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ACQUIRED BRAIN INJURY NETWORK OF PENNSYLVANIA, INC.

215-699-2139 or 800-516-8052 Fax: 215-699-5139 2275 Glenview Drive, Lansdale PA 19446-6082 info@abin-pa.org www.abin-pa.org

April 19, 2012

Sylvan Lutkewitte, III, IRRC Chair 333 Market St., 14th floor Harrisburg PA 17101 RECEIVED

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RE: Comments on IRRC 2880, Participation Review Process for Medical Assistance Nursing Facilities

Dear Mr. Lutkewitte,

In the question and answer section and the main text of this document, the Department justifies its request for the authority, or a revision of its authority, to block nursing home bed additions or transfers in order to re-balance Pennsylvania's ratio of nursing home beds (NHB) to home and community based services (HCBSs). Throughout the document, this re-balancing concern is a constant theme. The Department prominently features the availability of HCBS services in various portions of the text as part of the decision making process permitting the expansion or transfer of NHBs. Unfortunately, many of the answers provided by the Department do not reflect the fact that the Department has dismantled the waiver system.

As a result, ABIN-PA takes the position that the Department should not control the re-balancing of the ratio between NHB and HCBS. Having control without oversight will allow the Department to restrict nursing home expansion, while at the same time continuing to severely restrict access to HCBS waivers, thereby making both waiver and nursing home services inaccessible to individuals with impairment in three of five life functions. This situation particularly impacts individuals disabled by brain injury - thus our interest in this matter.

The Department has <u>restricted access</u> to the remaining HCBS waivers for individuals under age 60, especially those with brain injury, in various ways:

- 1. <u>OBRA Waiver</u>: The OBRA waiver was designed for people who became disabled prior to age 22 but are generally not eligible for the Independence or Attendant Care Waivers because they are cognitively <u>unable to supervise</u> their own attendants. Many of these individuals became disabled as the result of a traumatic or non-traumatic brain injury. A traumatic brain injury is caused by physical force, while a non-traumatic brain injury may follow a high fever, hypothermia, a stroke, poisoning, malnutrition, hemorrhage, meningitis, etc. All are acquired brain injuries.
 - a. The Department stopped accepting OBRA Waiver applications three years ago.

- b. Recently, the Department limited waiver options for current participants, so those living in residential brain injury rehabilitation facilities with more than 8 beds will need to leave their homes and move elsewhere by **June 2014**.
- c. Now, the Department will need to assure that **nursing home placement** is available to accept current participants who cannot be served in less formal settings, since nursing homes routinely reject applicants with brain injury due to age, risk to other residents, per diem, and the need for 24/7 programming and supervision.
- 2. <u>The COMMCARE Waiver</u> The COMMCARE Waiver (no upper age limit) was designed to provide support and brain injury rehabilitation for people with traumatic brain injury which occurred at any age. These individuals are frequently excluded from the Independence and Attendant Care Waivers because they considered cognitively <u>unable to supervise</u> their care workers.
 - a. The Department stopped accepting COMMCARE Waiver applications **two years ago** and began a wait-list process which has not resulted in any new admissions.
 - b. Recently, the Department limited waiver options for current participants, so those living in residential brain injury rehabilitation facilities with more than 8 beds will need to leave their homes and move elsewhere by **June 2014**.
 - c. Now, the Department will need to assure that **nursing home placement** is available to accept current participants living in 8+ bed facilities who cannot be served in less formal settings, since nursing homes routinely reject applicants with brain injury due to age, risk to other residents, per diem, and the need for 24/7 programming and supervision.
- 3. <u>Independence Waiver</u>: The Independence Waiver is an independent living waiver, meaning that applicants must be able to direct their own care workers. The Department has a strong history of excluding applicants with traumatic brain injury from the Independence Waiver. This exclusion led to the creation of the COMMCARE Waiver. Currently, persons with traumatic brain injury who attempt to apply for or use the Independence Waiver face several challenges.
 - a. The Independence Waiver requires that the person have a physical disability, but the Department has been claiming that brain injury is not a physical disability.
 - b. This waiver excludes persons with a primary diagnosis of mental illness, while the Department has been claiming that the symptoms of brain injury constitute a mental illness. Unfortunately, the Department also excludes persons with brain injury from mental health services even though persons with brain injury are included in the federal definition of serious mental illness.

