

June 4, 2008

An open letter to every Service Recipient, Family Member, Legal Representative, Provider, Caregiver, etc. dealing with services through a Waiver Program with Tennessee DMRS.

Please be aware many changes are occurring within the Waivers; and more are planned. While timely and specific notification about changes has not always been forthcoming, it is clear changes do need to occur. It is also apparent that Advocates (in all manners this stems from) have a responsibility to stay informed and be proactive instead of reactive. It's time to stop the wailing, chest beating, and hand wringing and get seriously organized.

DMRS is issuing forth new Protocols, (replacing the current Protocols) which will affect any new ISPs, or ISP amendments which are **received** by DMRS on or after 8-1-08. (This does not mean effective date.) Personal Assistance, Day/Community Based/Employment, Residential, Supported Living, Behavioral, Clinical (Therapies), Modifications/Equipment, etc all have specific criteria which will have to be met. (Microboards will not be excluded.) These Protocols may be found on the DMRS website, along with a Q&A.

http://tennessee.gov/dmrs/provider_agencies/Protocols.html

They may also be found on the Prevent DMRS Cuts website:

<http://www.preventdmrscuts.com/>

More changes are expected in 2009, with rate changes, when the Waivers are renewed; though what these changes will be remains unclear.

Examples of some changes expected 8-1-08: Therapies will undergo concurrent reviews, usually at the 120 day mark, to determine if continuing therapies are "consistent with and not in excess of the amount of services needed". Parents, grandparents, and spouses will no longer be able to provide PA Services. Primary caregivers will have to provide their work schedules and place(s) of employment in order for PA Services to be provided. People living in an 8 bed group home wishing to move to a 4 bed group home will be unable to do so; however they will be able to move from a 4 bed to an 8 bed group home. Those in a Supported Living situation where the home has the capability of supporting more housemates will have to do so i.e. someone living by themselves in a 3 bedroom home which was left to them as part of a trust by their parents will now have to find 2 housemates. Staffing at Day/Employment cannot exceed what would be expected at home i.e. someone able to stay in their family home alone for 2 hours but needs continuous support while in the community and working will not qualify for continuous staffing. The amount of supporting documentation which will have to be submitted with the ISPs has increased substantially; this will likely include statements from family members. However, statements from families or Individuals Served should not be mistaken as an indicator that their preferences will be followed. DMRS is noting just because the Circle of Support "wants" something does not mean DMRS will determine this to be a "need", and Waiver Programs should be considered need based programs. (Does this imply the majority of us are expecting free handouts?)

CMS (Centers for Medicaid/Medicare) approves Home and Community Based Waivers for States (at a Federal level) and has guidelines which each State must meet, in order to receive Federal monies. Each State's Medicaid Program (in Tennessee's case TennCare) is responsible for overseeing these Waivers. As changes occur on a Federal level, States are expected to follow suit within certain timelines. Checking the different links on the CMS website is a good source for keeping an eye to the future with DMRS. Here are a couple links to watch:

<http://www.cms.hhs.gov/QuarterlyProviderUpdates/> &
<http://www.cms.hhs.gov/SMDL/SMD/list.asp>

Telling DMRS things aren't fair isn't going to change anything. Their responses basically are: – you have the right to appeal – TennCare is writing the protocols now – we're not sure about that answer - that will most likely be changing in the future, but we can't tell you how.

Publicly addressing specific issues, contacting elected officials, and offering reasonable alternatives is what enacts positive changes. When it comes to elected officials, having a disability does not exclude anyone from having the right to vote, unless specified within a court order for Letters of Conservatorship. (Tennessee is one of the few remaining states to allow this specification.)

Please talk to Providers – including ISCs – start attending whatever forums/presentations are available, there are organizations which people may go to for information and possible advocacy support, many websites list information on how to contact elected officials, there are people who will help write letters / make phone calls, etc. **NOW IS THE TIME TO BECOME INFORMED AND NOT GIVE UP. WE MAY BE WEARY, BUT WE CANNOT CONTINUE IN THIS DIRECTION.** *Life in a democracy should not be about developing survival skills because we are forced to live with a system that does not understand the concept of “quality of life” and where the rules constantly change; so much so that the “key holders” often don't know the rules.*