### FREQUENTLY ASKED QUESTIONS ON PERSONAL CARE ASSISTANCE (PCA) CHANGES 2009 LEGISLATIVE SESSION Updated December 10, 2009 MN Disability Law Center

**NOTE:** If you have a copy of this document and want to find the website for the MN Disability Law Center PCA Changes Project, type <u>http://www.mylegalaid.org/</u> in the address box on your browser, click on "Disability Law" to get the drop down menu and go to "Projects". Choose "PCA Changes, 2009" or use <u>http://www.mndlc.org/mdlc/current-projects/pca-changes</u>

## 1. <u>What are the changes which will affect current Personal Care</u> <u>Assistance (PCA) recipients</u>?

#### **ANSWER:**

1) Eligibility (DHS calls this "Access to PCA Services") for PCA services has been tightened.

Must have either:

--- Dependency in an Activity of Daily Living (ADL),

Or

--- Qualify as Having Level I Behavior.

1) Dependency for at least one ADL:

New and stricter definition of "Dependency" requires that the person has a need on a daily basis for:

- Hands-on physical assistance to complete the task or
- Cuing and constant supervision to complete the task

**NOTE:** The old criteria for dependency included: "Help of another – Person able to participate." Prompting to begin or accomplish tasks **no longer qualifies** as a dependency.

Activities of Daily Living (ADLs) Include:

(1) Grooming;

- (2) Dressing;
- (3) Bathing;
- (4) Transferring;
- (5) Mobility;
- (6) Positioning;
- (7) Eating;
- (8) Toileting.

## 2) Level I behavior is a behavior which requires the immediate response of another person and includes:

- (1) Physical aggression towards self; or
- (2) Physical aggression towards others; or
- (3) Destruction of property.

**NOTE:** to qualify for Level 1 behavior, one of the behaviors must have occurred within the past 12 months. (DHS trainer stated the 12-month standard during the Assessor trainings given across the state in the fall of 2009.)

See DHS Document #7, "Instructions and Guidelines," pages 7-9 for discussion of changes in behavior documentation requirements

NOTE: Over 500 persons under 65 and perhaps 150 seniors are expected to be terminated from PCA services entirely because they are not dependent under the new definition in an ADL or do not qualify as having Level I behavior.

## 2) Reduction in PCA hours. Hours of PCA service will be reduced for thousands by instituting a new assessment with a specific formula to determine hours of care.

See the three step authorization chart and new decision tree with the 10 new home care ratings (HCR) and time allotted for each HCR. The document is on the DLC website entitled "DHS Colored Assessment Chart [10-09] and Decision Tree with Base Amount of Hours [1-1-10]," http://www.mndlc.org/mdlc/current-projects/pca-changes

NOTE: It is estimated that between 6,000 and 7,000 current PCA recipients out of over 15,000 recipients under age 65 and nearly 2,500 seniors will have their hours of service cut by some amount. It is expected that some may receive an increase in hours.

### **3)** Limit the monthly hours a PCA can be paid.

The Legislature limited the hours a PCA could work to 310 hours per month. The Governor reduced the PCA monthly work hours further to 275 hours through unallotment.

## **QUESTIONS ON NEW ASSESSMENT FORMULA**

## 2. <u>Where can I get information about the new assessment?</u>

#### **ANSWER:**

The new assessment document is on the DHS website (PCA portal) http://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-3244-ENG

and there is a link on the Minnesota Disability Law Center website to the assessment and the chart summarizing the assessment, <u>http://www.mndlc.org/mdlc/current-projects/pca-changes</u> .

There are three steps:

- (1) Determine eligibility for PCA service (dependency in an ADL and/or Level I behavior);
- (2) Determine the home care rating based on the number of activities of daily living (ADL), behavioral issues and complex health needs; and
- (3) Add:
  - (a) Time for critical ADLS's (eating, transferring, mobility, toileting);
  - (b) Behaviors if these occur four times a week:
    - (1) Increased vulnerability due to cognitive deficits or sociallyinappropriate behavior;
    - (2) Resistive to care, verbally aggressive; or
    - (3) Physical aggression toward self, others or property destruction; and.

*NOTE:* The maximum time for all behavior criteria allowed is 90 minutes per day in addition to the basic home care rating number of hours in step 2

(c) Complex health conditions, such as catheters, bowel program, wound care or other interventions, which are listed can add 30 minutes per complex health procedure.

