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Autism • Intellectual Disabilities

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February 12, 2008

Mr. Kevin Casey, Deputy Secretary
Office of Developmental Programs
Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105-2675

Via email: ra-ODPComment@state.pa.us

Re: Comments on the Draft Bulletin *Procedures for Surrogate Health Care Decision Making*

Dear Deputy Secretary Casey,

Thank you for the opportunity to provide comments and make recommendations on the draft bulletin entitled *Procedures for Surrogate Health Care Decision Making*.

The Pennsylvania Association of Resources for Autism and Intellectual Disabilities (PAR) is a statewide association whose members provide the full range of supports and services to more than 45,000 individuals with intellectual disabilities including 8,000 people living with autism in over 5,600 locations.

PAR thanks the Office of Developmental Programs (ODP) for revising the draft bulletin to more accurately reflect the ability of facility directors to make certain health care decisions pursuant to the MH/MR Act of 1966. This draft bulletin is a marked improvement over the previous draft. However, there are still some areas that require more clarification.

PAR's primary concerns are that MR providers have clear guidance about which law to follow – the MH/MR Act of 1966 or Act 169 of 2006 (where they differ), and under which circumstances MR providers are allowed or expected to intervene in health care decision making. Equally important is that the bulletin is not clear that the facility director is not to be involved in end of life decisions, as Act 169 mandates.

Our specific comments and recommendations are included below. Additionally, as an attachment to our comments we are providing a copy of the draft bulletin with our recommended edits tracked for easy reference.

Comments and Recommendations:

In order to achieve clear guidance on the complex issue of surrogate decision making, we offer the following overriding recommendation.

Recommendation: Add to the Discussion Section on page 5 the following language “POLICY: Act 169 of 2006 does not repeal §417(c) of the Mental Health and Mental Retardation Act of 1966, 50 P.S. §4417(c). Accordingly, a facility director is permitted to make certain health care decisions within the law. Act 169 at sections 5455 and 5461 related to decisions by health care agents and health care representatives stands with the following exceptions, pursuant to the MH/MR Act of 1966:

To the list of eligible health care agents and health care representatives (Act 169, sections 5455 (a) and 5461, respectively), the following is also acceptable:

For principals with mental retardation who reside in a facility as defined in section 102 the MH/MR Act of 1966 the director of the facility, as defined in section 102 of the MH/MR Act of 1966, or the designee of the director of the facility; provided that the director of the facility or designee shall not make a decision to withhold or to withdraw life-sustaining treatment.

To the list of individuals exempted from acting as a health care agent or health care representative (Act 169, sections 5455 (b)(2) and 5461 (f)), the following exception is permitted pursuant to the MH/MR Act of 1966:

An owner, operator or employee of a health care provider in which the principal receives care unless the principal has mental retardation and the owner, operator or employee is either the director of the facility as defined in section 102 of the MH/MR Act of 1966, or the designee of the director of the facility at which the principal resides.”

Section: *Scope* (pg. 1)

Discussion: The medical community is not included in the scope of the bulletin. They, as well as the community MR system, need clarification regarding the impact of Act 169 on the MH/MR Act of 1966. Some medical websites, in explaining Act 169, currently do not recognize the MH/MR Act of 1966 as being applicable.

Recommendation: Add Medical Assistance Providers and State ICF/MR and State Psychiatric Hospital Directors to the list of entities included in the Scope section.

Section: Purpose (pg. 1)

Discussion: The draft bulletin states, “In light of Act 169, this Bulletin will clarify surrogate health care decision making procedures applicable to individuals with mental illness and mental retardation who are 18 years of age or older. It is expected that health care providers will rely on this bulletin and respect the decisions of surrogate decision makers appointed according to the process detailed herein.”

Individuals with mental illness are included in this section. Shouldn't the Office of Mental Health and Substance Abuse Services address this topic for those individuals?

Is it expected that health care providers seek legal counsel to interpret this bulletin? The bulletin encourages MR providers to do so. Further, it is not clear how ODP can enforce this bulletin with regard to health care providers in the medical community since ODP does not regulate that community.