Definition of Adults with a Serious Mental Illness Pursuant to Section 1912(c) of the federal Public Health Service Act, as amended by Public Law 102-321, "adults with a serious mental illness" are persons: (1) age 18 and over, and (2) who surrently have, or at any time during the past year, had a diagnosable

(2) who currently have, or at any time during the past year, had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-IV or their ICD-9-CM equivalent (and subsequent

revisions) with the exception of DSM-IV "V" codes, substance use disorders, and developmental disorders which are excluded, unless they co-occur with another diagnosable serious mental illness, and (3) experience functional impairment which substantially interferes with or limits one or more major life activities. (Federal Register Volume 58 No. 96 published

Thursday, May 20, 1993, pages 29422 through 29425).

- c. The Department has been imposing, without regulatory review, an additional requirement on persons with traumatic brain injury which is not listed in the eligibility criteria for the waiver. Instead of just the published requirement of impairment in three of five life functions, applicants with a traumatic brain injury must meet the additional unstated requirement that they be physically incapable of the activities of daily living without extensive physical assistance, not just cognitively incapable without coaching and cueing.
- d. Individuals who are not cognitively capable of directing their care worker can not apply for the Independence Waiver which was the reason for the creation of the COMMCARE Waiver over 10 years ago.
- e. Recently, the Department limited the definition of Community Integration to reduce supervision, creating a risk that services under the Independence Waiver will no longer be an adequate substitute for nursing homes for some participants and placing current participants at risk for discharge from residential facilities by September 2012.
- 4. <u>Attendant Care Waiver</u>: The Attendant Care Waiver provides physical assistance in the home but very few other services. This waiver is for people who are cognitively capable of directing their care worker - which many with brain injury are unable to do. This is appropriate only for fairly independent participants who do not need a variety of other services. This waiver is generally not sufficient for persons with traumatic brain injury.
- 5. <u>Act 150 Attendant Care</u>: This program charges a sliding scale and provides attendant care to individuals over the financial limit for waiver services. This program was recently closed to new admissions and is under a wait-list process.
 - a. This program is not available to people who are cognitively unable to direct their care worker even if family support is available. Thus, those with a guardianship cannot apply for this program. This eliminates all help for people who may have disability payments that put them over the income limit but are unable to pay for care with the excess.
 - b. This forces families with limited resources to assign children and elderly relatives to care for the disabled person so that other family members can remain in the workforce.

At the same time, the Department has not assured that nursing home beds are available to persons with traumatic brain injury, regardless of age:

1. The Department permits nursing homes to deny admission to those with traumatic brain injury.

2. The Department does not require all nursing homes to qualify to provide care to persons with traumatic brain injury. Instead, this disability is singled out and nursing homes must apply for permission to supple specialized medical services for those with traumatic brain injury. This restricts the availability of nursing home access for persons with brain injury and may encourage nursing homes to use the label of dementia for symptoms arising after falls in nursing homes.

If the Department retains control over both NHB decisions and HCBS Waiver availability, the Department can continue to assert that bed denials are necessary to increase the availability of HCBS while preventing access to HCBS through waiver restrictions for persons with disabilities under age 60.

Responsibility for both a decrease in nursing home beds and an increase in HCBSs creates inevitable conflicts of interest within the Department because of separate programs for those 60≤ and for those >60 with disabilities. Previously these interests were separated between the Department of Aging and the Department of Public Welfare, but now these interests are combined in one joint deputate, the Office of Long Term Living.

Joint management is difficult because these two populations have different sources of funding for community services. Those who are 60≤ are supported by lottery funding, senior centers and county based services. Those >60 with disabilities rely on a state-wide independent enrollment broker for waiver enrollment and then rely on approved services being arranged by a supports coordinator working for a provider approved by the Office of Long Term Living.

Measuring the availability of and access to all HCBSs services is difficult because of these two very different systems which depend on the age of the participant, except that the COMMCARE Waiver (now closed to new applicants) has no upper age limit. Thus any calculation of community resources requires the analysis of many factors and should be clearly spelled out before being allowed to affect the decision-making on nursing home bed expansion or transfer.

