MEMORANDUM

DATE:       June 26, 2015

TO:         Members of the Delaware State Senate
            and House of Representatives

FROM:       Ms. Daniese McMullin-Powell, Chairperson
            State Council for Persons with Disabilities

RE:         S.B. 93 (Autism Planning, Training & Resource Bodies)

The State Council for Persons with Disabilities (SCPD) has reviewed S.B. 93 which establishes an Interagency Committee on Autism and the Delaware Network for Excellence in Autism. As background, the Center for Disabilities Studies secured a federal grant to undertake an assessment of ongoing needs of infants, children, and adults with autism spectrum disorder. This resulted in the attached final report with recommendations issued in 2013. S.B. 93 is intended, in part, to facilitate implementation of the report through statutory establishment of an Interagency Committee on Autism and a Delaware Network for Excellence in Autism. Overall, the enactment should improve the service delivery system for individuals with ASD in Delaware. However, the legislation could be improved and SCPD has the following observations.

First, in line 10, the reference to “legal guardians” is somewhat limiting. Elsewhere, the legislation refers to “families” (lines 16 and 80-81); parents (line 59); and caregivers (line 59). The sponsors may wish to consider substituting “cohabiting family members” or simply “families” in line 10 to be more inclusive.

Second, the reference to “and related developmental disabilities” in lines 14-15 is redundant since it is already contained in the ASD definition (line 8). There is no harm in retaining the reference in lines 14-15 but it is unnecessary.

Third, literally, lines 13 and 18-20 “charge” the Committee to actually “implement the recommendations” in the 2013 Plan. The Committee will not have the funds or authority to actually implement all of the recommendations in the Plan. Consider substituting “Promote implementation of the recommendations...”.

Fourth, the reference to “state agencies” in line 23 is unduly limiting. For example, it would
exclude school districts. It may also exclude Medicaid MCOs and State contractors. Consider substituting “public agencies and their contractors”.

Fifth, there are multiple missing periods (lines 24 and 34).

Sixth, while lines 27-29 contemplate the Committee advising policymakers on legislation, there is no mention of advice and comment on regulations which can be equally important. Consider adding a charge to propose and comment on State regulations.

Seventh, line 33 is oddly worded and is grammatically infirm. Consider the following amendment: “Major categories of expenses that which includes all public, private, and in-kind support.” It’s also unclear if the reference is to ICA expenses or expenses of the entire ASD support network. This could be clarified.

Eighth, there are some odd omissions from the Committee membership. For example, the Governor’s Advisory Council for Exceptional Citizens (GACEC), the State’s special education council, is omitted. The State Council for Persons with Disabilities (SCPD) and the Developmental Disabilities Council are also omitted. In particular, the SCPD’s statutory responsibilities overlap with those of the Committee. See 29 Del.C. §8210(b).

Ninth, the membership has only 1 “individual with ASD” which could be considered a “token”. There are many individuals with Asperger’s or other autism spectrum disorders who could provide valuable perspective. In contrast, the SCPD is statutorily required to have at least a third of its membership composed of individuals with disabilities. See 29 Del.C. §8210(d)(6).

Tenth, in line 64, it would be preferable to substitute “public” for “state” since school districts would otherwise be excluded. This exclusion would be inconsistent with lines 77 and 90-91 which contemplate assisting “local education agencies”.

Eleventh, the Network is established as a program within the University of Delaware’s Center for Disabilities Studies (CDS). CDS enjoys an excellent reputation. The only reason for “pause” is that the overhead charged by the University can be prohibitive resulting in a fiscal note much higher than if the program were established within another non-profit agency.

Twelfth, the bill envisions funding 2 FTE Family Trainer Navigators. It may be preferable to expand this funding to 3 FTE Family Trainer Navigators so 1 could be assigned to each county. Splitting 2 FTE’s across 3 counties could result in 1 FTE for NCC and 1 FTE covering both Kent and Sussex Counties. Downstate coverage suffers under such a “riding circuit” model.

