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United States District Court, E.D. Pennsylvania.

Terri Lee HALDERMAN, et al.,
v.
Pennhurst State School and Hospital, et al.

No. CIV. A. 74–1345. | Dec. 23, 1997.

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Opinion

MEMORANDUM

BRODERICK, J.

***1** At the direction of the Court, the Special Master has filed a report on health care decisionmaking for Philadelphia Pennhurst class members. Difficulties have occurred in the past when a class member was terminally ill and had no family, guardian, or next of kin available to authorize the provision or withholding of health care, including life-sustaining treatment. The legal, medical, and ethical issues involved in end-of-life decisionmaking have garnered increased attention across the country in recent years. These decisions, as well as decisions on everyday medical treatment, pose special problems for people with mental retardation, many of whom lack the ability to make decisions for themselves. The Special Master should be commended for his comprehensive report on this difficult issue.

For the reasons set forth below, the Court will request the Commonwealth of Pennsylvania to continue its current efforts to clarify its mental retardation bulletin on substitute decisionmaking for medical treatment. In the meantime, the Commonwealth of Pennsylvania and Philadelphia County should identify each Philadelphia Pennhurst class member who is capable of making his or her own health care decisions. These individuals should be advised of currently available resources to assist them with everyday health care decisions and should be provided with the opportunity to make advance directives, such as executing a declaration in the nature of a living will and naming a surrogate decisionmaker. Finally, as part of the annual IHP/ISP planning process of each Philadelphia Pennhurst class member who has not made an advance directive, or sooner if necessary, the Commonwealth of Pennsylvania and Philadelphia County shall require the interdisciplinary team to designate an involved family member or other individual, as set forth below, pgs. 19–20, to authorize end-of-life decisions.

I. BACKGROUND

On March 25, 1996, counsel for the Halderman plaintiffs filed a motion for a preliminary injunction. Although this motion cited the circumstances of a particular class member, the relief sought was designed to remedy an alleged systemic issue in relation to health care decisionmaking for Pennhurst class members. Specifically, the plaintiffs requested the Court

> to grant a Preliminary Injunction requiring: the Commonwealth and Philadelphia Defendants to immediately develop and implement a policy regarding "Do Not Resuscitate Orders" (DNR Orders) and the roles, if any, of the IHP, case managers and Interdisciplinary Teams in such medical decision-making for class members, and to present such a policy within ten (10) days to the Special Master for review and approval. A Preliminary Injunction is also requested to require said Defendants to provide education to Class Members and their families and guardians on the issues surrounding DNR Orders, and to initiate that effort within thirty (30) days. It is also requested that Defendants be required to ensure that their contractor provider agencies notify Defendants of any consideration or proposals for use of DNR Orders in advance of the entry of such orders.

***2** *Plaintiffs' Motion for Preliminary Injunction and Memorandum,* March 25, 1996, at 6.

On April 10, 1996, defendant Commonwealth of Pennsylvania filed an answer opposing the plaintiffs' motion. In addition to addressing the allegations regarding the specific class member's situation, the Commonwealth also indicated that,

> questions concerning termination of life-sustaining treatment are left

> to individual class members and their next of kin, or in the absence of next of kin, to a court appointed guardian ad litem. Case managers and the interdisciplinary team ('IDT') have no authority to make such decisions for class members. Representatives of the County and Commonwealth have been meeting to develop policies to address issues concerning advance directives (i.e. voluntary declarations governing the initiation, continuation, withholding or withdrawal of life-sustaining treatment) and health care decisionmaking. In September, 1995, the County's Morbidity & Mortality Committee circulated a questionnaire on advance directives to the provider community. Beginning in February, 1996, an ad-hoc Health Care Decision Making Work Group has been meeting. The long term goals of the Group are to develop policies and procedures on the use of advance directives.

Commonwealth Defendants' Answer in Opposition to Halderman Plaintiffs' Motion for a Preliminary Injunction Regarding DNR Orders, April 10, 1996, at 1 and 2.

Defendant Philadelphia County also opposed the plaintiffs' motion. The County incorporated the Commonwealth's response and emphasized that the Commonwealth and County were working on the development of a policy regarding health care decisionmaking for persons with mental retardation who are not capable of making their own health care decisions.

