



STATEMENT OF
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SUBCOMMITTEE ON SPECIAL EDUCATION
COMMITTEE ON EDUCATION
PENNSYLVANIA HOUSE OF REPRESENTATIVES

APRIL 10, 2008

I have been asked by the Chairman to comment on draft legislation currently before the Subcommittee that would establish two savings programs to assist adult children with special needs to transition into employment or other higher education. Let me say at the outset that, while my comments are from the perspective of my work at The Arc Community Trust of Pennsylvania (the "Arc Trust"), they are my comments and do not necessarily represent the individual or collective views of the directors of the Arc Trust.

The Arc Trust is a Pennsylvania non-profit corporation whose purpose is to serve as trustee and administrator of special needs trusts for the benefit of people with disabilities. These trusts are permitted under federal and Pennsylvania law and allow the beneficiaries to access trust funds to meet their special needs and enhance the quality of their lives without losing needs-tested government programs such as Supplemental Security Income ("SSI") and medical assistance ("MA"). Distributions from special needs trusts to beneficiaries are subject to detailed rules concerning the manner and purpose of the distributions. These rules are established by the PA Department of Public Welfare and the Social Security Administration and it is our job, as Trustee, to be sure the rules are followed so that the trust beneficiaries do not lose their SSI, MA and other benefits.

The Arc Trust currently administers approximately 560 special needs trusts with an aggregate balance of approximately \$23 million.

Given what we do, it is no surprise that a primary goal of the Arc Trust is to see that persons with special needs in Pennsylvania have available the full panoply of services and supports. Therefore, in looking at the proposed bill, I am concerned that a family of a person with special needs be able to enroll in a special needs savings program without risking that person's eligibility for SSI and MA. As you know, in many instances SSI and MA are available only if a person's "available resources" are below certain (very low) thresholds -- \$2,000 in the case of SSI. If the special needs savings programs proposed by the draft bill are treated as available resources by SSA and DPW, many families will avoid establishing special needs savings program accounts for fear of losing eligibility for SSI and MA. A look at how SSA treats educational savings plan accounts is instructive. Generally speaking (and vastly over-simplifying) Section 530 accounts are treated as available resources and Section 529 accounts are not. I urge the committee and its staff to work directly with DPW and SSA as the legislation (and, perhaps more importantly, the regulations) are developed to avoid unintended consequences to people with special needs.

Two other issues of coordination with other programs occurred to me when I read the draft bill:

First, the bill contains a very fuzzy definition of "special needs." Without having made up my mind on the issue, I wonder if this definition should be coordinated with the definitions of disability used by DPW and SSA for their programs for people with special needs.

Second, I am unclear as to the intended significance of age 21 in the draft bill. I assume that it is intended to dovetail with the age at which the public school district's obligation to provide free appropriate public education ("FAPE") ends, presumably to prevent the school districts from using the existence of a SNAP account as an excuse for avoiding its own responsibilities. Unfortunately the mechanics of this aren't spelled out.

Finally, the draft bill quite reasonably leaves a lot of the details to be fleshed out by the Special Needs Account Program Bureau, including definition of the sorts of expenses that can be paid for from a SNAP account and the procedures for accessing funds in an account. It may be jumping the gun a bit, but our experience with what we call "educational trusts" suggests some of the questions that the Bureau will need to wrestle with before the program can get into full swing.

Some background: A significant portion of the special needs trusts that we administer at the Arc Trust are educational trusts, that is, trusts that are funded by a school district for the benefit of a student as part of the settlement of a dispute about whether the school district has provided FAPE to the student. These trusts usually differ from other special needs trusts in that they have an

end date (typically age 21) and restrict disbursements from the trust to carefully defined "appropriate educational expenditures." Our experience administering these educational trusts suggests some questions that the Bureau will need to answer as it sets up the programs:

1. Who can request distributions from the account? Just the beneficiary? Parents? Others designated by the beneficiary?
2. Will payments from the accounts only be made directly to vendors or will beneficiaries be able to get cash payments from the accounts? How will vendors be qualified as appropriate, if at all?
3. Can accounts be used to reimburse for educational expenditures made or incurred before the account was established?
4. Can accounts be used to pay for general-use technology such as computers or only for assistive technology?
5. Can accounts be used to pay for services rendered by relatives of the beneficiary?
6. Can accounts be used to pay for therapies related to the beneficiaries disabilities but not related directly to educational or vocational training?
7. Can accounts be used to pay for transportation? For housing?
8. In our experience many beneficiaries make disbursement requests at the last minute (two days before tuition is due, for example). How will the Bureau deal with timing issues?

There are many more, of course, and I will be happy to share our experience with the Bureau's staff at the appropriate time.

Thank you for the opportunity to speak with you today. As I mentioned earlier, we at the Arc Trust are always supportive of efforts to expand the range of services available to people with special needs.