This regulation must hold the Department responsible for providing the following data about the geographical area served by the nursing home to justify any decision on nursing bed expansion or bed transfer:

- 1. Regarding 60≤ MA-eligible persons:
 - a. The number of $60 \le MA$ -eligible persons living in the area served by the nursing home.
 - b. The number requiring HCBS services because of significant impairment in three of five life functions.
 - c. The number receiving adequate HCBS services in the home (which programs?).
 - d. The number receiving no HCBS or requiring additional HCBS services and the Department action required to assure that these HCBS services will be provided.
 - e. The number requiring the COMMCARE Waiver (no age limit traumatic brain injury rehabilitation services and support) and the Department action required to assure that access to the COMMCARE Waiver and its related services will be provided.

- f. The number attending the senior centers and whether any Department action is required to assure adequate access to senior centers.
- g. The number requiring nursing home placement and Department action required to assure that nursing home placement is successful.
- h. The number of empty MA nursing home beds in facilities within driving distance for that person's family which are equipped to accept applicants with brain injury or other special needs that have been identified in the assessment.
- i. Other.
- 2. Regarding >60 MA-eligible persons:
 - a. The number of >60 MA-eligible persons living in the area served by the nursing home.
 - b. The number who require services because of significant impairment in three of five life functions.
 - c. The number receiving waiver services (which waivers?).
 - d. The number having no access to waivers or requiring additional HCBSs waiver services and any Department action required to assure that waiver access and sufficient services are provided, particularly:
 - i. Individuals 18 to 21
 - ii. Individuals who cannot supervise a care worker
 - iii. Individuals with traumatic brain injury who are blocked from the OBRA, COMMCARE (any age), Independence, and Attendant Care Waivers.
 - e. The number of >60 MA-eligible persons who are attending senior centers and any Department action required to assure adequate access to senior centers.
 - f. The number requiring nursing home placement.
 - g. The number of empty MA nursing home beds in facilities within driving distance for that person's family which are equipped to accept applicants with brain injury or other special needs that have been identified in the assessment.
 - h. The number of waiver applicants who were found NFI and the reasons for that finding.
- 3. Regarding nursing homes
 - a. The number with specialized medical care authorization for traumatic brain injury in the relevant geographic area.
 - b. The actual cost to nursing homes of the services required by specific individuals with traumatic brain injury and how this additional money can be provided by the Department.
 - c. Assure that nursing home openings in the target area have the skills to meet the needs of un-served persons needing nursing home placement in that vicinity.

While the Department takes credit for the money saved by blocking the addition of nursing home beds, the calculation does not indicate any increased waiver costs for those who would have occupied those beds and ignores the question of who has access to waiver funding. While HCBS may be available in a given community, or Statewide, only those >60 who qualify for open waivers will have access, while the remaining individuals need nursing home beds to receive necessary care.

Also, to date, the Department has shown no interest in assuring that individuals truly have the choice between nursing homes and HCBS. Those with brain injury generally are not approved for admission by nursing homes and also are blocked from existing waivers.

While specialized medical nursing homes might be an option, the Department has not provided sufficient incentive to create a pool of these facilities so that services are truly available. Instead, the Department collects names on a COMMCARE Waiver waiting list that never changes while explaining that they block nursing home expansion to promote HCBS.

With all HCBS waiver options blocked for persons with traumatic brain injury, the Department cannot be given more power to block nursing home expansion while claiming interest in expanding HCBS. The only place that a person with a traumatic brain injury can get meals, laundry, medical care and a bed is in prison. One third are arrested within 5 years of their injury, and 85% of those in prison have had a brain injury compared to 8.5 % of the general community.

Someone must speak up and announce that the emperor has no clothes. A reality check must take place. Mass participation in this ideological and/or philosophical mirage must end. You cannot have it both ways unless you are focused on saving money by excluding people with disabilities from all services by blocking both waiver access and nursing home expansion. This situation appears to <u>violate</u> both the Americans with Disabilities Act and the Olmstead decision.