Thirteenth, the line 91 reference to “local education agencies” would exclude charter schools. The term “local education agency” (LEA) is usually interpreted to only cover school districts. The term would also exclude assistance to private schools. See, e.g., attached Autism Delaware article describing plans to open a private school for autism and the arts in Kent County. If desired, the reference to “local education agencies” could be made more expansive.
Fourteenth, S.B. 93 ostensibly uses different terminology to refer to the same director. Compare S.B. 93 (line 93) reference to “Statewide Director of the Delaware Autism Program” with S.B. 92 (line 43) reference to “Director of Autism Educational Services”. It would be preferable to adopt the same terminology.

Thank you for your consideration and please contact SCPD if you have any questions regarding our observations on the proposed legislation.

cc: Teresa Avery, Autism Delaware
    Alex Eldreth, Autism Delaware
    Brian Hartman, Esq.,
    Governor’s Advisory Council for Exceptional Citizens
    Developmental Disabilities Council

SB 93 autism planning training and resource bodies 6-23-15
Blueprint for Collective Action
Introduction

The California Center for Disability Studies has conducted a comprehensive statewide campaign of the ongoing crisis of children, youth, and adults with autism spectrum disorder (ASD) in California and the challenges in providing services and supports to respond to their needs. This statewide ASD planning initiative, funded under a grant from the federal Health Resources and Services Administration (CFDA 5P15H080001), was designed as a comprehensive community assessment leading to the development of a strategic plan to improve services for individuals with autism spectrum disorder. It was implemented across a two-year period with the vision and deliberate emphasis on stable participation. This collaborative effort consisted of multi-faceted, systematic information-gathering that engaged hundreds of parents, professionals, and community members. The statewide ASD planning initiative represents a shift in the orientation of current needs assessments, but rather an evolving plan of inquiry designed to yield information about critical areas needing improvement as well as detailed outcomes and the associated activities that will lead to those outcomes.

The statewide planning initiative utilized this document integrated into the process of the California’s Legislative Task Force on Autism and Developmental Disabilities and California’s Early Statewide System to ensure a systemic and unified vision for future efforts. The Blueprint for Californians with Autism represents a plan for improvement that is highly integrated across the state’s varied service areas, including education, early intervention through post-secondary, independent living, and behavioral health. Family involvement is a cornerstone throughout across planning and implementation.

On the cover: Finding a way out, we use diagnosed with autism when we are young and have learned to cope with our disabilities. Many adults. Photo by Crystal Westgate.
Context of the Challenge

The Center for Disease Control and Prevention (CDC) identifies autism as an urgent public health concern. Although the number of children served in the public school system has increased, the number of children with autism spectrum disorder (ASD) who are identified and placed in specialized programs has remained consistent over the past decade. The rate of identification has remained fairly stable, with slight increases in recent years.

In the United States, approximately 1 in 59 children is identified as having ASD. This rate has been consistent since the early 2000s, with the most recent data showing a prevalence of 1 in 54 children. This stability in prevalence rate is despite efforts to increase screening and identification of children with ASD.

The challenges associated with identifying and serving children with ASD are significant. One of the primary challenges is the difficulty in accurately diagnosing autism in young children. This difficulty is compounded by the variability in symptoms and the lack of consensus on diagnostic criteria.

The image shows a graph depicting the prevalence of ASD over the past several years, illustrating the stability in identification rates. The graph indicates that while there has been an increase in the number of children identified with ASD, the rate of increase has been relatively small.

In conclusion, while the identification of children with ASD has increased, the rate of identification has remained relatively stable. This suggests that while more children are being identified, the overall prevalence of ASD remains unchanged. The challenges in accurately diagnosing and serving children with ASD continue to be significant and require ongoing attention and research.
The planning process identified obstacles that hindered early intervention and education. This initiative aimed to create a unified and efficient system of support for individuals with ASD. The planning process aimed to improve education and support for individuals with ASD. The planning process aimed to improve education and support for individuals with ASD.

**Blueprint Timeline and Methodology**

The Blueprint for Collective Action aims to address the need for improved early intervention and education for individuals with ASD. The Blueprint provides a roadmap for implementing a comprehensive system of support for individuals with ASD. The Blueprint also addresses the need for increased awareness and understanding of the challenges faced by individuals with ASD. The Blueprint includes initiatives to improve education, support, and services for individuals with ASD.

