## CENTER FOR SCHOOLS AND COMMUNITIES

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PA. STATE BOARD OF EDUCATION

July 27, 2007

Jim Buckheit
Executive Director
State Board of Education
333 Market Street
Harrisburg, PA 17126-0333

Dear Mr. Buckheit:

We thank you for the opportunity to again provide testimony on the important subject matter of Chapter 14, Special Education Services and Programs. The following comments are specifically directed to the topic of transition planning described in the IEP requirements (14.131.IEP, item 9). We strongly support the proposed regulations which maintain the onset of transition planning at age14 and believe this period of preparation will support positive outcomes for youth beyond their departure from the school setting.

We strongly recommend that this proposal also give consideration to students' health care issues. In approximately ten years of work with the Special Kids Network, a program of the Pennsylvania Department of Health, we have come to understand that health status is a major factor in the students' successful transition to adulthood, and health must be a required component of every student's transition plan. Just as postsecondary goals are established and monitored for training, education, employment, and independent living, health goals should be established and monitored. We respectfully request that Health be specifically listed in 14.131 IEP, item 9 to ensure that students' health care needs are recognized and addressed as a mandatory component of the transition process.

In 2002 the Pennsylvania Protection and Advocacy, Inc. and the Pennsylvania Health Law Project (PHLP) engaged in a one year assessment funded by the Pennsylvania Developmental Disabilities Council to determine the status of transition planning for 14-21 year olds with developmental disabilities in Pennsylvania. An Advisory Committee was established to review and comment on every aspect of the study. The committee was made up of a racially and geographically diverse group of individuals with the majority of members being people with developmental disabilities. The remaining committee members were family members, advocates and providers.

A consumer survey was conducted with 81 students from across the state, 53 who were still in school and 28 who had left high school. The findings in regard to health issues include the following:

- In the area of health, these students were asked whether they discussed and/or had opportunities for accessing and managing their own health care. Of the 53 students still in school only 3 reported that they discussed accessing their own health care, 34 reported not discussing this and 16 did not respond.
- Only 1 student reported having instruction in how to get a prescription filled, when to call the doctor, and how to schedule appointments. 27 students reported not receiving this same type of instruction and 26 did not respond.
- Of the 28 students who were no longer in school only 1 student reported discussing how to access health care, 20 students reported never discussing this and 7 did not respond.

• Only 2 of these students reported having instruction in how to get a prescription filled, when to call the doctor, and how to schedule appointments, 15 reported never having this instruction and 7 did not respond.

Overall 11 students reported that they manage their disability and overall health, 62 do not

and 8 did not respond.

• Finally when it comes to managing their health care coverage only 6 students report doing this, 65 do not and 10 did not respond.

Based on findings from this assessment, a written report prepared by the Pennsylvania Health Law Project outlines a number of recommendations to improve the delivery of transition services across the Commonwealth. With respect to health care, the assessment identified the need for students to understand health care coverage and their own health care needs. First, the report recommends that students receive information and instruction in understanding their current health care coverage as well as in planning for adult health care coverage. Secondly, the report specifically states that "... transition plans must include outcomes based on what each student needs to maintain wellness".

The Pennsylvania Department of Health has recognized the disparities in health services for youth with special health care needs. The Department recognizes that when these youth leave school, they transition from their parents' health care coverage to having different or no insurance coverage, from seeing pediatric specialists to searching for adult medical specialists, and from good coverage for medications to having to understand new systems for obtaining their medications.

Working with the State Leadership Team on Transition, agencies, and families, in March of 2006, the Department of Health created the Transition Health Care Checklist to guide youth, families, and professionals during this time of change. This is one of a number of resources that have been developed both statewide and nationally which can be used to assist professionals in working with students on health care issues during the transition process. While these are valuable tools, providing them as a resource is not enough. Health factors must become a required component of the transition plan as described in 14.131. IEP, item 9 to ensure that students have the information and instruction necessary to manage their own health care needs.

Thank you for the opportunity to share information about the importance of including health as a component of transition planning for children with special needs. Your careful consideration of our request is appreciated and we will be happy to share additional information with you at your request.

Sincerely,

Dan Brant

Special Kids Network System of Care

Lynn M. Cromley

Director, Center for Schools and Communities

Lynn M Crowley