

TESTIMONY FOR THE CT EDUCATION COMMITTEE - MARCH 3, 2011
Support in Favor of SB 1038 An Act Concerning Individualized Education Programs

Good Afternoon, Representative Fleischmann, Senator Stillman and Members of the Education Committee.

My name is Alice B. Buttwell and I live in New Milford, CT. I am strongly in favor of Bill SB 1038 - An Act Concerning Individualized Education Programs. I am a parent of a 22-year old young adult son who has a history of complex special health care needs and disabilities throughout his life. Parent/caregiver and educator concerns and issues haven't really changed much in some 18 years, ever since I was involved in my son's first Individualized Educational Program (IEP), then subsequently on a personal and professional basis helping other parents of children needing special education services.

I am in strong opposition to restraints and seclusion but only as **necessary to protect** a student from harming themselves or others. I am in strong favor of teaching these vulnerable children coping strategies, sensory techniques, communication, problem-solving and/or replacement behaviors in order to be able to de-escalate and avoid the need for a restraint and seclusion. Lots of hard work, smart training and consistent daily practice throughout each day in simulated role-playing and real-life situations by well-trained experts from school or outside consultants in such practices should be strongly considered. Frequent practice, communication strategies (and/or expressive language) and social skill building should be an integral part of such children's Individual Education Plan, along with meticulous and accurate data collection, so that eventually and hopefully the child can internalize how to deal with whatever reason they are escalating so he/she can hopefully function better self-control in all arenas or changing environments in school, home and community life

Special Education and all of its accompanying services, rights and laws, is a complex process that requires what I call initially "parent/caregiver crash course learning" when you find out your child has any kind of disability or special health care needs that further continues to be a process of ongoing learning and training throughout the lifespan of their child/ren. This is something that has to be proactive and move forward quickly in order to navigate the educational process and other arenas of life for our child/ren. It requires learning not only about your child and their respective diagnosis/es, but the actual special education process, therapies, and accommodations your child will continue to need at any given time, as well as knowing how to write the goals and the process of carrying them out to meet the objectives. . This is definitely not an easy job for any parent to do, especially for whatever stage and time the child has been diagnosed, and considering how exhausting and overwhelming it can be depending on the needs of your child/ren and the resources of each parent caregiver.

Many parents rely and think that our educators have all the answers or are more knowledgeable than them. Then they begin the process of trying to find out the information and help they need to help their child/ren in order to move forward and work with the special education process and staff. Then they may find a rude awakening in some school districts that there are special education departments who are not knowledgeable about the strength of coordinating and monitoring educational teams for academics, accommodations, therapies, behavior plans and other arenas related to the immediate, changing and ongoing needs and goals and objectives of their child and the impact on that child and family should the child not get the help that they need on an individualized and fairly timely basis, along with stability and consistent continuity of care overall

*Each child has the need for services specific to their individual need based on their disability and special health care needs. These needs continue to change in many arenas at any given time in their lives during the special education process and most are related to the issues concerning each individual child including their environments. These needs require vigilance of ongoing monitoring and foresight of the educational team who work with each child and their parent/caregivers, as their frequency of change also differs according to their individual learning style. No child is alike nor will be at any place in any given time. We are talking about children that require lots of educator and parent time, patience and hard and smart work in order to help them grow, develop and transition each step of the way in order to help them prepare to achieve whatever their potential might be.

*Many times neither school staff nor parents have a knowledge or understanding of guidelines and procedures to ensure they are developing and implementing appropriate restraint and seclusion policies or the skills and knowledge necessary to develop, implement and monitor IEP's within the laws.

*Their complex, individual services are necessary to help them grow and to sustain a quality of life that is not the same for each child, adolescent or young adult. Their learning experiences, from pre-school up through and including transitioning from adolescent to young adulthood and out of school, will help them to sustain that quality of life to become to achieve their fullest potential, if not almost same or equal to their typical non-disabled peers, but many times can only do so if they get the care and services they need with the stability and ongoing continuum of education and care throughout their school years.

*Most services related to special education include academics, special accommodations (ex. assistive technology, seating, etc) speech and language and communication skills that includes daily practice in real life and simulated situations, physical therapy, nursing, occupational therapy that includes sensory integration therapies (that many families and special education teams are unfamiliar with), auditory processing, computers, social skill training, functional behavioral assessments, various types (cognitive behavioral, ABA, etc) of therapeutic individualized behavioral plans that should be shared and educated strongly as a team that carry over not only in the classroom but other educational areas, at home, and in the community. Noting in the IEP, a personal separate record should also be documented as an emergency plan in a nurse's or principal's office should the school think they should be calling the police and/or DCF. Parents might also want to bring a copy of this record to their local school area police.

- Some of my suggestions would be: to have a similar model of medical-legal partnerships available for complex cases as a prevention method and way to move forward – effective cost and time saving instead of having parents and schools hire attorneys all the time. This would have to be explored and developed as a possible solution in specific cases. Parents and schools can't afford to waste personal and tax-payers monies, but more so we cannot afford the time nor the money to hold up precious lives of our vulnerable children.
- Continue to include or more awareness to include Nurse care coordinators for the Medical Home Initiative for Children&Youth with Special Health Care Needs
- Review the job description across the board for the role, responsibilities, education, and training of the Special Education Director to ensure that each individual has the management and monitoring skills, mandated knowledge and training of the entire special education process, laws, policies, as well as the restraint and seclusion procedures and laws. I am not familiar with this but I would think they would be mandated to take a test in state and federal laws related to specific aspects of the special education process to become credentialed as a Special Education Director.