## 3. <u>Are those using the CONSUMER SUPPORT GRANT (CSG)</u> <u>affected by the PCA changes to eligibility, PCA hours limits and</u> <u>the assessment?</u>

#### **ANSWER:**

YES. See the new CSG Monthly Budget Chart for the new limits. A link to the chart is available on the DLC website: <a href="http://www.mylegalaid.org/mdlc/current-projects/pca-changes">http://www.mylegalaid.org/mdlc/current-projects/pca-changes</a> or on the DHS website: <a href="http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs16\_147182.pdf">http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs16\_147182.pdf</a>

## 4. What should I do to prepare for the assessment?

#### **ANSWER:**

- a. If you have medical documentation of your disability and need for assistance, it is important to have copies of that for the assessment.
- b. If you have Level I behavior, it is important to have documentation of those problems from your physician, mental health provider or psychologist, school, day care provider, or anyone else in the community aware of the issues.
- c. If you have complex health procedure needs which have been ordered by your doctor such as tube feeding, wound care, bowel program, seizures, and so on, it is important to have the doctors' orders for the assessment. If you have been getting PCA service help with those needs, use the documentation of those needs from your current PCA provider. The new law says that to get PCA time for complex health procedures, they must be ordered by a doctor. You are not required to show the assessor the doctor's orders, but if you can do that, you will avoid problems and reduce the need to appeal.
- d. Read the "Instructions and Guidelines," to find out what the process is like. A link to the document is on DLC website
  <u>http://www.mndlc.org/mdlc/current-projects/pca-changes</u>
  or the DHS website:
  <u>http://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-3244A-ENG</u>
- e The guidelines have been updated since some assessors were trained, so be sure they follow the online instructions. (For instance, the draft Guidelines defined "constant supervision" as 100% visibility, eyes on the person, but the updated Guidelines on p. 10 define constant supervision as "continued interaction and/or visibility to ensure person's safety and task completion.")

## **TERMINATION OF PCA SERVICES**

## 5. <u>What if I am terminated from PCA services</u>?

#### **ANSWER:**

If you are cut off of PCA services and think that the assessor did not fairly consider your need for physical help or cuing and constant supervision or your behavioral issues which meet the Level I criteria, you have **the right to appeal**. You will get two mailings about changes in your PCA services: 1) your completed "Assessment and Service Plan" from the county or health plan nurse and 2) a computer generated notice from the Minnesota Department of Human Services that your PCA services have been terminated and information about your appeal rights.

In thinking about the fairness of your assessment, it will be helpful to review your completed assessment and the DHS "Instructions and Guidelines" for Assessors. A link is available on the DLC website:

http://www.mylegalaid.org/mdlc/current-projects/pca-changes and the DHS PCA Portal Website:

http://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-3244A-ENG.

It is important to review your assessment so that you can be specific at your appeal about where mistakes were made or you disagree with the assessment.

If you decide to appeal, it is very important that you ask for the appeal in writing within 30 days of the date on the notice. Also, if you need your PCA services to continue during the appeal, you must ask for continued services when you request an appeal. If you need an interpreter to be at the hearing, you should call or write the human services judge as soon as possible. Tell the human services judge what help you need. The human services judge will make sure that an interpreter is at the hearing. These services are available to you at no charge. Your request for an appeal and for your PCA services to continue during the appeal process must be sent or faxed, within 30 days of the notice, to:

Minnesota Department of Human Services Appeals Office P.O. Box 64941 St. Paul, MN 55164-0941 PHONE: Metro 651-431-3600 Outstate (800) 657 3510 TTY: (800) 627-3529 FAX: 651-431-7523

DHS has a lot of information **about appeals** on their website <u>http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION&</u> <u>RevisionSelectionMethod=LatestReleased&dDocName=id\_016399#</u> (If you have trouble with the link, copy and paste it into the address box on your browser and click.) However, if you think the assessment was accurate and you no longer qualify for PCA services because of the changes, then it is most important to try to find other services as soon as possible. The Assessor nurse is required to provide you with a list of other possible services. See questions below on other services.

There are a number of organizations to call for help with your appeal. Arc Minnesota, NAMI Minnesota, Brain Injury Association of Minnesota, MS Society, Minnesota Disability Law Center (MDLC), Legal Aid office in your area. See resource list at the end of the questions.

