



# DISABILITIES LAW PROGRAM

COMMUNITY LEGAL AID SOCIETY, INC.

100 W. 10th Street, Suite 801  
Wilmington, Delaware 19801  
(302) 575-0660 TTY (302) 575-0696 Fax (302) 575-0840  
www.declasi.org

## MEMORANDUM

To: SCPD Policy & Law Committee  
From: Brian J. Hartman  
Re: Legislative & Regulatory Initiatives  
Date: June 10, 2015

I am providing my analysis of nine (9) legislative and regulatory initiatives. Given time constraints, the commentary should be considered preliminary and non-exhaustive. The analyses of Items 7-9 (S.B. No. 107; S.B. No. 92; S.B. No. 93) were previously submitted to the Councils to facilitate timely submission of commentary to policymakers.

### 1. DOE Final School Transportation Regulation [18 DE Reg. 961 (6/1/15)]

The SCPD and GACEC commented on the proposed version of this regulation in April, 2015. A copy of the April 22, 2015 GACEC letter is attached for facilitated reference. The Department of Education has now adopted a final regulation incorporating many amendments prompted by the commentary.

First, the Councils noted that it was difficult to determine if the standards applied to charter schools. Many inconsistent references were identified. In response, the DOE clarified that the standards do apply to charter schools and incorporated many conforming amendments. The DOE also added a new "purpose" section at the beginning of the regulations to clarify their application to nonpublic schools.

Second, the GACEC suggested that the DOE consider defining "significant" in §2.1.16. The DOE opted to not define the term since "we do not wish to be too specific in what type of accident/incident must be reported,..." At 962.

Third, the Councils identified an inconsistency in the standards applicable to the driving records of trainers. The DOE amended the language to achieve consistency.

Fourth, the Councils noted that the term "district" was sometimes capitalized and sometimes not capitalized. The DOE amended references to achieve uniformity.

Fifth, the GACEC suggested that the DOE require an applicant to supply a DMV letter to the school. The DOE agreed and revised §6.8.6.

Sixth, the Councils recommended deletion of “be sent” in §7.1.2.2. The DOE effected the deletion.

Seventh, the Councils observed that the standards sometimes authorized supports based on an IEP or Section 504 plan and sometimes omitted a reference to a Section 504 plan. The DOE responded as follows:

It was noted that the regulation is sometimes inconsistent with authorizing supports based on an IEP or 504 Plan. The sections 10.16, 18.1.7 and 23.1 were examined. The Department will ensure the first two references include the words “504 Plan”, but it will not change 23.1 as students with a 504 Plan do not get private placement and thus the change would not apply.

At 962. Since §23.1 appears to implement 14 Del.C. §3124, which only covers IDEA-eligible students, I do not recommend follow up on this comment. However, the federal §504 regulations require schools to provide private and residential placements (with transportation) if required to provide a student with a FAPE. See 34 C.F.R. §104.33.

Since the regulation is final, and the DOE addressed each recommendation proffered by the Councils, I recommend sending a “thank you” communication.

## 2. DFS Final Early Care & Education & School-Age Centers Reg. [18 DE Reg. 974 (6/1/15)]

The SCPD and GACEC commented on the proposed version of this regulation in April. A copy of the April 30, 2015 GACEC letter is attached for facilitated reference. The Division of Family Services has now adopted a final regulation incorporating many amendments prompted by the commentary.

First, the Councils recommended adding a cross reference to limit the scope of an exemption. The Division added a clarifying cross reference.

Second, the Councils recommended an amendment to the definition of “Section 504 Plan. The Division inserted the suggested phrase “with a disability”.

Third, the Councils identified multiple concerns with a section requiring OCCL notification if a child is injured and requires medical treatment. DFS added a minor amendment to exclude “first aid”.

Fourth, the Councils recommended adoption of a more expansive reporting duty in the event of medication errors and uniformity in the timetable for reporting. DFS noted that this is a new requirement. It amended the timetable standards to require an initial report within 1 business day followed by a written report within 3 business days.

Fifth, the Councils recommended adding a requirement that extended physical restraint be reported to the Division. DFS banned physical restraint altogether through an amendment to §65.5.6.

Sixth, the Councils recommended banning certain forms of physical restraint (e.g. prone (face-down) restraint and seated basket holds). DFS responded that it is banning physical restraint altogether.

Seventh, the Councils endorsed the addition of references to the ADA and the DEAL. DFS acknowledged the endorsements.

Eighth, the Councils recommended a revised reference to a "GED Test" based on recent Department of Education amendments. DFS revised the reference to conform to DOE terminology.

Ninth, the GACEC questioned whether someone with a high school diploma and 24 months of experience is sufficiently qualified to be an early childhood curriculum coordinator. No change was made.

Tenth, the Councils identified a grammatical error in §27.10.1. The grammar was corrected.

Eleventh, the GACEC recommended an amendment to §28.4.2 since an administrator or coordinator could not split time on a 50% basis among 3 or more centers. DFS did not address the observation.

Twelfth, the Councils recommended the addition of a limitation on staff cell phone use while caring for children. DFS added conforming language.

Thirteenth, the Councils questioned a ban on small wading pools. DFS responded that national standards support the ban since they do not permit adequate control of sanitation and safety and are correlated with transmission of infectious diseases.

Fourteenth, the Councils questioned some temperature references. No change was made.

Fifteenth, the Councils objected to allowing children to ride bikes with wheels below 20 inches in diameter without helmets. DFS expanded the scope of activities in which helmets must be worn.

Sixteenth, the Councils objected to the ratio of toilets to children/staff. DFS responded that it wished to adopt the same ratio standard for multiple covered settings. No change was made.

Since the regulation is final, and DFS favorably addressed most concerns, I recommend sending a "thank you" communication.

### 3. DMMA Final HCBS Waiver Statewide Transition Plan [18 DE Reg. 966 (6/1/15)]

The DLP commented on the March 17, 2015 proposed Statewide Transition Plan for Compliance with Home and Community-Based Settings Rule. The SCPD and GACEC adopted the DLP commentary. The SCPD added supplemental commentary. The Division of Medicaid and Medical Assistance is now publishing commentary from multiple sources, responses, and a chart outlining changes to the Plan prompted by the commentary. See 18 DE Reg. at 968. The chart is 35 pages long (pp. 47-82 of Plan) with 99 sections. Apart from individuals, nine organizations submitted comments. Plan, at 46.

I am attaching May 5, 2015 letters from DMMA to the DLP and SCPD which lists 44 DLP comments and 9 supplemental SCPD comments followed by the DMMA response.

Given the length of the commentary and responses, I am only highlighting some of the significant results.

DLP Comment #5: The DLP recommended adding the SCPD to the “oversight body”. DMMA agreed to “look at the composition of the oversight body and add members as needed.”

DLP Comment #6: The DLP objected to the obtuse reference to the oversight body meeting “regularly”. DMMA changed the standard to at least monthly meetings.

DLP Comment #9: The DLP recommended using the Employment First Commission as a source of information and analysis. DMMA agreed to incorporate the Commission’s data into the evaluation of employment services.

DLP Comment #14: The DLP recommended clarification of the role of the DDDS Advisory Council given inconsistent references. DMMA agreed and clarified that the Council operates as a steering committee.

DLP Comment #15: The DLP recommended adoption of a protocol for Council subcommittees to ensure they are not comprised of a high percentage of providers to the exclusion of other representatives. DMMA agreed and modified the Plan to address this concern.

DLP Comment #16: The DLP objected to a 90-day period for providers to submit a corrective action plan. DMMA agreed and shortened the timetable to 30 days.

DLP Comment #17: The DLP recommended that DDDS and DMMA handle disputes rather than the Advisory Council. DMMA agreed and modified the Plan.

DLP Comment #24: The DLP recommended adding references to changing statutes. DMMA agreed and modified the Plan.

DLP Comment #27: The DLP questioned identification of the Governor’s Commission on Community-Based Alternatives to Individuals with Disabilities as the primary stakeholder group since it meets infrequently. DMMA agreed and encouraged the Commission to meet more frequently.

DLP Comments #29 - #31: The DLP questioned whether MCO providers would have any incentive to complete surveys. The DLP also noted the lack of a benchmark/goal percentage for completed surveys. DMMA agreed to develop benchmarks, develop a follow-up process to promote completion of surveys, and consider incentives to encourage providers to participate in training.

DLP Comment #33: The DLP recommended including fair hearing results in assessing MCO performance. DMMA agreed and modified the Plan.

DLP Comment #36: The DLP questioned inconsistent references to “remediation strategies” versus “corrective action plans”. DMMA agreed and modified the Plan to refer to corrective action plans.

DLP Comment # 38: The DLP questioned the lack of a specific end date for legislative changes. DMMA agreed and inserted a March 17, 2019 deadline for legislative action.

DLP Comment # 39: The DLP criticized the 5-month period for provider completion of self-assessment surveys as too long. DMMA agreed and shortened the time period.

DLP Comment #40: The DLP recommended that DMMA conduct a “pilot” of its survey. DMMA agreed and amended the Plan.

DLP Comment #43: The DLP questioned whether the DDDS Advisory Council would have the capacity to complete “look-behind” reviews of a 20% sample of provider self-assessments. The DLP also promoted “on-site” reviews. DMMA agreed, noted its expectation that the Council would create sub-groups, and modified the Plan to include “on-site” reviews.

DLP Comment #44: The DLP encouraged establishment of an on-line survey tool (e.g. Survey Monkey) to allow individuals to comment on specific programs. DMMA agreed to explore use of such an online survey tool.

SCPD Comment #3: The SCPD criticized the time line as too extended. DMMA agreed and shorted time periods in the Plan.

SCPD Comment #4: The SCPD promoted inclusion of a relocation process for individuals who are being provided services in settings which cannot come into compliance with the regulations. DMMA agreed and modified the Plan to include a relocation process.

SCPD Comment #5: The SCPD promoted “on-site” assessments. DMMA agreed and modified the Plan to refer to “on-site” assessments.

I recommend sending DMMA a “thank-you” communication for considering the commentary and submitting specific responses.

#### 4. DSAMH Prop. Substance Abuse Facility Licensing Regulation [18 DE Reg. 938 (6/1/15)]

The Division of Substance Abuse & Mental Health proposes to replace the existing standards covering the licensing of substance abuse facilities in their entirety. The current standards were adopted in 2010. At 938. The revisions are intended, in part, to reflect DSAMH's adoption of the American Society of Addiction Medicine (ASAM) Level of Care Criteria. Id.

I have the following observations.

First, it is unclear to what extent these regulations cover facilities serving minors. Title 16 Del.C. §2205(3), §2206(1) and §2207 require DHSS to collaborate with the DSCY&F in the licensing of substance abuse treatment programs. Cf. 16 Del.C. §§2210(c). However, the DSAMH regulation ostensibly covers facilities serving minors or adults and requires any facility providing substance abuse services to be licensed by DHSS. See §2.1, 2.2, and 4.1.1. Failure to comply is a crime. See 16 Del.C. §2209. Standards applicable to minors appear in many sections (e.g. §§5.1.2.2; 7.1.2; 15.2.2.2.4). Some sections apply only to adults (e.g. §§13.1.1.1 and 14.1.1). Most standards do not differentiate between minors and adults. In contrast, the DSCY&F has its own substance abuse treatment facility regulations and requires licensing under its standards. See 16 Del.C. §2208(a) and 9 DE Admin Code 105.2.1. Section 2208(a) authorizes DHSS to delegate the licensing of substance abuse treatment facilities to the DSCY&F. However, there appear to be child standards in both the DHSS and DSCY&F regulations. Requiring facilities to comply with inconsistent regulatory standards is confusing and somewhat dysfunctional.

Second, it is unclear to what extent these regulations cover facilities providing mental health services. The title to the regulation only refers to substance abuse facilities. However, some standards ostensibly apply to "stand-alone" mental health treatment facilities without substance abuse components. See, e.g. §3.0, definition of "applicant"; and §4.3.3. Cf. §7.1.3 (both substance abuse and mental health bills of rights applicable). Some standards suggest that the standards only apply to mental health facilities if combined with substance abuse treatment component (§4.1.1; §1.0).

Third, in §3.0, definition of "Inactive Status", the Division may wish to correct grammar.

Fourth, in §3.0, definition of "Qualified Medical Professional (QMP)", substitute "Assistant" for "Assistants" since all other references are singular.

Fifth, in §3.0, definition of "Quality Assurance", consider substituting "the avoidance, identification and/or resolution of client care quality issues" for "to avoid, identify and/or resolve client care quality issues" since earlier references are gerunds (e.g. "monitoring" and "evaluating").

Sixth, in §3.0, definition of "Signature/signed", the criteria are somewhat "overbroad". There are individuals with physical disabilities who could not write a first and last name. Moreover, the Delaware Code is not prescriptive See 1 Del.C. §302(23) which allows individuals with limitations to sign with a mark.

Seventh, in §3.0, definition of "Substance", substitute "affect" for "affects" for proper grammar.

Eighth, "ending" punctuation has been omitted throughout §4.2.

Ninth, in §4.3.5.2, the duplicate reference to "information" should be deleted.

Tenth, §4.4.2 suggests that an unannounced inspection could only occur upon receipt of a complaint or report of an adverse event. This could be invoked by a facility to oppose an unannounced inspection. The inclusion of the limitation is unnecessary and DHSS should consider deletion. Section 4.4.3 simply allows unannounced inspections.

Eleventh, programs with independent accreditation "will be granted a license which is valid for up to three (3) years" and "be exempt for the period of their license from Division monitoring pursuant to these regulations, except for complaint based investigations and corresponding actions by the Division." See §§4.11.3 and 4.11.4. This exemption should be reconsidered. It violates 16 Del.C. §2207(b) which requires DHSS to conduct inspections "periodically" and "at least every 2 years". Moreover, it makes little sense for the Division to "tie its hands" with respect to inspections. By analogy, the Delaware Psychiatric Center was JCAHO-accredited for many years. That did not equate to "state of the art" treatment as documented in findings of a legislative task force and U.S. DOJ investigation. Moreover, an agency could be "on probation", have "conditional accreditation", or have many deficiencies identified by an accrediting body and DSAMH would be barred from all monitoring in the absence of a complaint. Cf. §§4.11.6 and 4.11.8 (DSAMH receives notice of deficiencies but cannot monitor).

Twelfth, §4.12.3 is "brittle" in making the term of any waiver equal the term of the agency's license. There may be short term situations (natural disaster; fire; HVAC breakdown) which may justify a short-term waiver but not a long-term waiver. Some licenses last for 3 years (§4.11.2). It would be preferable to authorize waivers to be in effect for a period which shall not "exceed" the term of the applicant's current license.

Thirteenth, in §5.0, it would be preferable to require training in the applicable bills of rights identified in §7.1.3 as well as PM46 and abuse/neglect reporting. For example, §5.1.2.3 could be amended as follows: "Policies and procedures regarding clients' rights and protections, including those identified in §7.0." The current regulation curiously requires training in reporting "child" abuse/neglect but not adult abuse/neglect. See §5.2. This anomaly should be addressed.

Fourteenth, in §6.3.1.3, the term “may be” should be substituted for “maybe”.

Fifteenth, in §8.2.1.10.5, it would be preferable to include a “sign off” by the client’s guardian, if applicable. Cf. §15.2.2.2.4.2.

Sixteenth, the sections on discharge planning (§8.2.1.12 and 8.2.1.13) would benefit from the incorporation of input from anticipated post-discharge providers. Compare 16 Del.C. §5161(b)(4).

Seventeenth, in §8.2.1.13.2.11, it would be preferable to include a “sign off” by the client’s guardian, if applicable. Cf. §15.2.2.2.4.2.

Eighteenth, in §10.1.4., substitute “Review by” for “Be reviewed by” for proper grammar and consistency with preceding subparts.

Nineteenth, in §11.1.1.1, subparts sometimes end with a period, sometimes end with a semicolon, and sometimes have no terminal punctuation.

Twentieth, in §15.5.1.1.3, substitute “the client’s” for “their” since there is otherwise a plural pronoun with a singular antecedent.

Twenty-first, there is some “tension” between §15.8.5.2 and §15.5.1.3. The former disallows an initial dose of Methadone to exceed 30 mg while the latter disallows an initial dose of Methadone for pregnant clients to exceed 40 mg. This is also counterintuitive, i.e., a pregnant client could receive a higher initial dose of Methadone than anyone else. Finally, capping an initial dose in the regulation may not be clinically prudent. Logically, a 350 lb. client might qualify for a higher dose than a 115 lb. client.

Twenty-second, §15.14.3 categorically disallows the admission of a client for more than two detoxification treatments episodes in one year. This is unduly brittle. For example, a client with an unsuccessful detoxification treatment in January and March could not be admitted in December despite clinical “readiness” and changed circumstances. The categorical limit is an unrealistic burden on access to treatment.

Twenty-third, there are several sections which cite to “Title 16 Delaware Administrative Code 6001”. See §16.1.3.4; §16.1.3.8; §17.1.4.7; §19.1.4.3; §19.1.4.5; §20.1.4.3; and §20.1.4.5. That is the reference to the current regulation. The individual references should be to the relevant section of the current regulation or simply refer to the current regulation. For example, the references to recovery plans could read as follows: “ Individualized interdisciplinary Recovery Plan, consistent with ~~Title 16 Delaware Administrative Code 6001~~ §8.2.1.9, completed within X hours of admission.”



Twenty-fourth, §20.1.4.8 reads as follows: “Referral and assistance shall be provided as needed for the client to gain access to other.” Obviously, some words have been omitted at the end. Based on the similar §19.1.4.8, I assume the following words were omitted: “needed SUD or mental health services.”

I recommend sharing the above observations with DSAMH with copies to the DSAMH Advisory Council, DelARF, and the DSCY&F Office of Child Care Licensing and DPBHS.

#### 5. H.B. No. 126 (Minimum Age of Prosecution)

This legislation was introduced on May 5, 2015. As of June 8, it awaited action in the House Judiciary Committee. It is earmarked with an incomplete fiscal note.

The legislation would disallow prosecution of child for conduct occurring when the child was under the age of 10. Instead, young children could be referred to appropriate intervention and treatment programs. Indeed, their participation in such programs could be court ordered or otherwise required. The legislation adopts the American Bar Association (ABA) standard (age 10) as the minimum age of responsibility for juvenile prosecutions. The synopsis notes that at least eleven (11) other states, including Pennsylvania, have the adopted the ABA standard. Additional background is included in the attached commentary from Rep. Barbieri.

I have the following observations.

First, the legislation is consistent with recent public policy and public sentiment. For example, in 2010 legislation (H.B. No. 347) was enacted to limit school reporting of child offenses to the police. Prior to 2010, schools were required to report “criminal” conduct of any child age 9 or older to the police. The mandatory reporting threshold was changed to age 12 for most offenses as a matter of public policy. See, e.g., the attached June 4, 2010 News Journal editorial which describes the discipline of a 6 year old Delaware student who brought his Cub Scout utensil to school to eat his lunch. Referrals of young children to law enforcement has been a matter of historic concern. See, e.g., the referral of a 6 year old to the Attorney General for “offensive touching” of a teacher (attached 12/12/96 and 12/13/96 News Journal articles).

Second, young children can be traumatized and terrorized by police involvement. In 2013, the Delaware Supreme Court criticized the intense police questioning of an innocent 8 year old who was informed he could be arrested if he didn’t tell the truth and incarcerated where “people are mean and children are treated like criminals” and “siblings would be upset and would not be able to see them.” See attached July 11, 2013 News Journal article.

Third, nationally, a model which diverts troubled children from arrests to support services has proven effective. See attached December 2, 2013 New York Times article. See also attached National Center for Mental Health & Juvenile Justice, “Better Solutions for Youth with Mental Health Needs in the Juvenile Justice System” (2014), published at <http://www.modelsforchange.net/publications/519>.

Fourth, the federal government is promoting interventions which divert children from the juvenile and criminal justice systems. See attached January 9, 2014 News Journal article. In part, this initiative recognizes the disproportionate discipline and prosecution of minorities. Id. See also attached January 10, 2014 News Journal article. As the above “Better Solutions” publication notes, between 65% to 70% of youth in contact with the juvenile justice system have a diagnosable mental health disorder” and many would be better served by diversionary programs.

I recommend sharing the above observations with policymakers. Commentary could be shared with the ACLU, Public Defender, and Office of the Child Advocate.

#### 6. H.B. No. 94 (Supplemental Nutrition Assistance Program)

This legislation was introduced on April 16, 2015. It was tabled in the House Health & Human Development Committee soon after introduction.

The legislation would amend State law by adding the following limit on purchases: “Benefits provided pursuant to this Chapter shall only be used for foods, food products, and beverages that have beneficial nutritional value.” The Department of Health & Social Services would be directed to issue implementing regulations to “identify specific foods, food products, and beverages, or general categories of foods, food products, and beverages ...that have beneficial nutritional value.” DHSS would also be required to apply for a waiver from the U.S. Department of Agriculture (USDA) to permit implementation of the law.

This bill is identical to H.B. No. 293 which was introduced in April, 2014. It was also tabled in the House Health & Human Development Committee. Both the SCPD and GACEC identified concerns with the predecessor bill. See attached May 14, 2014 GACEC memo and May 29, 2014 SCPD memo. In pertinent part, the commentary included the following observations:

*As reflected in the attached articles, the USDA has never granted a SNAP waiver limiting benefits to perceived healthy foods. The legislation is opposed by DHSS and the Delaware Food Bank. The Food Bank CEO offered the following observation:*

*The biggest barrier between low-income Delawareans and a healthy diet is not a lack of will or self-control, but a lack of affordability and accessibility. ... Fresh, healthy food is just more expensive than the alternatives and in some neighborhoods it's not even stocked in some stores.*

*Since the benefits average \$1.40 per person per meal, recipients are hard-pressed to budget for acquisition of basic food products. The attached Delaware News Journal editorial questioned the wisdom underlying the bill and suggested adoption of positive incentives for electing healthier foods:*

*Limiting shopping choices to 'nutritional foods' is wrong-minded and meddlesome at the 'Big Brother' level. Rewards in the form of a little extra subsidy for better health choices will do a lot more to change food stamp recipients' poor eating habits.*

*Finally, a one-size-fits-all list of "healthy" foods may be an illusory goal. Some would posit that "red meat" is unhealthy, that canned soup with typically high sodium content is unhealthy, and that non-organic produce is unhealthy. Individuals may be on special diets which may not match a regulatory list of "approved" foods.*

The Councils may wish to consider sharing reservations on the current bill.

#### 7. S.B. No. 107 (Home Health & Personal Assistance Agency Services)

*The following analysis was forwarded to the Councils on June 1, 2015. On June 2, the SCPD incorporated the analysis into correspondence submitted to the prime sponsor. This prompted the exchange of multiple emails among the DLP, SCPD, and DHSS which was continuing on June 10.*

This bill was introduced on May 20, 2015. As of June 1, it awaited action by the Senate Health & Social Services Committee.

As background, the Department of Health & Social Services (DHSS) is required to establish regulatory standards covering both home health agencies and personal assistance agencies. See 16 Del.C. §§122o and 122x.

Home health agencies are statutorily authorized to provide a wide array of home health services, including nursing; audiology; nutrition; social services; home health aides; and speech, occupational, and physical therapy. See 16 Del.C. §122o1. Home health aides are authorized to provide assistance with feeding, bathing, dressing, grooming, and incidental household services. Id.

Personal assistance agencies offer services which do not require the judgment and skills of a nurse or other professional, i.e., assistance with activities of daily living, homemaker services, companion services, and health care support delegated by competent individuals pursuant to 24 Del.C. §1921(a)(19). See 16 Del.C. §122x2.

S.B. No. 107 is intended to remove restrictions on the settings in which the home health and personal assistance services can be provided. The current law categorically disallows provision of such services to "residents of hospitals and nursing facilities" (lines 11-12 and 18-19). Consistent with the synopsis and informal comments shared with the SCPD, DHSS believes that residents in long-term care or acute care settings may benefit from an option to contract for supplemental home health and personal assistance services. The following are examples:

A. An individual receiving physical therapy from a particular therapist while living at home enters a nursing facility for short-term rehabilitation. The individual may prefer to continue to be served by the same therapist while in the nursing facility.

B. An individual with chronic, complex physical support needs is very comfortable with services of a particular home health aide. The individual enters a hospital on a short-term basis. The individual may prefer that the same home health aide provide assistance with bathing and grooming. By analogy, the Department's attendant services standards (§4.0) allow attendants to provide support services for up to 10 days to participants who are admitted to hospitals.

C. A resident in an assisted living setting receives notice from the facility that his needs have become so extensive that he requires nursing home placement. The resident could contract with a home health agency for sufficient supports to permit continued residency in the assisted living setting.

There are some ostensible "limitations" in implementing the intent of the legislation.

First, unless DHSS amends its MCO contracts, it is unlikely that MCOs will routinely offer to pay for home health or personal care services within long-term or acute care settings. It is predictable that such services will be viewed as the responsibility of the facility and not medically necessary. As a practical matter, the option to receive home health or personal care services in such settings will be limited to "private pay" individuals.

Second, long-term care facilities and hospitals may balk at allowing health care workers who are not facility employees or contractors to provide services in their settings. The facilities may object based on liability concerns, confusion among other residents about the status of these health care workers, and competition from agencies for optional services otherwise available at higher cost from the facilities. I understand that DHSS anticipates including a requirement in its regulations that the home health/personal assistance agencies must obtain the written approval of the facility before providing services in the facility. I suspect few facilities will be willing to provide such approval without some incentives.

