

Public Comments to CMS-2296-P

Medicaid Program Home and Community Based Services Waivers

Dear Sir / Madam:

Thank you for allowing stakeholders regarding this issue to provide feedback.

I have an 18 year old daughter who has been diagnosed as having Autism. As we all know autism is a very wide umbrella and in the classification of disorders it is probably a very polite description of my daughter. She is unaware to the dangers in her vicinity therefore requiring complete supervision during her waking hours. She does not typically interact with people but likes to be around people. She is non-verbal and has no formal communication skills. She is mobile, still wears diapers, and has the functionality of an 18 month old child.

She currently goes to a typical high school but is in a private classroom with 6 other students with like characteristics. In her early years, the rhetoric was inclusion. My daughter was and is incapable of participating in almost any normal social functions whether it is for pleasure, school or work. In most instances she would be disruptive to her peers and sometimes self-destructive.

Her participation in a private classroom gives the appearance of normalcy, the privacy of being different, and the ability to retreat when she needs to. She has an aid with her from the moment she leaves our house in the morning to the moment she returns home in the afternoon.

I would like to think that living at home is the best place for her to be and for the moment it is when there are two adults in the house to help out and generous hours provided through I / O waivers. However good it is – fun and normalcy it is not. Every day is stressful. What are the alternatives for my daughter when either me or my wife die or we are too old to physically man handle her?

We have looked at many facilities including large group homes and small homes setup by parents and families to try and support young adults (or even older adults) that cannot take care of themselves or defend themselves at all. One of the misnomers in my mind with these types of adult settings is that they are required to attend day habilitation services. Have you ever seen and observed these types of facilities? My daughter would be incapable of surviving in these types of settings – I would view these facilities as places that would put my daughter in daily danger.

My daughter often gets overwhelmed and when she does she tends to want to retreat to her bedroom. Having to travel to day habilitation services would be very difficult on many days and what would happen to her during the day if she really needed to retreat to her “safe” place. The two locations with uncontrolled travel arrangements between facilities would often be a problem. There are many school days where we cannot get her to school or have to pick her up from school.

We have looked at several farm settings including Bittersweet Farms and SafeHaven Farms. These facilities provide a setting where there is a fairly close proximity of living facilities and various controlled day habilitation services providing my daughter the ability to retreat to her own home / room when she

does get overwhelmed. The overall environment provides a safety net where she can observe her peers for social satisfaction and also be able to retreat when required. There are multiple houses with multiple staff available all the time. I like the idea of multiple staff observing other staff...I feel that is in my daughter's best interest. If she was in a single house with multiple tenants in an urban setting there would be a limited number of staff to support the residents and the facilities and seldom, if any, overlapping staff observing each other.

I understand the want of anyone and everyone to promote inclusion whether it is a school or housing facility. But the ability for some of children or adults to actually thrive in that environment is not always possible. The "Farm" setting and the word "Rural" shouldn't be confused with no social interaction or the idea that these "Residents" are cut off from anything. The farm that we are looking at is less than a 30 minute drive from our home and is located 15 minutes from a city with 50,000 people, a mall, McDonalds, an airport...The "Residents" are free to come and go for short or long periods of time. It is not unusual for families and friends to stop by to play / interact with them, eat lunch with them, take them to lunch, go out for an outing or an extended vacation with the family. And in most instances, the "Residents" are "happy" when they get back "home".

There is a wide range of emotional, social, and physical disabilities within the group being supported and there is no "right" choice that works for all of them. Taking away one of the options that we as a parent believe may be the "right" choice for our daughter doesn't seem to be in anyone's best interest. Allow us as parents to try and make the "right" choices for our sons and daughters and don't limit us to our choices based on some other advocates beliefs that what they are saying is more important or they know better than "us parents" to make recommendations and choices for our disabled sons or daughters. We want our children to be safe and happy today and in an environment that we feel is the "best" for them. And feel that when we die, we made the right choice for our children and they will be secure and safe as they can be.

Thank You,

Peter and Dru Barnett

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