**To ensure that all Delawareans with ASD have the opportunity to develop the skills and knowledge necessary to live independent and interdependent lives within the community.**

**The Blueprint**

- **Core Principles**
  - Early intervention
  - Improved education
  - Increased support

**Initiatives**

- **Early Intervention Program**
  - Early detection
  - Early support

- **Improved Education Program**
  - Increased access to educational resources
  - Improved teacher training

- **Increased Support Program**
  - Increased access to social services
  - Increased access to employment opportunities

**Timeline**

- **Year 1**
  - Early intervention program implementation
  - Improved education program implementation

- **Year 2**
  - Increased support program implementation
  - Evaluation of program effectiveness

**Methodology**

- **Data Collection**
  - Surveys
  - Focus groups

- **Data Analysis**
  - Quantitative analysis
  - Qualitative analysis

- **Implementation**
  - Multi-agency collaboration
  - Community involvement

**Conclusion**

The Blueprint for Collective Action provides a comprehensive framework for addressing the needs of individuals with ASD. The Blueprint aims to improve education, support, and services for individuals with ASD. The Blueprint also addresses the need for increased awareness and understanding of the challenges faced by individuals with ASD. The Blueprint includes initiatives to improve education, support, and services for individuals with ASD.
Statewide Survey

in late 2011, the Center for
Disabilities Studies distributed a
survey assessment survey to three
groups of stakeholders in Delaware:
1) families and providers of children
with autism spectrum disorders;
2) caregivers of adults with autism
spectrum disorders; and
3) service providers with autism
spectrum disorder.

Each group received a slightly
different version of the survey, in all:
211 parents/guardians of children
with ASD; 91 caregivers of adults
with ASD who are adult self-advocates
with ASD completed the survey.

The survey assessed the survey
evaluated the following topics:
1) Receipt of a diagnosis and
2) medical care
3) Employment challenges for
4) Family support
5) Service needs
6) Unmet challenges

The survey was conducted after
a similar survey distributed in
Pennsylvania by the Center for
Autism Research. Survey questions
were modified slightly to enhance
their applicability to Delaware, and
includ[ed] questions about medical
providers and how far families
involved to see a provider.

This survey was distributed via
e-mail and in paper form. A paper
copy was sent via mail by the
Delaware Department of Education
and the Department of
Developmental Disabilities.

In the survey, we included
information for the Center for
Disabilities Studies.

Focus Groups

The Center for Disabilities Studies
conducted three focus groups with
parents of children with ASD in
Delaware between February 17 and
March 7, 2012. Focus groups were
held in Glenside, Malvern, and
Wilmington. The focus group
interviews utilized a semi-structured
deviation protocol. Questions
addressed the following topics:
1) The process of obtaining a
diagnosis
2) Positive and negative
experiences with education
3) Positive and negative
experiences with medical
healthcare
4) Positive and negative
experiences with vocational
rehabilitation and employment
5) Thoughts on the intersection
of all of the service systems
in Delaware, including how
they work together to provide
comprehensive, high-quality
services

Each focus group was facilitated by
two individuals: one professional
staff member from the Center for
Disabilities Studies and
one professional staff member
from Autism Delaware. Prior to
participating in the focus group,
the participants signed an
informed consent document that
had been approved by a research
review board at the University of
Delaware. Participants were informed
that their participation was voluntary, they did not
have to answer any questions they did
not want to, and they could choose
not to participate in follow-up or
interviews at any time. Participants
were also informed to that
focus groups would be audio recorded
as a way of ensuring that accurate
information was obtained for analysis.

