

Meeting in Lansing on Monday March 9, 2020

We are not here for more money, we are here to show you where the money should be spent; on our adult kids not on Lakeshore Regional Entity staff or consultants at Beacon Health Solutions.

(I feel that all the CMH staff from top down should have a client or two that they follow and see what that person does and see their needs.)

Our Concerns:

- **First: Mandated Paperwork must be completed ON TIME or services and funding is cut:**
 - Yearly forms include:
 - Guardianship
 - Caregiver recertifications
 - Redetermination through DHHS even though redundant must be completed to keep Medicaid funding
 - Person Centered Plan / Individual Plan of Service which if not done correctly can decrease your child services
 - Daily forms include: Logs, Timesheets, Home Help Logs and Person-Centered Plan Goals
- **Second: Services Issues:**
 - This is Sean's story sent by his mother Pat Strong-Ade:
 - Sean is 33 years old with Autism
 - He does not read or write
 - He cannot cross a street safely
 - He is not interested in TV or computers
 - He will eat or drink very weird and dangerous things or eat quantities of regular food to the point of illness
 - It took three decades for him to learn to ask for help with limited success. We are still working on this potentially life-saving skill.
 - And yet he has learned to enjoy this world, spread good cheer and help others despite his profound challenges
 - He loves to be busy. He thrives when he feels useful. He excels at large muscle motor skills. One of his favorite pastimes is splitting wood.
 - We were fortunate to find AACORN (a privately run farm setting in Kalamazoo County for I/DD kids). Of course at our expense - since it is out of our county. AACORN was just the kind of place where Sean could shine and contribute his wonderful gifts. He is now "the chicken man" and literally leaps out of the car upon arrival to throw on his muck boots and race to the chicken coop to gather eggs.
 - A rural setting gives Sean the chance for independence and the freedom of movement he needs. He cannot cross a street or parking lot safely without support. But at the farm, he can safely move about with little restriction.
 - **for Sean, AACORN is a place called home....**

- Over the past 5 years, elimination or threat of elimination of group programs has been a fear for many parents and clients. We've been told that Center Programs did not integrate our kids in society. What seems to have been overlooked is that a center program like a school might be the perfect setting for some of our kids. A Center Program may be the only way a person gets out of their home or group home so they can be part of society which is the objective for all our kids
- Here is Evan's story sent by his mother Sandra Keirnan
 - Evan is 36 years old with Down's Syndrome (intellectually at age 5)
 - Evan needs a structured environment since he doesn't cope well with change
 - For 12 years he volunteered at a bakery assembling and stamping boxes with a support person but without help that has ended
 - The past 2 years he volunteered at the local police station where he did cleaning with a support person but that also has ended due to no staff
 - With his volunteering, he has become an ambassador for people with disabilities since he has become well-known in the community
 - For the past 7 years he attended Bella Vita Solutions, a Center Program, which provides CLS and Skill Building services
 - At the end of March 2020, Bella Vita Solutions, like other Center Programs in the Lakeshore Region, will no longer be in existence.
 - Before we close doors, let us not forget that; **“The true measure of any society can be found in how it treats its most vulnerable members.”**
- **Third: Caregiver Issues:**
 - **Hiring a caregiver;**
 - It is mandated that they complete classroom and online classes plus background checks then sign contracts with the fiscal intermediaries. One parent says that by the time all this is accomplished 3 or more weeks have past and the potential employee has found other work. This needs to be stream-lined.
 - **Recipient Rights** - great idea - or - not so much
 - One parent's story; the son was put in a group home and while there he refused to eat. The parent removed him from the home when he could not walk and his weight went down to 90#. The son's refusal to eat gave staff the right not to feed him under the guise of **“RECIPIENT RIGHTS”**.
 - Another parent's daughter was not bathed for the same reason: **“RECIPIENT RIGHTS”**.
 - One of my daughter's caregivers said she could not raise her voice to my daughter due to **“RECIPIENT RIGHTS”** (even if it would save her from going into traffic?)
 - Recipient Rights needs to change to something similar to the **“Good Samaritan Law”** or we need **Common Sense** classes.
 - **“Conceal/Carry License”** Never did I think to ask if a caregiver had a conceal and carry license and had it on them or in their vehicle. I do not

- want a gun anywhere near my daughter for her safety and that of others. If she is in the front seat and the gun is in the glove compartment - that's scary
- **Marijuana users;** Medicinal or Recreational - not something I want with caring for my daughter. She can move very quickly so I want people with quick reaction times
 - **Fourth: Everyday Living:**
 - I heard **a report on NPR** about families caring for their loved ones on "hospice". It revealed that most of the 24/7 care was provided by family and not hospice staff. This was an added stress on families. As much as I empathize with these families; there is an end with the care. For us - there is no end; We do 24/7 CARE for our adult kids - until we die or are incapacitated.
 - **Taking a trip** can mean extra planning;
 - One family took a one month trip out of the country with their two disabled daughters in wheelchairs. One daughter is on tube feeding. They had to carry a month's supply of formula on the planes. It could not go in cargo due to freezing. To do this they had to get permission from each airline.
 - When I travel with my daughter who is incontinent of bowel and bladder, I have one suitcase filled with depends and extra clothing and the hotel must have laundry facilities that we can use.
 - **Damage to homes;** one family had to plywood their son's bedroom walls because he had punched out the drywall. They put bars on the windows but left enough space for his radio so he could turn it on but not grab it or escape through the window. His bedroom door was locked so everyone could get some sleep even though he was up most of the night listening to music. As a young boy, he had been successful in getting out of his yard by punching down their wooden fence. All of this not only creates a finance burden on parents but puts them under extreme stress and it does not end...
 - **Fifth: Perception by other people**
 - I was at a neighborhood get together and told one of the neighbors that I have a daughter with Autism. He chuckled and said that his aunt at age 96 was finally an "empty nester" because her disabled son at age 66 had died. He thought this was so funny - I was not amused !
- Lastly:**
- It is very sad when a parent's wish is that their adult child will die one day before the parent dies since we have no trust in getting good care for our kids after we are gone.

Thank you

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