Vermont
Family
Network

February 7, 2019

Testimony to the House Education Committee re: H. 140 – Advisory Council on Special Education

Presented by: Karen Price, Parent of a child with a disability and the Director of Family Support, Vermont Family Network.

Thank you for the opportunity to speak with you today. I am testifying as a parent of a child with a disability who has been on an Individualized Education Program (IEP) for his entire school experience. I am also speaking as a parent-professional. I have worked at the Vermont Family Network (VFN), the federally designated Parent Training and Information (PTI) Center in Vermont for 14 years. This is the position defined in (a) (1) (L) of H. 140. I have also participated in Vermont's Special Education Advisory Council (SEAC) for close to five years and can speak a little to its level of function. I support H 140 as it would bring Vermont in compliance with federal law regarding membership and duties of state advisory panels (SAP), which have important functions in ensuring high quality, impactful special education and good outcomes for students with disabilities.

The Individuals with Disabilities Education Act (IDEA) is clear that parents of a child with a disability are expected to be equal participants along with school personnel, in developing, reviewing, and revising the IEP for their child. This is an active role in which the parents (1) provide critical information regarding the strengths of their child and express their concerns for enhancing the education of their child; (2) participate in discussions about their child's need for special education and related services and supplementary aids and services; and (3) collaborate with the school staff and service providers in deciding how their child will be involved in the general curriculum, how the child will participate in state and district-wide assessments, what services the school will provide to the child, the setting in which they will be provided and periodic progress reports. Parents must have the opportunity to participate in IEP meetings with respect to the identification, evaluation, eligibility and educational placement of their child, and the provision of a free and appropriate public education (FAPE) for their child. These are legal requirements under federal law.

As you might be able to tell from the brief description of the parents' role, there is a great responsibility on the part of a parent of a child with a disability to not only understand the special education regulations but also how to exercise their procedural safeguards, known as parents' rights. Special education laws and regulations can be very confusing for parents who are already overwhelmed with the daily challenges involved in raising a child with a disability. This is why IDEA requires that parent, training and information (PTI) centers operate in every state and that PTIs be parent organizations i.e. run by a board of whom the majority are parents of children with disabilities. PTIs are also staffed by skilled parents of children with disabilities. VFN Family Support Consultants support families in accessing services for their children in the school and in the community, and work to build strong parent-professional partnerships with schools to support the success of *all* students. As required by the IDEA, VFN helps parents to advocate for the provision of a FAPE in the Least Restrictive

Environment (LRE) to which their children are entitled. To achieve the IDEA expectations of a PTI, VFN operates a statewide telephone helpline, provides in-person support to families, and occasionally attends school meetings with parents. VFN also provides written materials and conducts workshops on a broad range of topics of interest to families and professionals who work with children with disabilities. Parents contact us when they have concerns and questions about their child in school. In 2018, we had over 3900 contacts with parents and another 700 with professionals who call on behalf of families.

So, you've heard that the IEP team that determines appropriate services to a child must include the parent as an equal member. The reality is that we hear daily from parents who do not feel meaningfully included in the special education process. They feel that their input is not considered when decisions are made about their children's IEP and that there is a basic power imbalance at the IEP table. Parents often have to vigorously advocate for even the most basic special education services. When there is a disagreement in an IEP meeting, the local education agency (LEA) makes the decision. The parent then has the right to engage in dispute resolution over the specifics of the disagreement. This could take the form of filing an administrative complaint, mediation or due process. However, because schools have access to legal representation and financial resources that most parents do not, many parents are not able to use the dispute resolution process as it was intended. The vast majority of parents lacks the money to retain an attorney and may be intimidated at the thought of engaging in formal dispute resolution with their child's school. Parents, in truth, are less "equal" members of the IEP team than are school professionals.

For the most part, parents can feel terribly alone advocating for their individual children. Part of my role at VFN is to gather information on challenges faced by parents and to bring them to the table where system-wide decisions are made. Those of you here who consider education legislation hear often from principals, superintendents, educators and other professionals who have resources that may include lobbyists. The state level is not that different from the IEP table. The parents' voices are not as loud or heard as frequently as those of the professionals.

This is why it is so important for Vermont's SEAC to be robust and to consist of a majority of parents of children with disabilities or individuals with disabilities. A functional state advisory panel that is made up of the voices of children with disabilities (through their parents) and youth to inform the State Agency of Education and the State Board of Education of unmet needs in special education is imperative for the development of policies and procedures that result in positive and impactful change for children with disabilities in school.

During my time at the SEAC, there has never been a majority of parents in the membership. There has also appeared to be only minimal interest on the part of the Vermont Agency of Education or the Vermont State Board of Education to become familiar with or use this council for the purpose it was intended. I have spoken to my counterparts in different states regarding their state advisory panels and know that a well-run state advisory panel can effect real change for children with disabilities in school. Parents' experiences describe accurately the reality of their child's education, rather than how their child's education SHOULD be - according to regulations and law. Without accurate feedback based on real-life experiences, the system cannot respond appropriately. Correcting the membership and function of the SEAC is the first step in lifting family voice.

Thank you for inviting the Vermont Family Network to present the parent perspective.

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