment: we believe if you disagree with the number of hours, 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.) See Fair Hearing below for more information. If an ETR is awarded it is only good for one year and if still appropriate will need to be requested again at the next assessment.

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 or the hours generated for personal care services, your next step 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. 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 decision of the CRM or the ADSA ETR committee to allocate Exception to Rule hours. 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 has no authority to change hours, but can force DDD to give a second review for accuracy. It is to your benefit to go through this process. You do not need an attorney to participate in the pre-hearing phone call with the judge and DDD. This phone call is only to see if you have spoken with DDD 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 happens before the Fair Hearing and satisfies your concerns, the Fair Hearing can be cancelled.

IMPORTANT: Keep a copy of all communications with DDD 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 seems that there are different emphases than in the past "for example, **a diagnosis paired with a treatment will 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 counted. 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. Parent advocates have asked for improvements in this area. 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.

There is a concern that the Assessment does not measure a person with congenital abnormalities well i.e., malformations with resulting medical problems may not be reflected on the tool. Parent advocates have also asked for improvements in this area.

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 **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.

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 ADSA and is available (but is not an MPC provider) and assists your s/d with and ADL. School is also considered an informal support. Total hours could be reduced because it would be viewed as a "met need". **Many of the parent advocates find this questioning about informal supports to be biased** because residential providers (i.e. adult family homes) would answer this much differently than parents.

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, "is anyone providing help with this task without being paid to do it?" 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.

Due to the results of a court decision (3/7/06), DDD cannot take an automatic ("shared living") reduction in hours because the caregiver lives with the person with disabilities. As of 9/1/07 you may have found that the MPC hours increased due to the WA Supreme Court's decision.

SUPPORTS INTENSITY SCALE (SIS)

The Supports Intensity Scale (SIS) is another portion of the DDD assessment. It is a nationality 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. 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 DDD 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 MEDICAID PERSONAL CARE (MPC) AND WAIVER PERSONAL CARE (WPC)?

During these difficult economic times, our state could choose to significantly limit MPC/WPC. Both MPC and WPC are not "essential" services. They are "optional" services which 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/d's. It also can be an opportunity to tell your legislators that:

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 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

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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. ~JPO, MLT