Participants were given a $25 gift
card for participating in a focus group.
Focus group interviews were
transcribed verbatim. Transcripts
were read and coding was assigned
in passages of text. Primary
codes were developed in accordance
with the interview guidelines. Secondary
codes were developed under each
primary theme in order to capture
detailed concepts within the
transcripts.
ASD Statewide Summit

On June 7, 2012, all stakeholders invested in the lives of individuals with ASD in Delaware gathered at a statewide summit and participated in group assessments and planning tasks based on the Coalition Framework approach in a Creative Problem Solving (CPS) format. A series of activities were implemented to allow opportunities to express individual concerns or position within a group structure. Additional mechanisms gave participants the opportunity to provide individual perspectives relative to identified strategies and solutions outside of the group process. The resulting data presented from the more than 120 participants enabled the internal advisory committee to establish the initial structure of an improvement plan.

Summit Outcomes

- Participants articulated shared values in health regarding the support of individuals with ASD and reached consensus on these statements:
  - We believe that adults with autism should have appropriate training and skills.
  - We believe that youth with autism should be provided with opportunities to develop skills in self-determination and advocacy, including the understanding of their own abilities.
  - We believe that all families should have the same expectations for their children, and that, therefore, cultural differences should be respected.
  - We believe parents should have access to appropriate information, training, and support to enhance their children’s skills.
  - We believe that autism spectrum diagnoses are a right to an array of services accessible to support them toward independence in a community of support.
  - We believe that autism spectrum diagnoses are a right to an array of services accessible to support them toward independence in a community of support.
- An Executive Planning Council was established with responsibility for coordinating the individual working groups that emerged from the summit.
- In six to eight meetings held from December 2012 until April 2013, these working groups conducted broad meetings to refine their recommendations, culminating in a draft of the Statewide Plan for Improvement in May 2013.

Blueprint for Collective Action Highlights

The activities of the summit were designed to identify prominent themes regarding system challenges, family needs, and other issues that require better coordination and improved improvement. A substantial amount of qualitative data was generated, and a content analysis suggested a common set of improvement areas.

- Employment and Transition
  - Improve transition for students with ASD
  - Increase employment opportunities

- Community Supports
  - Improve access to community supports
  - Increase opportunities for community engagement

- Education
  - Improve access to educational opportunities
  - Increase opportunities for post-secondary education

- Early Intervention
  - Improve access to early intervention services
  - Increase opportunities for early identification

- Family Supports
  - Improve access to family support services
  - Increase opportunities for family education and training

- Health Services
  - Improve access to health services
  - Increase opportunities for mental health support

- Research and Data
  - Improve access to research and data
  - Increase opportunities for evidence-based practices

The development of a state-wide autism resource center was identified by all three workgroups as a mechanism to provide training, technical assistance and information resources to families, schools, adult service providers and others, refining best practices. The autism resource center has been envisioned as a single entity that would be responsible for the implementation of the statewide plan and provide services across the state.
IMPROVEMENT AREA V:
Transition to Adult Life

OUTCOME A

- Develop strategies and interventions to improve transition to adult life
- Increase awareness and support for individuals with ABD

OUTCOME B

- Enhance collaboration between agencies and service providers to support transition to adult life
- Implement guidelines for transition planning

OUTCOME C

- Evaluate the effectiveness of transition programs
- Collect feedback from participants to improve transition services

OUTCOME D

- Implement a needs assessment study
- Develop a comprehensive action plan

And now I have a couple of questions...
IMPROVEMENT AREA VI:

Family Support & Stakeholder Engagement

OUTCOME A

- Develop and implement strategies to involve family members in the service delivery process.
- Foster partnerships with community organizations to enhance family involvement.
- Provide training to staff on effective communication with families.

OUTCOME B

- Develop evidenced-based practices to support families in coping with the stress of HIV/AIDS.
- Establish a family support group.
- Implement family-friendly policies in healthcare settings.

OUTCOME C

- Increase awareness among families about the importance of early intervention in HIV/AIDS prevention.
- Provide resources for families to access mental health services.
- Implement bilingual services to better serve diverse family populations.
**Outcome A:**
1. An emergency committee for health will be established as a liaison mechanism with state and federal governmental and community-based organizations to address public health issues and concerns related to health and well-being and to develop and implement strategic plans.
2. Develop and implement strategies to address public health issues and concerns related to health and well-being and to develop and implement strategic plans.