The Department is currently blocking people from choosing service options that are less restrictive than nursing homes. Openings are only available in the Independence Waiver and the Attendant Care Waiver, but not for people who are too significantly compromised or for people with traumatic brain injury. This position limits the use of waivers to those who can live independently, rather than providing a choice of options which are less restrictive than nursing homes. Olmstead clearly requires the least restrictive environment, while the independent living movement prefers to limit HCBS waiver access to those who can direct their own care workers - presumably the others should go to a nursing home in violation of the ADA and the Olmstead decision.

These waiver barriers have a ripple effect, causing providers under the Department of Health Head Injury Program to reject clients who would need to be discharged into waiver services.

Thus the premise of this regulation, that nursing home beds must be limited to balance the growth of home and community based waiver services is an unfounded dream that has been exposed by the action of the Department in closing waivers to new admissions, limiting waiver services and facility size, and failing to create a pool of nursing homes offering the specialized medical services needed by those with traumatic brain injury who are being singled out for exclusion.

Here are comments to the replies of the Department to questions posed:

Page 3 - "(12) Describe who and how many people will be adversely affected by the regulation. How are they affected?

No one will be adversely affected by the regulation. Nursing facilities that are enrolled MA

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providers or wish to become MA providers and the MA recipients who are or may receive services from those facilities will be beneficially affected by this regulation. Facilities will benefit by having a more reliable, transparent process for seeking additional MA beds. MA recipients will also benefit by having assured access to medically necessary nursing facility services and a more balanced long-term living system."

COMMENT: MA applicants who have no access to waivers will not benefit by denying additional beds to nursing homes.

Page 6 "(17) In the table below, provide an estimate of the fiscal savings and costs associated with implementation and compliance for the regulated community, local government, and state government for the current year and five subsequent years."

COMMENT: The total saved does not subtract the cost of serving these same people under waiver services. This indicates to me that no waiver services are anticipated for the people who would have occupied these beds.

Page 7 - "(18) Explain how the benefits of the regulation outweigh any cost and adverse effects.

Both nursing facilities and the Department will benefit from having enforceable standards that control the participation review process. MA recipients will benefit from the assurance that they will have adequate access to medically necessary nursing facility services. These benefits outweigh the requirements of collection of data by facilities submitting bed/bed transfer requests."

COMMENT: This system does not assure access to nursing home beds. People with brain injury are not accepted into nursing homes - and they have no access to waivers - thus the state is protected from these costs.

Page 8 "(21) Are there any provisions that are more stringent than federal standards? If yes, identify the specific provisions and the compelling Pennsylvania interest that demands stronger regulations.

These regulations assure Medicaid care and services will be provided in an efficient and economic manner and in a manner consistent with simplicity of administration and the best interests of the recipients pursuant to section 1902 of the Social Security Act." *COMMENTS: Medicaid care and services are not being provided to people who lack access to nursing homes or waivers - most especially those with brain injury.*

Page 8 "(22) How does this regulation compare with those of other states? How will this affect Pennsylvania's ability to compete with other states?

This regulation is consistent with the Department's ongoing efforts to ensure that MA recipients continue to receive access to medically necessary nursing facility services. Pennsylvania will not be competing with other states, as this regulation controls the participation of MA nursing facilities that are located in this Commonwealth."

COMMENT: Individuals with brain injury do not currently have access to nursing home facilities. The Department has responded to ABIN-PA that individual nursing homes have no obligation to accept a particular applicant if they feel they cannot serve that applicant. The waivers are closed to these very same applicants. Where are these Nursing Facility Clinically

Eligible applicants to be served? Doesn't the Department have an obligation to assure that there is an adequate pool of interested nursing home providers?

Page 9 "(25) Please list any special provisions which have been developed to meet the particular needs of affected groups or persons including, but not limited to, minorities, elderly, small businesses, and farmers.

A significant majority of the MA recipients receiving care in a nursing facility are older adults, and the overall impact of the regulation on that group is beneficial."

COMMENT: This answer focuses on older adults, which was not the point of the question. The Department clearly is not addressing the needs of those under 60 with disabilities or COMMCARE applicants of any age with no access to waivers.

