Newsletter #57 Medicaid Updates (NOW/COMP Waivers) and a personal thought

Dearest Advocates:

I typically do not discuss personal issues or perspectives on this newsletter but I felt inspired to do so today prior to giving you an update on the Medicaid waivers in Georgia-

This morning I received a wonderful email from my dear friend, Stacie, that gave me a link to a video entitled "99 Balloons". I watched this video with tears and joy and sadness. (Be sure when you watch this video to have your tissues ready). I re-lived the first few months after Jacob was born (NG-tube feedings, open heart surgery, therapy and doctors appointments and my beginning of my advocacy work in the Babies Can't Wait Program). You see- I was diagnosed at 20 weeks of pregnancy that Jacob had Down syndrome, excess water on the brain and severe heart defect and was told he may not live through pregnancy. Looking back the last 8 yrs, Jacob is my miracle child that has impacted the world with his dedication and love.

Fast forward to one hour ago – I attended a "Boosterthon" fund raiser for Jacob's school. Jacob was with his second grade class running laps around the track to help raise money for the school. Every lap he ran, I was filled with such love. Three years ago, he could not have run one lap due to endurance and medical issues. Today, he ran 18 laps (a little over 1 mile). Yes, he was slower than everyone else and he had to be encouraged a little bit more with his paraprofessional and friends to run <u>BUT</u> he did it! **"Run Jacob Run"** is what I kept yelling out as he came around the track.

As you watch this video, think about all the things our children teach us everyday. The world would be a better place if we were more like our children. Full of love and ability to push through in the most difficult situations. Please don't take life for grant and enjoy every minute with our very special children!

People ask me all the time – How do I continue to spend so much time on advocating for individuals with disabilities and not being paid? I'll tell you- Jacob and the million of other "Jacob's" in this world need a voice and need to make sure they receive the necessary supports to maximize their true potential!

As we continue to see the financial situation in this country and in Georgia get more critical, please remember that our voices must be heard in order for others to understand the needs of our children. Get involved! UNITED- WE WILL MAKE A DIFFERENCE!

Enjoy: http://www.youtube.com/watch?v=th6Njr-qkq0

Now for updates on NOW/COMP implementation-

As many of you are aware, starting November 1, 2008 the New Options Waiver Program (NOW) formerly Mental Retardation Waiver Program (MRWP) and Comprehensive

Supports Waiver Program (COMP) formerly Community Habilitation Supports Services (CHSS) go live. These are disability waivers in Georgia. There has been a lot of confusion on how this is going to impact families and providers that currently utilize or work with these waivers.

I wanted to make sure **ALL** the families that have Natural Support Enhancement (NSE) services under the MRWP waiver are aware that they should be contacted in the next few days from someone from the Office of Developmental Disabilities. Below is the actual "script" that they were told to tell families about the changes in the NOW waiver. You will also be receiving a letter in the mail in the coming days.

There are <u>A LOT</u> of meetings taking place right now with providers, parents and various disability organizations working to making sure that the transition to the new waivers to done with minimal disruption to services to individuals with disabilities.

With that said, I have personally been actively working on some key issues that I hope to have answers too very soon so families can make **INFORMED** decisions about their child's waiver. (I.e. prior authorization dated 11-1-08 do <u>not</u> reflect the services approved in the individuals current ISP, providers not being able to provide services due to these codes, support coordination confusion on their roles during this transition, how the services will be expensed and the list goes on and on)

I realize that not everyone will be as impacted by this transition over to the new waivers but I am aware that many of us will. I will continue to work with Office of DD and other organizations to get the answers we need in order to make informed decisions. Keep you posted in the days/hours to come.

United...We Will Make A Difference!

Sincerely,

Heidi

(Proud Mother to Jacob - 8 yrs old with Down syndrome and Jared - 7 yrs old)

"Help the Children Now, So They Can Help Themselves Later!"

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Script from Office of Developmental Disabilities for Families that have NSE Services under the current MRWP to be converted to NOW on 11-1-08:

Talking Points

- 1. Your son or daughter will not lose dollars or the Home and Community based services waiver
- 2. We are now required by the federal government to break Natural Support Enhancement Services (or Consumer-Directed Natural Support Enhancement Services) into different service categories at different rates.
- 3. You will be receiving a letter in the next few days related to this. It will say:
 - Please do not continue okaying services beginning November 1, unless reviewed by your Support Coordinator
 - Families themselves cannot be reimbursed for services rendered.
 - There will be some new limits on what services can be provided under the new waiver
 - Your Support Coordinator will go over your individual services with you when they receive an approved prior authorization from the Regional Office.

If you have questions, contact your Support Coordinator, the DHR Regional Office in your region at one of these offices: Region One in Rome at (706) 802-5272, Region Two in Augusta at (706) 792-7733, Region Three in Tucker at (770) 414-3052, Region Four in Thomasville at (229) 225-5099, or Region Five in Savannah at (912) 303-1670; or the Office of Developmental Disabilities at 404-463-8037.