- Mandate that no one attend an IEP meeting without the relevant training, education and experience of the special education process. No one should substitute without these credentials just to fill a seat at a meeting.
- Mandate that there is at least one person in attendance at the IEP besides the parent who is absolutely familiar with the child's specific type of disability and/or special care needs.
- Implement a bank of advocates from the state for each school district for complex cases when required for the child's parent, especially a new parent or a child in crisis when calling a personal planning treatment plan (PPT) (see note below regarding 'parent advocate').
- Children under DCF with 'surrogate parents' for advocates should also be re-evaluated and every effort made to make this a more positive advocacy for our vulnerable children with multiple disabilities and special health care needs. We need 'specialized' advocates with experience and training. The state may want to hire 'stay-at-home' parents/caregivers who are experienced and trained with their own child and pay them per diem as they may not be able to work due to being a full or part-time caregiver.
- A low-cost resource center in every school or town for parents and educators that might be manned by a paid parent resource liaison or a SEPTA parent designee. Make up a welcome package of information for new parents in special education equipped with resources; have a phone, computer, printer and DVD player that could be used by the parent/s who may not have access to these items. The center can also be used by all education staff at schools, and even police if they need access to more specific information on complex children/youth/young adults in the school. Examples of some IEP resources that should be considered a high priority and necessary for new parents comes from the CT Family Support Council website www.cfsc.org/ Special Education Resource Guides: IEP, Special Education Made Easy, Before, During & After the PPT, as well as other statewide educational and medical, community, and personal websites and resources on a local, regional and statewide level. Information and fact sheets on each diagnoses, accommodations, etc. for parents and educators alike can be made available by referring to websites or contacting relevant agencies. Videos and fact sheets on Restraints and Seclusion policies, procedures and laws, functional behavioral analysis and plans and IDEA laws for use as an orientation or refresher update. Ct Parent Advocacy Center already has a video/CD lending library. Ideas to manage this cost and time effectively and efficiently are endless with team networks & networking throughout the state.
- Eventually mandate changes in Special Education College Curriculums
- Develop a specific curriculum for statewide training network for special education directors, teachers both regular and special education, paraprofessionals, nurses, occupational therapists, physical therapists, behaviorists, psychologists, gym, anyone and everyone involved in the special education curriculum of children. In addition to the designated behaviorist, everyone should be adequately trained in positive behavioral interventions (including paraprofessionals on the bus and bus drivers driving special education buses), as well as educated on restraints and seclusion practices and laws in order to collect necessary data and are aware of the individual's behavior plan.
- Inhouse training and refresher courses on restraint and seclusion policies, procedures and laws, and completion and processing of necessary documentation and notice to parents.
- Penalties or suspensions of educational staff for not following restraint and seclusion laws, as well as emergency or timely notice to parents of children in crises at school.

- All transportation staff drivers and non-school district I:I bus aides should also be bonded for confidentiality about any child whether or not they are included in a plan.
- A home-school communication checklist book should be developed in order to include data from home for the teacher and/or behaviorist so that both the school and parent/caregiver can have some idea to look for signs of any positive or negative behaviors that might need to be addressed and/or documented as part of the overall behavior intervention plan. All should be trained on information needed and how to document it.
- Medications can have effect on behaviors. For students on psychotropic or other prescription meds, a checklist would be helpful in identifying positive/negative symptoms related to medication side effects. This suggestion could be further developed for home-school communication so parents can share specific information needed by the doctor outside school who is monitoring medications as a way to track and tie in with the behavior plan.
- Job descriptions should be available for parents to review for paraprofessionals should there be something that needs to be added to an IEP for an individual child (such as responsibility for personal items if the child cannot be responsible for them, ex. Coats, handheld video games) and responsibilities clarified to paraprofessionals and parents alike.
- Develop a strategic statewide-training outlined network for parents/caregivers and foster parents who are raising children with disabilities and special care needs that they can pick and chose from in each region of the state. There are great resources out there, but parents are torn by time, cost and location constraints, and what kinds of programs to start with.
- statewide training network of the same for police stations in each town and/or region on disabilities in general, emergencies of children with special health care needs and disabilities, and positive behavioral interventions, restraints and seclusion laws.
- Change name of "surrogate parent" for children in DCF custody to 'surrogate advocate'. Their role is not of a foster care person, it only applies to advocating for education.
- Autism therapy insurance laws now go up to age 26. Many children with disabilities and special health care needs miss school without much tutoring or make up in the services they need. Some reasons may be hospitalizations related to their disabilities whether physical, neurological or mental health. Some of the children sent out-of-state do not get the services they need and have been called the stuck kids, including other wards of the state with disabilities. They can't possibly have all their academics and relevant services made up with a tutor in the hospital or out of the hospital. Each individual case is different. A consideration might be made to change the special education laws for such children to attend school up to age 26, depending on each situation.
- Transition plans should be carefully paid attention to and monitored at all stages of major identified transitions under IDEA.

Currently I work part-time for the Northwest Medical Home Initiative for Children and Youth with Special Health Care Needs. I was appointed to the CT Family Support Council and had worked part-time for some 9 years as the Northwest Regional Coordinator for the CT Family Support Network. Thank you for taking time to read this lengthy and delayed testimony on such complex matters related to our children/youth/young adults with special health care needs and disabilities.

Respectfully,
Alice B. Buttwell, New Milford, CT.