



**TESTIMONY OF THE OFFICE OF THE CHILD ADVOCATE FOR THE STATE OF CONNECTICUT: Raised Bill No. 5587 An Act Establishing a Council to Make Recommendations Concerning Services for Children and Young Adults with Developmental Disabilities**

**MARCH 8, 2016**

Good morning, Representative Abercrombie, Senator Moore, Senator Markley, Representative Wood, and distinguished members of the committee. This testimony is offered on behalf of the Office of the Child Advocate in **support of Raised Bill No. 5587, An Act Establishing a Council to Make Recommendations Concerning Services for Children and Young Adults with Developmental Disabilities.**

The broad statutory obligations of the Office of the Child Advocate (OCA) include reviewing, evaluating and reporting on the efficacy of child-serving systems throughout the state. OCA meets regularly with lawmakers, policy-makers and other stakeholders to review and advocate for policies and practices that will promote children's well-being. OCA responds to hundreds of calls for help regarding children annually. Many of these calls are from parents looking for help for a child with special needs.

Bill 5587 will assist children and families in the following ways:

1. Identifying the needs of children with developmental disabilities as an urgent public health priority.
2. Facilitating the strategic development of a continuum of care for children with developmental disabilities and their families.
3. Ensuring a coordinated and high quality service delivery system with an emphasis on outcomes and value for children and families.

## The Lack of Effective Services for Children with Developmental Disabilities is an Urgent Public Health Issue

OCA continues to receive frequent calls from parents, grandparents and providers regarding children with developmental disabilities and who have **significant unmet needs**: an 11 year old boy who was **arrested and repeatedly suspended** at school; **multiple children on homebound education**; a 7 year old boy with significant treatment needs who remained in **congregate care**; a 6 year old, **non-verbal child with bruises on his ear**, allegedly from a school aide; multiple children who were subjected to **repeated physical restraints**; multiple children who are in a **revolving door with the local emergency room**. The outlook for children with complex needs worsens over time without the provision of timely and effective services for them *and their families*.

### Connecticut Needs a Strategic Plan to Build an Effective Continuum of Care for Children with Developmental Disabilities And Their Families.

In recent years, OCA have received a rising number of calls and letters about children with developmental disabilities, sometimes as young as 3 years old, who are at significant risk due to lack of access to appropriate care.

Hi Sarah, I am so concerned about the revolving door Maria is stuck in every time she is admitted and discharged from the hospital ... I cannot tell you how as a parent I feel ... I know there is no cure, I know there is no miracle pill ... I love my daughter and if I could switch spots with her I would in a heartbeat so she can have and live a normal life. It has been hard visiting Maria at the hospital, because I wish I could just pick her up and bring her home and things will be better, but it never is ... In my heart I am not complete until I know Maria is ok, and that she receives the help she truly needs...The doctors and the state all recommend different things. I don't know if we can find the help to stabilize Maria and give her the chance that she needs. To be honest I feel lost. And I feel for my daughter. It seems we are nowhere.

### **What do Children and their Families Need?**

First and foremost children and their families need access to appropriate **educational services, care coordination, and home and community-based treatment services**. Services must be high-skilled and available across childhood; services must be delivered in a sustained way so that parents are not forced to rely on crisis-driven, episodic care. *Crisis driven services are less effective and much more expensive.*

Families whose children have developmental *and* mental health treatment needs require a lot of help from outside of the school system as well. Callers frequently describe their frustration with the lack of local service professionals who have expertise in providing services at home and in the community to children with developmental disorders. Even institutional care providers are often under-staffed and under-trained to properly support children with developmental disabilities.