Third, there is a technical problem caused by the interplay among lines 18-19, 16 Del.C. §122x2, and 24 Del.C. §1921(a)(19). Personal care services include "services as set out in §1921(a)(19) of Title 24" [16 Del.C. §122x2]. Section 1921, which authorizes delegation of a broad range of health care services, is expressly inapplicable to persons in a "medical facility or a facility regulated pursuant to Chapter 11 of Title 16". Therefore, while S.B. No. 107 seeks to allow personal assistance to be provided in hospitals and nursing homes, residents may be "hamstrung" in benefitting from personal assistance given the exclusion in §1921.

I recommend a general endorsement of the legislation subject to recognition that its effects may be limited by the above considerations.

## 8. S.B. No. 92 (Autism Services)

*The following analysis was submitted to the Councils on May 28, 2015. I believe the GACEC incorporated the critique into a June 1 communication with policymakers. The bill was released from the Senate Education Committee on June 3.*

This legislation was introduced on May 12, 2015. As of May 28, it awaited action by the Senate Education Committee. The Committee is scheduled to hear the bill on June 3. The bill is earmarked with an “incomplete” fiscal note.

The bill revamps the current statutory framework for the Delaware Autism Program (DAP) initially adopted in the early 1980s. I have the following observations.

First, the bill does not update the statute covering supportive services and residential units for children with autism. See attached 14 Del.C. §3123. Consistent with the attached articles from 2010, there was a significant controversy over the residential program. I do not believe the differences among stakeholders were ever finally resolved. It may be preferable to incorporate revisions to §3123 into S.B. No. 92.

Second, S.B. No. 92 ostensibly uses different terminology to refer to the same director. Compare S.B. No. 93 (line 93) reference to “Statewide Director of the Delaware Autism Program” with S.B. No. 92 (line 43) reference to “Director of Autism Educational Services”. It would be preferable to adopt the same terminology.

Third, in line 46, I recommend substituting “with” for “from”. In the same line the reference to “(see subsection (d))” merits revision since a) the Peer Review Committee is mentioned in subsection “(g)”, not subsection “(d)”; and b) the reference is superfluous and does not conform to the legislative drafting guide.

Fourth, periods are omitted at the end of lines 46, 60, 84, and 97.

Fifth, lines 49-60 are rather prescriptive in defining the required experience of the Director. One could posit that they are overly prescriptive. For example, someone who “inherited” and implemented a structured professional development program and a performance management plan over a period of years, but did not develop the initial plan, would not qualify. It may be preferable to include some of the standards in the certification contemplated at lines 61-62.

Sixth, there are many references to assisting districts (e.g. lines 69, 81, 88) and some funding is derived from districts (lines 98-99). However, charter schools might also benefit from training and technical assistance opportunities. The sponsors may wish to consider whether to limit training and technical assistance to districts. In other contexts (e.g. lines 73-74), the Director is authorized to assist “state departments” and act as a liaison to agencies serving adults.

Seventh, there may be some "duplication" in training responsibilities between the Director and the Network established by S.B. No. 92. Compare S.B. No. 92 (lines 68-69, 79-83) with S.B. No. 93 (lines 63-65, 79-81, and 90-91). I recognize that S.B. No. 93 (lines 92-93) contemplates collaboration between the Network and Director. Given different funding streams, this may work in practice or it may result in disagreements over responsibilities.

Eighth, lines 85-86 authorize funding for at least 1 training specialist per 100 students with an educational classification of ASD. It appears the specialists would be employed by the Director rather than districts and that the director could "cash in" the specialist funds for contractual services rather than hiring specialists (lines 105-106). The synopsis predicts there will be 15 specialists hired based on the funding formula. The sponsors could consider an alternate model in which the districts employed the specialists. This would promote better integration among the balance of district special education staff and participation as a district representative on IEP teams. Some safeguards would have to be put in place to prevent supplanting of speech-language pathologists and other specialist positions. Since there are 19 districts, the formula could also be adjusted to ensure each district earns at least 1 specialist. Otherwise, the approach in the bill may result in "enriched" staffing within the DAP which places district-operated, local programs at a staffing disadvantage.

Ninth, lines 113-131 represent a revised version of current 14 Del.C. §1332(d). The retention of the Peer Review Committee and Statewide Monitoring Review Board (SMRB) merit reconsideration. Consider the following:

A. Consistent with the attachments relating to the 1984 legislation creating the Committee and Board, the impetus was the desire to provide safeguards in the residential program as juxtaposed to day programs.

B. Lines 119-122 require the Board to review annually both the eligibility and program of every district student with a classification of ASD. The synopsis to the attached 1980 legislation is informative. It recites that there were only 32 students statewide with an ASD classification. Now there are hundreds. It not realistic to have a single board review the eligibility and educational program of all of these students every year.

C. It is not appropriate to have some central board determining classification of students within districts.

D. Lines 125-126 establish the authority of the Board to resolve disputes between agencies. Districts can be determined to be "out of compliance" (lines 128) and forced to develop a "corrective action plan" (line 130) This scheme is inappropriate. The current Department of Education regulation limits the authority of the Board to an "advisory capacity". See 14 DE Admin Code 929.2.2.3.6. I suspect the DOE has not followed the statutory mandate in recognition of its inconsistency with the overall IDEA procedural safeguards system.

E. Having a single board rule on the appropriateness of programming will stifle innovation. At one time, ABA therapy was considered untested and controversial. Now it is mainstream. Consistent with the attached July 7, 2014 CMS Information Bulletin, innovation in ASD programming is thriving: “While much of the current national discussion focuses on one particular treatment modality called Applied Behavioral Analysis (ABA), there are other recognized and emerging treatment modalities for children with ASD, including those described in the ASD Services, Final Report on Environmental Scan...” .

I recommend sharing the above observations with policymakers.

9. S.B. No. 93 (Autism Planning, Training, & Resource Bodies)

*The following analysis was submitted to the Councils on May 28, 2015. I believe the GACEC incorporated the critique into a June 1 communication with policymakers. On June 3 the bill was released from the Senate Education Committee.*

This legislation was introduced on May 12, 2015. As of May 28, it awaited action by the Senate Education Committee. The Committee is scheduled to hear the bill on June 3. The bill is earmarked with an “incomplete” fiscal note.

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. No. 92 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. I have 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 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 ~~and 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.

Twelve, 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. No. 93 ostensibly uses different terminology to refer to the same director. Compare S.B. No. 93 (line 93) reference to “Statewide Director of the Delaware Autism Program” with S.B. No. 92 (line 43) reference to “Director of Autism Educational Services”. It would be preferable to adopt the same terminology.

I recommend sharing the above commentary with policymakers.

#### Attachments

E:leg/615bils  
F:pub/bjh/leg/2015p&l/615bils

**GOVERNOR'S ADVISORY COUNCIL FOR EXCEPTIONAL CITIZENS**

GEORGE V. MASSEY STATION  
516 WEST LOOCKERMAN STREET  
DOVER, DELAWARE 19904  
TELEPHONE: (302) 739-4553  
FAX: (302) 739-6126

April 22, 2015

Tina Shockley  
Education Associate – Policy Advisor  
Department of Education  
401 Federal Street, Suite 2  
Dover, DE 19901

**RE: 18 DE Reg. 759/14 DE Admin. Code 1105 [DOE Proposed School Transportation Regulation (April 1, 2015)]**

Dear Ms. Shockley:

The Governor's Advisory Council for Exceptional Citizens (GACEC) has reviewed the Department of Education (DOE) proposal to adopt some discrete amendments to its regulation covering school transportation. The synopsis (p. 760) indicates that the amendments are prompted by changes in the Delaware Code in the following contexts: 1) maximum age of school bus; 2) criminal background checks for drivers and aides; 3) in-service training for drivers and aides; 4) annual physical for school bus aids; and 5) district disbursements. The GACEC would like to share the following observations.

First, it is difficult to determine which standards apply to charter schools. For example, §2.1 indicates that charter schools and districts are responsible for implementing a list of responsibilities. However, the list in some cases literally only applies to districts. See, e.g., §§2.1.7, 2.1.8, 2.1.13, 2.1.17. Criminal background checks and/or in-service training are apparently not required for charter school bus aides (§§2.1.8, 7.1.2.2, 7.1.3, 7.1.5, 7.1.6, 7.1.7, and 7.2.) This conflicts with 14 DE Admin Code 745.3.1. Criminal background checks are apparently not required for charter school bus drivers (§§6.8.4 and 6.8.6). This also conflicts with 14 DE Admin Code 745.3.1. Safety standards (§9.1) do not apply to charter schools. Transportation benefit standards sometimes only refer to districts (§§11.1, 11.3, 11.6.1) and sometimes include charter schools (§§11.9, 12.2.1.1, and 12.6.2). Standards requiring bi-annual re-inspections by the Division of Motor Vehicles (DMV) do not apply to charter school buses (§21.0).

Second, in §2.1.16, DOE may wish to define 'significant'.

Third, there is some tension between §§5.3.2 and 5.5.2. The former requires new applicants for CDSBD trainers to “not have more than three (3) points in the past three years”. The latter requires renewing CDSBD trainers to have “no more than three (3) points on their driving record”. Thus, the standard for recertification is more liberal than the standard for initial qualification. It is possible that this is intentional but the DOE may wish to evaluate the justification for maintaining different standards.

Fourth, the regulation periodically capitalizes “district”. See, e.g., §§6.8.6 and 9.1. The DOE may wish to review the regulation to ensure uniformity in references.

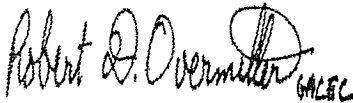
Fifth, in 6.8.6, Council asks that DOE consider modifying the language to clearly require the driver to provide a copy of the letter from the DMV to the public school or district.

Sixth, the grammar in §7.1.2.2 is incorrect. In the first sentence, consider deleting “be sent”.

Seventh, the regulation is inconsistent in sometimes authorizing supports based on an IEP or Section 504 plan and sometimes only authorizing supports based on an IEP (excluding a Section 504 plan). Compare §§9.16, 17.1.7, and 22.1. Transportation is a related service under Section 504 and includes transportation to and from residential programs. See 34 C.F.R. §§104.33(c).

Thank you for your consideration of our observations. Please contact me or Wendy Strauss at the GACEC office if you have any questions.

Sincerely,

Handwritten signature of Robert D. Overmiller in cursive, with the acronym "GACEC" written in small letters at the bottom right of the signature.

Robert D. Overmiller  
Chairperson

RDO:kpc

CC: The Honorable Mark Murphy, Secretary of Education  
Dr. Teri Quinn Gray, State Board of Education  
Mr. Chris Kenton, Professional Standards Board  
Susan Haberstroh, Department of Education  
Mary Ann Mieczkowski, Department of Education  
Paula Fontello, Esq.  
Terry Hickey, Esq.  
Ilona Kirshon, Esq.



STATE OF DELAWARE  
STATE COUNCIL FOR PERSONS WITH DISABILITIES  
MARGARET M. O'NEILL BUILDING  
410 FEDERAL STREET, SUITE 1  
DOVER, DE 19901

VOICE: (302) 739-3620  
TTY/TDD: (302) 739-3699  
FAX: (302) 739-6704

MEMORANDUM

DATE: April 29, 2015

TO: Ms. Kelly McDowell, DFS  
Office of Child Care Licensing

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

RE: 18 DE Reg. 778 [DFS Proposed Early Care & Education & School-Age Centers Regulation]

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Services for Children, Youth and Their Families/Division of Family Services (DFS)/Office of Child Care Licensing's proposal to amend its *DELCARE Rules for Early Care and Education and School-Age Centers* regulation. The proposed regulation was published as 18 DE Reg. 778 in the April 1, 2015 issue of the Register of Regulations. SCPD commented on earlier proposed versions of this regulation published in June [17 DE Reg. 1156 (6/1/14)] and December, 2014 [18 DE Reg. 438 (12/1/14)]. DFS has now incorporated changes into a new proposed regulation. SCPD has the following observations on the proposed regulations.

First, Section 3.3.7 identifies certain school-based programs as exempt. However, §7.2 requires school-based programs operated by non-employees of the school to be licensed. For clarity, a reference to §7.2 should be included in §3.3.7. Otherwise, someone reviewing the exemption section could interpret §3.3.7 as exempting school-based programs regardless of operation by non-employees of the school. For example, the reference to "(t)his exclusion shall include all programs operated by these schools" could be interpreted as covering a situation in which the school contracts with a third party to provide the child care program.

Second, in §4.0, definition of "Section 504 Plan", SCPD recommends inserting "with a disability" between "child" and "to".

Third, Section 13.3.2 requires a licensee to notify OCCL if a child is injured "while in the care of the center when the center is informed the child required medical/dental treatment". See also §61.3. SCPD has a few concerns with this standard.

A. It provides an incentive to "hide" or "not treat" an injury since reporting is not required if the child does not receive medical treatment. Concomitantly, it provides an incentive not to ask a parent if a child were treated "off-site" since that would "trigger" the reporting requirement.

B. The term "medical treatment" is unclear and a licensee who wishes to avoid attention/scrutiny may interpret the reference to only apply to treatment by a physician. The regulations note that some centers will have a registered nurse (§55.0). If the R.N. treats a wound or injury, does this qualify as "medical treatment" triggering the reporting requirement? Licensees are required to provide "first aid" (§§34.0 and 61.0). Does provision of "first aid" qualify as "medical treatment"? Section 61.1.2 appears to differentiate between "first aid" and "medical care".

Fourth, Sections 13.3.5 and 60.5 require licensees to report medication errors (including administering drug to wrong child or administering the wrong dose) only if the error "results in medical treatment". This is an imprudent approach. Comparable regulations require reporting of errors which result in discomfort or jeopardize health. See, e.g. 16 DE Admin Code 3310.2.0 (definition of "reportable incident"); 16 DE Admin Code 3301, 2.0 (definition of "reportable incident"). Adopting a "medical treatment" "trigger" for reporting also provides a licensee with a disincentive to refer a child for medical treatment to avoid attention/scrutiny. By analogy, §60.5 requires immediate reporting of medication errors to a parent regardless of manifest harm or need for medical treatment. Finally, §§13.3.5 and 60.5 are not consistent. The former requires a written report within 3 business days while the latter does not.

Fifth, in its June and December commentary, the Council recommended adding extended physical restraint to the list of reportable "events". This has not been incorporated into the latest proposed regulation. For example, while mechanical restraint is banned (§65.5.6), there are no standards for "physical" restraint which could theoretically last for extended periods without triggering a report to the OCCL. Obviously, some immediate physical restraint to prevent injury or elopement may be appropriate. However, use of physical restraint for extended periods should be reportable.

Sixth, there is no limit on certain forms of physical restraint. By analogy, IBSER regulations ban prone (face-down) restraint and seated basket holds. See 16 DE Admin Code 3320.20.11. Some limits could be included in §65.0.

Seventh, DFS added a reference to the ADA and DEAL to §14.2 per the Councils' earlier recommendations. SCPD endorses this provision.

Eighth, Section 27.3.3 refers to the "GED Test". The Department of Education changed its

“GED” regulation and the current reference is “secondary credential assessment” which encompasses a GED and alternatives. See 17 DE Reg. 469 (11/1/13) (proposed); 17 DE Reg. 724 (1/1/14) (final). In other sections, the regulation refers to “high school diploma or equivalent recognized by Delaware Department of Education”. See, e.g., §§27.7.1 and 77.2.1.

Ninth, Section 27.10.1 has a plural pronoun (they) with a singular antecedent (intern). Consider substituting “the intern is” for “they are”.

Tenth, SCPD endorses Section 28.6 since it deters staff participating in “personal activities which would interfere with providing care to children”. One of the most prevalent sources of “inattention” may be cell phone use. At a minimum, the regulation could be amended to explicitly require licensees to adopt a policy on cell phone use. For example, the following third sentence could be added to §28.6: “Without limitation, each licensee shall adopt and implement a written policy on direct-care staff cell phone use during hours of operation.”

Eleventh, Section 36.13 categorically bans use of “portable wading pools”. The rationale for such a ban is not intuitive. If it’s hot, toddlers and pre-schoolers would ostensibly benefit from playing in a small inflatable or soft-sided pool. It would be helpful if the Division could explain the rationale regarding the categorical ban regarding “portable wading pools”. In addition, the Division may want to consider additional language which would require staff to be present in this context.

Twelfth, in §36.17, last sentence, the reference should be to “below 60 degrees F and above 90 degrees F”.

Thirteenth, the Council previously objected to allowing children to ride bikes with wheels below 20 inches in diameter without a helmet. Section 41.0 could still be interpreted as exempting children from wearing a helmet if the wheels are less than 20 inches in diameter. This would violate Title 21 Del.C. §4198K.

Fourteenth, the Council previously objected to the ratio of toilets to children/staff. The new regulation (§43.2) is worse than the December version. For school age children, the December regulation had a toilet to child ratio of 1:15. The latest regulation has a toilet to child ratio of 1:25. As noted previously, the ratio should be lowered.

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

cc: Ms. Vicky Kelly  
Brian Hartman, Esq.  
Governor’s Advisory Council for Exceptional Citizens  
Developmental Disabilities Council



**DELAWARE HEALTH  
AND SOCIAL SERVICES**  
DIVISION OF MEDICAID AND  
MEDICAL ASSISTANCE

May 5, 2015

Brian J. Hartman  
Disabilities Law Program  
Community Legal Aid Society, Inc.  
100 West 10<sup>th</sup> Street  
Suite 801  
Wilmington, Delaware 19801

Subject: Delaware's Statewide Transition Plan for Home and Community-Based Settings

Dear Mr. Hartman:

Delaware Health and Social Services/Division of Medicaid and Medical Assistance (DHSS/DMMA) appreciates your sincere and thoughtful comments on Delaware's Statewide Transition Plan for Home and Community-Based Settings. DMMA considered all comments received from the public in preparing the statewide transition plan. The statewide transition plan including a summary of public comments received and the agency's response is available on the DMMA website at: <http://dhss.delaware.gov/dmma/>.

We acknowledge your specific comments and offer the following in response:

1. **Comment:** At the outset, the advertised time period for public comment does not meet the federal standard. The relevant CMS regulation requires "at least a 30-day public notice and comment period" [42 C.F.R. §441.710(a)(1); 79 Fed Reg. 3033 (January 16, 2014)]. In contrast, the attached excerpt from the DHSS Website (downloaded on February 9, 2015) recites that "(c)omments must be received by 4:30 p.m. on March 6, 2015." Since there are only 28 days in February, posting on February 6 would not result in a 30-day comment period if due by March 6. The Plan itself (p. 8) contemplates a comment "estimated end date" of March 9.

**Response:** The end of the public comment period was revised to March 9, 2015. DMMA accepted comments up through this date, in compliance with the federal requirement for a minimum 30-day public notice and comment period. DMMA looks forward to providing additional opportunities for public comment as the Plan is implemented.

2. **Comment:** DMMA has opted to not include the Pathways and PROMISE programs within the scope of the Plan (p. 3) since the programs were previously approved by CMS after issuance of the January, 2014 CMS regulations. I question the compatibility of this approach with the general CMS view that the plan will detail "how the State will operate all section 1915(c) waivers and any section 1915(i) State plan benefit" [42 C.F.R. §441.710; 79 Fed Reg. 3034 (January 16, 2014)]. Even if not required, it may be conceptually preferable to have a single, integrated plan covering the waivers to promote a consistent approach rather than multiple plans.

**Response:** Centers for Medicare & Medicaid Services (CMS) has made it clear in several venues that the Plan requirements prescribed in the HCBS final rule (the Rule) apply to the existing HCBS programs operating as of the effective date of the final rule, March 17, 2014. All new programs are required to meet the requirements effective upon approval. For example, section 441.710(a)(3)(i) of the Rule notes: "States submitting state plan amendments for new section 1915(i) of the Act benefits must provide assurances of compliance with the requirements of this section for home and community-based settings as of the effective date of the state plan amendment." Furthermore, in negotiations with CMS regarding approval of both the Pathways and PROMISE programs, CMS notified DMMA that the programs would not be approved unless all requirements of the HCBS final rule, including requirements for HCB settings, were first met. These programs have been approved by CMS. The quality assurance sections of the Pathways application approved by CMS include measures to monitor the ongoing compliance of program services and settings with the Rule.

3. **Comment:** The CMS regulations stress the importance of the "person-centered planning process" [42 CFR §441.301]. The Plan contains some brief references to a "person-centered plan" (pp. 3, 12). The Plan would benefit from the incorporation of more specifics on revamping the current DDDS ELP plans and DSHP care plans to conform to the federal standards. At a minimum, the matrix on pp. 18-19 could specifically highlight the "person-centered planning process" as one of the core state policies meriting review.

**Response:** The Essential Lifestyle Plan (ELP) is considered a best practice for person-centered planning for persons receiving HCBS. The ELP has been in continuous use by DDDS since 1998. The Rule makes it clear that the expectation is that states must already be compliant with the requirement for person-centered planning as of March 17, 2014, the effective date of the Rule. Since DDDS is already compliant with this requirement, there is no need to address it in the Transition Plan. DDDS continues to refine the ELP process, as the needs of our population change. In addition, DMMA's existing contract with the MCOs require the MCOs to use a person-centered planning process in developing a member's DSHP Plus LTSS case management plan, clinical care coordination plan, or Money Follows the Person transition plan.

4. **Comment:** On p. 3, the State recites that it is listing "the service definition from the approved waiver". This is not entirely accurate. For example, the "definitions" of "prevocational services", "day habilitation" and "residential habilitation" are partial excerpts from the attached (pp. 40-45) service definitions in the DDDS waiver. "Transportation" references included in the DDDS waiver service definitions have been uniformly omitted from definitions in the Plan. This suggests that transportation will not be addressed in the Plan. Waiver-funded transportation should be included in the Plan. For example, use of integrated transportation (taxi; bus; mileage reimbursement) may be preferable to use of para-transit or an identified van with only riders with disabilities.

**Response:** The language provided in the Plan are excerpts from the approved service definitions intended to convey the intent of the definition. Transportation is not a stand-alone service under the DDDS waiver; it is a component part of residential habilitation, day habilitation and prevocational services, as allowed by CMS. Transportation will be evaluated in the context of whether it facilitates the ability of consumers to access resources in the community.

5. **Comment:** The State identifies an "oversight body" comprised of representatives of five (5) DHSS divisions (p. 8). I recommend adding the State Council for Persons with Disabilities to the "team". It is a State agency charged with reviewing "all state policies, plans, programs....concerning persons with disabilities...conducted or assisted...by state departments' and making "recommendations to...all state departments...respecting ways to improve the administration of services for persons with



disabilities and for facilitating the implementation of new or expanded programs." See attached 29 Del.C. §8210.

**Response:** DMMA agrees to take a look at the composition of the oversight body and add members as needed. We will also consider smaller work groups.

6. **Comment:** The Plan (p. 8) mentions that the "oversight body" will meet "regularly". This is unduly obtuse. It would be preferable to at least include a minimum schedule (e.g. quarterly; monthly).

**Response:** The Plan was updated to include that the Cross-Agency Oversight Body will meet at a minimum monthly but will meet more frequently if necessary depending on the task at hand.

7. **Comment:** On p. 10, the first "bullet" refers to "State laws, regulations, policies, etc. and provider policies". I recommend specifically including "budgets". If funds or incentives are disproportionately allocated to restrictive or non-integrated settings, the Plan is undermined. Elsewhere, the Plan acknowledges the prospect of budgetary changes: To the extent that remediation strategies have financial implications for the providers and for the State, budget strategies may need to be developed. At p. 15.

Review DSHP rates for adequacy to support the requirements of the Rule (especially related to smaller staffing ratios in day programs).

Include a budget strategy related to any necessary changes to rates. At p. 22.

**Response:** Delaware's reimbursement methodology for HCB services under the DDDS waiver is based on the wage scale for the direct support workers providing the HCB services and related costs. Rates are the same for all providers and there are no incentive payments. The DMMA budget for HCBS is currently adequate to fund the services at current payment rates. If the rates need to be adjusted in order to pay for a change in the way services are delivered, additional funds can be requested at that time.

8. **Comment:** The State (p. 10) recites as follows: "As available, NCI data will be analyzed by type of residence in order to identify non-compliance with HCB settings." The NCI data also addresses vocational and employment settings. See attachment. Therefore, it would be preferable to also "mine" the NCI data for information on vocational and employment settings.

**Response:** DDDS intends to utilize the NCI data to the greatest extent possible to assist with the assessment of services and settings against the Rule.

9. **Comment:** On p. 10, the Employment First Commission should be added as a source of information and analysis. Per 19 Del.C. §747, the Commission reviews and analyzes data on employment of persons with disabilities. Apart from the NCI data, the Commission may have supplemental information to assist with assessment of access to integrated, competitive employment.

**Response:** As the Employment First Commission develops outcome data, it will be incorporated into the process used to evaluate employment services.

10. **Comment:** The references to "Governor's Advisory Council" (p. 10) and "GAC" (seriatim) are not apt. The current statute (29 Del.C. §7910) refers to the "Advisory Council to the Division of Developmental Disabilities Services".