Recommendation: Remove the phrase “mental illness.”

Recommendation: Replace the phrase “it is expected that health care providers will rely on” with “health care providers are encouraged to.”

Section: Definitions (pgs. 2-5)

Discussion: The draft bulletin includes a definition for the term advance health care directive. However, to make the law clear right up front, the definition of this term should clearly state (as it does on page 9) that no surrogate decision maker may execute an advance health care directive or name a health care agent on behalf of an incompetent individual. We have learned of several instances where an incompetent individual is having advance health care directives made on their behalf. This is not legal, yet it is occurring.

Recommendation: Add to the definition advance health care directive the following statement, “no surrogate decision maker may execute an advance health care directive or name a health care agent on behalf of an incompetent individual.”

Discussion: There is a typo in the definition of facility; the word ‘for’ needs to be inserted after facility. It currently reads: “*privately operated intermediate care facility the.*”

The definition of the term facility director appears to be inconsistent with the MH/MR Act of 1966. ‘Facility’ means any mental health establishment, hospital, clinic, institution, center, day care center or other organizational unit, or part thereof, which is devoted primarily to the diagnosis, treatment, care, rehabilitation or detention of mentally disabled persons. ‘Director’

means the administrative head of a facility and includes superintendents (50 P.S. § 4101). It follows that a facility director includes any administrative head of any organizational unit part thereof as determined by the provider, and the draft bulletin's limitation of "facility director" to administrators or chief executive officers is incorrect. The practical import of this distinction is that an administrator or chief executive officer need not specifically delegate the authority of a facility director to a subordinate; it can be inherent in the subordinate's position.

Recommendation: Correct the typo in the definition of facility.

Recommendation: Revise the bulletin's definition of facility director to the definition of facility director in the MH/MR Act of 1966.

Discussion: The draft bulletin does not include a definition of 'surrogate decision maker.' Because this is a new term that replaces substitute health care decision maker, it would be helpful to clarify what is meant by "surrogate" and to clarify it as the statute defines it.

Recommendation: Include a definition of the term surrogate decision maker to be consistent with Act 169 of 2006 which defines surrogate as "A health care agent or a health care representative" and add "or a facility director," which is consistent with the MH/MR Act of 1966.

Discussion: It would be useful to add the examples to the definition of health care provider so that it is clear that if your organization is listed as a facility, it qualifies as a health care provider.

Recommendation: Cross reference the definition of facility in the definition of health care provider, pages 3 and 4, respectively.

Section: *Individuals Who Are Not Competent and Who Do Not Have End-Stage Medical Conditions or Are Not Permanently Unconscious* (pgs. 6-7)

Discussion: The draft bulletin states, "The facility director may authorize elective surgery and other treatment only with the advice of two physicians not employed by the facility." While this provision regarding elective surgery upon the advice of two physicians is taken directly from the MH/MR Act of 1966, it is not current practice in today's environment. For example, Act 169 does not include the two physician mandate. Since the draft bulletin delves into interpreting the Act, PAR suggests a further interpretation is needed with regard to the two physician requirement in order to recognize the reality of modern practice.

In the MA funded environment that providers work in, it is difficult to find even one physician willing to provide service. Managed health care organizations are not going to pay for multiple examinations every time a person needs a medical procedure completed. Also, this section does not seem to recognize that physicians are frequently and increasingly requiring consent for routine treatment.

The term “other treatment” is extremely problematic. This language is an addition which is not in the MH/MR Act of 1966. This phrase has been inserted by the Department, and the Department consequently needs to plainly answer several questions, including whether the individuals that providers support need two dermatologists in order to get skin cream? Does the state want providers to schedule two dentist appointments when a person has a cavity? Insurances will not generally pay for people to have duplicative services or two physicians.

Recommendation: The term "other treatment" should be clarified. The Department should clarify when it is necessary for two physicians to authorize treatment. Is it only required when the treatment is invasive and non-routine? There needs to be clear direction when two physicians are needed, especially when the MH/MR Act of 1966 only requires the approval of two physicians for elective surgery, and not for anything else.