**Joshua was placed in a residential treatment setting at age 10 for treatment of his Autism; he has extraordinary sensory needs and becomes emotionally dysregulated when the environment is too stimulating for him. Not only is a congregate setting highly likely to *exacerbate* Joshua's sensory issues, but the staff at the facility are untrained in recognizing and responding appropriately to Joshua's reactions to overstimulation.**

**State Reports Continually Document the Dire Lack of Services for Children with Developmental Disabilities.**

According to a 2013 **state report**, though “[y]oung children [with ASD] in the Connecticut Birth to Three Program have access to effective intensive home-based services, ... [*o*]nce children turn three, it can be challenging for families to access effective services.”<sup>1</sup>

The same report outlined **hospital utilization** for Medicaid-eligible youth with ASD: “Between 6 and 7% of behavioral health inpatient hospitalizations

for youth enrolled in HUSKY A and B are for youth with an ASD diagnosis... [and] “Youth with ASD have a significantly longer length of stay in the hospital than youth without an ASD diagnosis.” (Id. pg. 15.) Youth with an ASD diagnosis stay longer in inpatient care than their peers not identified as having ASD while utilizing the same services. (Id.)

Too many children are stuck in this ***revolving door between home and the hospital***. This is because of a lack of an appropriate and effective continuum of care.

**OCA Hears from Hospital Professionals about Lack of Support for Children with ASD: frustration levels are HIGH.**

OCA has heard regularly from community health care professionals expressing urgent concern regarding children with developmental or intellectual disabilities who have co-occurring mental health disorders and who are *unable to access appropriate levels of care*. These children may experience prolonged stays in the emergency department or in-patient hospital unit due to the lack of an appropriate and available discharge plan. Solutions, when rendered, may be inadequate and extremely expensive, e.g., out-of-state hospital placement for younger children.

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<sup>1</sup> (Autism Feasibility Working Group Study, published 2013, pg. 9.)

## Inadequate Educational Supports for Children with Developmental Disabilities

OCA receives frequent concerns about the well-being of children with developmental disabilities in public school: inappropriate utilization of “homebound” status; school refusals; utilization of restraint and seclusion; lack of adequate related services such as speech and language support, behaviorist services, occupational therapy. When children hit age 10, 12 and 14, having not received appropriate educational services and wrap-around supports, they then may demonstrate complex needs that *exceed what caregivers can provide!*

***Families may call OCA looking for “placement” for a child because they are exhausted trying to care for the child without adequate supports from school or the community.***

## Over-reliance on Restraint and Seclusion for Children with Developmental Disabilities

***NATIONAL EXPERTS: Restraint and seclusion for children with developmental disabilities are the result of treatment failure.***

Multiple state reports show that children with developmental disabilities are ***restrained and secluded in school at significantly higher rates*** than other children with special education needs. Such measures are ineffective, traumatizing, and dangerous for children and adults. In the last 2 school years for which data was collected and reported in Connecticut, children with Autism accounted for almost *half of all restraints and seclusions of children with disabilities in the state.*

## Connecticut Taking Steps to Improve Service Delivery

In the past few years, Connecticut has put-forth new initiatives to support children with developmental disabilities, the most significant of which is the recently expanded Medicaid coverage for treatment services for children with Autism Spectrum Disorders. There are recent pilot initiatives to build capacity within school districts and sub-acute hospital settings working with higher-end children with developmental disability. These are important steps as the state works to ensure all children and families have access to the services that they need.

## Bill 5587 will help the State Create a Strategic Plan/Vision for Children with Developmental Disabilities: Create a Cost Effective and High Quality Continuum of Care

The bill facilitates bringing together leading state experts and key stakeholders from state agencies and the community to address gaps in our service delivery system for children and families, develop a framework for evaluating the *efficacy of funded services to children*, and create a strategic funding plan to ensure appropriate access to early intervention and treatment services for children age birth to 21.

The Provision of Bill 5587 May be Woven into the Governor's Proposal in SB17.

It may be beneficial to amend SB17 (creating an Intellectual Disability Partnership) to include key provisions of Bill 5587. The Office of the Child Advocate would like to work with all stakeholders to achieve final language that operates to the benefit of children and families. OCA is optimistic that consensus language will be developed.

Thank you again for the opportunity to submit this testimony.

Sincerely,

Sarah Eagan, J.D.  
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