**Response:** We have made the necessary modifications to the Plan.

11. **Comment:** On p. 11, the following sections of the Delaware Code should be added to the review:
- a. Collaborative Team law (codified at 14 Del.C. §3124) since "review will include Employment First Act (codified at 19 Del.C. §§740-747), since it overlaps with CMS standards;
  - b. DDDS enabling law (codified at 29 Del.C. §7909A);
  - c. DDDS Advisory Council enabling law (codified at 29 Del.C. §7910) since it is given a central role in assessment;
  - d. Interagency residential and non-residential settings out of state for which waiver funds are currently being used" (pp. 14 and 34);
  - e. Nurse Practice Act (codified at 24 Del.C. Ch. 19) since restrictions impact settings in which residents receive services; and
  - f. Community-based Attendant Services Act (codified at 16 Del.C. Ch. 94) since DDDS receives funds under Act and Plan mentions at p. 26.

**Response:** The list included in the Plan was not intended to be exhaustive. All relevant Administrative codes will be reviewed during the assessment.

12. **Comment:** On p. 11, the following "Administrative Code" provisions should be added:
- a. IBSER regulations (16 DE Admin Code 3320) which cover AdvoServ; and
  - b. Family Care Home regulations (16 DE Admin Code 3315) which may cover shared living providers; and
  - c. PASRR regulations (16 DE Admin Code 20000).

**Response:** The list included in the Plan was not intended to be exhaustive. All relevant Administrative codes will be reviewed during the assessment.

13. **Comment:** On p. 12, policies to be reviewed should include PROBIS and HRC. The relevant CMS regulation (42 C.F.R. 441.530) addresses privacy and freedom from coercion and restraint. Both the PROBIS and HRC are the main DDDS components protecting such rights. See attached, excerpt (pp. 100-101) from DDDS Waiver.

**Response:** The policies referenced are included in the list of "DDDS policies" that will be reviewed against the Rule during the assessment.

14. **Comment:** The Plan is inconsistent in sometimes referring to a single GAC work group (p. 12; p. 14) and sometimes referring to multiple GAC work groups (p. 10 at top; p. 20 at bottom). I believe the Plan contemplates the Council acting as a "steering committee" with the authority to establish multiple subcommittees.

**Response:** We agree with this comment. The first paragraph on page 10 of the Plan was clarified to note that the GAC is intended to operate as a steering committee.

15. **Comment:** The Plan should include standards for the composition of the Council subcommittees/work groups to promote objectivity and absence of conflicts. The Plan suggests (p. 42) that DDDS envisions including a single provider representative on the assessment subcommittee. However, there is nothing in the Plan which would preclude establishment of a subcommittee comprised of a high percentage of providers who may have a vested interest in adopting an anemic assessment instrument. The membership of the subcommittees would ostensibly not be limited to the

small (7 member) Council membership. Perhaps the Council could vote to establish a protocol in which the Council chair and DDDS director would jointly appoint the members of the subcommittees. Alternatively, the Plan could include some explicit membership standards to ensure the objectivity of the subcommittees. It would also be prudent to include one or more DDDS employees on the subcommittees.

**Response:** We agree with this comment. The GAC will determine the composition of the working groups. It is our expectation that the groups are representative of the major stakeholder groups. We have added language to the Plan to this effect. DDDS employees will attend all GAC and GAC working group meetings both to act as staff to the group and also to provide expertise.

16. **Comment:** On p. 13, first paragraph, and p. 19, top entry, the implication is that providers will submit a corrective action plan contemporaneously with their self-assessment results. However, the Plan (p. 22) gives them 90 days to prepare a corrective action plan which then must be reviewed and approved by the State. The 90-day period is ostensibly too long to simply develop a corrective action plan. I recommend a 30-day period.

**Response:** We agree with this comment. We have modified the Plan to indicate that the Corrective Action Plan must be submitted within 30 days.

17. **Comment:** The Plan (p. 13) contemplates a Council subcommittee conducting "look- behind" reviews of a sample of provider self-assessment results. The Plan also envisions the Council developing "dispute resolution processes for the findings". I recommend that DDDS develop and implement the dispute resolution processes. The Advisory Council should not be cast the role of arbiter of such disputes. Disputes and appeals should be handled by DDDS and DMMA. Cf. reference on p. 14: "An appeal process will be developed to dispute the State's findings of noncompliance." The DDDS Office of Quality Improvement is identified (p. 15) as the agency which monitors compliance with the Community Rule for providers with and without a corrective action plan.

**Response:** We agree with this comment and have made the necessary modifications to the Plan (on pages 14, 15, and 16).

18. **Comment:** On p. 13, second paragraph, fourth sentence, substitute "indicate" for "indicates".

**Response:** We agree with this comment and have made the necessary modifications to the Plan.

19. **Comment:** On p. 13, in the first set of bullets, I recommend including IBSER group homes which are not neighborhood group homes. The IBSER regulations (§6.2.1) "grandfathered" residences with more than ten residents and the only agency regulated by the IBSER regulations operates its own PROBIS which reduces oversight.

**Response:** The list included in the Plan was not intended to be exhaustive. All relevant sections of the Administrative Code will be reviewed during the assessment.

20. **Comment:** On p. 13, final bullet, I recommend modifying the reference to read "(i)nformed consent of the individual or legal representative. See 42 C.F.R. §441.301(1).

**Response:** We agree with this comment and have made the necessary modifications to the Plan.

21. **Comment:** On p. 17, last entry, the reference to "charter" is odd. Councils do not create "charters". The deadline (March 17, 2015) to develop the operational standards is also too short.

**Response:** Because the Plan is requesting the GAC to perform a role that is specific and time-limited and is somewhat different than what it is supposed to do under Title 29 of the Delaware Code, we felt that it was important to define that role via a Charter or other similar document.

22. **Comment:** There are some inconsistencies in the time periods in the matrix. The following are examples.

A. On p. 18, development of the self-assessment instrument has a proposed end date of 4/24/15. On p. 20, development of the self-assessment instrument has an end date of 5/31/15. On p. 21, development of the self-assessment instrument has an end date of 5/31/15.

**Response:** The provider self-assessment tools described on pages 18 and 20 & 21 are different tools. The tool described on page 18 with a due date of 4/24/15 is the tool for providers to assess their policies and procedures, etc. The tools for which the due date is 5/31/15 is for the providers to use to assess their actual settings.

B. On p. 18, last entry, providers have a 7/31/15 end date to complete their self-assessment. In contrast, p. 21 indicates that only 3 providers will complete the assessment as a pilot to identify "bugs" in the survey instrument by 7/15/15 and a revised survey instrument will be developed by 8/15/15.

**Response:** The survey tool on p. 18 with the due date of 7/31/15 is related to the provider policies and procedures. The survey tool referred to on page 21 is to assess the individual settings. They are two different survey tools.

23. **Comment:** On p. 19, there is a 2/28/16 end date to complete a "look-behind" review of a 20% sample of the provider self-assessments. In contrast, on p. 21, final entry, there is an 8/31/16 end date to review a 20% sample of provider self-assessments.

**Response:** The tool referred to on p. 19 with the due date of 2/28/15 is related to the provider policies and procedures. The tool referred to on page 21 with the 8/31/15 due date is related to the HCB settings.

24. **Comment:** On p. 20, there are references to changing policies but no references to changing statutes and regulations which will be reviewed per p. 11.

**Response:** We have made the necessary modifications to the Plan to address this inconsistency.

25. **Comment:** Pages 22-23 contemplate DDDS submission of waiver amendments to CMS. I believe DMMA, as the Delaware Medicaid agency, submits such amendments.

**Response:** You are correct. We have modified the Plan to clarify that DMMA will submit any amendments to CMS.

26. **Comment:** On pp. 25 and 34, the Plan recites that "DMMA will consider using its External Quality Review Organization (EQRO) to develop the surveys." This is a rather tentative feature to incorporate in a Plan and suggests that the State is unsure how it will develop the instruments.

**Response:** The reference to using the EQRO conveys that the State is exploring all possible options to determine the most appropriate course of action for developing the surveys.

27. **Comment:** On p. 25, the State identifies the Governor's Commission on Community-Based Alternatives for Individuals with Disabilities as the primary stakeholder group to inform the decision-making regarding assessments. My impression is that the Commission meets rather infrequently. Moreover, there is no "end date" for confirming the Commission's role as the advisory body for the assessment process (pp. 31-32).

**Response:** We agree with this comment and have made the necessary modifications to the Plan. DMMA has discussed with the Commission the importance of their role in implementing the Plan and the need to meet more frequently. The February 23 date is intended to serve as the start and end date for this task.

28. **Comment:** On p. 27, I recommend adding the Nurse Practice Act, 24 Del.C. Ch. 19, to the list of Delaware Code provisions to review.

**Response:** The list included in the Plan was not intended to be exhaustive. All relevant Administrative codes will be reviewed.

29. **Comment:** On p. 27, the Plan envisions MCOs distributing surveys to network providers. I question whether such providers will complete the surveys. Query what incentives exist for providers to complete the surveys? Medicaid MCO reimbursement rates are low and providers may want to be paid for their time. Concomitantly, the Plan has no benchmark for the percentage of providers who will complete the surveys. Will 30%, 50%, or 70% be sufficient?

**Response:** We agree with this comment and have modified the Plan to note that benchmarks will be established in addition to creating a process for following up with providers failing to meet requested response timeframes.

30. **Comment:** On p. 27, the Plan contemplates providers participating in training to learn how to complete the surveys. Consistent with the preceding comment, what incentive exists for providers to participate in the training.

**Response:** We agree with this comment and have modified the Plan to note that DMMA will take into consideration the need for incentives.

31. **Comment:** On p. 27, the Plan envisions participants completing surveys. No incentives are identified. Will a 30%, 50%, or 70% submission rate be sufficient? A benchmark should be identified and incentives considered.

**Response:** We have modified the Plan to note that benchmarks will be established in addition to creating a process for following up with providers failing to meet requested response timeframes.

32. **Comment:** On p. 28, second set of bullets, I recommend inserting a reference to revising "budgets".

**Response:** We agree with this comment and have made the necessary modifications to the Plan.

33. **Comment:** On p. 29, "fair hearing results" could be added to the list of information related to MCO performance.

**Response:** We have modified the Plan to add analysis of fair hearing results to the list of potential compliance monitoring activities.

34. **Comment:** It is unclear how Logisticare, the Medicaid transportation broker, will be assessed for compliance with the HCBS Rule. Consistent with Comment #4 above, transportation can be integrated or segregated.

**Response:** Only those services provided in either a non-residential or residential HCB setting, per CMS expectations, are addressed in the Plan. Transportation services do not fall into this category. As noted in response to comment #4, transportation will be evaluated in the context of whether it facilitates the ability of consumers to access resources in the community.

35. **Comment:** On p. 32, the reference to the Commission creation of a "charter" is odd. A Commission does not create a "charter".

**Response:** Because the Plan is requesting the GAC to perform a role that is specific and time-limited and is somewhat different than what it is supposed to do under Title 29 of the Delaware Code, we felt that it was important to define that role via a Charter or other similar document.

36. **Comment:** The Plan (p. 33) contemplates providers competing remediation strategies if they determine, via a self-assessment, that they are not in compliance with the HCBS Rule. I question the use of the term "remediation strategy". The DDDS requirement of a "corrective action plan" (p. 13) is a more precise term and implies that a more formal document would be completed. Moreover, the Plan (p. 36) uses the term "corrective action plan". I recommend deletion of references to "remediation strategy" and substitution of "corrective action plan" for consistency. There is no requirement (p. 33) that provider "remediation strategies" be shared with DMMA. It would obviously help DMMA assess MCO conformity with the Plan if the MCOs shared the "remediation strategies" submitted by providers with the State. The Plan (p. 36) otherwise envisions DMMA monitoring of provider "corrective action plans". Even this is a less strident standard than adopted for DDDS providers. DDDS must approve provider corrective action plans (p. 13) but there is no analogous requirement that DMMA approve provider corrective action plans (p. 36).

**Response:** We agree with this comment and have modified the Plan to refer to corrective action plan as appropriate.

37. **Comment:** On p. 33, the Plan includes a proposed end date of "9/31/15". There are only 30 days in September.

**Response:** We have corrected the Plan.

38. **Comment:** On p. 34, first entry, there is a "disconnect" between the action item (changing policies and procedures) and the proposed end date (a vague "legislative timeframe"). There is no proposed end date for completion of State policy changes.

**Response:** We have added language to the Plan indicating that any changes requiring legislative action must be taken before March 17, 2019.

39. **Comment:** On p. 35, the Plan contemplates a 5-month period (10/1/15 to 2/29/16) for providers to conduct a self-assessment and participants to complete participant surveys. This period is unnecessarily long.

**Response:** We agree with this comment and have made the necessary modifications to the Plan to shorten the time period for completion of the participant self-assessment.

40. **Comment:** While DDDS conducts a pilot of its survey (p. 21), DMMA conducts no pilot. DMMA could reconsider this aspect of the Plan.

**Response:** The DSHP portion of the Plan has been modified to incorporate a pilot survey (page 38).

41. **Comment:** At the outset, I anticipate that some groups may prefer a restrained plan designed to either maintain the status quo or authorize Medicaid funding of questionable settings. I encourage the State to incorporate robust assessment standards which do not merely pay "lip service" to the CMS guidance but demonstrate that the State wholeheartedly embraces the underlying values reflected in the guidance.

**Response:** We are committed to developing a robust process, including assessment standards. We believe that the approach as outlined in the Plan positions us to do just this.

42. **Comment:** The Plan contemplates both provider and State development of "remediation strategies" to address identified shortcomings. At p. 33. This "targeted" approach to "fixing" specific instances of non-conformity with CMS standards is a logical component of the Plan. However, the Plan could be strengthened through identification of systemic initiatives designed to increase the State's capacity to offer an array of conforming settings. This would be particularly informative in the context of employment... Rather than waiting to "react" to identification of shortcomings identified through self-evaluation, other states are increasing the capacity of integrated employment opportunities NOW.

**Response:** DMMA is committed to providing a wide range of available HCBS. We point you to the Pathways and the PROMISE programs as examples of our commitment to develop and increase meaningful opportunities for employment for Medicaid eligible persons.

43. **Comment:** The Plan envisions the Department engaging in a "look-behind" review of a 20% sample of provider self-assessments of policies and procedures. At pp. 6 and 13. The Plan contemplates completion of these reviews by a single "sub-working group of the GAC". At p. 6. Realistically, even if the 7-member DDDS Advisory Council assembles a "working group" with some additional members, it may be hard-pressed to conduct a meaningful "look-behind" of numerous providers which operate multiple programs. Moreover, the Plan could be strengthened by clarifying that the "look-behind" is not comprised solely of a marginally effective "paper" review. The "look-behind" should include on-site observation and interviews with program staff, participants, and their representatives (including family members).

**Response:** We agree with this comment. The Plan indicates that the GAC may create one or more sub-working groups to conduct specific activities under the Plan. It is our expectation that the look-behind reviews will be conducted on site. We have added language to the Plan indicating this.

44. **Comment:** The Plan contemplates use of participant surveys to gather information (p. 27) as well as survey-based NCI data (p. 3). As a supplement to this planned assessment process, the State could consider establishing an on-line survey tool (e.g. through Survey Monkey) to allow individuals the opportunity to comment on specific programs. Some individuals may be more comfortable with the ease and anonymity of completing an on-line survey and the questions could be more targeted to CMS standards than the NCI survey.

**Response:** We will explore the use of an online survey tool as an option for responding to the participant survey.

DMMA values your input and will continue to engage stakeholders and solicit feedback during the transition process, including review of the assessment tool, remediation strategy, and changes to Medicaid policies that are created as part of the transition process.

Thank you for sharing your comments and concerns on this important issue.

Sincerely,

A handwritten signature in cursive script that reads "Sharon L. Summers".

Sharon L. Summers  
Social Service Administrator

Cc: Stephen M. Groff, Director, DMMA



MAY 12 2015



**DELAWARE HEALTH  
AND SOCIAL SERVICES**  
DIVISION OF MEDICAID AND  
MEDICAL ASSISTANCE

May 5, 2015

Daniese McMullin-Powell  
Chairperson  
State Council for Persons with Disabilities  
O'Neill Building  
410 Federal Street  
Suite 2  
Dover, Delaware 19901

Subject: Delaware's Statewide Transition Plan for Home and Community-Based Settings

Dear Ms. McMullin-Powell:

Delaware Health and Social Services/Division of Medicaid and Medical Assistance (DHSS/DMMA) appreciates your sincere and thoughtful comments on Delaware's Statewide Transition Plan for Home and Community-Based Settings (the Plan). DMMA considered all comments received from the public in preparing the Plan. The Plan, including a summary of public comments received and the agency's response, is available on the DMMA website at: <http://dhss.delaware.gov/dmma/>.

We acknowledge your specific comments and offer the following in response:

1. **Comment:** The State has committed to strong and ongoing engagement of stakeholders. In addition to taking and incorporating public comment into the creation of the Statewide Transition Plan (p.39-42), the plan specifically incorporates stakeholder groups, the Governor's Advisory Council (for the 1915(c) Waiver) and the Governor's Commission on Building Access to Community Based Services, as a steering committee for the implementation of the rule. However, consistent with the DLP commentary, SCPD recommends that it be added to the list on p. 8 and p. 31 regarding the "oversight body". SCPD staff noted its willingness to collaborate with the Governor's Commission regarding this issue at the Commission's recent February 20th meeting. These stakeholder groups will help develop assessment instruments and protocols (p.10, 25). The state will continue to seek stakeholder input throughout implementation (p.7). The plan recognizes that it provides only "high level" review and that "[m]oving forward, the specific approach and details surrounding each program will be further defined and will reflect the input and guidance of the particular program's stakeholders." (p. 7)

**Response:** It is our intent to include as wide a representation of stakeholders as possible in the implementation of the Plan. The Cross-Agency Oversight Body is one forum for stakeholder engagement intended to bring together state agencies with direct responsibility for implementing parts of the Plan. We will continue to evaluate membership on the Cross-Agency Oversight Body as implementation of the Plan rolls out.

2. **Comment:** The Plan uses multiple sources of information to assess compliance with the rule. In addition to using provider self-assessments (which will require documentation by providers, such as from written policies and training curricula), the state will also utilize NCI data (which includes participant interviews) as part of the analysis of settings in the DDDS 1915(c) Waiver and will incorporate feedback from participants receiving care. A sub-work group of the Governor's Advisory Council will conduct "look behind" review of a sample of provider selfassessments to validate for the DDDS 1915(c) Waiver (p.12). In addition, if a provider selfassessment is normal, but NCI data raises concerns, the DDDS 1915(c) setting will be selected for a "look behind review" even if it was not part of the selected sample (p.13).

**Response:** We agree with this comment and believe it is important to have multiple sources of information in the assessment process.

3. **Comment:** The time line the state has established seems very extended. The time line estimates that remediation strategies will not be implemented until February and May of 2017, leaving barely two years for the actual implementation, including the relocation of any individuals from settings that prove unable to come into compliance. SCPD urges Delaware to move more quickly and give the HCBS service system more time to reach compliance by 2019.

**Response:** We agree with this comment and have made the necessary modifications to the Plan. Provider corrective action plans (CAPs) can begin immediately after DMMA approval, which will occur within 30 days of receiving the CAP. Implementation of statewide remediation activities will begin in 2016.

4. **Comment:** The Plan does not discuss a relocation process for individuals who are being provided services in settings that cannot come into compliance with the regulations. This is an important process to establish early.

**Response:** We modified the Plan (on pages 19 and 34) to reference a relocation process and to note that the relocation process will be tailored to each individual, and that DMMA/DDDS will work with the individual and his/her family/caregiver, provider, etc. to develop a smooth transition process that will protect the health and welfare of participants through the process.

5. **Comment:** The Plan does not appear to verify compliance through on-site visits. It is unclear from the Plan if the look-behind reviews of a 20 percent sample of settings will include on-site visits as part of the assessment process, for either the 1915(c) Waiver or DSHP (SCPD assumes that DSHP will follow the 1915(c) Waiver plan and conduct look-behinds of a 20 percent sample but the plan should clarify this). On-site visits are an important part aspect of any analysis of setting compliance, and SCPD encourages the State to include conducting on-site visits of settings in this look-behind review.

**Response:** We agree with this comment. It is our expectation that the look-behind reviews will be conducted on site. We modified the Plan (on pages 17, 32, and 42) to include this language.

6. **Comment:** There is no discussion of how Delaware will ensure that individuals have a choice of "nondisability specific" setting and private units. The HCBS Rule requires that individuals receiving HCBS services have the choice of a non-disability specific setting (i.e., settings that are not comprised only or primarily of people with disabilities) and of a private room in residential settings. The Plan does not discuss how Delaware will ensure that individuals have that choice. This is a fundamentally important part of the rule and people cannot be offered that choice if there is not capacity. Delaware must evaluate its current capacity of non-disability specific settings and develop a

plan to increase capacity as needed to fulfill this requirement. The lack of capacity of non-disability specific settings is particularly acute for non-residential services, where the majority of the state's current settings are disability-specific.

**Response:** Choice of non-disability settings is an inherent part of the person-centered planning process. This is one of the components of the HCBS final rule that will be reviewed as part of the assessment of State laws, regulations and policies as well as provider practices regarding person-centered planning. DMMA is committed to providing a wide range of available HCBS. As part of the Plan implementation process, available capacity will be evaluated. Factors such as provider rates will be taken into consideration and adjustments made as appropriate.

7. **Comment:** SCPD is unclear why the only stakeholder for the following action items at p. 32 is the Delaware Healthcare Facilities Association:

- Identify HUD Homes and any financial or other terms that impact compliance; and
- Conduct review of Delaware landlord/tenant code vis-a-vis the Rule.

**At a minimum, the SCPD/Governor's Commission Housing Committee should be included as a stakeholder.**

**Response:** It is our intent to include as wide a representation of stakeholders as possible in the implementation of the Plan. See response to comment #1.

8. **Comment:** There are multiple references to the "Governor's Commission on Community Based Alternatives for Individuals with Disabilities". The actual reference should be the "Governor's Commission on Building Access to Community Based Services".

**Response:** We acknowledge the comment but we cannot change the name in that this is the name of the body in Executive Order 50.

9. **Comment:** As Delaware moves forward in its efforts to comply with the CMS Rule, SCPD encourages the State to strictly follow the Olmstead guidance on integrated v. segregated settings and the CMS guidance on settings that have the effect of isolating individuals receiving HCBS from the broader community (both attached). SCPD looks forward to collaborating with the State to implement the requirements of the CMS Rule, in which we believe the spirit is to create real community options for people with disabilities. In addition, during this time of transition, SCPD believes that the spirit of the Rule is not to "leave people on the streets", but to ensure smooth transitions for people with disabilities, families, providers and the State.

**Response:** In providing HCBS, we are held to the requirements of both the Olmstead legislation and the HCBS final rule.

DMMA values your input and will continue to engage stakeholders and solicit feedback during the Plan implementation process, including review of the assessment tool, remediation strategy, and changes to Medicaid policies that are created as part of the transition process.

Thank you for sharing your comments and concerns on this important issue.

Sincerely,



Sharon L. Summers  
Social Service Administrator

Cc: Stephen M. Groff, Director, DMMA

---

## Advocating for Juvenile Justice Reform

By Rep. Mike Barbieri

Our juvenile justice system must not only hold youth accountable for their actions, but also protect children from unsafe environments and help them become productive members of their communities. Prosecuting very young children for minor offenses does not accomplish these goals.

Children under the age of 10 have not developed the mental capacity to understand the consequences of their actions, and many react in response to underlying problems at home or in the community. Our job as a state should be to identify and address these problems, not send these children through the criminal justice system unnecessarily.

Since 2009, 93 children between the ages of seven and nine have been arrested and prosecuted in Delaware. Most offenses were minor, and the vast majority of charges were dismissed or terminated in the child's favor. These cases cost valuable resources that could be better used to help these children.

House Bill 126 would address this problem by prohibiting criminal and juvenile delinquency prosecution of children under the age of 10. As an alternative, these children might

instead be required to participate in programs addressing behavioral issues. This is already a mandate of the state: to provide services to any child believed to be abused, neglected, or in need of mental health treatment.

Our children are the future of Delaware. They deserve every opportunity to fulfill their potential. By connecting these young offenders with the appropriate care, we can help them become citizens who will someday build better communities for their own children.

ng

6-4-10-16

delawareonline.com

Journal  
ewspaper  
s Riddle  
id Publisher  
  
John Sweeney  
Editorial Page Editor

QUOTE OF THE DAY  
*"This has hijacked his entire legislative agenda."*

Historian Douglas Brinkley on President Obama's reputation after the Gulf oil spill

VIEW

# Common-sense approach to school discipline needed

Delaware law requires that all crimes by students 9 and older be reported to police. A new bill, endorsed by the state Senate on Wednesday, raises the age to 12.

Parents across the country have been urging elected officials

## ZERO TOLERANCE

to rethink the wisdom of kicking kids out of school for innocent infractions.

The dismissal of a 6-year-old Downes Elementary School student who had a Cub Scout utensil — part knife, fork and spoon — to eat his lunch with put the national spotlight on Delaware's law. District policy required that the child spend 45 days in an alternative school.

The Christina District Board of Education ultimately overturned that requirement, but not before the state joined the ranks of oth-

ers whose attempts to reduce school crime have appeared laughable.

Other states have recognized the foolishness done by such a blanket approach. Two years ago, Florida lawmakers ordered school boards to first make sure that only students who pose a serious threat are expelled. They removed petty misconduct as grounds for expulsion or arrest.

