Original: 2034

Pennsylvania Association of
P • A • R • F
Rehabilitation Facilities

Enhancing the quality of life for persons with disabilities.

2400 Park Drive • Harrisburg, PA 17110-9357
(717) 657-7608 • Fax (717) 657-8265

May 30, 2001

Robert E. Nyce, Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

Re: Regulation #10-129 Head Injury Program

Dear Mr. Nyce:

The Pennsylvania Association of Rehabilitation Facilities appreciates the opportunity to comment on the final form regulation concerning the Pennsylvania Department of Health Head Injury Program.

PARF represents more than 120 providers of medical, residential and vocational rehabilitation services throughout the Commonwealth. PARF speaks in behalf of specialized acute and post acute rehabilitation programs for survivors of head injury. In addressing the need for rehabilitation, PARF members support survivors and their families and assist them in securing the help and support they need.

For many years, PARF and its Head Injury Committee have been working with state government, especially with the Departments of Health and Public Welfare, to develop effective and efficient head injury rehabilitation services. We have advocated for the reforms proposed by the Department of Health and for the new home and community-based programs and services through the Department of Public Welfare. We have been active in seeking DOH regulation since the Head Injury Program was initiated.

The final form regulations under consideration have been reviewed carefully by our association. We have concluded that they will provide for a program of service that could assist individuals with head injury who can benefit from short-term rehabilitation. These regulations provide an effective framework for operating that program. We endorse these provisions. Enclosed are comments that seek to clarify and improve the regulations.

However, the regulations do present a major problem for survivors of head injury currently enrolled in the program. The major problem presented by the regulations is its treatment of clients that the Department of Health had enrolled in its own program that was not under regulation. Our comments on this issue describe the many problems that will be encountered in addressing the needs of all the people in the current program when the current provision of the final form regulation is applied.

To resolve the problems, PARF asks that the Pennsylvania Department of Health assure that individuals currently enrolled in the head injury program are effectively grandfathered. No one of the current client group should be limited to one year of rehabilitation services. Instead, each one should be assured formally that all necessary services consistent with their need will be provided and funded. Such a formal commitment would be in keeping with the Department of Health's intention to meet the needs of the clients when they were enrolled in the program. For many in the head injury program, their needs have not substantially changed and the commitment of the Commonwealth of Pennsylvania should remain strong.

Thank you for the opportunity to assist you in considering these regulations. We look forward to your decision.

Sincerely,

Gene Bianco
President

Regulation #10-129
Pennsylvania Department of Health
Head Injury Program

Pennsylvania Association of Rehabilitation Facilities
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It is our understanding that the Department of Health has no intention of dumping the individuals currently enrolled in its program and leaving them without necessary services. To assure that such intentions are made clear to all parties, the Department of Health must include an effective grandfather provision in its regulations. The regulation must assure that services are provided year to year for those currently enrolled in the program.

Such a regulatory provision is essential for those individuals who lack any resources to purchase services. For them, services should be provided year to year until alternative funding for such services is available.

Likewise, for those individuals who have some resources that will be used to supplement public funds, it is necessary that they are guaranteed that they will receive services year to year after their private funds are applied to the cost of services. The regulations must provide that their private resources must be utilized but that they will continue to receive funding to continue the services that they need from year to year.

We are concerned about the difficulty that the grandfather clause in the final form regulation will pose for individuals currently in service. The regulations state that clients who are receiving "rehabilitation services as of the effective date of the chapter are eligible for the maximum enrollment period..." Several clients that are currently being served are not receiving "rehabilitation services". They are receiving an intensive level of services that are required secondary to their intensive neurobehavioral needs.

Page 28 Section 4.7.E.Duration of Enrollment states in ***Section 4.7.E.1*** that a client's enrollment period shall end prior to the time designated if the continuation of HIP services will not enable the client to progress to a higher level of functioning and transition to a less restrictive environment. Many HIP clients currently being served are in the least restrictive environment in which they are capable of being served.

In ***Section 4.7.E.2***, the regulations provide that services would be terminated when the client fails to cooperate or exhibits unmanageable behaviors. Again, these clients have severe neurobehavioral issues and even at the current level of treatment they are receiving, they are often "uncooperative" and do frequently exhibit behaviors that could be considered unmanageable.

Regarding current options for the clients enrolled in the program, it is our understanding that there is no available funding source that any of these clients could transition into or are eligible for through the Department or the Office of Social Programs. Such funding options were to have been in place one year ago and prior to the regulations being passed. However, the process of development of this waiver program has changed and seems to be in the very early stages.