Throughout the summer and fall of 1996, the Special Master raised the issue of health care decisionmaking at meetings with the parties to this action. The defendants believed that regulatory and/or legislative reform might be necessary but that such reform was unlikely to occur in the near future. After consultation with the Special Master, the Court issued an order on February 11, 1997 directing the Special Master to prepare a report and recommendations concerning a proposed process for health care decisionmaking for Pennhurst class members. This Order also dismissed the plaintiffs' March 25, 1996 motion without prejudice.

During the spring and summer of 1997, the Special Master and Maria Laurence, Senior Research Analyst with the Office of the Special Master, conducted a comprehensive review of health care decisionmaking for Philadelphia Pennhurst class members. The Special Master submitted a draft copy of his report to the parties for comment. After receiving comments from all of the parties, the Special Master submitted his final report to the Court on September 3, 1997.

In late September, 1997, counsel for the plaintiffs filed a response to the Special Master's report urging that the Special Master's recommendations be adopted. The Commonwealth of Pennsylvania and Philadelphia County filed comments agreeing that state policy on substitute health care decisionmaking for persons with mental retardation needed to be further developed, but opposing the Special Master's specific recommendations.

II. SPECIAL MASTER'S FINDINGS AND RECOMMENDATIONS

***3** The Special Master's report addresses surrogate health care decisionmaking in connection with elective medical procedures and end-of-life treatment for Philadelphia members of the Pennhurst class. Many class members are capable of making their own health care decisions. However, class members who are not capable of making such decisions sometimes face delays in receiving timely and effective medical treatment. In addition, there are currently no organized mechanisms or procedures to ensure that class members who can make their own health care decisions have made advance directives to guide decisions during end-of-life care, such as executing a declaration in the nature of a living will and designating a surrogate decisionmaker. There are also no guidelines on end-of-life decisionmaking for class members who are not capable of making advance directives and do not have actively involved family members to authorize treatment. The Court will review each of the Special Master's findings and recommendations.

A. *Special Master's Findings on Decisionmaking for Elective Medical Treatment*

The Special Master reports that decisions on elective health care for Philadelphia Pennhurst class members are generally made by the class member, by the class member's family, or by the director of the facility where the class member resides.

Class members who are capable of making their own medical decisions often do so. The Special Master reports that, although health care providers generally respect these decisions, providers will sometimes question a class member's judgment because of his or her diagnosis of mental retardation. In addition, the Special Master reports that more class members could make their own health

care decisions if they were offered the types of supports available to individuals without mental retardation, such as resources or organizations which explain medical terms in easy to understand language.

Many class members who are not capable of making their own health care decisions are fortunate enough to have close family members to authorize treatment for them. The Special Master reports that health care providers usually respect surrogate decisions by family members, although some family members have chosen to be appointed as guardians to ensure that their decisions are honored. The active involvement of family members provides the best support for class members who cannot make their own decisions. However, the Special Master reports that some families are concerned about what will happen when they are no longer available to make decisions for their loved ones.

Moreover, some class members have no family members or other authorized individuals to act on their behalf. For these class members, Pennsylvania law permits the director of the facility where persons with mental retardation reside to authorize medical treatment in limited situations. Section 417 of the Mental Health and Mental Retardation Act of 1966 provides:

> ***4** The director of any facility may in his discretion by and with the advice of two physicians not employed by the facility, determine when elective surgery should be performed upon any mentally disabled person admitted or committed to such facility where such person does not have a living parent, spouse, issue, next of kin or legal guardian as fully and to the same effect as if said director had been appointed guardian and had applied to and received the approval of an appropriate court therefor.

50 P.S. § 4417(c) (Purdon's 1969). This law is supplemented by a Commonwealth advisory on decisionmaking for persons with mental retardation, entitled "Mental Retardation Bulletin # 00–90–02, Substitute Decision Making for Medical Treatment." Nevertheless, the Special Master reports that medical treatment for Pennhurst class members is sometimes delayed by uncertainty over the interpretation of this state law and policy. The Special Master also reports that directors of facilities will frequently seek advice from additional physicians because of the fear of liability.

