

Disability Rights Network of Pennsylvania

A merger of PP&A and the
Disabilities Law Project

Advancing the rights of people with disabilities

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September 29, 2009

BY FAX AND MAIL

Kim Kaufman
Executive Director
Independent Regulatory Review Commission
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INDEPENDENT REGULATORY
REVIEW COMMISSION

Re: *Comments on Proposed Pre-need Regulations*

Dear Ms. Kaufman:

The Disability Rights Network of Pennsylvania (DRN) submits these comments on the Proposed Rulemaking on Pre-need Funeral Arrangements and Pre-Need Activities of Unlicensed Employees. DRN is the organization designated by the Commonwealth pursuant to federal law to advocate for and protect the rights of Pennsylvanians with Disabilities. Although we realize that the proposed regulations were issued some time ago, we only recently learned about them. Given the significant potential for negative impact on Pennsylvanians with disabilities, we ask that you consider DRN's comments prior to finalization of these regulations.

Most individuals with significant disabilities live on limited incomes and subsist on Supplemental Security Income (SSI) benefits. These individuals, as a result of their SSI eligibility, also are entitled to participate in the Medical Assistance (MA) program. The MA program is critical to provide individuals with significant disabilities with health care and support services they need to remain in their own homes and communities.

As you may know, SSI eligibility and, concomitantly, MA eligibility can be jeopardized if an individual has either higher income or greater "resources" than are permitted by federal law. The resource limit is quite low, allowing an individual to have no more than \$2,000 in assets to remain eligible for SSI and MA. In counting resources, however, federal law excludes an *irrevocable* burial fund as long as the fund does not exceed \$1,500. This allows individuals on SSI to set aside money for their funeral arrangements without jeopardizing their SSI and MA eligibility.

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DRN is extremely concerned that the proposed regulations could lead to the loss of crucial SSI and MA benefits for people with disabilities. Although we are confident that this is not the State Board's intent, the devastating, if unwitting, consequences for people with disabilities must be considered before the State Board finalizes these regulations. Specifically, Section 13.228, governs the transfer of pre-need funeral contracts from one funeral entity to another, but it fails to address the following key issues: (1) whether such transfers are limited to revocable contracts; (2) if such transfers apply to irrevocable contracts, how an irrevocable contract could be legally transferred; (3) if such transfers apply to irrevocable contracts, whether such transfers undermine their irrevocability so as to potentially jeopardize an individual's continued eligibility for government benefits; and (4) whether the transferee funeral entity must comply with the terms and conditions of the original contract and use all of the funds, interest, and earnings for funeral services. It is imperative that this provision is clarified to assure that individuals who have created irrevocable burial trusts to remain eligible for government benefits do not lose their benefits because of transfers of their trusts permitted by these state regulations.

In addition to DRN's concern about the impact of proposed Section 13.228, we also are concerned that some of the other proposed regulations governing pre-need planning could prove so burdensome that funeral entities will cease to engage in such planning so as to restrict the ability of individuals with disabilities to secure affordable, pre-arranged funerals and to have a choice of funeral entities that provide these services.

- Proposed section 13.206(a) would require licensed funeral directors to enter into pre-need contracts, rather than allowing the use of unlicensed employees as does current law in certain circumstances. Individuals with disabilities may be unwilling and, in many cases, unable to travel to meet face-to-face with the funeral director and, if they have already spoken with an unlicensed employee, they feel undue pressure if required to meet with the director. DRN thinks that the State Board should guarantee the right of an individual to meet with a funeral director before signing pre-need documents, but that the right can be waived by the individual or his/her legal representative. This can be accomplished by requiring a clear notice on documents signed by the individual or his legal representative that informs him of his right to meet in-person with the funeral director before signing, but that allows him or his representative to waive that right provided that clear information about the right is included on documents that the person must sign.
- Proposed section 13.229 would require a funeral director that ceases or sells its pre-need business to notify all consumers and provide them with the opportunity to transfer their funds to a new funeral entity. Current

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regulations are sufficient to protect the public by simply requiring that the purchaser of the business must certify whether it is willing to honor the contracts. By requiring notification even when the purchasing entity is willing to honor contracts, it makes it less likely that funeral entities will be willing to offer pre-need services.

Thank you for considering DRN's comments and recommendations. If you have any questions, please do not hesitate to contact me.

Sincerely,



Ilene W. Shane

Chief Executive Officer

cc: Sen. Robert M. Tomlinson, Chair, Senate Consumer Protection &
Professional Licensure Committee (by fax and mail)
Rep. Michael P. McGeehan, Chair, House Professional Licensure
Committee (by fax and mail)