## **REDUCTION IN HOURS OF PCA SERVICE**

## 6. <u>What if my hours of service are reduced and I want to appeal</u>?

#### **ANSWER:**

If you have your PCA hours reduced and think that the assessor did not fairly consider your need for physical help or cuing and constant supervision, your behavioral issues or your complex health procedures, you have **the right to appeal**.

You will get two mailings about changes in your PCA services: 1) your completed "Assessment and Service Plan from the county or health plan nurse required to be sent within 10 working days of your assessment (Assessment and Service Plan link available on DLC website and DHS website,

http://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-3244-ENG

and 2) a computer generated notice from DHS that your PCA units (15 minute per unit) have been reduced and information on how to appeal.

In thinking about the fairness of your assessment, it will be helpful to review your completed assessment and the DHS "Instructions and Guidelines" for Assessors, which is available on the DLC website:

http://www.mylegalaid.org/mdlc/current-projects/pca-changes

and the DHS PCA Portal Website:

http://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-3244A-ENG.

It is important to review your assessment so that you can be specific at your appeal hearing about where mistakes were made or where you disagree with the assessment.

Did the assessor note down all the areas (ADLs, qualifying behaviors and complex health procedures) with which you said you needed help? If there are activities of daily living, behaviors or complex health needs that you need help with that are not written on the assessment, those are the areas to gather information on for your appeal.

Remember, the amount of time you need for each activity is no longer important because the PCA time now is figured according to a formula for everyone.

The only way to get more PCA time is to qualify as dependent in more activities of daily living or having the listed behaviors or complex health procedures for which PCA time is allowed.

If you want to appeal, it is very important that you ask for your appeal in writing within 30 days of the date on the notice. Also, if you need your PCA services to continue while you appeal, you must ask for continued PCA services during the appeal process. If you need an interpreter to be at the hearing, you should call or write the human services judge as soon as possible. Tell the human services judge what help you need. The human services judge will make sure that an interpreter is at the hearing. These services are

available to you at no charge. Your request for an appeal **and** for your PCA services to continue during the appeal process must be sent, within 30 days of the notice, to:

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There are a number of organizations to call for help with your appeal. Arc Minnesota, NAMI Minnesota, Brain Injury Association of Minnesota, MS Society, Minnesota Disability Law Center (MDLC), Legal Aid office in your area. See list of resources at the end of the questions and answers.

## **REFERRALS TO OTHER SERVICES REQUIRED**

7. <u>What if my hours of service are reduced or I am terminated</u> <u>because of the changes made to PCA services, but I think the</u> <u>assessment was accurate?</u>

# What if I cannot get along with fewer hours of PCA service, how can I get the help I need?

#### **ANSWER:**

If you think the assessment was accurate and you no longer qualify for PCA services or your reduction in hours was consistent with the changes to PCA services, then it is most important to try to find other services if you need help at home, as soon as possible.

You should receive the PCA Assessment and Service Plan document within 10 working days of your assessment. This 10-page assessment should have been filled out by the Public Health Nurse and signed when you were assessed. The public health nurse is supposed to provide you with a list of other services on the last page of the assessment, called "Recipient Referrals."

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION& RevisionSelectionMethod=LatestReleased&DDocName=id\_003726#

(If you have trouble with the link, copy and paste it into the address box on your browser and click.)

You can call your county, listed on the DLC websites and DHS, or health plan and request:

- A home and community waiver slot through your county;
- Adult or child mental health services, or
- Other MA home care services such as a home health aide;
- MA Health Care services such as physical therapy, psychology, etc.

You have the **right to apply** for these other services. If you are turned down, the county must provide you a written notice of denial and information on how to appeal the denial. Disability advocacy organizations may be able to help you appeal. See the resource list at the end of the questions. An appeal must be sent in writing within 30 days of the notice of denial to the DHS Appeals Office address listed in Questions 2 and 3.