B. ***Special Master's Findings on Decisionmaking for End-of-life Treatment***

The Special Master reports that there are currently no policies or procedures which ensure that Pennhurst class members who are capable of making their own health care decisions have made advance directives for end-of-life decisionmaking. As heretofore stated, the Special Master's report was prompted by the plaintiffs' motion to require the defendants to immediately develop a policy regarding "do not resuscitate" orders. The Commonwealth recognized in response to the plaintiffs' motion that questions concerning termination of life support treatment are currently left to individual class members and their next of kin. In other words, there is currently no policy or mechanism to guide health care providers on end-of-life treatment for Philadelphia members of the Pennhurst class. Decisions are now made on an ad hoc basis for each class member whenever a medical emergency arises.

Class members who are capable of making their own health care decisions may execute advance directives which authorize the provision or withholding of medical treatment and name a surrogate decisionmaker. Under Pennsylvania's Advance Directive for Health Care Act, for example, "an individual of sound mind who is 18 years of age or older ... may execute at any time a declaration governing the initiation, continuation, withholding, or withdrawal of life-sustaining treatment." 20 Pa.C.S.A. § 5404(a) (Purdon's 1997 Supp.). However, neither the Commonwealth nor the County currently keep track of those class members, if any, who have made advance directives.

Other class members cannot make advance directives because the severity of their mental retardation prevents them from being able to make health care decisions. According to the Special Master, the annual IHP/ISP planning process does not currently include specific recommendations regarding class members' needs for supports in the area of health care decisionmaking.

***5** In the absence of written advance directives, the Special Master reports that health care providers generally seek close family members to authorize end-of-life treatment. This procedure works well for class members who are fortunate to have family members actively involved in their lives. As heretofore stated, the active involvement of family members provides the best support for class members who are not capable of making their own health care decisions. Unfortunately, not every class member enjoys active support from family members, and class members who do are likely to lose those supports as they get older and family members pass away.

The Special Master also reports that several people he interviewed expressed concern that health care professionals rely on family members, no matter how

distant, to make medical decisions. Health care providers will generally accept the closest blood relative to authorize end-of-life treatment. Relatives who have had little or no contact with a class member for many years cannot offer the same level of support as people on a class member's interdisciplinary team. Interdisciplinary teams generally consist of family members, if available, advocates, social workers, clinicians, the case manager, and staff from the class member's day program and residential facility. These individuals are better situated than distant relatives to oversee end-of-life decisionmaking for class members who cannot make their own health care decisions.

C. *Special Master's Recommendations*

The Special Master recommends that Philadelphia Pennhurst class members be provided with support mechanisms to assist them with health care decisions and/or authorize medical treatment. The Special Master's report includes five recommendations:

First, the Special Master recommends that the Commonwealth of Pennsylvania should review and revise its Mental Retardation Bulletin # 00–90–02 on substitute decisionmaking for medical treatment. The Special Master also recommends that Philadelphia County develop its own policies and/or guidelines on health care decisionmaking for Philadelphia Pennhurst class members. Any County policies or guidelines should be reviewed by the Commonwealth to ensure that they comply with state law and policy.

Second, the Special Master recommends that Philadelphia County provide training to class members and their interdisciplinary teams on the various supports available for health care decisionmaking. The Special Master recommends that "[a]lternatives for both assisting people in decision-making as well as communicating their decisions need to be utilized whenever possible. Teams need to be trained to determine a person's decisionmaking capacity, and then identify and provide the supports the person requires." *Special Master's Report,* Sept. 3, 1997, at 28.

Third, the Special Master recommends that each class member's team should consider the need for health care decisionmaking supports on an annual basis as part of the IHP/ISP planning process.

***6** Fourth, the Special Master recommends that Philadelphia County immediately identify class members who do not have the ability to make health care decisions for themselves, who do not have involved family members, and who currently have serious medical conditions which might require end-of-life treatment in the immediate future. The Special Master also recommends that the County identify class members who have had trouble receiving medical treatment because of questions about proper authorization. Once these class members are identified, the Special Master recommends that the County enlist surrogate decisionmakers and/or other supports for them as appropriate.