Section: *Individuals Who Are Not Competent and Who Have Either End-Stage Medical Conditions or Are Permanently Unconscious* (pgs. 7-8)

Discussion: This is the most confusing and problematic section of the draft bulletin, as evidenced by the following statements and their sequence. Before discussing each of these statements specifically, it must be noted that the MH/MR Act of 1966 neither specifically addresses nor provides guidance on end-of life care. The Act of 1966 pertains only to providing treatment. The draft bulletin seems to permit facility directors to make end of life decisions in this particular section; however, to our knowledge there is no basis in law for that. For example, see the following quotation from the draft bulletin:

- “Under Act 169 the attending physician determines whether an individual has an end stage medical condition or is permanently unconscious. **In contrast**, the MH/MR Act of 1966, which applies to health care decisions by facility directors, requires the advice of two physicians for recommended treatment of health care conditions, including end stage medical conditions.”
 - Comment: For reasons noted above, this statement appears to be incorrect. The MH/MR Act of 1966 does not address or provide guidance on end of life care. In addition, these statements provide no clarification regarding the application of Act 169 and the MH/MR Act of 1966, and in fact confuse the issue. The bulletin needs to clearly state which statute is to be applied in MR facilities, i.e. the MH/MR Act of 1966 – per our overriding recommendation included above.

Providers are liable on many fronts – ODP needs to help reduce this risk for this particular issue by providing sound legal clarification that providers can rely on.

- “Where the facility director becomes the surrogate decision maker for an individual who has an end-stage medical condition or is permanently unconscious, the director must first review the individual's support plan and all relevant medical history and records to help identify the individual's medical status historically and immediately prior to making a surrogate health care decision.”
 - Comment: Although the suggestion in the draft bulletin that the facility director review the ISP and relevant medical history and records is a good one, in practice this could cause risk to the health of the individual under some circumstances and timeliness in making health care decision is necessary. The director is informed by members of the team regarding the current medical status compared to a previous health status. Extensive discussions often occur when a person reaches an end of life stage. Through these discussions with team members, physicians, friends and even family, a general agreement is reached. Reading records often is not the best way information is gathered to guide current care actions.
- “The facility director must be informed of the consensus of the individual’s team consensus regarding the decision to be made, based upon team members' direct knowledge of and familiarity with the individual, so the facility director will have sufficient information to make a decision that the individual would make if able to do so.”
 - Comment: In these situations, who constitutes the team? Can members of the team be excluded in this process? What happens if one member of the team does not support the decision of the rest of the members of the team? How does the director document the decision of the team?
- “Even where another surrogate decision maker is identified, the facility director should continue to monitor the situation to ensure that the law is followed and that decisions are made with the best interest[s] of the individual as the paramount concern.”
 - Comment: A facility director cannot ensure that others follow the law. They can encourage and advocate, but they cannot force other decision makers to follow the applicable laws. Please clarify the authority the facility director can rely upon to monitor the situation and ensure the law is followed, particularly when others are the appropriate care decision makers.
- “In the event of a short-term absence of the facility director, the director may assign a designee to perform these functions.”

- Comment: The spirit of Act 169 and this bulletin is that people should have the individuals who are closest to them and most familiar with their wishes available when needed for decision making. This is often not the facility director. Organizations often have an individual (such as an ombudsman or a medical director) who is well suited for this role and is more generally available to respond to emergent needs. Also, preventing facility directors from designating an individual for this role for the long term will slow down the decision-making process as many facility directors do not have existing knowledge of treatment team decisions and will as a matter of course be required to postpone decisions while they collect information which is required by this section. This creates yet another barrier to timely care. We strongly recommend stating that a director may appoint a designee. The above discussion and recommendation regarding the definition of facility director also helps clarify this issue.
- The draft goes on to state that “In the event that the individual with an end-stage medical condition or who is permanently unconscious does not have a living will, health care agent, court-appointed guardian, or available and willing health care representative, the court should appoint a guardian with authority to act. Reasonable medical care should be provided pending the appointment of a guardian.”
 - Comment: The inclusion of these guardianship requirements directly after the section on permitting facility directors to make decisions for individuals with end-stage medical conditions is also confusing. The draft bulletin requests a court to appoint a guardian if other decision makers are not available; and facility directors are not included in the list of decision makers to be exhausted (in this particular section); yet directors and their decisions related to end of life care are discussed in the previous section. It needs to be clearly stated that facility directors are not permitted to make end-of-life decisions.