## 8. <u>Is there any way I can get more PCA hours than I qualify for</u> <u>under the new PCA assessment criteria</u>?

#### **ANSWER:**

Yes. Home and Community-Based Waiver services can include "extended" PCA services which can be more hours than you qualify for under the new PCA criteria. People who need more PCA hours may be able to get them through the CAC, CADI, DD or TBI waivers. Home and Community-Based Waivers are for those who qualify for institutional services such as a nursing home or intermediate care facility for persons with developmental disabilities, but need alternative services to remain in their homes, apartments or in a community group home. Information about waivers can be found on the DHS website: <a href="http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION& RevisionSelectionMethod=LatestReleased&dDocName=id\_003726#.">http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION& RevisionSelectionMethod=LatestReleased&dDocName=id\_003726#.</a>

(If you have trouble with the link, copy and paste it into the address box on your browser and click.)

If you already get waiver services, your allowed waiver budget may have to be increased by your county if your health, safety and welfare are threatened without more PCA services. You can call the Disability Linkage Line to help you get a hold of your county to apply for waiver services:

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION& RevisionSelectionMethod=LatestReleased&dDocName=dhs16\_137974#

(If you have trouble with the link, copy and paste it into the address box on your browser and click.)

or check www.MinnesotaHelp.info.

*NOTE*: Waiver slots are limited and you may be told there is a waiting list. You have the right to apply anyway and the right to appeal the denial of waiver services.

# 9. <u>What if I had been referred for other services, but cannot find any</u> providers?

#### **ANSWER:**

If you need other services, such as child or adult mental health services, services for fetal alcohol or a brain injury, and cannot find anyone to provide them, call the Disability Linkage Line (1-866-333-2466) for help in locating a provider. If you cannot find a local provider, call a disability advocacy group, CCD, the Minnesota Disability Law Center, an ombudsman's office or other Legal Aid office near you for help. See resource list at the end of the questions.

Since DHS told the Legislature that some PCA recipients would be better served with other services, if you cannot find the other services, it is important for the Commissioner of DHS, the Governor and your legislators to know this. If services are really not available, it is important for you to provide information about your experience so that those advocacy groups working for change have your information. You can document your problems and efforts through the PCA survey link on the CCD website, www.mnccd.org.

## 10. <u>I have a chronic illness or disability and have used PCA services</u> <u>but now have been terminated.</u> <u>What other service can come to my</u> <u>home and help me with medications, meals, doctor's appointments</u> <u>and maintaining my apartment</u>?

#### **ANSWER:**

One service that may help you if you are an adult, is called **Home Health Aide (HHA)**. A Home Health Aide is provided through a Medicare certified home health agency. Information is available on the DHS website:

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION& RevisionSelectionMethod=LatestReleased&dDocName=id\_000823#

(If you have trouble with the link, copy and paste it into the address box on your browser and click.)

You may also qualify for Adult or Children's Mental Health Services through your county. These services can include mental health aides who can come to your home. For adults, these aides are called **AMHRS** (**Adult Mental Health Rehabilitative Services.** Information about AMHRS is available on the DHS website:

<u>http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION&</u> RevisionSelectionMethod=LatestReleased&dDocName=id\_004956#)

(If you have trouble with the link, copy and paste it into the address box on your browser and click.)

For children, a behavioral aide can come to your home as part of a service called **CTSS** (**Children's Therapeutic Services and Supports**). Information about CTSS and the forms needed are on the DHS website:

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_CONVERSION& RevisionSelectionMethod=LatestReleased&dDocName=id\_053159 and

http://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-5704A-ENG)

(If you have trouble with the link, copy and paste it into the address box on your browser and click.)

You can start by calling the Disability Linkage Line, 1-866-333-2466, for providers of home health aides or adult or children's mental health services near you.

If you cannot get the services you need to maintain your home or apartment in the community, call a disability advocacy organization, CCD, Minnesota Disability Law Center, Ombudsman's Office or other Legal Aid office for help (See question #16 for contact information). Also, consider documenting your problems and efforts through the survey link on the CCD website, <u>www.mnccd.org</u>. You can also file a complaint with the Office of Civil Rights in Chicago, <u>www.hhs.gov/ocr/office/about/rgn-hqaddresses.html</u>

## 11. <u>I have been getting PCA services under the MT or CS rating</u> which has been eliminated. What should I do?

#### **ANSWER:**

The MT and CS ratings have been eliminated. People with those ratings are being offered a home and community waiver service slot. If you are cut and do not have replacement services, it is important to appeal as soon as you receive the notice of your cut. Also, if you have not yet had a PCA reassessment but know that you have a CS or MT home care rating currently, go to your county and apply for a home and community waiver slot as soon as possible. The legislation provided funding for waiver slots for people in the MT and CS home care rating to move to waivers, about 70 people across the state.

