



Kids belong at HOME!

The following statement is being issued on behalf of MFTD Waiver Families, a group of concerned family members of children who participate in the MFTD Waiver.

We are grateful to the Department of Healthcare and Family Services (HFS) for meeting with family members and advocates of the Medically Fragile Technology Dependent (MFTD) Waiver today, July 11, 2012, to discuss how our children can continue to be cared for safely in the home environment with appropriate supports.

We are pleased that HFS says their policy is to keep children out of nursing homes and hospitals. However, the SMART Act, as well as additional changes to the program developed by HFS, will undoubtedly force institutionalization. Director Julie Hamos recommended pursuing a legislative fix, but the current program is set to expire in six weeks, months before the next legislative session. Thus, the state is not able to make any changes to the funding of this program in time to prevent forced hospitalization of our children.

Therefore, we would ask HFS to commit to the following:

1. Immediate notification of all MFTD waiver families of changes to the program
2. A formal request for a 90-day extension of the current program from the Centers for Medicare and Medicaid Services
3. Immediate release of all relevant documents related to changes in the program to families and advocates, including drafts of the 1915(c) waiver application, the Medicaid state plan amendment, and a transition plan for families losing eligibility

We request that the state be as transparent as possible through this process and work with families as partners. It is clear to families in attendance today that the state has failed to develop a new comprehensive program for these children, even though the current program is slated to expire in six weeks. Families are rightfully concerned for their children's well-being.

Today, Director Julie Hamos repeatedly blamed the Illinois legislature for the changes to this program and suggested families contact their legislators. Considering that Ms. Hamos recommended eliminating the MFTD Waiver entirely in the February 10, 2012 stakeholder meeting and repeatedly misrepresented the benefits of this program to legislators, we find this argument not credible. In addition, HFS has chosen to go far beyond the mandate legislators created in the SMART Act in making changes and cuts to this program, adopting provisions never discussed in previous stakeholder meetings or intended by legislators.

Our children have the right to live at home according to the Americans with Disabilities Act. We as parents will continue to fight for our children's rights, especially the right to remain at home where they belong.