<u>CDL - 1 Face Sheet - 2nd page - "The overall goal of the final form rulemaking is to serve the best</u> <u>interests of MA recipients by supporting the growth of home and community-based services (HCBS),</u> <u>which consumers prefer as a setting for LTL services, while ensuring that MA recipients continue to have</u> <u>access to medically necessary nursing facility services."</u>

COMMENT: This rule does not support the growth of home and community based services because it does not lift the suspension of COMMCARE or OBRA or Act 150 Attendant Care, the bed limit on all waivers, or the change in the service definition for Community Integration in all waivers. These restrictions have eliminated all hope of community services for people with brain injury. This is very economical for the Department because the Department feels no obligation to make nursing homes with specialized medical services available to this population to reduce the routine denial of nursing home admission for this group of people.

Page 2 - Background - "It also authorized the Department to amend the 1998 statement of policy, after soliciting public comments, if the Department determined such changes to the Statement of Policy would "facilitate access to medically necessary nursing facility services or... assure that long-term living care and services under the medical assistance program will be provided in a manner consistent with applicable Federal and State law, including Title XIX of the Social Security Act." After soliciting and considering public comments, the Department published an amended statement of policy and its responses to the public comments at 40 Pa.B. 1766 (April 3, 2010)."

COMMENT: This rule restricts access to nursing home beds at a time when the Department has already eliminated access to home and community based services for persons with serious functional impairments due to brain injury through the suspension of admissions to the COMMCARE and OBRA Waivers and restrictive changes to current participants under the COMMCARE, OBRA and Independence Waivers. While all of the details may be legal, this appears to be a violation of the ADA and the Olmstead decision.

Page 3 - "No cost to MA recipients is anticipated as a result of this regulation."

COMMENT: The applicant who needs the bed and has no access to a waiver will bear a heavy cost because the Department has no obligation to guarantee access to services.

Page 5 & 6 "One commentator asked the Department to identify all residents of nursing homes within specific age ranges who have a traumatic or non-traumatic brain injury, and to

provide information on an individual Olmstead planning process that assures brain injury rehabilitation is needed to prepare the individuals for participation in community services under the Independence or CommCare waivers.

Response

This final-form rulemaking regulates the enrollment and participation of nursing facilities as providers in the MA Program. Although the Department requests data relating to specialized medical services if an applicant proposes to serve individuals needing those services, under §§ 1187.174(7) and 1187.176(a)(2)(iii), this final-form rulemaking does not specifically address or identify individuals with brain injury. Therefore, this comment, which is more in the nature of an information request, is outside the scope of the comment and response process."

COMMENT: Brain injury is an injury from which people recover with proper care; however, nursing homes can no long prepare residents with brain injury for release to a waiver, because waiver admissions for these individuals have been suspended. At the same time, nursing homes are not required to apply to provide specialized medical service so they can accept these individuals. Thus the Department discriminates against persons with brain injury by denying access to both waivers and appropriately equipped nursing homes. Thus the Department cannot claim to be adjusting nursing beds for the sake of re-balancing, because it is denying both nursing home beds and access to home and community waiver services. It is true that the Department is saving a great deal of money by legally excluding from waiver services the people who cannot find nursing homes that will accept them.

<u>Page 7 "For example, an increase in bed capacity may be needed if nursing facility services are not</u> <u>available for MA recipients who reside in a particular locale or who have specialized medical needs that</u> <u>are not being met by the current MA nursing facility provider complement."</u>

COMMENT: The Department must increase bed capacity for specialized medical needs for those on the wait-list due to brain injury. At present, nursing homes are not required by the state to address specialized medical needs such as brain injury. Nursing homes do not want to put these patients in with frail elderly, and thus would rather not accept these applications. The state must end this permitted exclusion from nursing home admission. Perhaps the Fair Acres case applies.

Page 16 "The Department disagrees with the commentator's recommendation to eliminate this provision. Consideration of the availability of HCBS has been a part of the Department's needs assessment for additional MA-certified beds in a particular area since the first statement of policy was issued in 1998. The Department explained:

In considering its MA Program needs, the Department will also examine whether those needs can be appropriately met through the provision of HCBS rather than additional nursing facility beds. The Department views HCBS to have several important benefits. Among other things, many older residents of this Commonwealth and residents with disabilities prefer HCBS over institutional services. Given a choice, the Department believes that many people would choose to remain in their own homes and communities rather than reside in a nursing facility. Moreover, in many, if not most, instances, the Department has found that HCBS are less expensive than institutional services. 28 Pa.B. 141 (January 10, 1998)."