Last year, Texas started requiring that intent, self-defense, disciplinary history and whether the child has special needs be considered in suspension cases.

Those specific mandates respect the discretion of school officials. But first, let's raise the mandatory age for reporting offenses to police, which House Bill 347 does. It sets a reasonable marker for invoking zero tolerance policies.

AT&T

Chief Executive: Van B. Honeycutt

12-17-96 WJ

B  
S

# Girl, 6, in trouble for 'offensive touching'

By **TERRI SANGINITI**  
Staff reporter

**MIDDLETOWN** — To first-grader Stephanie Martin, it was a harmless love tap on her teacher's rear end.

To Appoquinimink school district officials and the attorney general's office it was "offensive touching," worthy of a possible five-day suspension.

District officials allege that during recess Friday afternoon at Silver Lake Elementary School, 6-year-old Stephanie



Stephanie Martin

poked primary teacher Laurie Wicks in the buttocks.

Wicks reported the incident Monday to principal Gail Quimby, who suspended Stephanie.

Stephanie.

"I'm confused," said Stephanie's mother, Gerrie Martin. "She likes Mrs. Wicks and was doing this as a love pat for attention. And they want to get her for offensive touching."

A 4-year-old state law requires district officials to report to authorities such crimes as offensive touching, assaults, extortions and crimes involving weapons and drugs.

The law was designed to force school districts to involve law enforcement in cracking down on crime in schools. It fines school officials \$250 for a first offense and \$500 for a second offense if they fail to notify authorities.

Appoquinimink school officials said their hands were tied by the law in this case.

"This House Bill 85 is the law of the land and we have to be careful of how it's interpreted," said district Superintendent Tony Marchio.

See STEPHANIE — A4

# Stephanie: 'I told her I'm sorry'

FROM PAGE A1

School officials have allowed Stephanie to remain in school while her mother appeals the suspension. Martin is scheduled to meet with Marchio at 1 p.m. today to discuss the suspension.

"We have to work through situations and do in our heart what's best for the kid. Based on the information, I'm going to do what's right," Marchio said.

State House Education Committee member Rep. Philip D. Cloutier, R-Heatherbrooke, said the law was not designed to apply in cases like this.

"The system here has failed. We should learn from it. We certainly don't hope to engage the Attorney General and state police every time a first-grader has a tantrum."

School officials contacted the attorney general's office, which informed them that the incident with Stephanie and Wicks qualified as offensive touching under the law. However, police had not been called as of Wednesday and Stephanie has not been charged with any crime.

Ronald A. Meade, who oversees student discipline for the state, said, "It's very rare for children in grades K-3 to violate H.B. 85."

"Students in grades K-3 have been exempt except under extraordinary circumstances from being reported from those offenses because they don't understand," Meade said.

Martin said Quimby told her Monday she felt the law should not be applied to youngsters in the first, second and third grade.

Quimby could not be reached Wednesday for comment.

Wicks declined to comment.

Wednesday night because the incident is under investigation.

"Mrs. Quimby said she is devastated with the whole scenario," Martin said. "She considers H.B. 85 inappropriate for first-, second- and third-grade babies. The principal told me herself it would not benefit Stephanie to be suspended."

Since H.B. 85 became law, Cloutier said teachers statewide sometimes resent the mechanics of the law, which requires they report all infractions. However, he said they don't dispute the law's purpose to control discipline in the classroom.

"Nothings suggests [the law] is at fault. People are at fault," he said.

A number of incidents in schools have involved police and resulted in suspensions since the law was passed.

In 1994, a 15-year-old William Penn High School student was expelled from the Colonial School District after he showed up for school with a part of a Halloween costume that resembled a weapon.

This past year, a 5-year-old kindergartner was suspended for three days from Richey Elementary School in Newport after he pulled a 4½-inch knife from his book bag to show students on a school bus. Last month a Burnett Elementary School student in Wilmington was suspended for five days for discharging pepper spray on a crowded school bus. Police were called in each incident.

Martin said Stephanie has been upset ever since she was sent to the principal's office Monday and told she was being suspended.

"She said, 'Mommy, I was only

giving her a love tap, and I told her I'm sorry and I keep getting in trouble.'"

## TODAY'S WEATHER

HIGH LOW

47 40



# First-grader is cleared in 'love tap'

## Sponsor says law wasn't meant for cases like this

By ROBERT MOORE  
Staff reporter

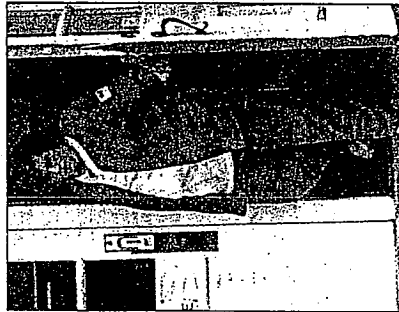
A "love tap" that almost led to a 6-year-old's suspension from first grade has legislators rethinking the law that Appoquinimink school officials blame for their actions.

Still known by its legislative designation, House Bill 85 was drafted in 1993 in response to complaints about school violence and about image-conscious

school administrators who failed to report crimes in their classrooms.

Now, the case of 6-year-old Stephanie Martin, whose mother said she was to be suspended for giving her teacher a "love tap" on the backside to get her attention during recess, has forced even the sponsors of the bill to acknowledge its flaws. Legislators say they will review the law during their next session.

See LAW — A12



The News Journal's LUCK MCGOWEN  
Gerrie Martin leaves Appoquinimink School District headquarters after meeting with superintendent.

## Superintendent blames media

By TERRI SANGINITI  
Staff reporter

ODESSA — First-grader Stephanie Martin, threatened with the wrath of the Appoquinimink School District for giving a teacher a "love tap" on the rear end, Thursday got off with nary a slap on the wrist.

After a 20-minute meeting with District Superintendent Tony Marchio, Stephanie's mother emerged with news the 6-year-old would not be suspended.

Surrounded by reporters outside district headquarters, a grinning Gerrie Martin said, "I set out to

fight for this 6-year-old and I wasn't going to give up. I feel like I've won now. She's going to be OK with this."

After meeting with all parties — teacher Laurie Wicks, who received Stephanie's attention, alternately called a "love tap" or "poke", Silver Lake Elementary School Principal Gail Qumby, and Gerrie Martin — Marchio said no action was warranted.

He attributed the drama to media overreaction and the "dilemma" faced by school officials trying to comply with H.B. 85, a controversial state law requiring schools to report student crimes, including assaults, extortion and offensive touching.

The incident occurred during recess Dec. 6. School officials reported the contact to the attorney general's office, which advised that the child's action constituted of-

fensive touching and a reportable offense under H.B. 85 — but not one that would be prosecuted.

On Monday, Gerrie Martin said, school officials called and asked her to pick up Stephanie from school because she was being suspended — a sanction put on Thursday's meeting, which was not attended by her daughter.

Marchio said he "did what I am compelled to do and interpret the law with common sense and with the best interest of the student in mind." He said Stephanie, who has apologized, would never have been suspended.

"It's really unfortunate, but a lot of times we can get so bogged down in things that it's really unclear as to what we can't do and what we should do," he said. "I think we've all learned a lesson."

# Law: Some say it hurts more than helps

FROM PAGE A1

"When the bill was written, it was never our intent for something like this to be prosecuted," said state Rep. Oakley M. Banning, D-Middletown, a co-sponsor of the bill which passed into law in 1993.

The Appoquinimink School District on Thursday reversed its decision to suspend Stephanie over the Friday incident at Silver Lake Elementary School in Middletown.

The district's claim that H.B. 85 forced its hand in the case has focused attention, once again, on the intent and the history of the law.

"I don't want to see the law watered down, but I am concerned that it is hurting more than it is helping our children," said Margaret Tansley, president of the Delaware Congress of Parents and Teachers.

The bill set strict reporting requirements that were to ensure school officials notify police of alleged assaults, offensive touching incidents, terroristic threats and extortion by students or parents on school property. It also required that any offenses involving drugs or weapons be reported. Failure to re-

the newspaper. See how bad you are?"

Since it went into effect in the 1993-1994 school year, critics of the law came from all corners. Parents blamed it for a jump in expulsions and suspensions. The American Civil Liberties Union, concerned with students' understanding of the law, put on a conference to field questions about the law.

Rep. Stephanie A. Ulbrich, R-Newark South, a legislative advocate on school issues, said she already has some ideas about how to tighten the law to avoid "unintended consequences like [the Appoquinimink] case," she said.

She said would consider easing the penalties against teachers and principals for violating the law.

"Without suggesting that a major overhaul of the bill take place, I do think we need to take a thorough look at it," said Ulbrich.

Others said giving school officials more discretion might be the answer. "I don't know whether we gave them authority to use common sense," said Rep. Banning.

"Without suggesting that a major overhaul of the bill take place, I do think we need to take a thorough look at it."

**Rep. Stephanie A. Ulbrich,  
R-Newark South**

port incidents covered by the law could result in fines of \$250 or more.

But, critics say, the law makes no allowances for the very young. They also complained that, as written, the law strips teachers and principals of the discretion to deal with minor infraction before involving law enforcement.

"I am very concerned that we don't end up stigmatizing children," Tansley said. "What are we saying in this case? That the only way we can communicate with our children is to say, 'Look, here is your picture on the front page of

DC  
BU

Buy  
bu  
W  
ci  
ir

# Cops: Case shows problems and need for guidelines

caution is necessary when it comes to younger children.

"I think the way this was handled was totally wrong. I have a real problem with this," Johnson said.

"Yvonne would never slip port doing anything like this with a school, with elementary school, with out a parent. I can't imagine any parent would support it," she said.

Johnson said she thought it might be a good idea for lawmakers or police to consider rules requiring parents' consent before involving law enforcement, especially for younger students.

CONTACT SEAN O'SULLIVAN AT 324-2777 OR OSULLIVAN@DELAWAREONLINE.COM OR ON TWITTER @SEANOULLIVAN.  
CONTACT MATTHEW ALBRIGHT AT 324-2428 OR MALBRIGHT@DELAWAREONLINE.COM, OR ON TWITTER @M1J\_MALBRIGHT.

able. The Delaware Attorney General's Office, which is defending Pritchett, declined comment.

Attorneys representing the plaintiff did not return calls seeking comment.

State Police spokesman Sgt. Paul Shavack said he couldn't comment on the lawsuit, but defended the school resource officer program in general.

"We feel confident that our SRO program is effective, and the troopers assigned to the schools statewide have developed cooperative relationships with both the school administrators and the students," Shavack wrote in an email.

"We also feel that our troopers' presence and working relationships within the schools they serve provide a safe and secure environment for

school and home-schooled children for the rest of the year. The 15-page decision reviving the family lawsuit says judges handed down June 25.

In it, Justice Carolyn Berger found the family made a sufficient showing that the child was improperly deprived of his liberty during the questioning, noting that "a reasonable child would not believe he was free to leave" when an officer in uniform, handcuffs, took him into a room and closed the door.

Berger also wrote that Pritchett's motivation to hold the 8-year-old in custody was "suspect," because the trooper said he knew the boy had nothing to do with the theft.

"One could reasonably infer, she wrote, that Pritchett was simply using the child to elicit a confession which a jury could find was unreasonable.

The trooper also told the students that bad children were sent to the Stevenson House, where children are placed like criminals" and that their siblings would be upset and would not be able to see them.

The Stevenson House is a state-operated juvenile detention center in Milford.

The 8-year-old then started to cry, prompting Pritchett to turn to AB and say, "This is crazy now. Look at him," according to court papers. The incident prompted AB — the fifth-grader — to confess.

Pritchett said afterward he had done a great job and "it takes a man to stand up to a bully" but the 8-year-old did not recall those comments.

The child was held by Pritchett and his mother withdrew him from

However, a three-judge panel of the Delaware Supreme Court recently revived the lawsuit against state Trooper David Pritchett, the state of Delaware and the state police (the family settled with the school district). The panel found there was enough evidence of a potential violation of a child's rights that the case should go forward to trial.

According to the original lawsuit, officials at Shields Elementary School in Imling were looking into a bullying incident — reporting it to Pritchett after he gave a talk on bullying — during which a student reportedly took a dollar on an autistic student on a bus.

The fifth-grader, called AB in court papers, was quickly identified as likely culprit but AB blamed the third-grader who rode on the same bus.

Principal David McDowell participated in the initial questioning but was called away when AB accused the younger boy of the theft. Pritchett then instructed a secretary to call the 8-year-old to the office.

While walking the boy from the office to a room where AB was being questioned, the trooper told the boy he knew he didn't commit the theft, according to court documents.

"You're not in any trouble. I just need you to be brave and come in here," Pritchett told the student, according to court papers.

"When I tell you the story of what's happened and I look at you, you just say 'no you didn't do it,'" But once inside the room, the child said Pritchett "used a mean voice and told him II or 12 times that Pritchett had the authority to arrest and place him in jail if he didn't tell the truth."

Continued from Page A1

fifth-grader while investigating the theft of one dollar.

According to court papers, the questioning was so intense, complete with threats of the children being sent to a juvenile facility for lying, that the 8-year-old — who was not a suspect — burst into tears. His parents pulled him out of school over the January 2008 incident and filed a lawsuit in January 2010 charging the officer violated the child's rights.

This case indicates exactly the kind of problem that occurs when you have a school resource officer in a school dealing with discipline issues," said Richard Morse, legal director for the Delaware chapter of the American Civil Liberties Union. "We think it would be a lot better if these matters were dealt with by educators."

When police are involved, students can end up with a criminal record rather than having a demerit, detention or suspension, Morse said.

The initial lawsuit filed by the mother of the 8-year-old, whose name is being withheld by The News Journal, was tossed out of Kent County Superior Court Resident Judge William L. Witham Jr., who found that the child's rights were not violated by the questioning.

See COPS, Page A5

## COURT DECISION

### Ruling revives suit, debate on school cops

By Sean O'Sullivan and Matthew Albright  
The News Journal

When the Delaware Supreme Court revived a family's lawsuit last month over a school resource officer's intense interrogation of their third-grade son, it reignited the debate over having police officers stationed at schools to investigate matters that used to be handled by school administrators.

The incident started when a Delaware State Police trooper, who was on assignment as a school resource officer in the Cape Henlopen School District, questioned the third-grader and a

YOUR OPINION  
Tell us what you think at [delawareonline.com](http://delawareonline.com)

**Should school resource officers be allowed to question a student without a parent present?**

YESTERDAY'S POLL RESULTS: 81

the students and the faculty," he added.

But some civil liberties and parents groups say the incident illustrates the potential pitfalls of having police involved in school discipline.

Yvonne-Johnson, president of the state Parent Teacher Association, said her group is generally a strong supporter of SROs and is pushing for one in every high school in the state.

However, she said this particular case shows that

able. The Delaware Attorney General's Office, which is defending Pritchett, declined comment.

Attorneys representing the plaintiff did not return calls seeking comment.

State Police spokesman Sgt. Paul Shavack said he couldn't comment on the lawsuit, but defended the school resource officer program in general.

"We feel confident that our SRO program is effective, and the troopers assigned to the schools statewide have developed cooperative relationships with both the school administrators and the students," Shavack wrote in an email.

"We also feel that our troopers' presence and working relationships within the schools they serve provide a safe and secure environment for

However, a three-judge panel of the Delaware Supreme Court recently revived the lawsuit against state Trooper David Pritchett, the state of Delaware and the state police (the family settled with the school district). The panel found there was enough evidence of a potential violation of a child's rights that the case should go forward to trial.

According to the original lawsuit, officials at Shields Elementary School in Imling were looking into a bullying incident — reporting it to Pritchett after he gave a talk on bullying — during which a student reportedly took a dollar on an autistic student on a bus.

The fifth-grader, called AB in court papers, was quickly identified as likely culprit but AB blamed the third-grader who rode on the same bus.

Principal David McDowell participated in the initial questioning but was called away when AB accused the younger boy of the theft. Pritchett then instructed a secretary to call the 8-year-old to the office.

While walking the boy from the office to a room where AB was being questioned, the trooper told the boy he knew he didn't commit the theft, according to court documents.

"You're not in any trouble. I just need you to be brave and come in here," Pritchett told the student, according to court papers.

"When I tell you the story of what's happened and I look at you, you just say 'no you didn't do it,'" But once inside the room, the child said Pritchett "used a mean voice and told him II or 12 times that Pritchett had the authority to arrest and place him in jail if he didn't tell the truth."

Continued from Page A1

fifth-grader while investigating the theft of one dollar.

According to court papers, the questioning was so intense, complete with threats of the children being sent to a juvenile facility for lying, that the 8-year-old — who was not a suspect — burst into tears. His parents pulled him out of school over the January 2008 incident and filed a lawsuit in January 2010 charging the officer violated the child's rights.

This case indicates exactly the kind of problem that occurs when you have a school resource officer in a school dealing with discipline issues," said Richard Morse, legal director for the Delaware chapter of the American Civil Liberties Union. "We think it would be a lot better if these matters were dealt with by educators."

When police are involved, students can end up with a criminal record rather than having a demerit, detention or suspension, Morse said.

The initial lawsuit filed by the mother of the 8-year-old, whose name is being withheld by The News Journal, was tossed out of Kent County Superior Court Resident Judge William L. Witham Jr., who found that the child's rights were not violated by the questioning.

See COPS, Page A5

## COURT DECISION

### Ruling revives suit, debate on school cops

By Sean O'Sullivan and Matthew Albright  
The News Journal

When the Delaware Supreme Court revived a family's lawsuit last month over a school resource officer's intense interrogation of their third-grade son, it reignited the debate over having police officers stationed at schools to investigate matters that used to be handled by school administrators.

The incident started when a Delaware State Police trooper, who was on assignment as a school resource officer in the Cape Henlopen School District, questioned the third-grader and a

The New York Times

"A STORY THAT  
SEIZES YOU WITH A  
VISCERAL FORCE."  
— *The New York Times*

December 2, 2013

# Seeing the Toll, Schools Revise Zero Tolerance

By LIZETTE ALVAREZ

FORT LAUDERDALE, Fla. — Faced with mounting evidence that get-tough policies in schools are leading to arrest records, low academic achievement and high dropout rates that especially affect minority students, cities and school districts around the country are rethinking their approach to minor offenses.

Perhaps nowhere has the shift been more pronounced than in Broward County's public schools. Two years ago, the school district achieved an ignominious Florida record: More students were arrested on school campuses here than in any other state district, the vast majority for misdemeanors like possessing marijuana or spraying graffiti.

The Florida district, the sixth largest in the nation, was far from an outlier. In the past two decades, schools around the country have seen suspensions, expulsions and arrests for minor nonviolent offenses climb together with the number of police officers stationed at schools. The policy, called zero tolerance, first grew out of the war on drugs in the 1990s and became more aggressive in the wake of school shootings like the one at Columbine High School in Colorado.

But in November, Broward veered in a different direction, joining other large school districts, including Los Angeles, Baltimore, Chicago and Denver, in backing away from the get-tough approach.

Rather than push children out of school, districts like Broward are now doing the opposite: choosing to keep lawbreaking students in school, away from trouble on the streets, and offering them counseling and other assistance aimed at changing behavior.

These alternative efforts are increasingly supported, sometimes even led, by state juvenile justice directors, judges and police officers.

In Broward, which had more than 1,000 arrests in the 2011 school year, the school district entered into a wide-ranging agreement last month with local law enforcement, the juvenile

justice department and civil rights groups like the N.A.A.C.P. to overhaul its disciplinary policies and de-emphasize punishment.

Some states, prodded by parents and student groups, are similarly moving to change the laws; in 2009, Florida amended its laws to allow school administrators greater discretion in disciplining students.

“A knee-jerk reaction for minor offenses, suspending and expelling students, this is not the business we should be in,” said Robert W. Runcie, the Broward County Schools superintendent, who took the job in late 2011. “We are not accepting that we need to have hundreds of students getting arrested and getting records that impact their lifelong chances to get a job, go into the military, get financial aid.”

Nationwide, more than 70 percent of students involved in arrests or referrals to court are black or Hispanic, according to federal data.

“What you see is the beginning of a national trend here,” said Michael Thompson, the director of the Council of State Governments Justice Center. “Everybody recognizes right now that if we want to really find ways to close the achievement gap, we are really going to need to look at the huge number of kids being removed from school campuses who are not receiving any classroom time.”

Pressure to change has come from the Obama administration, too. Beginning in 2009, the Department of Justice and the Department of Education aggressively began to encourage schools to think twice before arresting and pushing children out of school. In some cases, as in Meridian, Miss., the federal government has sued to force change in schools.

Some view the shift as politically driven and worry that the pendulum may swing too far in the other direction. Ken Trump, a school security consultant, said that while existing policies are at times misused by school staffs and officers, the policies mostly work well, offering schools the right amount of discretion.

“It’s a political movement by civil rights organizations that have targeted school police,” Mr. Trump said. “If you politicize this on either side, it’s not going to help on the front lines.”

Supporters, though, emphasize the flexibility in these new policies and stress that they do not apply to students who commit felonies or pose a danger.

“We are not taking these tools out of the toolbox,” said Russell Skiba, a school psychology professor at Indiana University who promotes disciplinary changes. “We are saying these should be tools of last resort.”

In Broward County, the shift has shown immediate results, although it is too early to predict overall success. School-based arrests have dropped by 41 percent, and suspensions, which in 2011 added up to 87,000 out of 258,000 students, are down 66 percent from the same period in 2012, school data shows.

Under the new agreement, students caught for the first time committing any of 11 nonviolent misdemeanors are no longer arrested and sent to court. Rather, they attend counseling and perform community service.

Nor do students face suspension for minor infractions. Instead, they also attend a program called Promise for three days or more. Repeat offenders get several chances to change their behavior before more punitive measures kick in.

One recent afternoon, an 18-year-old senior sat in the cafeteria at the Pine Ridge Alternative Center, where students are sent in lieu of a suspension, and spoke with a psychology graduate student on a counseling team. The girl had been caught with a small amount of marijuana in her car on her high school campus, a misdemeanor that would have led to a suspension or arrest in the past. It was the first time she had gotten in trouble at school.

"I was freaking out," she said. Her first fear was that she would be barred from prom. Here, though, she saw the larger picture and came to view the incident as "her second chance."

She learned about bullying and drugs and alcohol. "It was a slap in the face," she said. "I don't even want to smoke anymore."

Other students here learn to manage their anger, if that is their issue. Parents are involved in the process. And counselors have helped identify problems at home including abusive situations, something that administrators said underscores how invaluable the counseling component has been for the Promise program, said Belinda Hope, the principal at Pine Ridge.

Mr. Runcie and others said the more punitive measures tended to make a bad situation worse. Suspended and expelled children would be home alone or on the street, falling behind academically. Those arrested could be stigmatized by criminal records.

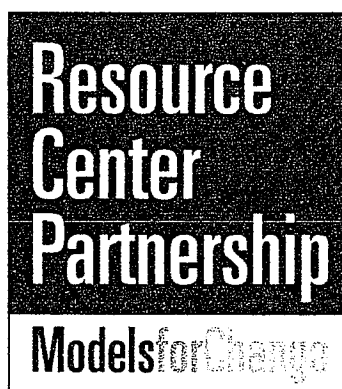
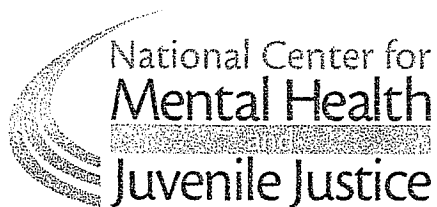
"The data showed an increase in the harshness of the disciplinary practices in schools — what was once a trip to the principal's office is now a trip to the jail cell," said Judith Browne Dianis, co-director of the Advancement Project, a civil-rights group involved in the effort.

Juvenile judges were among the first to express alarm over the jump in the number of students appearing in court on misdemeanors, an increase they said is tied to the proliferation of school police officers.

“We started to see the officers as a disciplinary tool,” said Judge Elijah H. Williams of Broward County Circuit Court, a juvenile judge who said he was “no flaming liberal” but saw the need for change. “Somebody writes graffiti in a stall, O.K., you’re under arrest. A person gets caught with a marijuana cigarette, you’re under arrest.”

# Better Solutions for Youth with Mental Health Needs in the Juvenile Justice System

By the Mental Health and Juvenile Justice Collaborative  
for Change: A Training, Technical Assistance and Education  
Center and a member of the Models for Change Resource  
Center Partnership





## Introduction

Sarah, an eighth grader, was experiencing problematic behavior in middle school. In sixth and seventh grades, she was repeatedly getting into trouble for starting fights with other students and making statements about her interest in harming others. Instead of referring her to the police, the school referred her to a diversion program.

Upon referral, Sarah met with a mental health clinician who administered the Massachusetts Youth Screening Instrument-2, a mental health screening tool. The screen indicated a need for follow-up, so she underwent a clinical evaluation where it was determined that Sarah had some mental health issues, primarily related to trauma after witnessing the murder of one of her parents several years ago. She was referred to therapy to help with her anger issues and her depression. Her guardian became engaged in therapy with her, and in-home visits by the young girl's social worker resulted in the development of an academic plan that included support in school and constant check-ins to monitor progress.

As a result, Sarah's aggressive behavior subsided and her academic performance improved substantially, all without any involvement with the juvenile justice system.

What makes Sarah's success story possible? What can be done to create positive outcomes for more youth with mental health needs in the juvenile justice system?