Finally, the Special Master recommends that both the Commonwealth of Pennsylvania and Philadelphia County ensure that each class member has a family member, next of kin, or other authorized individual or group to assist with or authorize medical treatment. Many class members are able to make health care decisions on their own or with limited assistance from others. These class members can authorize their own elective treatment and can make advance directives, such as executing a declaration in the nature of a living will and naming a surrogate decisionmaker for end-of-life care. Other class members, however, are not able to make their own health care decisions. Active family members can serve as surrogate decisionmakers for some class members who fall into this category. For others, the director of the facility where the class member resides can authorize elective treatment with the consent of two independent physicians. However, the Special Master suggests that guardians must be appointed for class members who lack other supports. The Special Master has identified several organizations in Philadelphia and other counties which currently provide guardianship services and could serve as models for a guardianship program for Pennhurst class members.

In concluding his report, the Special Master states: "It can be anticipated that as class members age, the need for surrogate health care decision-making will become more pronounced. There is no need at this time for the Federal Court to become involved in individual health care decision-making for class members. Pennsylvania laws and regulations provide options to address the issues which have been identified. However, these issues need to be addressed in a proactive manner by the defendants." *Special Master's Report,* Sept. 3, 1997, at 43.

III. DISCUSSION

The Special Master's report offers a comprehensive review of health care decisionmaking options for Philadelphia members of the Pennhurst class. The Special Master and his staff should be highly commended for providing the Court with valuable insight into this difficult subject. After thoroughly reviewing the report, the Court agrees that the Commonwealth of Pennsylvania and Philadelphia County should develop clear guidelines on surrogate health care decisionmaking for Philadelphia Pennhurst class members. However, the Court believes that the Commonwealth and County should first make every effort to better utilize the current options available under state law and policy before implementing new

requirements.

***7** The Special Master has advised the Court that many Pennhurst class members in Philadelphia County are capable of making their own health care decisions. It is the Court's understanding that these individuals could utilize the health care supports which are currently available to all individuals who can make their own health care decisions, whether or not they are members of the Pennhurst class. Accordingly, the Court will direct the Commonwealth of Pennsylvania and Philadelphia County to identify members of the Philadelphia Pennhurst class who are capable of making their own health care decisions and to take affirmative steps to advise these individuals and members of their interdisciplinary team on any health care decisionmaking supports which are currently available. These efforts should occur as part of the annual IHP/ISP planning process mandated by the 1985 Final Settlement Agreement, 610 F.Supp. 1221 (E.D.Pa.1985).

The Special Master has also reported that more class members could make their own health care decisions if they were offered limited assistance from outside resources, such as persons or organizations who explain medical terms and procedures in easy to understand language. These class members should be given every opportunity to make their own health care decisions. The Commonwealth and County should identify and provide training to these class members and their interdisciplinary teams on any resources which would allow them to make their own health care decisions.

The Court will also direct the Commonwealth of Pennsylvania and Philadelphia County to advise class members who are capable of making their own health care decisions on the use of advance directives for end-of-life decisionmaking. These class members should be provided with every opportunity to make advance directives, such as executing a declaration in the nature of a living will and designating a surrogate decisionmaker in accordance with the Pennsylvania Advance Directive for Health Care Act, 20 Pa.C.S.A. § 5401 et seq. (Purdon's 1997 Supp.), and any other applicable state law. The Commonwealth and the County should provide these class members and their interdisciplinary teams with training on the use of advance directives and other support options currently available for health care decisionmaking.

Unlike class members who can make their own health care decisions, for whom supports are currently available but underutilized, class members who cannot make their own health care decisions face greater challenges. The Pennsylvania Mental Health and Mental Retardation Act of 1966 permits directors of facilities where persons with mental retardation reside to authorize medical treatment in limited situations. 50 P.S. § 4417(c) (Purdon's 1969). This law is supplemented by a 1990 Commonwealth advisory on decisionmaking for persons with mental retardation, entitled "Mental Retardation Bulletin # 00–90–02, Substitute Decision Making for Medical Treatment." According to the Special Master, however, many directors of facilities strictly construe these rules for fear of liability, and treatment is sometimes delayed or withheld.

***8** The Commonwealth of Pennsylvania has agreed to review, clarify, and revise its current policy on substitute decisionmaking for persons with mental retardation. In response to the Special Master's report, the Commonwealth has stated that it wants to develop a statewide policy for all persons with mental retardation living in residential facilities whether or not they are members of the Pennhurst class. The Commonwealth has advised the Court that it is currently preparing a draft of a revised health care policy which clarifies the authority of directors of facilities to make health care decisions. The Commonwealth has also indicated that it would like to provide a mechanism whereby directors of facilities are authorized, subject to review by the appropriate officials, to make decisions regarding emergency medical treatment. These changes will require administrative efforts.