COMMENT: Unfortunately, for all intents and purposes, the Department has already dismantled its HCBS Waiver programs through suspension of admissions, changing the definition of community integration, and imposing an 8 bed limit which affects 125 people out of 650 on the COMMCARE Waiver and others on the OBRA Waiver. Who are the people that the Department keeps talking about? Are these people who are eligible for an aging waiver or county based services? This document does not reflect reality for those on the under 60 waivers. The Department has been decreasing rather than increasing waiver services to those >60.

Page 17 "The Department's experience during the past 10 years has only reinforced these views and its commitment to balance the LTL service system to provide MA recipients with more service choices to meet their needs."

COMMENT: To the contrary, the Department has been decreasing choice in the last three years by suspending admissions to the OBRA Waiver, then suspending admissions to the COMMCARE Waiver, then changing the bed limit to 8 and finally changing the definition of community integration. The Department has also been responsible for blocking brain injury applicants from the Independence Waiver by saying that their disability does not have a physical cause. Also, the Department has permitted the denial of Nursing Facility Clinically Eligible status by the addition of an undisclosed exclusion that is applied only to people with traumatic brain injury. Those with traumatic brain injury will not be granted NFCE status through impairment in three of five functional areas - they must require extensive physical assistance with activities of daily living (as opposed to coaching and cueing).

Page 17 "For many consumers, HCBS continues to be a more preferable and less costly option than institutional care. By enabling consumers to receive necessary care and services in their own homes, HCBS can delay or prevent institutionalization of individuals who would otherwise require care in nursing facilities."

COMMENT: The Department has deliberately blocked access to the waivers by people with developmental disabilities and also people with traumatic brain injury. The Department has also restricted waivers to services in homes or in group settings limited to 8 beds. Now, the only alternative for people needing complex intense brain injury rehabilitation is a nursing home, yet the Department wants more power to deny bed requests and fails to assure a pool of nursing homes equipped to provide specialized medical services to people with traumatic brain injury who have difficult behaviors, complex needs, or require long term rehabilitation. And of course, while claiming to promote nursing home alternatives, Pennsylvania can save even more money by blocking access to the waivers.

Page 17 "Balancing the LTL service system does not mean that the Department will never approve increases in MA nursing facility beds. It does mean, however, that the Department intends to evaluate requests for the increases in the context of creating a balanced continuum of publicly-funded care. By directing the Department to continue to use the statement of policy and develop regulations in reviewing and responding to bed requests, the General Assembly endorsed this approach. See Act 2007-16. Consequently, as has been done ever since the first statement of policy was issued in 1998, the

Department will continue to consider the availability of HCBS as a relevant factor in assessing the need for additional institutional capacity in the MA Program."

COMMENT: This regulation gives too much power to the Department to restrict the number of nursing home beds while failing to require that the Department fund adequate waiver services for the people who would otherwise occupy those beds. For those with brain injury, denying waiver admission does not result in a nursing home bed because nursing home providers are not interested in providing the complex services needed at the rates that the Department is willing to pay. Thus restricting nursing home beds and restricting waiver access puts the Department in the best position financial position while denying access to essential care.

Page 25 "Consideration of the availability of HCBS has been a part of the Department's needs assessment for additional MA-certified beds in a geographic area since the first statement of policy was issued in 1998. By directing the Department to continue to use the existing statement of policy and develop regulations in reviewing and responding to bed requests, the General Assembly sanctioned this approach. Jd., 62 P.S. § 443.1(8). Moreover, the General Assembly has specifically endorsed a balance of institutional and home-and-community based long term care as "in the best interests of all Pennsylvanians." Act of July 25, 2007 (P.L. 402, No.56) (Act 56).

As noted above, balancing the LTL service system does not mean that the Department will never approve increases in MA nursing facility beds. What it does mean, however, is that the Department will evaluate requests for increases in the context of creating a balanced continuum of publicly-funded care."