**Whenever safe and appropriate, youth with mental health needs should be prevented from entering the juvenile justice system in the first place.**

The short answer is this: whenever safe and appropriate, youth with mental health needs should be prevented from entering the juvenile justice system in the first place. For youth who *do* enter the system, a first option should be to refer them to effective treatment within the community. For those few who require placement, it is important to ensure that they have access to effective services while in care to help them re-enter society successfully.

There's no denying that these outcomes come with practical challenges. But we know that reform is possible – with the right people collaborating to build systems that help communities improve the way they respond to youth with mental health needs.

The aim of this paper is to encourage and support other communities to work toward similar reform for these youth.

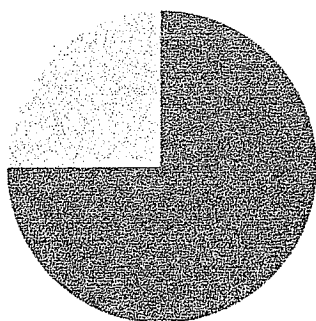
### **How widespread is the challenge of mental health in America's juvenile justice system?**

Each year, more than 600,000 youth in America are placed in juvenile detention centers, and close to 70,000 youth reside in juvenile correctional facilities on any given day.<sup>1</sup> Youth in the juvenile justice system experience mental health disorders at a rate that is more than three times higher than that of the general youth population.<sup>2</sup>

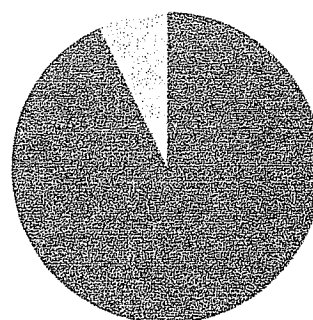
Studies have consistently documented that:

1. 65% to 70% of youth in contact with the juvenile justice system have a diagnosable mental health disorder;
2. Over 60% of youth with a mental health disorder also have a substance use disorder; and
3. Almost 30% of youth have disorders that are serious enough to require immediate and significant treatment.<sup>3</sup>

In addition, youth in the juvenile justice system have higher rates of exposure to traumatic experiences:



At least **75%** of youth in the juvenile justice system have experienced traumatic victimization.<sup>4</sup>



**93%** of youth in detention reported exposure to "adverse" events including accidents, serious illnesses, physical and sexual abuse, domestic and community violence - and the majority of these youth were exposed to six or more events.<sup>5</sup>

Many of these youth are unnecessarily placed in or referred to the juvenile justice system for relatively minor, non-violent offenses, often in a misguided attempt to obtain treatment services that are lacking in the community.<sup>6</sup> However, the unfortunate irony of this approach is that the mental health services typically available to youth in the juvenile justice system are often inadequate or simply unavailable, as documented by a series of investigations conducted by the U.S. Department of Justice.<sup>7</sup>

Instead of relying on the justice system to address a youth's mental health needs, it is now recognized that the more appropriate and effective response involves community-based treatment interventions that engage youth and their families.

## **What new scientific breakthroughs can help youth with mental health needs who come into contact with the juvenile justice system?**

Over the last decade, significant advances in research, program and resource development have resulted in a wide array of new tools and new knowledge that can help the juvenile justice and related child-serving systems improve their response to youth with mental health needs. These advancements include:

- New research-based mental health screening and assessment tools and protocols to guide their use with youth in the juvenile justice system.
- New evidence-based intervention and treatment programs that produce positive results and are cost-effective.
- Adolescent development and brain research that has greatly enhanced our understanding of adolescent behavior and a youth's capacity for change. This greater understanding has also influenced juvenile justice law and policy.

Building on these advancements and embracing a "research to practice" continuum, the John D. and Catherine T. MacArthur Foundation created Models for Change: Systems Reform in Juvenile Justice – a national juvenile justice initiative aimed at developing successful and replicable reform models in select states that could be shared and adapted by other jurisdictions across the country. Through this work, states such as Pennsylvania, Illinois, Louisiana and Washington, and later Colorado, Connecticut, Ohio and Texas, have changed their policies and practices to better meet the mental health needs of youth involved in the juvenile justice system.

While the individual states identified the specific areas of reform they wished to address, all aimed (and succeeded) at implementing reforms that effectively held young people accountable for their actions, provided for their rehabilitation, protected them from harm, increased their life chances and managed the risk they posed to themselves and to others.

The ensuing work undertaken in the states and communities mentioned above has resulted in new models, publications, toolkits and training curricula that not only document the system improvements that have occurred over the last decade but also provide guidance to other sites interested in tackling similar reforms. Significant innovations related to mental health emerged, including resources such as:

- New school, probation and police-based diversion models for youth with mental health needs
- New mental health training resources for juvenile justice staff and police
- Resources to support family involvement within the juvenile justice system
- Advanced protocols and processes for screening and assessment to identify mental health needs and risk among juveniles
- New resources for implementing evidence-based practices for justice-involved youth
- New guidelines for juvenile competency

Here's a closer look at efforts in two leading states:

### Louisiana

Louisiana has transformed its juvenile justice system to embrace evidence-based practices<sup>1</sup> (EBPs) for youth. Following criticism, including an investigation by the Department of Justice, for their over-reliance on institutional care for youth in the juvenile justice system and the conditions of confinement that existed within the state's correctional institutions, the state has moved in a decidedly different direction.



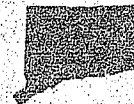
With support from MacArthur, Louisiana has actively worked to reduce its reliance on incarceration and increase awareness of and the availability of community, evidence-based practices for youth. In just a few short years the state has increased the use of research-based behavioral health screening and assessment instruments and recently moved to statewide adoption of the Structured Assessment of Violence Risk in Youth (SAVRY) - a research based risk assessment instrument for youth. In addition, they have substantially increased the availability of EBPs in the state (there are now statewide Functional Family Therapy teams) and in turn, increased the number of youth with access to these services to almost 50%. More youth are receiving services in the community, fewer youth are placed in in-home care and public safety has improved.

The transformation was recognized when Louisiana was cited at the 2012 Blueprints for Violence Prevention Conference as "among the top four states in this country to show growth in evidence-based community programs."

<sup>1</sup> Evidence based practices or programs (also called EBPs) refer to prevention or treatment approaches that have been proven to work with scientific evidence.

### Connecticut

Zero tolerance policies in Connecticut's schools were contributing to high rates of school arrest and expulsion, particularly for youth with behavioral and mental health needs. In response, the state created the School-Based Diversion Initiative (SBDI) which uses mental health responders (provided by Emergency Mobile Psychiatric Service [EMPS] units) to respond to school-based incidents involving youth with mental health needs as an alternative to contacting the police or referring to juvenile court.



The program is designed to reduce the number of school arrests, suspensions and expulsions by linking youth with mental health needs who are at risk of juvenile system involvement with appropriate community based services and supports. The program, piloted in two schools in 2009, has expanded to 17 middle schools in 9 communities. A 2012 evaluation by the Connecticut Center for Effective Practice found that student arrests in participating schools has significantly decreased, as have suspensions and expulsions. At the same time, EMPS referrals and utilization have increased.

## How can more communities adopt these better solutions for youth with mental health needs in the juvenile justice system?

The advancements across the country for youth with mental health needs are significant. Many more jurisdictions are searching for new ways to help youth with mental health needs in the juvenile justice system. These systems could benefit substantially from this new knowledge and these new resources if they had the opportunity. Now they do. The MacArthur Foundation recently supported the establishment of the Mental Health Juvenile Justice Collaborative for Change: A Training, Technical Assistance and Education Center to promote the expansion of research-based mental health reforms.

The Collaborative for Change, coordinated by the National Center for Mental Health and Juvenile Justice (NCMHJJ) at Policy Research Inc., is a dedicated effort to share these new innovations and actively support their adaption, replication and expansion in the field. Partners in this effort include the National Youth

Screening and Assessment Project at the University of Massachusetts Medical School and the Technical Assistance Collaborative.

The Collaborative for Change is designed to serve juvenile justice and mental health system administrators, policy makers, program providers and direct care staff by providing a wide array of technical assistance and support services on mental health and juvenile justice including:

- A web-based resource center (<http://cfc.ncmhjj.com>) that provides around the clock, online access to information and practical resources
- A Help Desk, staffed by NCMHJJ professionals, prepared to answer general questions beyond the scope of the website.
- Consultation and assistance for more complex requests provided by NCMHJJ professionals and subject matter experts working with the Collaborative. This consultation is provided by email, phone or in special cases, on-site technical assistance.
- On-site training by experienced national trainers

Over 25 national, state and local mental health and juvenile justice leaders are working with the Collaborative for Change to help provide this assistance to the field. Many of these experts were responsible for the actual development and implementation of the mental health innovations coming out of Models for Change and the Mental Health/Juvenile Justice Action Network. This "peer to peer" approach is a key component of the Collaborative's technical assistance and training strategy.

### What can be done?

There is growing recognition among researchers and practitioners across the country that:

- There are large numbers of youth with mental health needs involved with the juvenile justice system.
- Many of these youth would be better served in community-settings with access to effective evidence-based treatments.
- Some of these youth will not be appropriate for diversion to the community but still deserve access to effective treatment while they are involved with the juvenile justice system.

Acknowledging these facts is the first step. The next step involves taking appropriate action. However, in order to take this action, most communities need guidance around the best strategies, tools, program models and interventions to implement in order to effectively address the problems. Drawing on the lessons learned and knowledge gained from model states, the Collaborative for Change is aimed at providing this assistance to the field.

**Visit the Collaborative for Change at <http://cfc.ncmhjj.com>, or phone the toll-free Help Desk at 1-866-962-6455.**

### The substantive focus of the Collaborative for Change includes:

1. Mental health screening within juvenile justice settings
2. Diversion strategies and models for youth with mental health needs
3. Adolescent Mental Health Training for Juvenile Justice Staff and Police
4. Guidance around the implementation of evidence-based practices
5. Training and resources to support family involvement in the juvenile justice system
6. Juvenile competency

## About the Models For Change Resource Center Partnership

The Mental Health Juvenile Justice Collaborative for Change is a project of the National Center for Mental Health and Juvenile Justice and is supported by the John D. and Catherine T. MacArthur Foundation, as part of its Models for Change Resource Center Partnership.

The Resource Center Partnership works to advance juvenile justice systems reform across the country by providing state and local leaders, practitioners and policymakers with technical assistance, training, and the proven tools, resources and lessons developed through the John D. and Catherine T. MacArthur Foundation's Models for Change: Systems Reform in Juvenile Justice initiative.

The Partnership is anchored by four complementary, connected Resource Centers that address four important issues in juvenile justice:

- Mental health: The Mental Health and Juvenile Justice Collaborative for Change, led by the National Center for Mental Health and Juvenile Justice. For more information, visit: [cfc.ncmhjj.com](http://cfc.ncmhjj.com)
- Stronger legal defense for indigent youth: National Juvenile Defender Center. For more information, visit: [njdc.info/resourcecenterpartnership.php](http://njdc.info/resourcecenterpartnership.php)
- Appropriate interventions for youth charged with non-delinquent-or status-offenses: The Status Offense Reform Center, led by the Vera Institute of Justice. For more information, visit: [www.statusoffensereform.org](http://www.statusoffensereform.org)
- Coordinated systems of care for young people involved in both the juvenile justice and child protective systems: The Robert F. Kennedy National Resource Center for Juvenile Justice, led by the RFK Children's Action Corps. For more information, visit: [www.rfknrcjj.org](http://www.rfknrcjj.org)

The Partnership also includes a strategic alliance of national experts and organizations representing state leaders, mayors, judges, law enforcement, prosecutors, corrections professionals, court personnel and justice reform advocates. These partners further enrich the tools, best practices and training offered by the Centers and provide direct connections to professionals working in juvenile justice.

For more information about the Models for Change Resource Center Partnership, visit: [modelsforchange.net/resourcecenters](http://modelsforchange.net/resourcecenters)

# Mental Health and Juvenile Justice Collaborative for Change: A Training, Technical Assistance and Education Center

The Mental Health and Juvenile Justice Collaborative for Change, led by the National Center for Mental Health and Juvenile Justice, is a training, technical assistance, and education center designed to promote and support adoption of new resources, tools, and program models to help the field better respond to youth with mental health needs in the juvenile justice system.

## Works Cited

1. Abram, K., Teplin, L., Charles D., Longworth, S., McClelland, G., & Dulcan, M (2004). Posttraumatic stress disorder and trauma in youth in juvenile detention. *Archives of General Psychiatry* 61 (4): 403-410
2. Merikangas, K.R., He, J.P., Burstein, M., Swanson, S.A., Avenevoli, S., Cui, L., Benjet, C., Georgiades, K., & Swendsen, J. (2010). Lifetime prevalence of mental disorders in U.S. adolescents: results from the National Comorbidity Survey Replication—Adolescent Supplement (NCS-A). *J Am Academy Child Adolescent Psychiatry* 49(10):980-9.
3. Shufelt, J.S. & Cocozza, J.C. (2006). *Youth with Mental Health Disorders in the Juvenile Justice System: Results from a Multi-State, Multi-System Prevalence Study*. Delmar, NY: National Center for Mental Health and Juvenile Justice.
4. National Child Traumatic Stress Network, Justice System Consortium. (2009). *Helping Traumatized Children: Tips for Judges*. Los Angeles, CA & Durham, NC: National Center for Child Traumatic Stress.
5. Office of Juvenile Justice and Delinquency Prevention. (2010). *Statistical Briefing Book, Law Enforcement & Juvenile Crime, Juvenile Arrests*. Online. Available: <http://www.ojjdp.gov/ojstatbb/crime/qa05101.asp?qaDate=2010>
6. Skowrya, K. & Cocozza, J. (2007). *Blueprint for Change: A Comprehensive Model for the Identification and Treatment of Youth with Mental Health Needs in Contact with the Juvenile Justice System*. Delmar, NY: National Center for Mental Health and Juvenile Justice.
7. United States Department of Justice. (2011). *Department of Justice Activities Under the Civil Rights Institutionalized Persons Act: Fiscal Year 2010*. Washington DC: United States Department of Justice. Online. Available: [http://www.justice.gov/crt/about/spl/documents/split\\_cripa10.pdf](http://www.justice.gov/crt/about/spl/documents/split_cripa10.pdf)
8. Sickmund, M., Sladky, T.J., Kang, W., & Puzanchera, C. (2011). *Easy Access to the Census of Juveniles in Residential Placement*. Online. Available: <http://www.ojjdp.gov/ojstatbb/ezacjrp/>

# Feds urge change in school discipline

**By Kimberly Helting**  
Associated Press

WASHINGTON — The Obama administration on Wednesday pressed the nation's schools to abandon what it described as overly zealous discipline policies that send students to court instead of the principal's office. Even before the announcement, school districts around the country have been taking action to adjust the policies that disproportionately affect minority students.

Attorney General Eric Holder said problems often stem from well-intentioned "zero-tolerance" policies that can inject the criminal justice system into school matters.

"A routine school disciplinary infraction should land a student in the principal's office, not in a police precinct," Holder said.

But it's about race, too, the government said in a letter accompanying the new guidelines it issued Wednesday.

"In our investigations, we have found cases where African-American students were disciplined more harshly and more frequently because of their race than similarly situated white students," the Justice Department and Education Department said in the letter to school districts. "In short, racial discrimination in school discipline is a real



Attorney General Eric Holder, shown in 2010, issued new recommendations Wednesday on classroom discipline that seek to end apparent discrimination. AP

## AMONG THE RECOMMENDATIONS

- » Ensure that school personnel understand that they, not security or police officers, are responsible for administering routine student discipline.
- » Draw clear distinctions about the responsibilities of school security personnel.
- » Provide opportunities for school security officers to develop relationships with students and parents.

The policies often spell out uniform and swift punishment for offenses such as truancy, smoking or carrying a weapon. Violators can lose classroom time or even end up with a criminal record.

In many parts of the country, there already has been a shift toward recognizing that school discipline policies can be discriminatory, said Judith Browne Dianis, co-director of the Advancement Project, a think tank that specializes in social issues affecting minority communities.

Associations representing teachers, principals, school superintendents and school board members agreed that a disparity exists. "Numbers don't lie. They are there," said Beverly Hutson, a former high school principal in New Jersey who is director of professional development at the National Association of Secondary School Principals.

James said he hopes the administration's effort will provide leverage for districts with parents, teachers and communities.

Associations representing black kids seen by teachers as a threat where he didn't think action was warranted.

That happened in Meridian, Miss., where the Justice Department spearheaded a settlement with the school district to end discriminatory disciplinary practices. The black students in the district were facing harsher punishment than white students for similar misbehavior.

Absent a voluntary agreement, the department could go to court to provide relief for individual students, among other things.

Zero-tolerance policies became popular in the 1990s and often have been accompanied by a greater police presence in schools.

including suspending or expelling misbehaving students, improved support services for disruptive students and better training for teachers and administrators.

The federal school discipline recommendations announced Wednesday are nonbinding. They encourage schools to ensure that all school personnel are trained in classroom management, conflict resolution and approaches to de-escalate classroom disruptions — and understand that they are responsible for administering routine student discipline instead of security or police officers.

Still, Education Secretary Arne Duncan has acknowledged the challenge is finding the proper balance to keep schools safe and orderly.

The state's largest school district entered into an agreement with the U.S. Department of Education's Office for Civil Rights to take several corrective actions in the fu-

ture — including suspending or expelling misbehaving students, improved support services for disruptive students and better training for teachers and administrators.

The federal school discipline recommendations announced Wednesday are nonbinding. They encourage schools to ensure that all school personnel are trained in classroom management, conflict resolution and approaches to de-escalate classroom disruptions — and understand that they are responsible for administering routine student discipline instead of security or police officers.

50% off food and soft drinks  
at The R Lounge  
\$30 value for \$15!



## COMMENT

# School discipline is broken and in need of a fix

Most of us have heard the saying: The definition of insanity is doing the same thing over and over again and expecting a different result.

Unfortunately, this approach has guided discipline policies in Delaware schools for years through the widespread use of overly punitive "zero tolerance" responses to student misbehavior. The result is students are repeating grades, dropping out of school and being pushed out of the classroom into the juvenile justice system, and students of color are feeling the impact of these policies more than their peers.

The good news is that a more rational approach to school discipline is being promoted by the federal government. After research suggested that substantial racial disparities in discipline date were not explained by more frequent or more serious mis-

behavior by students of color, on Wednesday, Attorney General Eric Holder and Education Secretary Arne Duncan announced new guidance to help school districts administer student discipline without discriminating on the basis of race, color or national origin.

Discipline reform is sorely needed in Delaware where out-of-school suspensions are used too often and unfairly. Statewide, 74 percent of all students suspended for 10 days or more are boys; 52 percent are African-American. In fact, African-American and Latino students are suspended three to four times more often than their white peers, even in schools where they represent a substantially lower enrollment rate. A federal investigation into the Christina School District found that African-American students were punished more harshly than white students for the same misbehaviors, and that African-Americans experiencing their first referral were more than three times more likely than white

students to have the suspension be out-of-school, rather than in-school.

Many Delaware children are being kept out of school for minor offenses that can and should be handled inside school. Some of these offenses are too broadly defined and open to a wide range of interpretations, such as defying authority, inappropriate behavior and defiance of school authority; other behaviors are as minor as cellphone or dress code violations.

In times gone by, wise cracks or insubordination were understood as typical adolescent rebellion and addressed accordingly. Now, students can expect to be suspended for these behaviors, sometimes for days, missing essential learning time in the classroom.

The bottom line is that too many students never catch up, particularly those already struggling academically.

This leads to a domino effect of disastrous consequences that we all pay for in the form of poverty, violence

and prison costs.

Yes, there is a need for discipline, particularly in the cases of serious and dangerous offenses. But we must also work to create positive school climates that keep students learning and provide opportunities for them to understand accountability and responsibility using more restorative measures.

The new federal guidance can help Delaware address discipline differently.

Specifically, it recommends that schools:

- » Undertake a comprehensive approach to classroom management and student behavior by using evidence-based prevention strategies; promoting social and emotional learning; involving students through peer mediation and restorative justice programs; and reducing inappropriate referrals to law enforcement.

- » Maintain clear, consistent age-appropriate policies that allow students to improve their behavior prior to disciplinary action; involve families, students and school per-

sonnel when being developed; provide for adequate due process; remove students from the classroom as a last resort; ensure that alternative settings provide academic instruction; and return students to class as soon as possible.

- » Train all school personnel to apply school discipline policies and practices in a fair and equitable manner.

- » Use ongoing, data-driven efforts, including gathering feedback from families, students, teachers and school personnel to prevent, identify, reduce and eliminate discriminatory discipline and unintended consequences.

By taking a more common-sense approach, we can better ensure equal access to public education for all students and a system the justly implements discipline without regard to race, gender, socioeconomic status, or ability.

Shannon Griffin is the ACLU of Delaware Community/Project Organizer. Her work is focused on creating safe and productive public schools for all students.



Governor's Advisory Council for Exceptional Citizens (GACEC)  
516 West Loockerman St., Dover, DE 19904  
302-739-4553 (voice) 302-739-6126 (fax) <http://www.gacec.delaware.gov>

**MEMORANDUM**

**DATE:** May 14, 2014

**TO:** The Honorable Members of the Delaware General Assembly

**FROM:** Terri Hancharick, Chairperson  
GACEC

**RE:** House Bill No. 293 (Supplemental Nutrition Assistance Program)

The Governor's Advisory Council for Exceptional Citizens (GACEC) has reviewed House Bill No. 293 which would amend State law by adding the following limit on purchases: "Benefits provided pursuant to this Chapter shall only be used for foods, food products, and beverages that have beneficial nutritional value." The Department of Health & Social Services (DHSS) would be directed to issue implementing regulations to "identify specific foods, food products, and beverages, or general categories of foods, food products, and beverages ...that have beneficial nutritional value." DHSS would also be required to apply for a waiver from the U.S. Department of Agriculture (USDA) to permit implementation of the law. Council is **opposed** to the proposed legislation.

As reflected in recent News Journal articles, the USDA has never granted a SNAP waiver limiting benefits to foods that are considered to be healthy. The legislation is opposed by DHSS and the Delaware Food Bank. The Food Bank CEO offered the following observation:

The biggest barrier between low-income Delawareans and a healthy diet is not a lack of will or self-control, but a lack of affordability and accessibility. ... Fresh, healthy food is just more expensive than the alternatives and in some neighborhoods it's not even stocked in some stores.

Since the benefits average \$1.40 per person per meal, recipients are hard-pressed to budget for the purchase of basic food products. A recent News Journal editorial questioned the wisdom underlying the bill and suggested the adoption of positive incentives for electing healthier foods:

Limiting shopping choices to 'nutritional foods' is wrong-minded and meddlesome at the 'Big Brother' level. Rewards in the form of a little extra subsidy for better health choices will do a

lot more to change food stamp recipients' poor eating habits.

Finally, a one-size-fits-all list of "healthy" foods may be an elusive goal. Some would theorize that "red meat" is unhealthy, that canned soup with typically high sodium content is unhealthy, and that non-organic produce is unhealthy. Individuals may be on special diets which may not match a regulatory list of "approved" foods.

Thank you for your time and consideration of our position and observations. Please feel free to contact me or Wendy Strauss should you have questions.



STATE OF DELAWARE  
STATE COUNCIL FOR PERSONS WITH DISABILITIES  
MARGARET M. O'NEILL BUILDING  
410 FEDERAL STREET, SUITE 1  
DOVER, DE 19901

VOICE: (302) 739-3620  
TTY/TDD: (302) 739-3699  
FAX: (302) 739-6704

MEMORANDUM

DATE: May 29, 2014

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

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

RE: H.B. 293 (Supplemental Nutrition Assistance Program)

The State Council for Persons with Disabilities (SCPD) has reviewed H.B. 293 which would amend State law regarding the Supplemental Nutrition Assistance Program (SNAP) by adding the following limit on purchases: "Benefits provided pursuant to this Chapter shall only be used for foods, food products, and beverages that have beneficial nutritional value." The Department of Health & Social Services (DHSS) would be directed to issue implementing regulations to "identify specific foods, food products, and beverages, or general categories of foods, food products, and beverages ...that have beneficial nutritional value." DHSS would also be required to apply for a waiver from the U.S. Department of Agriculture (USDA) to permit implementation of the law.

As background, consistent with the attached articles, approximately 17% of Delawareans (152,000) participate in the Supplemental Nutrition Assistance Program (SNAP). Benefits are paid entirely from federal funds but the State shares administrative costs. SNAP recipients cannot use the assistance to purchase beer, wine, liquor, cigarettes, tobacco, nonfood items, vitamins, medicine, hot food, and any food that will be eaten in a store. SCPD opposes the proposed legislation based on the following considerations.

As reflected in the attached articles, the USDA has never granted a SNAP waiver limiting benefits to perceived healthy foods. The legislation is opposed by DHSS and the Delaware Food Bank. The Food Bank CEO offered the following observation:

The biggest barrier between low-income Delawareans and a healthy diet is not a lack of will or self-control, but a lack of affordability and accessibility. ... Fresh, healthy food is just more expensive than the alternatives and in some neighborhoods it's not even stocked in

some stores.

Since the benefits average \$1.40 per person per meal, recipients are hard-pressed to budget for acquisition of basic food products. The attached News Journal editorial questioned the wisdom underlying the bill and suggested adoption of positive incentives for electing healthier foods:

Limiting shopping choices to 'nutritional foods' is wrong-minded and meddlesome at the 'Big Brother' level. Rewards in the form of a little extra subsidy for better health choices will do a lot more to change food stamp recipients' poor eating habits.

