

Dear Ms Jacksi,

My name is Mick Wenlock. I am the father of Sean Freeman Wenlock a client of Denver Options.

Sean has been a client for over 10 years. He is a deaf/blind adult aged 29 years. He lives at home with us, his parents as he always has. He requires 24 hour a day supervision. he suffers from seizure disorder and is developmentally disabled.

For the last 8 years he has had one caregiver - Doc Davis. Aside from us, his parents, this is the longest relationship he has had. He has been making great progress, he is healthy and outgoing and much of this is due to the continuity of good care.

Now your agency has come along and made major changes - no consultation, no information just major havoc created in both our life and our sons.

I do not think that you or your staff appreciate what it is you are doing. We first heard of this around the second week of May. This whole thing is supposed to change on JULY 1ST!!!! We still have not received ANYTHING from your department. I have never met your people, you certainly have never had ANYTHING to do with our son's support.

And now you are changing it all - and without one word of explanation.

This whole thing is being done "on the quiet". Not any more.

You are an employee of the State of Colorado taxpayers - of which I am one. As one of your employers I would like an explanation of what you and your staff are doing to my son and his care.

Regards

Mick Wenlock
720-810-0833

On Jun 13, 2009, at 5:21 PM, Sharon Jacksi wrote:

Dear Mr. Wenlock:

The changes in SLS funding that are to occur July 2009 are a function the Centers for Medicare and Medicaid requirements for our Medicaid Waiver SLS program, primarily requiring consistent rates and authorization limits across the state. Unfortunately, that does decrease flexibility in some ways for some families. This change has been in process for more than a year and the CCBs have been informed throughout this process.

That being said, I definitely want to understand what is happening for your son. While these changes require re-visiting services delivered and the rates staff are paid, DDD wants to ameliorate these issues as much as possible for individuals and their families. I will have the

Program Administrator, Jo Kammerzell, contact the CCB and you for more information about your situation and we will see how we can help. I will personally check with Jo to see what we can do, after we get all the information. We will start working on this next week.

In the meantime, if you could send back some info now, it would help me see the extent of the problem:

Why will your provider, Doc, no longer be able to provide services? Does he work for an agency or do you pay him directly?

What is the cost of your son's services annually, if you know?

And, what services does he receive, e.g., personal assistance 3 hours a week every week?

And, do you know his Supports Intensity Scale score?

Sharon

Sharon S. Jacksi, Ph.D.
Director
Department of Human Services
Division for Developmental Disabilities
4055 S. Lowell Blvd.
Denver, Co 80236
303.866.7454 Fax: 303.866.7470
sharon.jacksi@state.co.us

Date: June 15, 2009 9:20:47 AM MDT
To: Sharon Jacksi <Sharon.Jacksi@state.co.us>
Cc: Jo Kammerzell <Jo.Kammerzell@state.co.us>
Subject: Re: Your agency's slashing of handicapped support

Dear Dr Jacksi,

Thank you for your prompt reply.

To answer your questions - Doc Davis is a contractor, he is paid by Denver Options out of Sean's grant. We do not pay him directly as we do not administer the funds.

Sean's current budget is \$35,000 a year - you can obtain a copy of his IEP from Denver Options which gives a breakdown of the costs. the majority of the costs are community involvement which is done 6 hours a day 5 days a week - minus vacations and sick days of course. The program also included three or four nights of respite care.

I have no idea of his Supports Intensity Scale score. I have no idea how such a score is arrived at or even if I agree with the methodology and philosophy behind it.

If I may take a moment - my son is deaf-blind. He has Congenital Rubella Syndrome. He did not go deaf and blind, he was born that way. He suffers from seizure disorder which is managed with Keppra. He is developmentally disabled, has very low language (sign language) skills - he knows a few words and gestures. He cannot feed himself, he can dress with cues and help and he goes to the bathroom though he needs help. He is occasionally incontinent. He must be watched over 24 hours a day. On occasion he will sleep only a few hours a night especially those days where he has not received enough exercise. His dental appointments need to be made years in advance as they have to be done under full anaesthetic.

On nights where Sean does not sleep well either my wife or I must get up with him. This is a common problem with CRS sufferers when they lack stimulation. Exercise is one of the best and simplest ways to give him the stimulation he needs and to burn off his energy. I have no idea where that falls on the Supports Intensity Scale.

For the last five years we have been working to get our son in the best physical shape we can - his weight is his ideal weight, he is fit, his metrics are great. This has not always been the case with him and has required a coordinated effort between us and Doc. Another point is that Doc has been with Sean for 8 years - prior to that Sean's caregivers/community helper whatever, changed every few months. To Sean's great distress. As the concept is almost impossible to explain to him this as resulted in months of stress in the past. Again - I have no idea whether this "scale" even considers such things.

I would appreciate knowing where deaf-blindness (CRS) gets taken into account in any evaluation. Which expertise was consulted? The last time the State of Colorado (actually DPS) did an evaluation on Sean someone had to be flown from Kansas as there was no-one here who had the expertise to do it. AS I said in my original e-mail NO_ONE contacted us - no-one seems to have checked to see what any possible consequences would be, no-one checked to see if there were ways that we could ameliorate the changes by using other avenues. While I would expect that sort of blind approach from a Treasury department I am disturbed to find it coming from a Department whose ostensible purpose is to help the Developmentally Disabled.

One mathematical and financial point I would like all to bear in mind.

Currently medicaid, the State of Colorado and Denver Options cover caring, supervising and working with Sean 30 hours per week. Given that Sean must be watched 24/7 that means that the remaining 138 hours a week are being covered by my wife and I. That little equation may give you an idea about why I am upset about these changes and that I am having to use up time to try and deal with it. As an example - Doc must go to your Department for the day on Wednesday this week to fill out applications - when you decided on this did you have any concern at all about what that means for my wife and I? I think not.

Thank you for your attention to this matter

Michael Wenlock