COMMENT: Since there is no access to HCBS for persons needing the OBRA Waiver or COMMCARE Waiver, and limited availability for persons needing the Independence Waiver, the Department should be required to use the existing statement of policy and develop regulations for reviewing and responding to bed requests that include an analysis of specific waiver availability and specific waiver services in the same location. For example, a bed request should not be turned down if there is an applicant in the community requiring the COMMCARE Waiver because that person cannot receive HCBS services. The blanket availability of waiver services is not a reliable measuring stick when all waivers and waiver services are not equally available.

<u>Page 25/26 "The Department will consider the availability of both existing nursing facility services</u> and alternative HCBS in assessing the need for additional institutional capacity in the MA Program and if the county or PSA of the requesting facility has sufficient nursing facility beds.

COMMENT: Again, blanket statements about HCBS availability could be based on a surplus of available services under the aging waivers, but the person needing the bed could be under 60 and require the OBRA or COMMCARE Waiver which are not open to new admissions.

Page 25 "§§ 1187.175(b)(2), 1187.176(b)(2) and 1187.177(c)(2)- Alternatives to nursing facility bed requests A commentator contends that the focus in considering alternatives to nursing facility services should be solely on the needs of the recipient and not the cost to the MA Program and recommended modifying the language and eliminating consideration of costs to the MA Program.

<u>Response</u>

The criteria relating to alternatives allows for the Department to manage and target increases in MA beds and determine where the beds are required. This process assures MA recipients have

appropriate access to care. Careful stewardship of institutional resources permit the expansion of other service options for MA recipients, such as more HCBS."

COMMENT: Since the Department stated earlier that HCBS were less expensive than nursing home beds, it is unclear why they have restricted access to the waivers, except that restricting access to waivers while at the same time denying the expansion of nursing home beds will save the Department the most money while they are pretending to have the best interests of potential HCBS participants at heart.

Page 7 of the regulation - Definitions - "Specialized medical services—Services that require staffing with advance training and need-specific equipment, including services needed by an individual who has severe dementia or traumatic brain injury or who requires a respirator for survival, or who receives bed side hemodialysis. Specialized medical services are not routinely provided in general nursing facilities and do not include the services of a dedicated Alzheimer's unit or infection isolation wing, osteopathic treatment or similar services."

COMMENT: Nursing homes with specialized medical services for those with traumatic brain injury need to be identified in a way that the public can locate them. These facilities might be suitable for the 70 plus persons currently wait-listed for the COMMCARE Waiver but no one appears to know which nursing homes provide this specialized care.

<u>Page 14 § 1187.173. Review and public process relating to bed requests. (d) Public process (1)(ii) Data</u> relating to the availability and cost of home and community-based services Statewide and by county.

COMMENT: The availability and cost of local or Statewide home and community based services is not relevant to a decision on beds because people who are significantly impaired in three of five life functions are not automatically Nursing Facility Clinically Eligible and those who are NFCE are not automatically qualified for home and community based services. The waivers for those under 60 have specific requirements that not everybody can meet, and four of the six waivers are closed to new admissions.

The Michael Dallas Waiver was dropped altogether. The OBRA Waiver has been closed to new admissions for three years. The COMMCARE Waiver has been closed to new admissions for two years. Act 150 Attendant Care is now closed to new admissions. The Independence Waiver, Attendant Care Waiver, and Act 150 Attendant Care are closed to people who cannot manage their own caregivers. The Independence Waiver excludes people who need constant supervision. The Independence Waiver also excludes traumatic brain injury on the basis of it not having a physical cause. The Independence Waiver also imposes an additional requirement on those with traumatic brain injury that they must require extensive physical assistance rather than coaching and cueing in activities of daily living, although this is not stated in the waiver requirements. All waivers exclude people who require residential brain injury rehabilitation facilities with more than 8 beds which provide constant medical and behavioral supervision in personal care homes.

A complex formula for the evaluation of these factors is required to assure that people with no access to home and community based services are not also denied the opportunity to enter a nursing home.

Also, a Statewide analysis is not relevant for people who are being excluded from existing waivers, or who would need to re-locate far from families and friends in order to

receive appropriate services. People should not be denied nursing home services because HCBS are available in another part of the state.