Because the Court's jurisdiction is limited to members of the Pennhurst class, the Court will request the Commonwealth of Pennsylvania to make every effort to see that a revised statewide policy on substitute decisionmaking is approved and promulgated as expediently as possible. In doing so, the Commonwealth should endeavor to establish mechanisms permitting interdisciplinary team members to designate surrogate decisionmakers for class members who cannot make their own health care decisions. Philadelphia County should ensure that any statewide policy on substitute decisionmaking for people with mental retardation is implemented on behalf of the Philadelphia Pennhurst class.

However, the Court believes that the Commonwealth of Pennsylvania and Philadelphia County should not wait until the Commonwealth revises state policy to provide decisionmaking supports to Pennhurst class members who have not made advance directives. The absence of competent decisionmakers who have been identified in advance often delays or contravenes effective health care for these class members. This is contrary to the medical needs of the Pennhurst class and contrary to the public policy of the Commonwealth. The Pennsylvania Legislature has found that "[t]he application of some procedures to an individual suffering a difficult and uncomfortable process of dying may cause loss of patient dignity and secure only continuation of a precarious and burdensome prolongation of life." 20 Pa C.S.A. § 5402(a).

A recent decision of the Pennsylvania Supreme Court permits close relatives of persons who have not made advance directives to act as surrogate decisionmakers. *In Re Fiori,* 543 Pa. 592, 673 A.2d 905 (Pa.1996). The Supreme Court held that a close family member, with the written consent of two physicians but without court approval, could authorize the termination of life-sustaining treatment for a person who was not capable of making medical decisions and had not made advance directives pertaining to life sustaining measures.

In re Fiori provides a valuable framework for creating a decisionmaking process for Pennhurst class members who are not capable of making their own health care decisions or have not made advance directives. First, the Pennsylvania Supreme Court ruled in *In re Fiori* that close family members are well-suited to serve as substitute decisionmakers. The Supreme Court wrote: "Close family members are usually the most knowledgeable about the patient's preferences, goals, and values; they have an understanding of the nuances of our personality that set us apart as individuals." *Id.* at 912. The Special Master has advised the Court that health care providers generally permit a family member to authorize termination of life sustaining treatment for Pennhurst class members.

***9** Nevertheless, the Special Master's report also reveals that health care providers will often accept authorization from a family member, no matter how distant, rather than from the class member's interdisciplinary team. This practice appears to be contrary to the Supreme Court's ruling in *In re Fiori.* Members of the class member's interdisciplinary team will usually be more knowledgeable about the class member's preferences and more concerned with the class member's interests than a distant relative. This Court predicts that the Pennsylvania Supreme Court would permit interdisciplinary team members to designate a suitable individual to authorize the termination of life-sustaining treatment for persons with mental retardation who have not made advance directives and who lack involved family members to serve as surrogate decisionmakers. It would appear that no one is better qualified than the interdisciplinary team to designate a surrogate decisionmaker for class members who have not made advance directives. The role of a surrogate is to determine the intent and desire of the class member as to whether life-sustaining treatment should be continued or withdrawn.

Second, the Supreme Court in *In re Fiori* specifically rejected the Attorney General's contention that the judiciary must always be involved in decisions to terminate life-sustaining treatment for individuals who have not made advance directives. The Supreme Court stated that court approval or appointment of a guardian ad litem is not always required. *In re Fiori,* 673 A.2d at 913 & n. 14. Quoting from Judge Beck's opinion in the Superior Court, the Supreme Court stated that the judiciary has no role to play:

> where there is a loving family, willing and able to assess what the patient would have decided as to his or her treatment, all necessary medical confirmations are in hand, and no one rightfully interested in the patient's treatment disputes the family decision. (Citations omitted.) Those who disagree with this view and who favor court intervention in every case often cite the need for the court to protect the patient. Underlying this rationale is the philosophy that only courts can provide the necessary safeguards to assure protection of life. This is a narrow and unhealthy view. It violates the essential and traditional respect for family. It is yet another expansion of the idea that courts in our society are the repository of wisdom and the only institution available to protect human life and dignity.

Id. (quoting 438 Pa.Super. 610, 652 A.2d 1350, 1358 (Pa.Super.1995)).