Finally, a one-size-fits-all list of "healthy" foods may be an illusory goal. Some would posit that "red-meat" is unhealthy, that canned soup with typically high sodium content is unhealthy, and that non-organic produce is unhealthy. Individuals may be on special diets which may not match a regulatory list of "approved" foods.

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

cc: The Honorable Jack Markell  
Mr. Brian Hartman, Esq.  
Governor's Advisory Council for Exceptional Citizens  
Developmental Disabilities Council

HB 293 supplemental nutrition assistance program 5-29-14

# Food stamp bill has nutrition provision

GOP-sponsored proposal not backed by Food Bank, others

By James Fisher  
The News Journal

A GOP-sponsored bill would limit food stamp spending in Delaware only to foods that have "proven beneficial nutritional value," a change its sponsors say would bring the federally funded program in line with other state efforts to promote healthy eating habits.

But the bill doesn't have any support from the main state agencies and non-profits that guide Delawareans through the process of applying for and using food stamp funds.

The proposed rule "feels like low-income discrimination, to some degree," Department of Health and Social Services Secretary Rita Landgraf said this month, at a panel discussion on hunger arranged by the Delaware Food Bank. Landgraf's department provides eligible Delawareans with funds for food from the Supplemental Nutrition Assistance Program, or SNAP.

The legislation has three Republican primary sponsors: Rep. Daniel Short, R-Senford; Rep. Timothy D. Dukes, R-Laurel; and Sen. Greg Lavelle, R-Sharples.

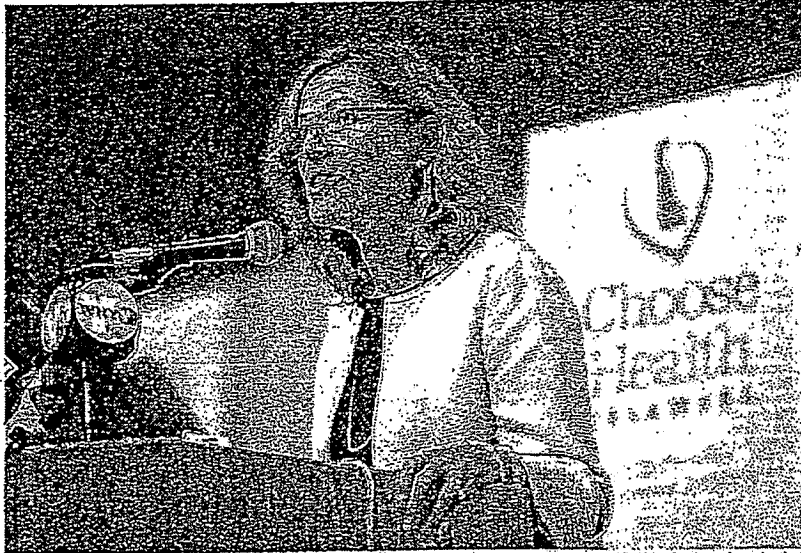
The bill would task Landgraf's department with crafting a list of healthy foods, and require that SNAP funds "shall only be used" to buy foods on that list.

The department's list, the bill says, should start with the foods approved by the Women, Infants and Children nutrition program and expand on it "with a focus on improving selection and affordability."

The bill's supporters say it would put SNAP in the service of making Delawareans healthier, in the same vein as initiatives to build walking-biking trails and a declaration that March is National Nutrition Month.

"Making healthy choices is not inherently more expensive than making unhealthy selections," Dukes said in a statement announcing the bill. "I just believe it is ludicrous to have a government nutrition program that subsidizes poor nutritional habits."

Officials at the Delaware Food Bank, which supplies millions of pounds of food each year to churches and civic groups and also encourages eligible peo-



The bill would task Health and Social Services Secretary Rita Landgraf's department with crafting a list of healthy foods, and require that SNAP funds "shall only be used" to buy foods on that list. JENNIFER CORSETTI/THE NEWS JOURNAL



Rep. Daniel Short

Sen. Greg Lavelle

Rep. Timothy Dukes

ple to sign up for SNAP, aren't getting behind the bill.

"The biggest barrier between low-income Delawareans and a healthy diet is not a lack of will or self-control, but a lack of affordability and accessibility," Food Bank CEO Patricia Beebe and coordinator Dan Reyes said in an op-ed about the bill. "SNAP allotments are inadequate to afford a sufficiently healthy diet."

Fresh, healthy food is just more expensive than the alternatives, they said, and in some neighborhoods it's not even stocked in stores.

Reyes, in an interview, said the pro-

**"I just believe it is ludicrous to have a government nutrition program that subsidizes poor nutritional habits."**

REP. TIMOTHY DUKES, R-LAUREL

posal would add to the social stigma people feel when they buy food with a SNAP card. "You're in line with a bunch of other people at your store, and your items are getting picked apart," Reyes said. "People on SNAP filling up their carts with soda, that's just not a reality."

The bill hasn't budged in the legislature since it was introduced on April 9 and assigned to the House Health & Human Development Committee. It would also require a never-before-granted legal waiver from the U.S. Department of Agriculture, which funds SNAP, to be implemented.

Dukes said he was surprised the Food Bank opposed his bill. "We really ought to take the 'N' out of SNAP if it's not going to be nutritional," he said in an interview.

"I think it all comes down to education, honestly."

Delaware hasn't often been out ahead of other states in placing more restrictions on the use of public assistance than the federal government requires. At least 10 states have passed laws requiring drug testing for some welfare recipients, according to the National Conference of State Legislatures, but Delaware isn't one of them. A recently enacted Florida law requiring tests for every single welfare recipient was halted by a federal judge, who ruled it amounted to an unconstitutional search.

Contact James Fisher at 983-6772; on Twitter @JamesFisherTNJ; or jfisher@delawareonline.com

# Try incentivizing food stamp changes

Our View 7:22 p.m. EDT April 22, 2014



(Photo: Getty Images)

SHARE

12  
CONNECT

TWEET

<https://twitter.com/intent/tweet?url=http://delonline.us/1idM9LM&text=Try%20incentivi>

Although maybe unintended, an air of meanness typically hovers over calls to reform the Supplemental Nutritional Assistance Program, better known as food stamps. As a result, Republican lawmakers' pitch for the "Delaware Nutritional Improvement Act," to get food stamp recipients to choose more healthy food items, will more than likely translate negatively.

First of all, this is a federal government-run program that has a long history of mismanagement when it comes to client abuse of the benefits. This reality summons up memories of President Ronald Reagan's talk of "welfare queens" and lazy single mothers with multiple children in fatherless homes or neighborhood shysters who barter food stamps for cash.

Second, the program is extraordinarily costly, so much so just within the last year Congress has favored trading off funding cuts in the millions to the monthly allotment for food stamp recipient's groceries in favor of funding higher federal subsidies to aid rural farmers.

But thirdly and more important, food stamps are a necessary bridge for millions of Americans who are out of work or face extreme income deficits, despite having a job.

Remove the assistance entirely or keep whacking away at the benefit in the name of balancing the budget, then be prepared for the results in terms of higher health costs and likely crimes committed — not in the name of typical urban malfeasance — but at the urging of grumbling empty stomachs. Those are the realities when a \$4.50-a-day food budget is the norm.

Isn't there a better way to address both problems of an overblown food stamp budget and the low-income assistance it provides?

Yes, backers of the Delaware Nutritional Improvement Act are correct about the benefit of more healthy food choices for welfare recipients. However, the message sent is not one of concern for food stamp recipients' diet necessarily, but meddling in the grocery carts of adults, many of whom are embarrassed to pull out those government slips to hand to the cashier. They are well aware of the scowls of those in line, who are able to pay with credit cards or cash.

Rather than punishing food stamp users for failure to stock their carts with more fruits and vegetables, than soda and potato chips, Delaware Republicans would be wise to remember the advice that Russian leader Nikita Khrushchev's handed out after he made name for his liberal government policies: "Call it what you will, incentives are what get people to work harder."

So why use the club of the law to penalize recipients' food choices? Limiting shopping choices to "nutritional foods" is wrong-minded and meddlesome at the "Big Brother" level. Rewards in the form of a little extra subsidy for better health choices will do a lot more to change food stamp recipients' poor eating habits.

SHARE

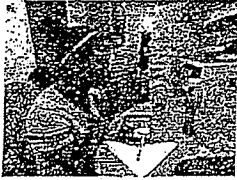
12  
CONNECT

TWEET

<https://twitter.com/intent/tweet?url=http://delonline.us/1idM9LM&text=Try%20incentivizing%20food%20stamp%20char>

# Food stamp use increasing in Delaware

William H. McMichael, Jon Offredo and James Fisher, The News Journal 12:53 a.m. EST March 9, 2014



(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

SHARE

438

CONNECT

<https://twitter.com/intent/tweet?url=http://delonline.us/liouzLS&text=Food%20stamp%20use%20increasing%20in%20Delaware>

TWEET

Each Delaware community experienced different problems.

In New Castle County, it was the loss of good-paying jobs. In Smyrna, thousands of newcomers seeking an affordable life stumbled into economic troubles. In Rehoboth Beach, younger workers and seniors struggled to make ends meet.

In each, increasingly, many Delawareans needed help with food.

The number of state residents receiving food stamps has nearly tripled over the past 10 years, far outpacing the relatively small increase of 14 percent in population.

For Joyce Robertson, 68, of Wilmington, it began in 2004, when she was forced to become legal guardian to her two granddaughters. "I've been on food stamps ever since," she said.

"When I go to the grocery store, if I get a family pack of chicken wings, it's \$12-and-something out of the \$99," she said. "So I split it and try to make two meals. Whatever they got on sale, I try to get it. And the rest, I go to a dollar store and get dollar hot dogs, and stuff like that."

Robertson says she can't afford to buy the juice and vegetables she knows her granddaughters need for a well-rounded diet. There's a food pantry at the nearby St. Patrick's Center, which provides emergency food for those in need. But demand is high and the pickings, she said, are sometimes slim.



Joyce Robertson of Wilmington shops for food at the Fresh Grocer in the Adams Four Shopping Center. "Whatever they got on sale, I try to get it," Robertson said. (Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

"You got to get there, like, 6 o'clock in the morning, to sign up, because there's a great big line," she said. "And if you don't get there that early ... there may be nothing left. There might be one orange, or one apple."

The News Journal obtained data from the Department of Health and Social Services showing the number of food stamp recipients in each ZIP code around the state for 2003 and 2013. The data show where food stamp use has increased the most, but every county experienced an increase of at least 97 percent.

<http://www.delawareonline.com/story/news/local/2014/03/08/food-stamp-use-increasing-in-delaware/62...> 4/29/2014



In New Castle County's 19713 ZIP code south of Newark, the population fell 2.7 percent, yet the number of food stamp recipients increased 299 percent. In Kent's 19977 in Smyrna, the population grew by an astounding 70 percent, while the food stamp population increased 250 percent. In the Rehoboth Beach area of Sussex, where population grew nearly 23 percent, the number of food stamp users skyrocketed 325 percent.

STORY: [One NCCo community looks to recover \(/story/news/local/2014/03/08/food-stamps-new-castle-county-as-big-employers-depart-one-community-looks-to-recover/6218579/\)](#)

STORY: [Rising need 'a big deal' in Smyrna \(/story/news/local/2014/03/08/food-stamps-in-delaware-rising-need-a-big-deal-in-smyma/6218761/\)](#)

STORY: [Coastal Sussex changes hit some hard \(/story/news/local/2014/03/08/food-stamps-in-delaware-coastal-sussex-changes-hit-some-hard/6218769/\)](#)

Overall, the state's food stamp rolls grew faster in the past decade, by 196 percent, than the national average of 124 percent. And it far surpassed increases in neighboring Pennsylvania and New Jersey, both of which dwarfed Delaware's rate of population growth.

Simply put, more than 152,000 Delawareans – 17 percent of the population – count on government help to eat. That's up from about 51,000 a decade ago. And the people who oversee food stamps in the state expect demand to remain high despite a healthier U.S. economy.

MAP: [Food stamp enrollment \(/story/news/local/2014/03/08/map-food-stamp-enrollment/6174565/\)](#)

"As the economy improves, our rate of growth has definitely tapered," said Elaine Archangelo, director of the Delaware Division of Social Services. "But I'm not expecting the caseload to decline in this slow-growth economy."

#### Economic woes

The food-stamp program is funded by the U.S. Department of Agriculture, and Congress appropriates money for it in the farm bill. Only the federal government pays for the direct aid, with states picking up about half of the administrative costs.

Currently, this year's food stamp benefits average out to pay \$1.40 per person per meal, according to the Center on Budget and Policy Priorities. It's not a lot, said Lawana Pipkin of Wilmington, a mother of seven children ages 18 to 2, with another on the way.



Wilmington resident Lawana Pipkin, a mother of seven children ages 18 to 2, had no milk for breakfast on a recent morning, and couldn't afford to buy more. (Photo: ROBERT CRAIG/THE NEWS JOURNAL)

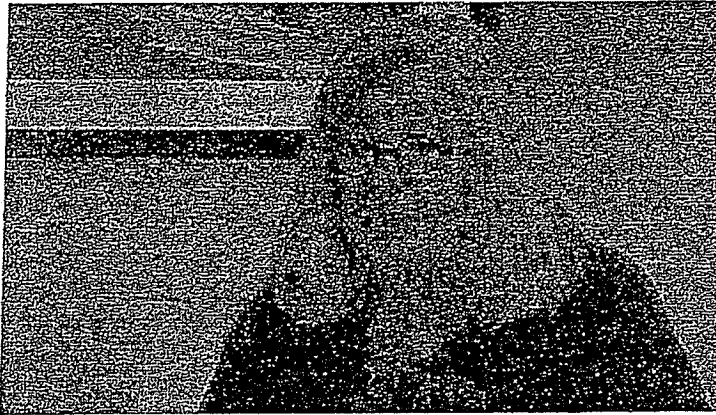
"It can become, like, stressful, very depressing," said Pipkin, who one morning last week had no milk for her children's breakfast and was unable to afford more. She was about a week shy of receiving her March food stamps.

Delaware, along with most states, actively encourages those eligible to sign up for food stamps, a benefit provided based on income. And as many states have done, Delaware expanded eligibility in recent years, automatically making households eligible for food benefits if they qualify for welfare.

"My opinion is, it's definitely primarily because of the economy," Archangelo said. "Food stamps are a little bit of a precursor of the economy tanking. We started to see the use of food stamps inch up before 2008. The low-income people that we serve tend to lose their jobs first."

The loss of quality jobs, particularly in New Castle County, has contributed to the rise, said Patricia Beebe, CEO of the Food Bank of Delaware, which provides donated food to 477 pantries and programs around the state.

"It's not just the loss of good-paying jobs. It's also what workers are getting paid," she said.



The huge increase in demand for food stamps is highly concerning, said Patricia Beebe, CEO of the Food Bank of Delaware. (3/9/14)

The top industry for employment growth in the state is fast food, said David Grimaldi, New Castle County's chief administrative officer.

"Fast food don't buy houses," said Tom Gordon, New Castle County executive.

[\(/story/news/local/2014/03/08/map-food-stamp-enrollment/6174565\)](#) Filling the gap'

Throughout Delaware, working families aren't earning enough to pay for a basic need – food. Of the 26,700 Delaware families receiving food stamps, half of them had one family member with a job in the last 12 months, and nearly a third had two workers in the household, according to the most recent data available from the U.S. Department of Agriculture.

Most people using the benefit also are caring for children, with 59 percent of food stamp households reporting at least one child younger than 18. The median income of a Delaware household relying on food assistance last year was \$23,104.

STORY: [Shopping trips involve careful planning \(/story/news/local/2014/03/08/food-stamps-in-delaware-shopping-trips-involve-careful-planning/6218567\)](#)

About 77 percent of eligible Delawareans actually receive the benefits, according to Matt Talley, food stamp outreach coordinator for the Food Bank of Delaware. The 23 percent who do not receive the benefit – "the most vulnerable people," he called them – often have not even applied.

These, he said, include seniors, many of whom have no access to transportation; Latino and Hispanic households who face additional language barriers; and the working poor – those with an income, but one that isn't enough.

Beebe, who describes her organization as being counted upon to "swoop in and try to put a finger in the dike," said the Food Bank is not catching up to demand.

"There is no way that we can continue to fill the gap," Beebe said.

President Barack Obama's economic stimulus bill in 2009 had increased food stamp benefits around the country for several years. But an effort in Congress to extend that last year couldn't overcome opposition from Republicans who said the benefits were ineffective and the system vulnerable to fraud.

"As long as we continue to follow that pattern," said Dan Reyes, who coordinates the Food Bank's Coalition to End Hunger, "we're just going to keep chipping away at a program that's designed to stimulate the economy while need increases."

<http://www.delawareonline.com/story/news/local/2014/03/08/food-stamp-use-increasing-in-delaware/62...> 4/29/2014

COLUMN: [Food stamps keep millions from going hungry \(/story/opinion/columnists/2014/03/07/food-stamps-keep-millions-from-going-hungry/6187543/\)](#)

COLUMN: [Playing politics with food stamps \(/story/opinion/columnists/rhonda-graham/2014/03/08/playing-politics-with-food-stamps/6205353/\)](#)

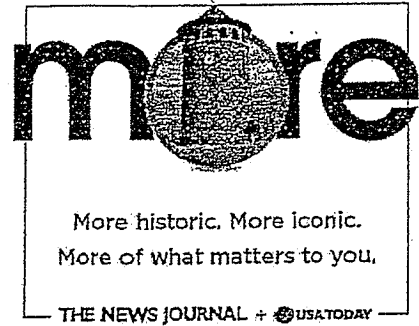
Contact James Fisher at (302) 983-6772, on Twitter @JamesFisherTNJ or jfisher@delawareonline.com. Contact Jon Offredo at (302) 678-4271 or at joffredo@delawareonline.com. Follow him on Twitter @jonoffredo. Contact William H. McMichael at (302) 324-2812 or bmc michael@delawareonline.com. On Twitter: @billmcmichael.

SHARE

438

CONNECT

<https://twitter.com/intent/tweet?url=http://delonline.us/1iouzLS&text=Food%20stamp%20use%20increasing%20in%20D>



MORE NEWS STORIES



[Christiana Care forensic nurse examiner team honored](#)

[\(/story/news/health/2014/04/28/christiana-care-forensic-nurse-examiner-team-honored/8421423/\)](#)

[\(/story/news/health/2014/04/28/christiana-care-forensic-nurse-examiner-team-honored/8421423/\)](#)

April 29, 2014, 9:06 a.m.



[Amtrak repairs downed wires](#)

[\(/story/news/traffic/2014/04/29/downed-wires-delay-amtrak-trains/8448769/\)](#)

[\(/story/news/traffic/2014/04/29/downed-wires-delay-amtrak-trains/8448769/\)](#)

April 29, 2014, 9:02 a.m.

**§ 3123 Supportive services and residential programs.**

(a) Any school district administering a program for children with autism may provide from its own personnel or contract with another state agency or a private service provider if necessary for appropriate supportive services, including, but not limited to, respite care, physical, art and music education, psychological services, language and speech therapy, physical and occupational therapy. The supportive services to be provided shall be based upon a program for each child as approved by the Department of Education; provided, that the State Board may review any objection to the Department's decision. The school district designated by the Department with State Board approval as the administering agency for a statewide program for autistic pupils shall annually submit in its budget a request for funds for such services.

(b) Community-based residential units for children with autism may be operated by a school district designated and approved by the Department with State Board approval as the administering agency for a statewide program for autistic pupils. When the school district operates a community-based residential program, that program shall meet the following minimum standards:

(1) Pre-puberty and post-puberty children shall be housed separately. In no case shall a child under age 12 be housed with a child over age 16 except as approved by the Human Rights and Peer Review committees of the statewide autistic program.

(2) Residential units shall be provided at the rate of 1 residential unit for each 4 residential pupils except that a maximum of 5 pupils may be housed in 1 residential unit. Pupils housed for the purpose of respite care, additionally defined to mean a period not to exceed 12 months, shall not be counted with respect to this provision. At no time shall the total number of pupils exceed 6 including respite placements.

(3) Residential teacher coordinators shall be provided for a period of 12 months per year at the rate of 3 full-time equivalent teacher coordinators per residential unit.

(4) Residential child care specialists shall be provided for a period of 12 months per year at the rate of 6 full-time equivalent residential child care specialists per residential unit. The Department with the approval of the State Board of Education shall determine the necessary educational requirements for the residential child care specialists.

61 Del. Laws, c. 190, §§ 5, 8; 64 Del. Laws, c. 381, §§ 1, 2; 71 Del. Laws, c. 180, § 151; 77 Del. Laws, c. 424, § 15.;



# Using group homes causes rift

## Director says residential service out of district's scope

By MIKE CHALMERS • The News Journal • August 16, 2010

Lia Park has autism, and by age 15, she still couldn't speak, couldn't use the bathroom and had a habit of severely gouging her own eye.

"Somebody had to always be with her," said her mother, Patrice Park. "She was dependent on us for all of her care."

Lia's frustrated parents turned to a special service offered through the Delaware Autism Program, where she was enrolled as a student. For two weeks, Lia lived in a Newark group home, where staffers successfully taught her to use the toilet.

"It was just an awesome experience," Patrice Park said. "It was part of her education program. It wasn't baby-sitting or putting her away somewhere."

The lessons worked so well that her parents began sending her to the home frequently to work on other behaviors. For the past six years, Lia regularly spent as many as five nights a week at one of DAP's three homes.

That's a problem, said DAP director Vincent Winterling.

The service isn't held to the same training, licensing and accreditation standards as another group home, he said. And the Christina School District, which hosts DAP in New Castle County, isn't supposed to run a residential treatment program, he said.

"What in God's name is the school district doing providing residential treatment?" Winterling said.

"We're not accountable, we're not licensed," he said. "Nobody really knows what the program is. I'm looking at it thinking, 'Come on, this is crazy.'"

Winterling wants to eliminate overnight stays, currently offered to only seven or eight of DAP's more than 700 children statewide. But Delaware parents and autism advocates are resisting.

"If it's not working, let's fix it," said Kim Herbert, of Pike Creek, whose 7-year-old twin sons have autism.

"My boys might need it someday, so I don't want to see it go anywhere," said Herbert, president of DAP's parent advisory council. "If we get rid of the residential home, there's no getting it back."

The Christina School Board has not made any decisions on Winterling's recommendations, said Wendy Lapham, spokeswoman for Christina School District.

Such residential treatment programs are falling out of favor among most autism advocates and researchers, said Jeff Sell, vice president of advocacy and public policy for the Autism Society, a national advocacy group. The trend is now toward offering services in the community or a family's home because it is less expensive and more effective, he said.

Residential programs "are what everybody wants to avoid," said Sell, who has twin 16-year-old sons with autism.

Services now offered by DAP's homes could be

Advertisement

**USA TODAY**  
**AutoPilot** ✈️

The new travel app for iPhone® and iPod touch®

Presented by:

**SEE HOW IT WORKS** >>>

Print Powered By



provided by behavioral experts who come to a family's home, Sell said.

Winterling said the homes could still be used to teach life skills to autistic children, just not overnight. He has proposed the service be phased out over the next year.

Fifteen students, from ages 12 to 21, currently receive the service at the homes. About half of them, including Lia Park, are leaving this month because they have turned 21, Winterling said.

"For the 12-year-olds, we can't be here for nine more years," Winterling said. "Something else is needed in your family's life, and the school district can't be it."

Winterling called the current program "a risk-management nightmare" because it doesn't meet the industry's standards for group homes. That leaves the program, its staff, the school district and the state open to legal blame if a student is injured or killed in an accident at one of the homes, he said.

"This is no longer the 30-year-ago world where you just gave your child and said, 'Take care of my kid,'" Winterling said. "We live in a litigious society."

Also, the three homes are in Newark, making the service impractical for families living downstate, he said.

The service should continue until a better one is in place, said Theda Ellis, executive director of Autism Delaware, an advocacy organization aimed at helping families affected by the disorder.

"What concerns me is closing this program without having an alternative," Ellis said. "We need some time to figure out who can do this."

Autism is a complex neurological disorder that affects the way a person communicates and interacts with others. It affects about one out of every 110 U. S. children, according to the Centers for Disease Control and Prevention.

Autistic children pose challenges for their families, parents said, but their issues are compounded when they reach adolescence.

Deanna Principe, of New Castle, wants the service to be available if her autistic daughter, now 11, needs it.

"It has turned into something it wasn't meant to be," Principe said. "But there's nothing else in place right now. So if that goes away, these families are left with nothing."

DAP, the nation's only statewide public school program for children with autism, started the residential service in 1985 when Marie-Anne Aghazadian and other parents pressed for an alternative to expensive, out-of-state group homes for children with difficult behavioral issues.

"We were a small group of parents who were able to win over a few legislators," Aghazadian said.

Aghazadian's son, Stefan, now 39, spent time in the homes to shower, dress himself and make basic microwave meals. He now lives in an adult group home.

"It allowed us to have a more typical family life," she said. "If he hadn't learned them in that setting, he would have never learned them."

Families with severely autistic children might have to accept that their child needs a full-time group home, Winterling said. There are no such homes for children in Delaware, so that means placing them in Pennsylvania, New Jersey or another state, he said.