According to the regulations under review, the Department of Health could implement the regulations, grandfather the existing clients, and then end their enrollment eligibility based upon the provisions cited above. Providers would be essentially responsible for very intensive clients and receive no reimbursement and be without alternative funding source to access either to continue working with the client or pass along to another provider.

Original: 2034

ELAINE KLEIN
671 RIVER ROAD
YARDLEY, PA 19067

June 1, 2001

2001 JUN -1 AM 8:57

VIA FAX (717)783-2664 & OVERNIGHT MAIL

Mary Lou Harris
Senior Regulatory Analyst
Independent Regulatory Review Commission
14th Floor, Harristown 2
333 Market Street
Harrisburg, PA 17101

Re: **Final-Form HIP Regulations**

Dear Ms. Harris:

My son, Scott Sarubin, is presently in the Commonwealth of Pennsylvania's Head Injury Program ("HIP").

I recently learned that the Department of Health forwarded to the standing committees of the House and the Senate final-form regulations related to the HIP. As a result, I obtained a copy to review. I was extremely surprised and dismayed to learn that the Department is intending to proceed with these regulations for the following reasons.

I attended meetings in June 1999 and October 1999, during which the Department of Health assured me that the HIP regulations would not be implemented until after a Department of Public Welfare waiver program was up and running. This was to assure that individuals being terminated from the HIP rehabilitation services would continue to receive the same services under another State supported program.

Again, in August of 2000, I was invited to attend a meeting by representatives of the Department of Health and the Department of Public Welfare. Much was discussed, including the promulgation of regulations by the Department of Health relative to the Head Injury Program. At the meeting, the Department representatives stressed that no HIP regulations would be adopted prior to the implementation of a Medicaid waiver that would provide the same services as the HIP to individuals eligible for services under that waiver. In other words, no individual who was Medicaid eligible would be without services as a result of their termination from the HIP. The Department of Health was in the process of identifying individuals in the HIP who would continue to require services and would qualify for the CommCare waiver. The were hopeful that Scott would be eligible for the CommCare program. Essentially, we were advised that the Department was in the middle of this evaluation process. It is my understanding that the Department of Public Welfare is still working on the waiver application, known as the CommCare waiver.

At the August meeting, the Departments were very concerned about individuals in HIP who continue to require a supportive environment. The Departments stated that they were making efforts to have the CommCare waiver program in place for HIP beneficiaries who might be displaced by the HIP regulations. The Department has, nevertheless, moved forward with its

regulations, in spite of the fact that there is no Medicaid waiver program in place to care for those individuals that will be terminated from rehabilitation services after 12 months. This presents the substantial likelihood that there will be many HIP beneficiaries that will be left without the care they are presently receiving and need, as a result of the adoption of the proposed regulations.

In the Comments and Responses section of the Proposed Regulations, the Department first recognizes the importance of the CommCare program to individuals presently receiving services pursuant to the HIP program:

> Comment
>
> DPW is seeking a waiver from the Federal Health Care Financing Administration to be able to use Medicaid funding for head injured individuals. How will the waiver program, and the transfer of funds from the Department to DPW, affect the operation of HIP?
>
> Response
>
> The DPW CommCare Waiver will complement HIP. HIP will fund eligible clients' rehabilitation for one year plus 6 months of transitional case management services. The DPW CommCare Waiver will meet the long-term needs of clients who require maintenance services. The Department has appropriated funds to DPW to be used to transfer Medicaid-eligible HIP rehabilitation clients to the CommCare program. Any funds appropriate to DPW for the CommCare Waiver which are not used will revert back to the Fund to be used for HIP services.

In a September 1, 2000 letter from Elaine M. Terrell, Director of the Head Injury Program, she summarizes the Department's plans related to the Head Injury Program and the CommCare waiver:

> The Department is presently working with the Department of Public Welfare, Office of Social Programs, in the development a home and community-based waiver to offer funding and services to Medicaid eligible brain injury survivors and to help ensure smooth transitions into appropriate family-centered, community based services.

See letter of Elaine M. Terrell, attached.

However, the Department has now apparently abandoned the notion that it is best to have the CommCare waiver safety net in place prior to terminating HIP rehabilitation to HIP beneficiaries and states so in rather harsh terms:

> Comment
>
> The proposed HIP regulations should not go into effect until the above-referenced waiver program is in place.
>
> Response
>
> The Department disagrees. Although the Department and DPW are both confident that the waiver program will go into effect, the Department's ability to administer HIP should not under any circumstances be held hostage to the success of an initiative on the part of another Commonwealth agency.

This speaks volumes about what the Department thinks of DPW and its ability to obtain this all important waiver. The Department must be required to wait until the CommCare waiver is in place before these regulations are approved.