**Outcome B:**
1. Work closely with state and local health departments to identify and address public health issues and concerns related to health and well-being and to develop and implement strategic plans.
2. Develop and implement strategies to address public health issues and concerns related to health and well-being and to develop and implement strategic plans.

**Outcome C:**
1. Identify and address public health issues and concerns related to health and well-being and to develop and implement strategic plans.
2. Develop and implement strategies to address public health issues and concerns related to health and well-being and to develop and implement strategic plans.
Moving Forward

The dramatic increase in the number of individuals diagnosed with ASD has created significant difficulties for families, social agencies, hospitals, clinics and facilities across Delaware. Systemic issues have not been designed for or prepared to address the needs of this growing population, and existing educational and social service agencies currently are not collaborating as effectively as they must. This climate of crisis motivated the statewide ASD planning project, which in turn facilitated the development of the Blueprint for Collective Action.

The project was endorsed and validated by the stakeholders representing Delaware's agencies, organizations and families. During the course of plan development, a strong and vital community of support and action has evolved within Delaware. Representing hundreds of voices and positions from every conceivable standpoint, this group is dedicated to advancing the interests of Delawareans with ASD, the resulting strategic plan outlines the following fundamental assumptions and foundational activities:

- The Blueprint for Collective Action has been developed from the collective actions of the statewide ASD planning process and awareness that ASD is a life-long condition that affects individuals of all ages and abilities. The Blueprint for Collective Action will be charged with developing a strategic plan for advocacy that will outline the objectives and strategies for achieving the desired outcomes.

- An Advisory Committee for Autism will be established to address the provision of services to individuals with ASD. This committee will address the provision of services to individuals with ASD and will be comprised of advocates, providers, educators, and other stakeholders.

- An advisory committee will be established to address the provision of services to individuals with ASD. This committee will be responsible for identifying the needs of individuals with ASD and for developing strategies to address these needs.

- The Blueprint for Collective Action will outline the objectives and strategies for achieving the desired outcomes. This will be accomplished through a series of tasks, each of which will be monitored and evaluated to determine its effectiveness.

"I don't want my thoughts to die with me — I want to leave this world as a scientist, as a writer, as a singer, as a dancer, as a musician," said Temple Grandin, a woman with autism.

"I want to leave something behind. I want to make a positive contribution — I want to leave something behind for the world," said Temple Grandin.

In summary, there is a dire need to address this issue. The Blueprint for Collective Action represents a unified effort to address the needs of individuals with ASD and to provide them with the services they require.
FOR IMMEDIATE RELEASE: Kent County Parents Propose School for Autism & Arts

Dover, DE - A group of parents in Kent County have joined together in the hopes of establishing a private school for autism and the arts. Central Delaware School of the Arts for the Exceptional, also known as "CDSAE," will provide schooling for 4th grade through age 21 for those eligible and will be located in a central location for Kent County residents. It will offer small class sizes and year round schooling, focusing on academics, social skills and executive functioning in an inclusive setting.

Curriculum will be modified to integrate Applied Behavior Analysis (ABA), a well-known and successful form of therapy for not only Autism Spectrum Disorder (ASD) but for typically developing children as well, to increase positive behaviors and extinguish unwanted behaviors.

Typically developing students will not be devoid of programming options, however. CDSAE will offer a variety of disciplines in the arts, including but not limited to photography, dance, vocals, and computer graphic design making it a fully functional school of the arts. The year-round programming will allow all students the freedom to hone their artistic abilities throughout the year, while building a sense of community with their fellow students and providing individualized academic challenges.

CDSAE board members are organizing three sessions in Kent County for public comments at the following dates/times:

Tuesday, May 12th 5:45 pm - 7:45 pm at Dover Public Library

Thursday, May 21st 6 - 8 pm at Price Community Center, 103 Dorman Street, Harrington

Thursday, May 28th 5:30 - 7:30 pm at Kent County Levy Court room 220

For more information, please contact Tyler Anaya, Founding Board Member, at (302) 943-2274 or at tstevens24_2000@yahoo.com.

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CDSAE's mission is to prepare students for career and college readiness through a holistic, person-centered approach. The school will use an ABA methodology in an inclusive environment focusing on the arts.