The homes cost \$150,000 to \$200,000 a year for


Advertisement

**USA TODAY**  
**AutoPilot** 

The new travel app for iPhone™ and iPod touch®

Presented by: 

**SEE HOW IT WORKS»**

Print Powered By  FormatDynamics™



each child, Winterling said. The state would have to pick up much of that cost.

"Is it a high cost? Yes, it is," Winterling said. "But we've got to have the discussion about what we're doing with these kids. Nobody's going to be put on the street."

Ellis said Delaware does not have money to put into residential services, and in this political and economic climate, state residents and legislators are unlikely to raise taxes to pay for the services.

"I don't disagree with Vince, but I don't think it's going to happen," Ellis said.

Stacey O'Rourke, of Pike Creek, wants the service to remain in place if her 5-year-old daughter and twin 3-year-old girls, all with autism, need it.

But only if it is safe, she said.

"To have a school manage a residential facility is a lot," O'Rourke said.

Contact Mike Chalmers at 324-2790 or [mchalmers@delawareonline.com](mailto:mchalmers@delawareonline.com).



Purchase this Photo

Patrice Park helps daughter Lia put on her shoes. For six years Lia Park spent as many as five nights a week at one of the Delaware Autism Program's three homes — and that's a problem, DAP's director said. (The News Journal/GINGER WALL)

Advertisement


**USA TODAY**  
**AutoPilot** 

The new travel app for iPhone® and iPod touch®

Presented by: 

**SEE HOW IT WORKS >>**



Print Powered By  Format Dynamics



Purchase this Photo

Sammy Principe, 11, swims at Camp Manito in Wilmington on Thursday. Sammy's mom, Deanna, wants the DAP service to remain. "If that goes away, these families are left with nothing," she said. (The News Journal/JENNIFER CORBETT)



Purchase this Photo

Deanna Principe helps daughter Sammy, 11, put on her backpack while picking her up at the Variety Autism Camp held at Camp Manito in Wilmington on Thursday. (The News Journal/JENNIFER CORBETT)

Advertisement

**Mom Dilemma #36:**  
Your daughter insists on wearing her princess costume to the grocery store. Allow it or not?

**momslike.com**  
THE COMMON MOM

Print Powered By FormatDynamics



8-23-15  
MS

delawareonline.com

**The News Journal**  
A Gannett newspaper  
**W. Curtis Riddle**  
President and Publisher

**F. Ledford**  
Executive Editor

**John Sweeney**  
Editorial Page Editor

**QUOTE OF THE DAY**

*"We pick a side and go with it, and if we're wrong, we're wrong."*

Sussex County developer Preston Schell of Schell Bros. on political endorsements by businesses

**OUR VIEW**

# Schools must do better job of helping autistic students

Unanswered questions about the legality of a residential program for autistic students being hosted by the Christina School District can no longer be ignored.

Until they are resolved, the school district and the Delaware Autism Program

**QUESTIONS OF COMPLIANCE** have a moral and legal obligation to see that the special needs children enrolled in it receive the appropriate standard of care.

There is no doubt that the special services offered through DAP are a saving grace for parents of students with this complex neurological disorder.

With 1 out of every 110 U.S. children diagnosed, many are so severely affected that they require care of highly skilled health care and behavioral specialists. DAP serves more than 700 children.

The organization has contributed to the state's positive reputation for services to children, who in most cases are taught separately from the majority student population.

That's why it's as concerning that the severest critic of the current circumstances comes from DAP Director Vincent Winterling.

"We're not accountable, we're not licensed," Winterling said. "Nobody really knows what the program is. I'm looking at it thinking, 'Come on, this is crazy.'"

What a ringing indictment of the very "risk-management nightmare" Winterling predicts.

While parents can make a case for positive outcomes on their children's development in the residential setting, priority one should be to make sure it's safe and medically compliant.

3-27-65 45

# District must not give up on autistic students

Last Monday's article, "Using group homes causes rift," on the Delaware Autism Program (DAP) group homes hit on many key points.

It should be recognized that the Legislature, the Christina School District and parents agreed 20 years ago that locally run group homes were the most cost-effective way to address the needs of these challenged students.

THELMA M. ELLIS

goals during the day in school or at home. Initially, the DAP also provided parent training so students in the residential program would be able to successfully transition back home.

That training never fully materialized as initially envisioned and has subsequently been reduced as the number of students increased.

I agree with Dr. Winterling that the group homes should be licensed and certified. Christina signed a memorandum of agreement four years ago that it would do that - it could and should complete that process. DAP group home staff consists of certified teach-

ers and paraprofessionals who are typically better paid than staff of typical residential programs, thus they should have even more skills than a standard residential program.

Concerning the argument that residential services are not an appropriate public education service, there is a rich history of school-run residential services for other unique disabilities, including Christina's Sterck School for the Deaf.

The reason for group homes for children with autism may be different, but the need is no less acute. See the fact that the DAP group homes are managed by public education is

not really the issue. The issue is will.

We have 10-25 children who are going to need the additional support that residential programming provides. To do it in the home would be ideal, but

Delaware does not have the professional expertise nor the funding to do this. Sending children out of state is not the answer and is not cost-efficient. Autism Delaware is not saying that the DAP must

run these homes, but we do believe there must be an in-state program for children with autism who require a residential component.

*Theda M. Ellis is executive director of Autism Delaware.*

# Future unclear for Delaware Autism Program homes

## Legislators, school board say they're out of loop

By NICHOLE DOBO • The News Journal • October 1, 2010

Nearly a month after the Delaware Autism Program's director publicly called for the closing of a residential program, some elected officials say they've been shut out of the decision-making process.

Officials from the state Department of Education hosted a meeting with several state agencies this week but declined to allow Christina school board members to take part. And two state legislators, one Republican and one Democratic, say there's been a troubling lack of information about issues surrounding DAP's three residential homes.

"Apparently they have circled the wagons," said state Rep. William A. Oberle, R-Beechers Lot, "and it's very difficult to figure out what is going on."

The homes serve as a temporary residential facility for a handful of children from across the state who need intensive help to reach education goals. The program's new director, Vincent Winterling, has said staff is not properly trained and there are liability issues.

Winterling, who declined to be interviewed for this story, said in an August interview with The News Journal that the homes should be closed and children in need of these services should be sent elsewhere. This would mean these children would be sent to neighboring states, with Delaware absorbing costs of \$150,000 to \$200,000 per child a year.

"Is it a high cost? Yes, it is," Winterling said in the earlier interview. "But we've got to have the discussion about what we're doing with these kids. Nobody's going to be put on the street."

The 25-year-old program is utilized and funded by

school districts statewide, but the operating power rests with the Christina School District. Most everyone agrees that changes need to be made at the homes, but it's not clear how to go about doing it. There appears to be a fundamental disagreement between the state and the Christina School Board in regards to who has the right to steer the decision-making process.

There's a fear that the state will come up with its own plan, cutting out the elected board and other key stakeholders, said Rep. Quinton Johnson, D-Middletown. The state needs to work with elected officials and the public, rather than making a decision, then pretending to take suggestions from others, Johnson said.

Christina school board member Elizabeth Scheinberg agrees, saying the school board and state should work collaboratively.

"If you are going to bring all the parties to the table, you ought to bring all the parties to the table," she said.

The elected officials weren't invited to the meeting about the problems facing the homes held Tuesday.

The purpose of the meeting was to "find a solution to use the community residences" in a way that will benefit families, said Martha Toomey, the state Department of Education's director of special education. She intends to find a way to keep the program open.

That could mean contracting out services to private



We focus on automating Marriott® Hotels' global invoice process. So they don't have to.

Learn more at [RealBusiness.com](http://RealBusiness.com)

   
Ready for Real Business

Print Powered By  FormatDynamics™



providers but keeping the children in state, she said.

Oberle -- who said he is against closing the homes -- has been waiting more than two months for detailed information about exactly what's wrong with the homes.

He has not yet received a response from Secretary of Education Lillian Lowery, and he's concerned that key decisions will be made before others are brought into the fold.

"This is the first time I feel like I've been stonewalled on an issue from her," Oberle said. "And I never thought I'd live long enough to say that."

Lowery explained that she did not communicate with Oberle because she had nothing to share.

It was a mistake not to get back to him, she said, apologizing that it happened.

State officials intend to host a public forum, Lowery said, but they first needed an initial meeting that only included some agency heads so that the issues could be outlined.

No date for the public meeting has been set, Lowery said.

"We have never done this before," Lowery said. "Before we get people stirred up, let's see what we have here."

Parent Kim Herbert, who is president of the DAP parent group and the mother of twin boys who have autism, said she believes Winterling makes valid points about problems in the homes.

The homes are in such a poor condition that she cried after seeing them, she said.

"Please, don't close it," Herbert said. "Let's figure out what we can do with it."

Officials need to work to keep the homes open because there are parents who need help with real issues beyond their abilities, advocates say.

"We have children with autism who definitely need a residential component to their education," said Theda Ellis, executive director of the Autism Society of Delaware. "We just don't have a lot of alternatives. Private school is very expensive."

Contact Nichole Dobo at 324-2281 or ndobo@delawareonline.com.



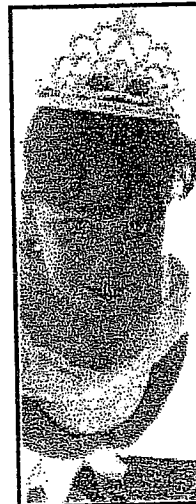
Rep. William Oberle said legislators haven't



Education Secretary Lillian Lowery said

On the Web

- Delaware Department of Education
- Christina School District
- Delaware General Assembly



Mom Dilemma #36:

Your daughter insists on wearing her princess costume to the grocery store. Allow it or not?

YES, at least she's dressed!

NO, I have some rules!

momslike.com where local moms meet

Print Powered By FormatDynamics



# Delaware Society for Children and Adults with Autism

P.O. Box 9666 • Newark, DE 19714-9666

Reasons why the Delaware Society for Children and Adults with Autism is supporting Senate Substitute #3 for Senate Bill #89.

- The Autistic Children who are presently being housed at the Governor Bacon Health Center will have to be moved by 1985 as that facility will close.
- Through private funds, a residential-educational facility has been made available to the Autistic Program to house the above mentioned children in the community.
- If such a facility becomes operational, the following mechanisms ought to be in place:
  - A peer review committee.
  - A human rights committee
  - An Autistic monitoring board.
- With these committees in place in conjunction with an educational residential community based facility and a job training-placement person, children that are now being serviced out of State could be brought back at a great saving to the State.
- The Delaware Society for Children and Adults with Autism feels very strongly that such community based educational-residential facilities should be planned very carefully without ignoring the rights of the children or the other members of the community.

JUL 17 1984 64 381



DELAWARE STATE SENATE  
132ND GENERAL ASSEMBLY

SENATE SUBSTITUTE NO. 3

FOR

SENATE BILL NO. 89

AS AMENDED BY

SENATE AMENDMENT NO. 1

AN ACT TO AMEND CHAPTER 31, TITLE 14, DELAWARE CODE, AS IT RELATES TO STANDARDS FOR RESIDENTIAL SERVICES FOR AUTISTIC PERSONS AND JOB TRAINING AND PLACEMENT SERVICES FOR AUTISTIC PERSONS.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF DELAWARE:

Section 1. Amend Section 3123, Chapter 31, Title 14, Delaware Code by redesignating the existing paragraph as subparagraph "(a)", inserting after the words "but not limited to" the words "respite care," and striking the last sentence of said subparagraph and inserting in lieu thereof the sentence, "The school district designated by the State Board of Education as the administering agency for a statewide program for autistic pupils shall annually submit in its budget a request for funds for such services."

Section 2. Amend Section 3123, Chapter 31, Title 14, Delaware Code by adding after the first paragraph the following:

"(b) Community-based residential units for autistic children may be operated by a school district designated and approved by the State Board of Education as the administering agency for a statewide program for autistic pupils. When the school district operates a community based residential program, that program shall meet the following minimum standards:

(1) Pre-puberty and post-puberty children shall be housed separately. In no case shall a child under age twelve (12) be housed with a child over age sixteen (16) except as approved by the Human Rights and Peer Review Committees of the Statewide Autistic program.

(2) Residential units shall be provided at the rate of one residential unit for each four residential pupils except that a maximum of five pupils may be housed in one residential unit. Pupils housed for the purpose of respite care, additionally defined to mean a period not to exceed twelve (12) months, shall not be counted with respect to this provision. At no time shall the total number of pupils exceed six (6) including respite placements.

(3) Residential teacher coordinators shall be provided for a period of twelve (12) months per year at the rate of three (3) full-time equivalent teacher coordinators per residential unit.

(4) Residential child care specialists shall be provided for a period of twelve (12) months per year at the rate of six full-time equivalent residential child care specialists per residential unit. The State Board of Education shall determine the necessary educational requirements for the residential child care specialists.

Section 3. Amend §1332, Chapter 13, Title 14, of the Delaware Code by adding thereto a new §(f) to read as follows:

"(f) The State Board of Education shall adopt such rules and regulations to establish and provide for Parent Advisory Committees, a Peer Review Committee, a Human Rights Committee, and appropriate liasons with the Department of Health and Social Services. The State Board of Education shall adopt such rules and regulations to establish and provide for an Autistic Program Monitoring Board, to be composed of no less than seven (7) members and which shall include one (1) non-voting public representative nominated annually by the Delaware Society for Children and Adults with Autism and who does not have a child enrolled in the autistic program. The Statewide Autistic Monitoring Review Board shall review at least annually the identification, evaluation, and educational program and placement of each autistic pupil and the provision for a free appropriate public education to such pupils. Disputes within or between districts or agencies shall be resolved by this Board. Procedural safeguards guaranteed to autistic pupils, their parents or guardians and to local school districts or agencies shall not be diminished by this provision."

SYNOPSIS TO HB 93 (1980)

1 in §1321 (e) (14) (a). Teachers shall be employed at the rate  
2 of the number of pupil units as of the last day of September  
3 of a regular school year. A fraction greater than one-half  
4 shall be considered a unit.

5 Section 7. Unless otherwise appropriated no additional funds  
6 shall be appropriated for carrying out the provisions of this Act during  
7 the fiscal year beginning July 1, 1980.

8 Section 8. Except as set forth in Section 7 of this Act, the  
9 provisions of this Act shall take effect July 1, 1980.

SYNOPSIS

Provision for the statewide autistic program as a contingency has proved to be most troublesome to budget and to coordinate. This bill sets forth the special school core staff ratios required but undefined in 14 Del.C., §3123.

This bill follows exactly the language of House Bill No. 875 introduced for the purpose of clarifying legislative intent with regard to the employment of specialized personnel, sharing of personnel, and aggregating units across district lines.

With regard to pre-kindergarten age children, in the previous three years, a total of 3 children were identified. The parent/child trainer position is for all children 0-21 and is presently funded with P. L. 89-313 funds.

With regard to authorization for pupil days beyond 217 days, programming and respite care services have already been budgeted through a federal developmental disability grant.

\* ← The very low incidence of autistic persons is reflected by the fact that 32 children were served statewide during the current fiscal year. Provision for 41 children statewide has been made in the budget for the coming fiscal year.

Correcting the under estimate for the residential unit through an amendment to the Omnibus Amendment Bill will allow the funding of all the above staff and services with existing federal, state, and local funds.





---

## CMCS Informational Bulletin

**DATE:** July 7, 2014

**FROM:** Cindy Mann, Director  
Center for Medicaid and CHIP Services

**SUBJECT:** Clarification of Medicaid Coverage of Services to Children with Autism

In response to increased interest and activity with respect to services available to children with autism spectrum disorder (ASD), CMS is providing information on approaches available under the federal Medicaid program for providing services to eligible individuals with ASD.

### Background

Autism spectrum disorder is a developmental disability that can cause significant social, communication and behavioral challenges. A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder. Currently, the Center for Disease Control and Prevention (CDC) estimates that approximately 1 in 68 children has been identified with ASD.<sup>1</sup>

Treatments for children with ASD can improve physical and mental development. Generally these treatments can be categorized in four categories: 1) behavioral and communication approaches; 2) dietary approaches; 3) medications; and 4) complementary and alternative medicine.<sup>2</sup> While much of the current national discussion focuses on one particular treatment modality called Applied Behavioral Analysis (ABA), there are other recognized and emerging treatment modalities for children with ASD, including those described in the ASD Services, Final Report on Environmental Scan (see link below)<sup>3</sup>. This bulletin provides information related to services available to individuals with ASD through the federal Medicaid program.

The federal Medicaid program may reimburse for services to address ASD through a variety of authorities. Services can be reimbursed through section 1905(a) of the Social Security Act (the Act), section 1915(i) state plan Home and Community-Based Services, section 1915(c) Home

---

<sup>1</sup> <http://www.cdc.gov/ncbddd/autism/facts.html>

<sup>2</sup> <http://www.cdc.gov/ncbddd/autism/treatment.html>

<sup>3</sup> <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf>

and Community-Based Services (HCBS) waiver programs and section 1115 research and demonstration programs.

### State Plan Authorities

Under the Medicaid state plan, services to address ASD may be covered under several different section 1905(a) benefit categories. Those categories include: section 1905(a)(6) - services of other licensed practitioners; section 1905(a)(13)(c) - preventive services; and section 1905(a)(10) - therapy services. States electing these services may need to update the Medicaid state plan in order to ensure federal financial participation (FFP) is available for expenditures for these services. In addition, for children, as discussed below, states must cover services that could otherwise be covered at state option under these categories consistent with the provisions at 1905(a)(4)(B) for Early and Periodic Screening, Diagnostic and Treatment services (EPSDT). Below is information on these coverage categories for services to address ASD. Under these section 1905(a) benefit categories all other state Medicaid plan requirements such as state-wideness and comparability must also be met.

### Other Licensed Practitioner Services

Other Licensed Practitioner services (OLP) services, defined at 42 CFR 440.60, are "medical or remedial care or services, other than physicians' services, provided by licensed practitioners within the scope of practice as defined under State law." If a state licenses practitioners who furnish services to address ASD, the state may elect to cover those providers under this section of their state plan even if the providers are not covered under other sections of the plan (e.g., physical therapist, occupational therapist, etc.). A state would need to submit a state plan amendment (SPA) to add the new licensed provider to their Medicaid plan. The SPA must describe the provider's qualifications and include a reimbursement methodology for paying the provider.

In addition, services that are furnished by non-licensed practitioners under the supervision of a licensed practitioner could be covered under the OLP benefit if the criteria below are met:

- Services are furnished directly by non-licensed practitioners who work under the supervision of the licensed practitioners;
- The licensed provider is able to furnish the service being provided;
- The state's Scope of Practice Act for the licensed practitioners specifically allows the licensed practitioners to supervise the non-licensed practitioners who furnish the service;
- The state's Scope of Practice Act also requires the licensed practitioners to assume professional responsibility for the patient and the service furnished by the unlicensed practitioner under their supervision; and
- The licensed practitioners bill for the service;

### Preventive Services

Preventive Services, defined at 42 CFR 440.130(c) are "services recommended by a physician or other licensed practitioner of the healing arts within the scope of his practice under state law to—

- (1) Prevent disease, disability, and other health conditions or their progression;
- (2) Prolong life; and
- (3) Promote physical and mental health and efficiency"

A regulatory change that took effect January 1, 2014, permits coverage of preventive services furnished by non-licensed practitioners who meet the qualifications set by the state, to furnish services under this state plan benefit as long as the services are recommended by a physician or other licensed practitioner. Under the preventive services benefit, in the state plan, the state must

- 1) list the services to be provided to ensure that services meet the definition of preventive services as stated in section 4385 of the State Medicaid Manual (including the requirement for the service to involve direct patient care);
- 2) identify the type(s) of non-licensed practitioners who may furnish the services; and
- 3) include a summary of the state's provider qualifications that make these practitioners qualified to furnish the services, including any required education, training, experience, credentialing, supervision, oversight and/ or registration.

#### Therapy Services

Physical therapy, occupational therapy and services for individuals with speech, hearing and language disorders, may be covered under the Medicaid therapies benefit at 42 CFR 440.110. Physical and occupational therapy must be prescribed by a physician or other licensed practitioner of the healing arts within the scope of his/her practice under state law and provided to a beneficiary by or under the direction of a qualified therapist. Services for individuals with speech, hearing and language disorders mean diagnostic, screening, preventive or corrective services provided by or under the direction of a speech pathologist or audiologist, for which a patient is referred by a physician or other licensed practitioner of the healing arts within the scope of his or her practice under state law.

States would need to include an assurance in the state plan that the state furnishes the therapy in accordance with 42 CFR 440.110. States would also need to describe the supervisory arrangements if a practitioner is furnishing the therapy under the direction of a qualified therapist. Finally, for audiology services, the state plan must reflect the supervision requirements as set forth at 42 CFR 440.110(c)(3).

#### Section 1915(i) of the Social Security Act

States can offer a variety of services under a section 1915(i) state plan Home and Community-Based Services (HCBS) benefit. The benefit may be targeted to one or more specific populations including individuals with ASD and can provide services and supports above and beyond those included in section 1905(a). Participants must meet state-defined criteria based on need and typically receive a combination of acute-care medical services (like dental services, skilled nursing services) and other long-term services such as respite care, supported employment, habilitative supports, and environmental modifications.

#### Other Medicaid Authorities

There are several other Medicaid authorities that may be used to provide services to address ASD. Below is a discussion of each of those authorities:

#### Section 1915 (c) of the Social Security Act

The section 1915(c) Home and Community-Based Services waiver program allows states to provide a combination of medical services and long-term services and supports. Services include

but are not limited to adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community. Participants must meet an institutional level of care but are served in the community. Section 1915(c) waiver programs also require that services be furnished in home and community-based settings. For individuals under the age of 21 who are eligible for EPSDT services, an HCBS waiver could provide services and supports for ASD that are above and beyond services listed in section 1905(a), such as respite care. Additionally, for individuals who are receiving state plan benefits as part of EPSDT that are not available to adults under the state plan, waiver services may be used to help these individuals transition into adulthood and not lose valuable necessary services and supports.

#### Section 1115 Research and Demonstration Waiver

Section 1115 of the Act provides the Secretary of the Department of Health and Human Services broad authority to authorize experimental, pilot, or demonstration programs that promote the objectives of the Medicaid program. Flexibility under section 1115 is sufficiently broad to allow States to test substantially new ideas, including benefit design or delivery system reform, of policy merit. The Secretary can approve an 1115 demonstration for up to five years, and states may submit extension requests to continue the program for additional periods of time. Demonstrations must be "budget neutral" over the life of the program, meaning they cannot be expected to cost the Federal government more than it would cost without the demonstration.

#### EPSDT Benefit Requirements

Section 1905(r) of the Act defines the EPSDT benefit to include a comprehensive array of preventive, diagnostic, and treatment services for low-income infants, children and adolescents under age 21. States are required to arrange for and cover for individuals eligible for the EPSDT benefit any Medicaid coverable service listed in section 1905(a) of the Act that is determined to be medically necessary to correct or ameliorate any physical or behavioral conditions. The EPSDT benefit is more robust than the Medicaid benefit package required for adults and is designed to assure that children receive early detection and preventive care, in addition to medically necessary treatment services, so that health problems are averted or diagnosed and treated as early as possible. All children, including children with ASD, must receive EPSDT screenings designed to identify health and developmental issues, including ASD, as early as possible. Good clinical practice requires ruling out any additional medical issues and not assuming that a behavioral manifestation is always attributable to the ASD. EPSDT also requires medically necessary diagnostic and treatment services. When a screening examination indicates the need for further evaluation of a child's health, the child should be appropriately referred for diagnosis and treatment without delay. Ultimately, the goal of EPSDT is to assure that children get the health care they need, when they need it – the right care to the right child at the right time in the right setting.

The role of states is to make sure all covered services are available as well as to assure that families of enrolled children, including children with ASD, are aware of and have access to a broad range of services to meet the individual child's needs; that is, all services that can be covered under section 1905(a), including licensed practitioners' services; speech, occupational,

and physical therapies; physician services; private duty nursing; personal care services; home health, medical equipment and supplies; rehabilitative services; and vision, hearing, and dental services.

If a service, supply or equipment that has been determined to be medically necessary for a child is not listed as covered (for adults) in a state's Medicaid State Plan, the state will nonetheless need to arrange for and cover it for the child as long as the service or supply is included within the categories of mandatory and optional services listed in section 1905(a) of the Social Security Act. This longstanding coverage design is intended to ensure a comprehensive, high-quality health care benefit for eligible individuals under age 21, including for those with ASD, based on individual determinations of medical necessity.