There is another aspect of the proposed regulations that deserves some consideration. Under the proposed regulations, individuals eligible for rehabilitation services are limited to one year of rehabilitation services and six months of case management services. Once all HIP funds available to provide these services are committed, new applicants are placed on a waiting list. When a beneficiary's 18 months expires, the person loses their benefits and is replaced by a person on the waiting list. The person recently terminated from benefits can reapply for HIP benefits. If there is no waiting list, and he is otherwise eligible, he receives another year of benefits. If there is a waiting list, his name is added to the waiting list and the individual must wait until there is a slot that opens up at which time he is once again entitled to HIP benefits.

The problem with this rather rigid approach is that the inflexible 12 months of rehabilitation services are unrelated to the persons progress in the program. The scenario to be considered is one in which a person at the end of the 12 month period requires just another two months of rehabilitation services to secure a rehabilitation plateau, but without that additional two months will regress to where they were just six months prior. The relationship between the benefits of the HIP program and the implications of an arbitrary 12 month rehabilitation services cut off could mean that a person with just a few more months of rehabilitation needed to reach a plateau where the person can be responsibly transitioned out of HIP, regresses, and now must reenroll for a more extended period of HIP rehabilitation. There needs to be some subjective assessment of whether a person should receive continued HIP benefits based on their potential for progressing off the HIP program, as opposed to a rigid 12 month rehabilitation, 6 month case management services timeframe.

In light of the forgoing, I request that the regulations be amended as follows:

Section 4.16. Effective Date.

(A) Effective Date.

Notwithstanding anything to the contrary in the preceding sections of these regulations, these regulations **shall not take effect** until such time as there is in place a Medicaid program that provides the same services and benefits as are presently provided to individuals presently receiving services under the HIP program.

Thank you for your consideration of my comments.

Very truly yours,

Elayne Klein

Elayne Klein

enclosure

DEPARTMENT OF HEALTH
...in pursuit of good health
(717) 772-4959

September 1, 2000

Scott J. Sarubin
c/o Mrs. Elayne Klein
671 River Road
Yardley, Pennsylvania 19067

Dear Mrs. Klein:

Recently, the Department of Health (Department) has been contacted by Traumatic Brain Injury (TBI) survivors about concerns related to the potential impact of the proposed Head Injury Program (HIP) regulations. As a follow-up to those concerns, this letter provides information about the Department's plans related to our HIP and is intended to keep you apprised of the Department's effort to improve the quality of life of individuals in Pennsylvania who have survived a head injury. The following summarizes our plan and activities:

- *Establish regulations for the Department's HIP:* Through regulations, the Department will define its funding authority [the Emergency Medical Services Act of 1985, 35 P.S. § 6934 (e)] and responsibility to serve individuals who have survived head injury, the nature, scope and quality of HIP rehabilitation services, who is eligible to benefit from these services, and help facilitate smooth transitions for individuals who have received HIP services so that they are appropriately reintegrated into their home, community, or to residential services.

- *Identify other resources to address the needs to current and future HIP clients:* The Department is presently working with the Department of Public Welfare, Office of Social Programs, in the development of a home and community-based waiver to offer funding and services to Medicaid eligible brain injury survivors and to help ensure smooth transitions into appropriate family-centered, community-based services.

- *Conduct a statewide needs assessment in 2001:* The plan is to conduct a statewide needs assessment. To accomplish this we will collaborate with key members of the TBI community and will seek input from traumatic brain injury survivors and their family members. With this needs assessment, the Department hopes to define the scope and availability for services across the Commonwealth, assess the present and potential future demand for post-traumatic brain injury services, create a demographic profile of Pennsylvanians in need of post-traumatic brain injury services, and assess the adequacy of these services. The Department will use this information to identify service delivery gaps and to plan its program in the future.

I hope the foregoing information helps to assure you the Department is making concerted efforts to meet and identify the chronic needs of TBI survivors and their families. I will continue to keep you informed of the Department's progress in these manners. If you have any questions, please feel free to contact me.

Sincerely,

Elaine M. Terrell

Elaine M. Terrell, Director
Head Injury Program
Division of Special Health Care Programs

ReedSmith LLP

RECEIVED
2001 JUN 1 PM 4:57
INDEPENDENT REGULATORY REVIEW COMMISSION

TO	Ms. Mary Lou Harris	**FROM**	Elayne Klein
Company	Independent Regulatory Review Comm.	Phone	609.520.6022
Fax	717-783-2664	Fax	609.951.0824
Phone		Date	June 1, 2001

Total Number of Pages Including Cover Page 5

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Original: 2034

Pennsylvania Association of
P • A • R • F
Rehabilitation Facilities

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May 30, 2001

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INDEPENDENT REGULATORY

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