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Senate of Pennsylvania

#3160

January 17, 2017

RECEIVED
JAN 17 2017
Office of
Developmental Programs

Honorable Ted Dallas
Secretary
Department of Health and Human Services
c/o Julie Mochon
Office of Developmental Programs,
625 Forster Street, Room 501,
Harrisburg, PA 17120

Dear Secretary Dallas:

I write to you following a series of meetings with local service providers as well as with parents of children with intellectual and developmental disabilities, all of whom expressed serious concerns to me about the Office of Developmental Programs' (ODP) proposed renewals of the Consolidated and Person/Family Directed Support (P/FDS) Waivers and related regulations. Although I am not providing a section-by-section commentary as suggested in a form on the Department's website, I hope this letter will serve to place my very serious concerns in the public record, as they are in line with those of the broader service-provider community. I am also aware that some of my concerns overlap with certain proposed regulations for which the public comment window has closed.

As you know, in response to Federal action, the Commonwealth has proposed significant cultural and legal changes to the community based services provided to adults with developmental disabilities. This change increases inclusion in the community and increases the expectation of competitive employment for every individual. Sadly, these changes reflect a one size fits all approach to what community inclusion is for every person with a developmental disability in the Commonwealth of Pennsylvania.

Each organization I have met with supports the spirit of inclusion and believes every individual has the right to self-determination in their chosen community. However, inclusion cannot be artificially or arbitrarily prescribed for every individual and cannot be imposed at the expense of individual choice and individual rights. I am greatly concerned that in the wave of the proposed changes, individual rights and preferences of individuals receiving services could be compromised and/or dismissed. Individual choice and self-determination are basic human rights and should not be compromised to fit in with the narrow scope the proposed changes offer.

The proposed changes claim to offer the opportunity for all persons with disabilities to be employed. However, the reality is that day programs are being fundamentally changed to dismiss socialization and recreation skills; to minimize adult daily living skills training; and to emphasize vocational goals and placement. In other words, persons with developmental disabilities are not getting the opportunity to work, they are being expected to work. Employment is the primary goal and the availability of services is being tied to successful vocational placement. Additionally, it is the expectation that provider services will be faded out and persons with disabilities will be completely independent within three years of being successfully placed in a job regardless of the individual needs of the consumer. This is not a realistic or fair expectation to place on a population that may not be able to work; may not be interested in working; and may need ongoing support services to function successfully in the community. Many of the consumers served locally have been attending day habilitation programs for 10, 20 and 30 years. They express satisfaction in a program that meets their needs for socialization, recreation, daily living skills and, for some consumers, employment goals. To place the expectation and burden of working in the community is unfair and does not respect individual choice or needs. This is not a change that was requested by persons with developmental disabilities or their families.

It is worth acknowledging that there is some room for individuals with developmental disabilities to decline a work option. However, the burden will be entirely on the community provider to extensively document and justify this choice. This demands that the limited resources community based organizations have will be focused on managing an onerous bureaucratic system instead of supporting the individuals they serve.

Some specific and practical concerns of mine exist in the following examples:

1. There is a change in the goal for community inclusion for community based services. It is expected that community based programs will work toward a 75% goal of inclusion for all individuals that participate in the program. Our local providers believe that inclusion is an integral part of their current programs. However, 75% of program time being included in the community for each participant is not a goal that will be supported by each consumer, nor does it support meaningful inclusion for each consumer. This results in a consumer lack of choice of where they can go in the community and of whom they can choose to be within the community. The proposed changes in the regulations clearly umbrella all consumers into one large group. Individual choice, culture, preferences, and goals should determine how services are designed and delivered. My concern is that program quality and individual preferences will be compromised to meet state program regulations and a narrow vision of inclusion, not what is best for the individuals being served. We should measure program quality by the goals determined by the consumer and the experience of the consumer in the program. This is connected to individual outcomes, not to artificial and arbitrary state codes and program goals that do not reflect individual preferences.
2. There is no acknowledgement of the lack of resources in rural communities and the limited number of free and low cost resources there are in urban areas. Literally, there are not enough community locations to meet the 75% inclusion goal. I would imagine this goal would be exponentially more difficult to achieve in rural areas.
3. The proposed changes prohibit the use of provider owned/leased space to be used for other programming that may increase community inclusion. For example, Goodwill Industries of NEPA has a building with a gymnasium. This gym is open to the local community for various activities and events. Under the proposed changes, they would not be able to use the gymnasium and consider it a community inclusion program. Throughout their 11 county service areas, they could not count Goodwill Industries Stores as a community inclusion environment (this includes shopping, volunteer work or employment). **This seriously compromises the successful model within which they currently work.** This proposed ruling severely limits their community options and takes away established events and rituals their consumers depend on and to which they look forward with great enthusiasm. I find it irresponsible, perhaps even unethical, to take away established events, rituals, and community outings from the consumers being served. Providers like Goodwill Industries of NEPA, Allied Services and The Arc of Northeastern PA do not have the resources, community activities or places to replace such current activities.