Recommendation: Clarify the Department’s legal basis for all of the above statements (i.e. how they are consistent with Act 169 of 2006) or delete the above statements and replace them with our overriding recommendation provided above.

Recommendation: If this recommendation is not accepted, add the following statement to the General Information section, as the first statement in that section, “The information provided in this bulletin is intended as guidance for mental retardation facility directors. It is best practice for a facility director to review or be informed of an individual’s former and current health status, and to consult with members of the team when faced with making critical health care decisions.” Additionally, if our first recommendation is not accepted, the word “must” should be replaced with “should” in relation to what facility directors are advised to do, since this is a policy bulletin that while providing guidance and offering direction, does not establish requirements.

Recommendation: If our first recommendation is not accepted, delete “In the event of a short-term absence of the facility director” so the sentence reads “The director may assign a designee to perform these functions.” Also delete the statement “The assigned designee may only be a person authorized to perform the facility director's functions in the director's absence.”

Section: *General Information* (pgs. 8-10)

Discussion: The draft bulletin states, “Agencies are encouraged to consult their own legal counsel for advice on the implementation of the statutes discussed in this bulletin.” Given the contradictions between the Acts, providers will receive varying interpretations and incur unnecessary legal expenses.

Recommendation: Adopt PAR’s overriding recommendation to clarify exactly what authority facility directors have pursuant to Act 169 of 2006 and the MH/MR Act of 1966 so that providers have sound guidance to rely upon when making healthcare decisions.

Discussion: This section of the draft bulletin should include Act 169’s direction that a "State or local government sponsored or operated program"... may not require an individual to execute an advance directive or appoint a health care representative as a condition of service (§5411 of Act 169).

Recommendation: Reference §5411 of Act 169 or state directly that no State or local government sponsored or operated program may require any person to execute a declaration as a condition for being insured for or receiving health care services.

Section: *Provider Agencies* (pgs. 11-12)

Discussion: The Department needs to offer training on Act 169, and health care decision making issues generally, to providers, county MH/MR staff, supports coordinators and others who fall under the scope of this bulletin. PAR offers our assistance in helping ODP with this training.

Recommendation: Provide training on Act 169 and health care decision making.

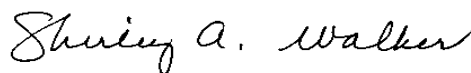
Discussion: The draft bulletin states in this section, “Anyone appearing to need skilled nursing care will be referred to the OBRA process for evaluation.” This is a disconcerting statement. This would set an inappropriate precedent that would be in conflict with ODP’s Everyday Lives values. Providers in the community system serve many individuals and continue to serve many individuals needing skilled nursing care until the end of their lives and have not found it necessary to transfer an individual to a nursing home or other skilled nursing care facility.

It is appropriate that the individual be allowed to remain in their home or a similar home with the proper supports and care givers who can communicate with them and understand their needs. The above statement could be used by administrative entities to refer high cost individuals to nursing homes where they would not receive active treatment, would not receive necessary maintenance therapies, and would be more susceptible to medical complications, such as decubitus ulcers and increasingly severe respiratory conditions. We urge that the Department not shift its responsibility for people with mental retardation to another service system.

Recommendation: Delete the above statement.

Thank you for considering our comments and recommendations. We would welcome the opportunity to meet with you at your request to clarify our comments.

Sincerely,



Shirley A. Walker
President and CEO