## QUESTION ON CIVIL RIGHTS UNDER *OLMSTEAD* DECISION, AMERICANS WITH DISABILITIES ACT (ADA)

## 12. <u>What if I have to leave my apartment or home because of cuts to</u> <u>my PCA services</u>?

#### **ANSWER:**

You may have a civil rights claim under the Americans with Disabilities Act (ADA) *Olmsted* Decision. People should not have to live in more restrictive settings when they have been able to live in homes and apartments with PCA services. If you are at risk of losing your home or apartment because of cuts in your PCA services, call the Minnesota Disability Law Center or other Legal Aid office for help (See question #16 for contact information) and fill out the survey linked on the CCD website, <u>www.mnccd.org</u>. You can also file a complaint with the Office of Civil Rights in Chicago, <u>www.hhs.gov/ocr/office/about/rgn-hqaddresses.html</u>.

## **QUESTIONS ON 275 HOUR LIMIT PCAs CAN BE PAID PER MONTH**

## 13. <u>What should I do if my PCA had usually worked more than 275</u> hours per month?

#### **ANSWER:**

You are still eligible for your authorized hours of care, so it is important for you to find and train an appropriate person to provide all of the hours you need. If your PCA provides care to you for your authorized hours over 275 hours per month without pay, you may not be assessed to need the hours of service you need. Also, it is important for everyone to have more than one person trained to provide the care they need in case of illness, emergency or other change in staff.

## 14. <u>What if I am not able to find someone to fill my hours or have</u> hired people who are not competent or leave after a short time?

#### **ANSWER:**

It is very important that you document the difficulties you have in filling your PCA hours of care. The Consortium for Citizens with Disabilities (CCD) has a website which allows you to provide information about your difficulties. You do not have to use your name to submit your experience. This information can be used to keep track of the impacts of PCA changes and to try to get changes to these PCA cuts. <u>http://mnccd.org/</u> If your well-being is threatened or you cannot continue to live at home, you should call the Minnesota Disability Law Center intake line for help – 612-334-5970; 1-800-292-4150; TDD: 612-332-4668.

## 15. <u>What should I do with this information I am keeping track of</u>?

#### **ANSWER:**

The Consortium for Citizens with Disabilities, CCD, has a website, <u>www.mnccd.org</u>, which would allow you to tell your story about what has happened if you get cut off of PCA services. (<u>http://tinyurl.com/PCAimpact</u>)

It is extremely important to keep track of this information so that if bad things happen, you can use it in any appeal you may have and you can fill out the CCD survey so this information can go to your legislators and ask for changes and use it in other ways to try to help people continue to live at home with the services they need.

## **Disability Advocacy Groups and Legal Aid Resources**

## 16. <u>How do I contact disability advocacy organizations or local Legal</u> <u>Aid offices</u>?

#### **ANSWER:**

Partial List of Disability Advocacy Organizations and Legal Aid Offices:

- Arc Minnesota, http:// <u>http://www.arcmn.org/;</u>
- Brain Injury Association of Minnesota, <u>http://braininjurymn.org/;</u>
- Courage Center, <u>http://www.courage.org</u>
- National Multiple Sclerosis Society, Minnesota chapter, www.nationalmssociety.org/chapters/MNM/index.aspx;
- Minnesota Organization for Fetal Alcohol Syndrome (MOFAS), <u>http://www.mofas.org;</u>
- National Alliance for Mentally Illness-Minnesota (NAMI), <u>http://www.namihelps.org/;</u>
- Consortium for Citizens with Disabilities, CCD, <u>www.mnccd.org</u>, Link for PCA stories (<u>http://tinyurl.com/PCAimpact</u>), Link for Consortium organization members <u>http://www.mnccd.org/index.asp?Type=B\_LIST&SEC={6E6AC651-53C4-44AE-</u> B6D8-DB5352D42765}
- Find a Legal Aid Office or other resource near you in Minnesota, <u>http://www.lawhelpmn.org/MN/StateAdvancedSearch.cfm/County/%20/City/%20/</u> <u>demoMode/%3D%201/Language/1/State/MN/TextOnly/N/ZipCode/%20/LoggedIn</u> /0

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