Page 15/16 "§ 1187.174. Information and data relevant to bed requests. In reviewing an applicant's bed request, the Department will consider the information provided by the applicant and any public comments received on the request. In addition, the Department may consider information contained in the Department's books and records or obtained from persons other than the applicant that is relevant to the applicant's bed request, including the following: (3) Data relating to the availability of home and community-based services in the primary service area identified in the bed request, the county in which the subject facility is or will be located, and, in the case of a bed transfer request, the county in which the surrendering provider is located."

COMMENT: In determining the need for additional nursing home beds or the reasonableness of a bed transfer, the Department should not be allowed to negate the need by noting sufficient available home and community services since these services are not necessarily available to all NFCE nursing home applicants. No HCBS are available to those under 60 who would require the OBRA Waiver, COMMCARE Waiver, and even some who need the Independence Waiver, because waiver access is being denied.

How will the collection of data reflect the difference between the availability of HCBS in a community compared to the number of people under 60 who cannot qualify for the waivers they need to fund those services?

Page 17 "§ 1187.175. Criteria for the approval of bed transfer requests.

(a) Upon consideration of the information specified in § 1187.174 (relating to information and data relevant to bed requests), the Department may approve a bed transfer request only if the following are satisfied:

(b) The Department may deny a bed transfer request even if the conditions specified in subsection (a) are satisfied if the Department determines one of the following:

(1) Approval of the request would negatively affect the Department's goal to rebalance the Commonwealth's publicly-funded long-term living system to create a fuller array of service options for MA recipients.

(2) There are alternatives to the transfer of beds, such as an increase in home and community-based services, that would be less costly, more efficient or more appropriate in assuring that long-term living care and services will be provided under the MA Program in a manner consistent with applicable Federal and State law.

COMMENT: See prior comments.

Page 19 "§ 1187.176. [Criteria for the approval of closed-campus CCRC bedl requests. (a) The Department may approve a closed-campus CCRC bed request only if the

following are satisfied:

(3) The closed-campus CCRC shall have a written policy that allows individuals who are admitted to CCRCs independent living units to remain in their independent living unit and receive home and community-based services.

(b) The Department may deny a closed-campus CCRC bed request even if the Conditions specified in subsection (a) are satisfied if the Department determines one of the following:

(1) Approval of the request would negatively affect the Department's goal to rebalance the Commonwealth's publicly-funded long-term living system to create a fuller array of service options for MA recipients.

(2) There are alternatives to nursing facility beds such as an increase in home and community-based services, that would be less costly, more efficient or more appropriate in assuring that long-term living care and services will be provided under the MA Program in a manner consistent with applicable Federal and State law.

COMMENT: See prior comments.

Page 21/24 "§ 1187.177.] Criteria for the approval of bed requests other than bed transfer requests [or closed-campus CCRC bed requests].

(c) The Department may deny a bed request even if the conditions specified in subsection (a) are satisfied if the Department determines one of the following:

(1) Approval of the request would negatively affect the Department's goal to rebalance the Commonwealth's publicly-funded long-term living system to create a fuller array of service options for MA recipients.

(2) There are alternatives to the bed request, such as an increase in home and community-based services, that would be less costly, more efficient or more appropriate in assuring that long-term living care and services will be provided under the MA Program in a manner consistent with applicable Federal and State law.

COMMENT: See prior comments.

Page 24 "[§ 1187.178.] § 1187.177. Time lines for completion of approved projects.

(a) If the Department approves a bed request, the approved project shall be completed in sufficient time so that the beds may be licensed, certified and available for occupancy within 3 years from the date of the Department's decision, or by another date as may be agreed to by the Department.

COMMENT: This rule must include the requirement that when a bed is denied, the Department must demonstrate within three years that the money saved was spent increasing access equally to HCBS by all persons in that local area and around the state who are NFCE.

In summary, this rule is based on a false premise. The denial of beds has no relation to the development of HCBS availability in the community because the waiver system has been demolished. The Department must be held accountable for the lives of the people with brain injury and other conditions who are being routinely excluded by the Department from both the waiver system and the nursing home system. Simply examining the availability of HCBS in the community gives a false picture because access is not uniformly available to persons who are equally disabled, due to COMMCARE and OBRA being closed to new admissions, and the Independence Waiver being subjected to various modifications, some of which have occurred behind the scenes without regulatory review.

Thank you for this opportunity to comment.

Regards,

Barbara A. Dively, Executive Director

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