I am also seriously concerned that the proposed changes will significantly increase program costs to a point where it will not be feasible to continue to provide services to individuals with developmental and intellectual disabilities. To my knowledge, providers have not been given the proposed rates, thus making it impossible to calculate actual projected costs. However, based on the information released and shared with me, I have the following, additional concerns:

1. If we are working toward an inclusion goal of 75%, there is nothing in the proposed changes that would support the additional costs of transporting individuals (providers are limited to taking 3 individuals at a time to any community location so more agency vehicles would be needed and there would be significantly more mileage put on each vehicle). There is nothing that supports the costs of providing enough staff (proposed changes require a 1:3 ratio, current regulations are a 1:8 ratio) for the small groups of individuals that would be in the community and/or the community based program. This impractical and cost-increasing goal seems arbitrary and capricious.

2. Proposed changes to newly licensed community based programs limit program enrollment to 15 individuals. The proposed limit of 15 individuals in a community day program severely impacts the cost effectiveness of continuing this program. This will make it impossible for many providers to open a new program and therefore will limit the options consumers have for day programs. This change ignores the diversity of the state and the diversity of programs between urban, sub-urban and rural provider service areas.

3. If forced to comply with the 75% inclusion regulations, several Northeast PA providers will be using their leased program space 25% of the time. Yet the costs for this program space will not decrease and all other costs (transportation, staffing etc.) will dramatically increase. This will result in a decrease in efficiency in the use of existing resources while adding little value to what are currently significant, positive experiences for consumers. This regulation will add little or no quality over current programs.

4. Proposed changes in training and certification requirements for direct care staff are cost prohibitive and unrealistic given the amount of industry turnover in direct care staff. Wages in this industry reflect a para-professional skill level. However, the proposed changes increase the training requirements, the skill level required and certifications required for direct care staff. Proposed changes also imply a professional level of education. However, the reimbursement rate historically does not support hiring direct support staff with professional educational backgrounds and advanced skill levels. There is no evidence, nor am I aware of any dialogue, to support the idea that additional costs incurred to meet these changes will be reflected in rates.

5. The Supports Intensity Scale is a unique, clinical assessment tool dedicated exclusively to identifying and measuring the support needs of persons with intellectual disabilities in order to help them lead a regular, independent life. This clinical tool is used to determine reimbursement rates for residential services. The SIS assessment is used to determine the functional skills of an individual. It does not measure the mental health functioning of an individual. It does not measure the impact of a crisis or decline in mental health. This assessment does not support the ongoing and changing needs of consumers. This is an inappropriate assessment to determine the level of supports a consumer needs and therefore it is an inappropriate assessment to determine the rates of reimbursement. Additionally, this tool is only reviewed every five years. There can be many changes that occur over a five-year period that would require a change in the amount of and intensity of services. The system should be more responsive to consumer needs and support the real-time costs of the services provided.

6. The current Reimbursement Rate Structure is both on the Cost and Fee Basis: Residential and Transportation programs are established on the Cost Basis, whereby providers complete annual cost reports. This is to reflect the true cost of services provided to the clients in these programs, and the Commonwealth then pays Providers based on actual costs. With Cost Based Rates, there have been modest increases as costs have increased over the past few years. Day and Employment Programs' rates are established on the Fee Basis, whereby the Commonwealth sets a fee, paid to the providers. As we all know, these rates have remained the same for at least five years even though costs have increased in these programs as well.

7. The proposed changes for reimbursement rates are to be all on the Fee Basis. I have been told that the Commonwealth may review Fee Based Rates on a three-year cycle. The Fee Based Residential reimbursement rates for services will also be tied to a SIS score. I am concerned about a client's unexpected and unpredictable decline with a provider limited to a SIS score reviewed only every five years. Even with a request for a new assessment to obtain an updated SIS score, it will take time for a team to meet, and update the assessment and SIS score. This will place the financial cost of providing additional services exclusively on the provider with no guarantee of reimbursement when and if the SIS score is changed. Even if there are no dramatic changes in an individual's SIS score, a review of the rates every five years is not sufficient to meet the annual increases faced by providers.

In closing, it is my hope that my concerns and the concerns of the service-provider community have an impact on the final regulations as they are ultimately adopted. I welcome the opportunity to discuss these issues at your discretion. With kind personal regards, I am

Very truly yours,

JPBlake

John P. Blake
Senate of Pennsylvania
22nd District

cc: The Honorable Lisa Baker, Chairperson, Senate Public Health and Welfare Committee
The Honorable Judy Schwank, Democratic Chair, Senate Public Health and Welfare Committee
Mr. David Toth, Legislative Specialist, Department of Human Services