The Court agrees with the Pennsylvania Supreme Court's reluctance for appointing guardians to authorize end-of-life treatment. Appointing a guardian can be a lengthy and expensive process, and may not always be in the best interests of Pennhurst class members. The Court will refrain from mandating a policy that requires the appointment of guardians.

As part of the annual IHP/ISP planning process of each Philadelphia Pennhurst class member who has not made an advance directive concerning the provision or withholding of life-sustaining treatment, or sooner if necessary, the Commonwealth of Pennsylvania and Philadelphia County shall require the interdisciplinary team to designate an involved family member to authorize end-of-life decisions. In the event an involved family member is not available, the interdisciplinary team may designate a person, not a member of the provider's staff, who has had a close personal relationship with the class member. In the event neither an involved family member nor an individual who has had a close personal relationship with the class member is available, the interdisciplinary team may request a non-profit association such as the Pennsylvania ARC (Association for Retarded Citizens) to recommend one of its members

to be designated.

CONCLUSION

***10** The Special Master and his staff should be commended for their comprehensive report highlighting the difficulties confronting Philadelphia Pennhurst class members in the area of health care decisionmaking. The Court has reviewed the Special Master's findings and recommendations and the parties responses thereto. For the foregoing reasons, the Court will request the Commonwealth of Pennsylvania to review and revise current state policy on substitute decisionmaking for persons with mental retardation. The Commonwealth should seek to provide a mechanism whereby interdisciplinary teams are permitted to designate surrogate decisionmakers to authorize medical treatment for persons who are not able to make their own health care decisions.

The Court will order the Commonwealth of Pennsylvania and Philadelphia County to identify each Pennhurst class member in Philadelphia who is capable of making his or her own health care decisions. These individuals should be advised of currently available resources to assist them with everyday health care decisions. They should also be provided with the opportunity to make advance directives, such as executing a declaration in the nature of a living will and designating a surrogate decisionmaker for end-of-life treatment.

Finally, as part of the annual IHP/ISP planning process of each Philadelphia Pennhurst class member who has not made an advance directive concerning the provision or withholding of life-sustaining treatment, or sooner if necessary, the Commonwealth of Pennsylvania and Philadelphia County shall require the interdisciplinary team to designate an involved family member or other individual, as set forth above, to authorize end-of-life decisions.

An appropriate Order follows.

ORDER

AND NOW, this 23rd day of December, 1997; for the reasons set forth in the Court's Memorandum of this date; the Court requests the Commonwealth of Pennsylvania to continue its efforts to clarify Mental Retardation Bulletin # 00–90–02 on "Substitute Decision Making for Medical Treatment," and circulate any changes for comment and promulgation as expediently as possible; and

IT IS ORDERED: The Commonwealth of Pennsylvania and Philadelphia County shall identify members of the Philadelphia Pennhurst class who are capable of making health care decisions on their own or with limited assistance from other resources. As part of the annual IHP/ISP planning process, the Commonwealth of Pennsylvania and Philadelphia County shall take affirmative steps to:

1. advise and train these class members and members of their interdisciplinary teams on any resources which are currently available to provide assistance with health care decisions, such as explaining medical terms and procedures in easy to understand language.

2. advise and train these class members and members of their interdisciplinary teams on the use of advance directives for end-of-life decisionmaking, including executing a declaration in the nature of a living will and designating a surrogate decisionmaker in accordance with the Pennsylvania Advance Directive for Health Care Act, 20 Pa.C.S.A. § 5401 et seq. (Purdon's 1997 Supp.).

***11** IT IS FURTHER ORDERED: As part of the annual IHP/ISP planning process of each Philadelphia Pennhurst class member who has not made an advance directive concerning the provision or withholding of life-sustaining treatment, or sooner if necessary, the Commonwealth of Pennsylvania and Philadelphia County shall require the interdisciplinary team to designate an involved family member to authorize end-of-life decisions. In the event an involved family member is not available, the interdisciplinary team may designate a person, not a member of the provider's staff, who has had a close personal relationship with the class member. In the event neither an involved family member nor an individual who has had a close personal relationship with the class member is available, the interdisciplinary team may request a non-profit association such as the Pennsylvania ARC (Association for Retarded Citizens) to recommend one of its members to be designated.