

TO: Human Services Committee

DATE: February 27, 2011

FROM: Wendy and Diane West, Sisters
of Jeffrey West, an ABI individual, currently on the ABI Waiver Wait List

SUBJECT: **Written Testimony** for H.B. No. 5893. An Act Concerning Home and Community Based Services for Persons with Acquired Brain Injury

We are the sisters of an ABI individual who is currently on the ABI Wait List, awaiting services for 21 months now. We are part of a family who is currently giving our brother 24-hour care at home, awaiting these services. We have been doing this since November of 2008. We are, at this point, exhausted, frustrated, outraged Caregivers, because of the way the current ABI Waiver program has been administered, since 2008, when the legislature first approved integrating the Money Follows the Person Program (MFP) into the ABI Waiver program.

Are you aware that 34 slots of the ABI Waiver Program for the period 2009-2011 (11 in 2009, 10 in 2010, 13 in 2011) have already been used for the MFP program, **and that people utilizing the MFP were automatically put to the top of the Wait List , or to state it more clearly, have bumped the people who are on the original ABI Waiver Wait List?** This was **prior** to the 35 additional slots being added to the ABI program, solely for the use of MFP people back in October 2010. How many of the original ABI slots were used before these additional slots were added cannot, nor **will not** be answered by anyone we have asked. Yet to have received the MFP funding, it was mandated that a certain number of ABI slots be used. **We believe the answer to: How many of these slots were used for MFP needs to be answered and that these slots should be given back to the people on the original ABI Wait List.**

By telling our story, we hope to bring to your attention the ordeal we have gone through during these past two years+, while awaiting ABI Waiver services for our brother; and, that the way the MFP was being integrated into the ABI program, prior to the additional slots, has made the wait so much longer for an individual, such as our brother, who applied for the Waiver through the original application process.

Our brother suffered a Traumatic Brain Injury in August of 2008. We were advised at that time to apply for the ABI Waiver program. He was young (50 years old), and the ABI Program would allow him to stay in his home and that the specialized services that the ABI program offers would be brought to his home. We spoke to DSS and they indicated the wait time would be about a year. We as a family decided this was the route to take for his best chance for recovery, especially with the additional complication of lose of his eyesight, and that we would take on the huge obligation, giving him 24-hour care at home for this period of time. The cost of 24-hour home care is staggering, approximately \$8,000 a month. We have been caring for him now 21 months (\$168,000). **Incidentally, this is an expense that the State of Connecticut would have incurred had we placed him in a nursing home.**

His application was submitted to DSS in June 2009. In August 2009 our attorney now advised us that we should now place our brother in a facility as he would automatically begin receiving services after a 6-month stay there. This, as we have come to find out is when the MFP program became integrated into the current ABI Waiver program. We declined to do this because in March 2009 **he was placed in a Nursing Home for a month**, after suffering multiple seizures due to his ABI. He spent most of his time in his room, was completely ignored 95% of the time, and staff seemed to have a preconceived idea of what an ABI person's behavior was like, and seemed actually afraid of him. His recovery went backwards while in the nursing home.

During all this time **DSS never informed people on their current ABI Wait List, that the protocol to obtain ABI services had changed: that MFP people would now be given priority, bumping, if you will, to those of us who had followed the original application process.** This is such a travesty for families like us, really caring about our loved ones **and their best chance for recovery.**

In January of 2011, DSS (Pamela Giannini) presented an informational talk to the Committee on Aging Services regarding the ABI Waiver Program. She stated that the wait time on the Wait List is a year and a half. Members of the committee challenged this figure, and we did as well. DSS responded that the wait time was an average of 661 days (approximately 22 months). She also stated that the movement on the Wait List is about one or two a month. If these figures **were true and accurate**, our brother should be in the 1-4 spot now. However, after 21 months he is number **37**. At this rate, he will not receive the services he needs for another 18-36 months. **So, in actuality, the wait time is more like 3-5 years.** DSS needs to be giving out correct information to you, the General Assembly, as you vote on these important matters.

Every brain injury expert states that the earlier rehabilitation is started the better the patient's chances are for a successful recovery and that the first 24 months is when therapy is most effective. Sadly, our brother has waited in his home for 21 months awaiting therapy. He and we will never know what his maximum recovery potential would have been. His recovery has been delayed because we cared enough to keep him in his home and not put him in a nursing home. Now we find had we institutionalized him he would be back in his home with the therapy that he so desperately needs. Governor Malloy, in his budget speech remarked about Connecticut's Safety Net and how the State of Connecticut **will** take care of its most vulnerable citizens. If this is true then we need to take care of those on the ABI Wait List.

Rep. Bacchiocchi has introduced HB 5893, in an effort to aid the 55 citizens on the ABI Wait List. Please consider this request and give these 55 the help that they need. Do not make them wait 3-5 years for help to come. Please do not punish the families of those 55 who believed that keeping their loved ones in their homes with family near **was** their best chance for recovery. Please do not force us to now take them out of their homes and place them in a nursing home in order to qualify for the MFP program. Institutionalizing those on the Wait List will be costly to the State and negate any savings realized through the MFP. We instead would like you to consider, giving back the slots to the people who were bumped on the ABI Waiver Wait list when these slots were given to MFP people, **prior** to the 35 additional slots for MFP approved in October 2010. Why don't you consider utilizing the funds that have been saved by the transition of those in MFP, that have been removed from institutions, and use that revenue to fund the services for these Wait List individuals.

We can be reached at (860) 428-6550, 66 Wales Road, Stafford Springs, CT 06076.

cc: Representative Penny Bacchiocchi
Senator Anthony Guglielmo
Health & Education Dept., Attorney General's Office
Re: Public Inquiry #366937