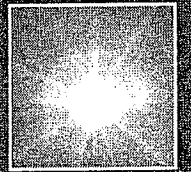
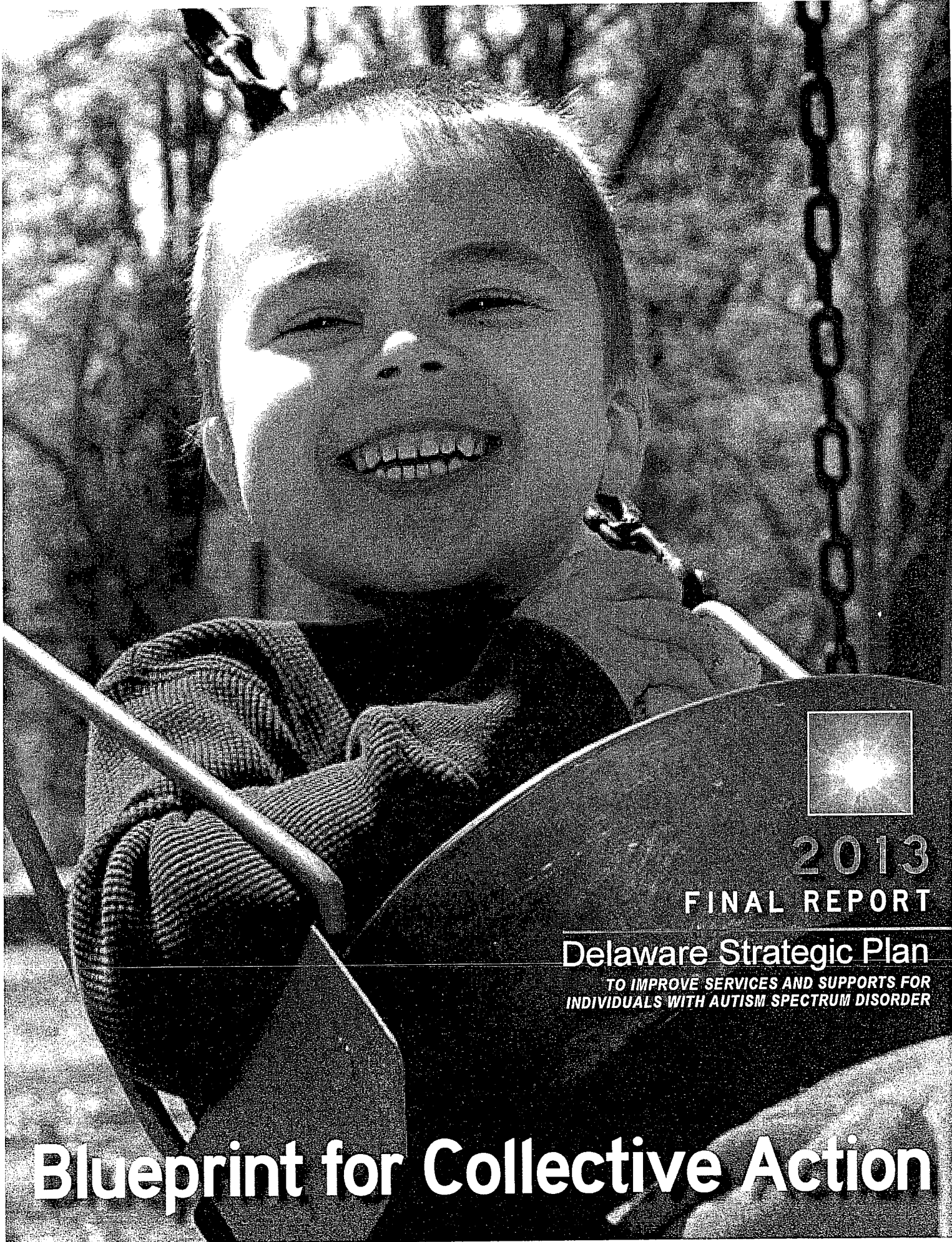
### **Implications for Existing Section 1915(c), Section 1915 (i) and Section 1115 Programs**

In states with existing 1915(c) waivers that provide services to address ASD, this 1905(a) policy clarification may impact on an individual's eligibility for the waiver. Waiver services are separated into two categories: waiver services and extended state plan services. Extended state plan services related to section 1905(a) services are not available to individuals under the age of 21 (individuals eligible for EPSDT) because of the expectation that EPSDT will meet the individual's needs. There are therefore a limited number of services that can be provided to this age group under 1915 (c) waivers, primarily respite, and/or environmental/vehicle modifications.

For states that currently provide waiver services to individuals under age 21 to address ASD, the ability to provide services under the 1905(a) state plan may have the effect of making these individuals ineligible for the waiver unless another waiver service is provided. This implication is especially important for individuals with ASD who may not otherwise be eligible for Medicaid absent the (c) waiver. States need to ensure that these individuals are receiving a waiver service, not coverable under section 1905(a), to ensure that they do not lose access to all Medicaid services by losing waiver eligibility. Individuals age 21 and older may continue to receive services to address ASD through the waiver if a state does not elect to provide these services to adults under its Medicaid state plan.

The same issues arise for children under the 1915(i) authority, which allows for services above and beyond section 1905(a) to be provided under the state plan. CMS is available to provide technical assistance to states that currently have approved waivers or state plans that may be impacted by this clarification. Similarly, states with existing 1115 demonstrations authorizing reimbursement for services provided to children with autism should contact CMS to ensure that EPSDT requirements are met.

We hope this information is helpful. If you have questions please send them to [AutismServicesQuestions@cms.hhs.gov](mailto:AutismServicesQuestions@cms.hhs.gov).



2013

FINAL REPORT

Delaware Strategic Plan

*TO IMPROVE SERVICES AND SUPPORTS FOR  
INDIVIDUALS WITH AUTISM SPECTRUM DISORDER*

**Blueprint for Collective Action**

## Contents

- 1 Introduction
- 2 Context of the Challenge
- 5 Blueprint Timeline and Methodology
- 6 Statewide Survey
- 7 Focus Groups
- 8 ASD Statewide Summit
- 9 Workgroup Accomplishments
  - a) Education
  - b) Medical
  - c) Employment / Independent Living
- 9 Blueprint for Collective Action Highlights
  - a) Interagency Committee for Autism (Leadership)
  - b) Autism Resource Center and associated functions
- 10 Improvement Areas and Outcomes
- 24 Moving Forward



## Introduction

The University of Delaware's Center for Disabilities Studies has conducted a comprehensive statewide appraisal of the ongoing needs of infants, children, youth and adults with autism spectrum disorder (ASD) in Delaware and the challenges in providing services and supports in response to those needs. This statewide ASD planning initiative, funded under a grant from the federal Health Resources and Services Administration (CFDA 93.110/HRSA-11-081), 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 a strong and deliberate emphasis on family participation. This formidable effort consisted of multi-faceted, systematic information gathering that engaged hundreds of parents, professionals and community leaders. The statewide ASD planning initiative represents more than merely a collection of isolated needs assessments, but rather an evolving plan of inquiry designed to yield information about critical areas needing improvement as well as desired outcomes and the associated activities that will lead to those outcomes.

The statewide planning initiative outlined in this document integrates the previous efforts of Delaware's Legislative Task Force on Adults with Autism and Delaware's Act Early State Team to assure a seamless and unified vision for future efforts. The *Blueprint for Collective Action* represents a plan for improvement that is highly integrated across the three identified areas of concern and action: education (early intervention through postsecondary); adult living/employment; and medical/mental health. Family involvement is a common denominator across planning and implementation efforts.

*On the cover: Willie is 4 years old. He was diagnosed with autism when he was 2 and has been in early intervention ever since. He enjoys puzzles, jumping on his trampoline and playing outside.  
Photo by Lane McLaughlin*

"It's so hard to find a doctor or a professional who really focuses, or really has expertise in autism... who understands our needs."

*-Delaware Parent*



## Context of the Challenge

The Centers for Disease Control and Prevention characterizes the rise in ASD as an urgent public health concern. Although at this time it is difficult to know the exact number of individuals in Delaware who are diagnosed with ASD, the school-age classification rate offers some guidance. During the 2012–2013 school year, 19,056 children were enrolled in special education in Delaware public schools. Of these, 1,208 children

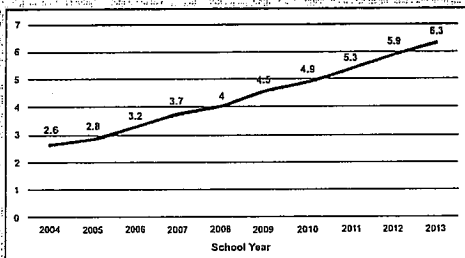
were classified with autism or ASD, accounting for 6.3% of students receiving special education.<sup>1</sup> The percentage of students classified with autism as a portion of all students in special education has tripled in the last eight years (Figure 1). New Castle County has the largest number of students classified with autism or an ASD, and Sussex County has the highest rate of public school students classified with autism or an ASD relative to the general

student population.<sup>2</sup> While the number of children served in the public school system continues to rise, we expect improvements in early identification to swell these numbers even more dramatically.

The *Blueprint for Collective Action* was developed as a response to the absence of a single entity charged with ensuring that high-quality care is provided in an efficient, coordinated,

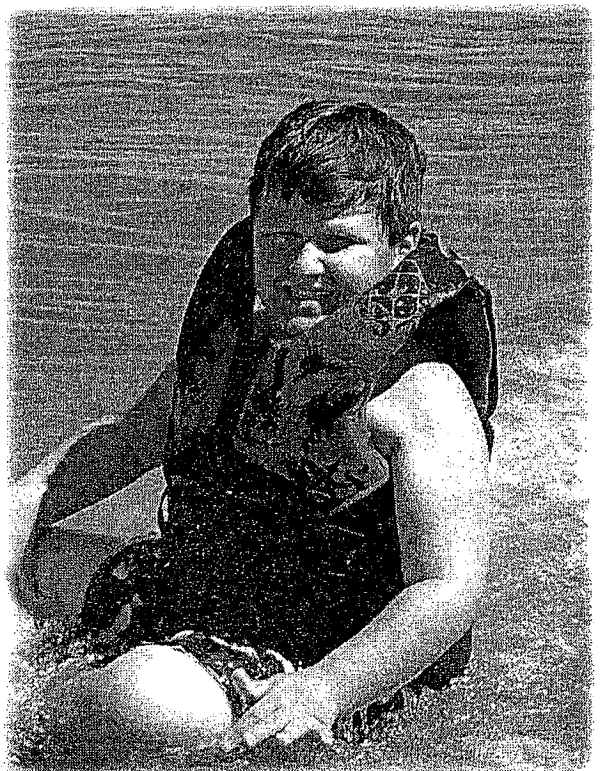
individualized and consumer-directed manner to individuals with ASD across all participating systems. While there has been great interest in building a statewide network of ASD-related providers, no single entity had the authority to address the systemic challenges presented by the dramatic increase in the incidence of ASD. Although education, health and adult life are related domains, each is addressed in isolation—with separate

Figure 1: Students with autism as a percentage of all students in special education from 2004 to 2013 (Source: Delaware Department of Education)

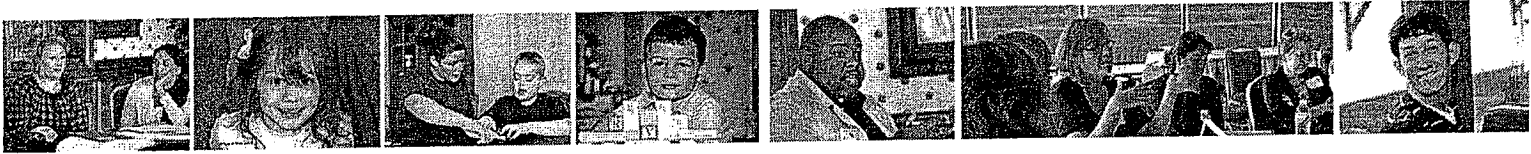


<sup>1</sup>Delaware Department of Education (2013)

<sup>2</sup>Delaware Population Consortium, Population Projection Series, Version 2011.0







mandates and resource allocations-leaving families of individuals with ASD with the daunting responsibility of coordination. This initiative was implemented to establish a structure for collaboration, resource leveraging and service coordination, with the ultimate goal being a unified and efficient system of support for individuals and their families.

Assessment and planning for this project began with a review of Delaware-specific data regarding the known incidence of ASD from the Birth to Three Early Intervention System, the Division of Developmental Disabilities Services and the Delaware Department of Education. Since this initiative began, however, significant new information has come to light that may influence the interpretation of local data. First, the Centers for Disease Control and Prevention reported that the incidence of ASD may be as high as one out of every 50 school-aged children. In contrast, the official federal government estimates remain one out of every 88 American children. Both these estimates are significantly

higher than was expected when the statewide ASD planning initiative began. This is further complicated by changes in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which now provides for a single umbrella diagnostic category of autism spectrum disorder rather than the familiar cluster of related diagnoses



(i.e., autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified). The effects of this major change in diagnostic categories have not yet been realized.

Diagnoses and classifications are not merely semantic distinctions.

The planning process identified obstacles that families already face in securing services due to the differences between medical diagnosis and educational classification. Students with ASD may not be eligible for special education even though they require intensive school-level support in such areas as social-emotional development, health and behavior. The *Blueprint* addresses this critical issue of differences between educational classification and medical diagnosis. It also recognizes that these discrepancies present problems for families seeking support, and poses challenges to the state's efforts to gather accurate information regarding incidence and prevalence of ASD within Delaware.

Families also want to see a workforce well-equipped to support individuals with ASD. Many school districts lack capacity to serve students with ASD; their staff require significant training and technical assistance in evidence-based intervention with this population. Improved pre-service training for general education teachers is

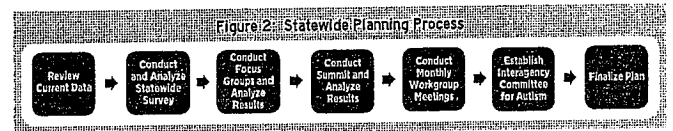
needed in deficit areas that are common among students with ASD (e.g., communication and social skills). Adult service agencies report lack of qualified support personnel and training for all agency employees. In addition, on-going technical assistance for

businesses that employ individuals with ASD is needed.

There is also a need to provide improved access to support and coordinated care for families of children with ASD. This includes better coordination among sub-

specialists, schools and primary care physicians. In addition, the need for improved family support upon diagnosis, training for community-based providers and improved access to postsecondary education were identified as key issues for individuals with ASD in Delaware.

## Blueprint Timeline and Methodology



The *Blueprint for Collective Action* arose from a process characterized by iterative phases leading to a collaborative plan reflecting statewide consensus and commitment. Informal meetings of key stakeholders were instrumental in the development and support of the project design. These stakeholders represented the three key areas targeted for improvement: education, health and adult living. This group concurred that the goal of the entire ASD planning initiative was:

*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.*

This goal functioned as a barometer by which all improvement outcomes and activities were assessed. Figure 2 shows the sequential progression

of the assessment process that ultimately yielded the *Blueprint*.

Using a mixed-methods evaluation process, both quantitative and qualitative approaches to data collection were utilized. After reviewing the results of previous initiatives, the project conducted a statewide survey; as the figure above indicates, these findings informed subsequent structured interviews, focus groups and group assessment processes.

## Statewide Survey

In late 2011, the Center for Disabilities Studies distributed a needs assessment survey to three groups of individuals in Delaware:

- 1) parents/guardians of children with autism spectrum disorders;
- 2) caretakers of adults with autism spectrum disorders; and
- 3) adult self-advocates with autism spectrum disorders.

Each group received a slightly different version of the survey. In all, 271 parents/guardians of children with ASD, 91 caretakers of adults with ASD and 19 adult self-advocates with ASD completed the survey.

The needs assessment survey explored the following topics:

- 1) Receiving a diagnosis and follow-up care
- 2) Barriers and limitations to accessing health care
- 3) Employment challenges for adults with autism spectrum disorders
- 4) Family impact
- 5) Service needs
- 6) Unwanted outcomes

The survey was modeled 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 included questions about Medicaid

"Diagnosis took what seemed forever. The waiting list was, like, nine months. Then they closed the waiting list. So we called Johns Hopkins. We called people in New York. We called CHOP. I was on everybody's waiting list."

—Newark Parent

providers and how far families traveled to see a provider.

This survey was distributed in both online and in paper form. A paper copy was sent via mail by the Delaware Department of Education and the Delaware Division of Development Disabilities Services. Links to the survey were included on websites for the Center for Disabilities

Studies, Autism Delaware, Parent Information Center and Delaware Family Voices. In addition to including a link on its website, Autism Delaware also sent a link to the survey via its Listserv, information about the survey and a link were also included in Project Bridge, a newsletter published by the Center for Disabilities Studies.

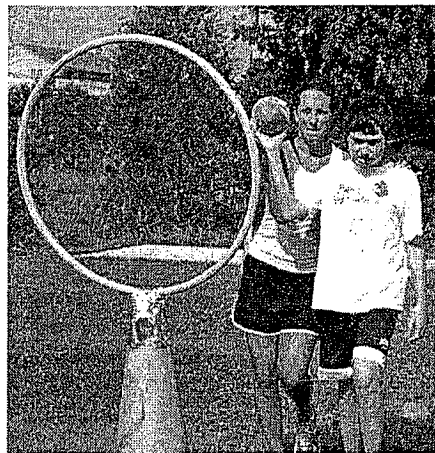
A statement at the beginning of the survey instructed parents/guardians of children and caretakers of adults to fill out a separate survey for each individual with autism or, if only filling out one survey, to reply to questions for the oldest person with autism for whom they provided care. Adult self-advocates with autism were instructed to answer questions regarding their current situation. Staff of the Delaware Education Research and Development Center were responsible for data analysis and reporting. The data presented in this document summarize responses to selected survey items addressing treatment, services, employment outcomes and the impact on caregivers and family members caring for an individual with ASD. Data are presented in the form of frequencies and percentages. More substantive interpretations of data are presented in chart form and are available on the Center for Disabilities Studies website at [www.udel.edu/cds](http://www.udel.edu/cds).

## 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 Georgetown, Middletown and Newark. The focus group interviews utilized a semi-structured interview protocol. Questions addressed the following topics:

- 1) The process of obtaining a diagnosis
- 2) Positive and negative experiences with the healthcare system (doctors, hospitals, pharmacies, therapists, etc.)
- 3) Positive and negative experiences with the educational system
- 4) Positive and negative experiences with vocational rehabilitation and employment
- 5) Thoughts on the interaction of all of the service systems in Delaware, including how they could improve the way 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



interviews, the participants signed an informed consent document that had been approved by a research oversight body at the University of Delaware. Participation was voluntary, they did not have to answer any questions they did not want to, and they could choose not to participate or withdraw at any time. Participants were also informed that the focus groups would be audio recorded as a way of ensuring that accurate information was obtained for analysis.

Participants were given a \$50 gift card for participating in a focus group.

Focus group interviews were transcribed verbatim. Transcripts were read and codes were assigned to passages of text. Primary themes were developed in accordance with the interview questions. Secondary themes were developed under each primary theme in order to capture dominant categories within the transcripts.

## ASD Statewide Summit

On June 7, 2012, all stakeholders involved in the lives of individuals with ASD in Delaware gathered at a statewide summit and participated in group assessment and planning using a process based on the Osborn-Parnes Approach to Creative Problem Solving.<sup>3</sup> A series of activities were implemented that allowed for opportunities to express individual concerns or positions within a group structure. Additional mechanisms gave participants the opportunity to provide individual perspectives relative to identified challenges and solutions outside of the group process. The resulting data generated from the more than 120 participants enabled the informal advisory committee to establish the initial structure of an improvement plan.

### Summit Outcomes

- Participants articulated shared values/beliefs regarding the support of individuals with ASD and reached consensus on these statements:
  - We believe that adults with autism have a right to live in our communities with the appropriate support.
  - We believe that youth with autism must have access to postsecondary education opportunities representing an array of options, including traditional college.
  - We believe that those working on behalf of supporting individuals



- 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 disability.
- We believe that all families do not have the same expectations for their children, and, therefore, cultural differences should be respected.
- We believe parents should have access to appropriate information, training and supports to make informed choices with their child.
- We believe that students with autism have a right to an array of services accessible to support them toward independence in a continuum of settings.
- Fact-finding and impressions/ideas sessions generated information regarding the current status of services and supports and offered insight into improvement planning efforts.
- An Executive Planning Council was established with responsibility for coordinating the individual working groups that emerged from the summit.
- In five to six meetings between September 2012 and April 2013, the three working groups continued fact-finding and refined their recommendations, culminating in a draft of the Statewide Plan for Improvement in May 2013.

### Stakeholders Represented:

- Hospitals and health professionals
- Delaware Department of Education
- Delaware Division of Developmental Disabilities Services
- Delaware Division of Vocational Rehabilitation
- Institutions of higher education
- Families and self-advocates
- Professional and advocacy agencies
- Schools and programs

<sup>3</sup>Jackson, S.G. & Treffinger, D. (2004). Celebrating 50 years of reflective practice: versions of creative problem solving. *Journal of Creative Behavior*, 38 (2), 75-101.

## Work Group Accomplishments

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

### Blueprint Project's Identified Improvement Areas

- Area I: Identification, Diagnosis and Classification
- Area II: Training and Technical Assistance
- Area III: Pre-Professional Training
- Area IV: Self-Determination, Self-advocacy and Social Network Development
- Area V: Transition to Adult Life
- Area VI: Family Support and Stakeholder Engagement
- Area VII: Systems Coordination

These areas drove the deliberations of all three workgroups, which were each composed of 10 to 12 people representing a variety of roles and perspectives. No member served on more than one workgroup. The education workgroup was facilitated by the same consultant that developed and facilitated the summit. The medical/mental health and adult life/employment workgroups were chaired by the project director. The project director and consultant worked together to assure that the work of the groups was articulated

within the developing plan. In addition, each workgroup had the option of additional consultation from identified experts, state officials and/or other relevant people throughout the process.

The workgroups generated a collection of envisioned outcomes related to the improvement areas. These converged in a conceptual pathway toward the stated outcomes. Next, the workgroups identified activities that were likely to lead to the accomplishment of the stated outcomes. These activities were reviewed and reorganized within the context of several combined workgroup meetings to forge a unified improvement plan.

## Blueprint for Collective Action Highlights

The workgroups collectively endorsed two systemic activities as a means to accomplish many of the activities of the plan. These include:

### The Interagency Committee for Autism (ICA)

The Interagency Committee for Autism is an executive group of state decision-makers that represents the key stakeholders and a small group of parents who are not linked to any organization. This committee is key to the implementation of the plan and has specific charges related to improved plan outcomes

and activities. The ICA has formed and will meet regularly as the implementation stage of the *Blueprint for Collective Action Project* unfolds.

### The Autism resource center and associated functions

The strategic plan emphasizes the need to address the scarcity of individuals who are trained, qualified and motivated to work with and support individuals with ASD. Each workgroup outlined the unique skills needed to effectively teach, support, employ and care for and about individuals with ASD across

the lifespan. Currently, there is no centralized resource for providing training and technical assistance across all domains. The development of a statewide 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, reflecting best practice. 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 systems.

## IMPROVEMENT AREA I:

### Identification, Diagnosis and Classification

DELAWARE STRATEGIC PLAN  
TO IMPROVE SERVICES AND SUPPORTS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

#### OUTCOME A

All parents, educational personnel and medical professionals will understand the relationship between medical diagnosis and educational classification including the skills and knowledge for referral to appropriate services.

- 1) A document (table or flow chart) will be developed and disseminated that clearly defines the parameters, differences and commonalities between the medical diagnosis and educational classification of ASD and outlines the appropriate referral process for parents, educational professionals, physicians/medical professionals, service providers and Child Development Watch.
- 2) A 10-15 minute web-based module will be developed regarding diagnosis and identification, what to expect and how to get resources for parents and professionals.
- 3) Conduct lunchtime meetings between pediatric physicians and other allied health professionals with special education directors at all Local Education Agencies (LEAs) to identify effective communication methods.
- 4) Build educational systems information into pediatric training at both Nemours and Christiana Care Health System (CCHS).
- 5) Present workshop at the American Academy of Pediatrics (AAP) Delaware Conference on educational systems and understanding the Individuals with Disabilities Education Act (IDEA) for children with ASD.

#### OUTCOME B

All infants, children and adults regardless of classification are known to the school and service providers (with parents informed consent) when ASD is present and provided reasonable considerations.

- 1) Provide training on the psycho-social needs (social skills) and impact of ASD to teachers (early childhood, K-12, post-secondary), medical and mental health professionals, early intervention providers, other support professionals and parents/guardians.

#### OUTCOME C

All students with ASD who are eligible for special education will be classified for the provision of appropriate educational services and support including and beyond the academic assessment areas.

- 1) Create a decision-making process for LEA/school-based teams to use in the identification and implementation of the most appropriate assessment and strategy tools.

#### OUTCOME D

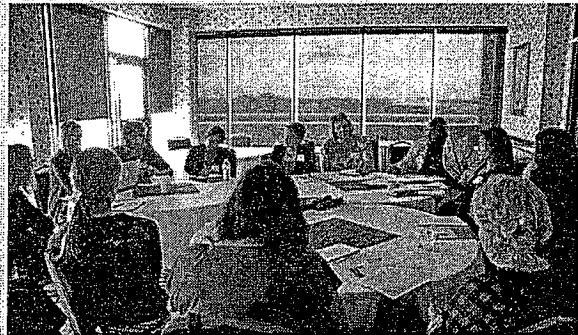
All medical professionals charged with diagnosing autism will use empirically-supported evaluation protocols.

- 1) Advocate for reimbursement from insurance for evaluation using empirically-supported protocols.
- 2) Develop a framework letter or brochure for physicians to provide to parents to use regarding the understanding of and importance of an empirically-supported evaluation of ASD; referral resources, parents' rights and the need for a comprehensive educational evaluation.

#### OUTCOME E

The standard for diagnostic practice for all categories of ASD will include an array of therapeutic recommendations.

- 1) Develop a workgroup of the Interagency Committee for Autism (ICA) reflecting representation of physicians, health and mental health professionals to address and outline method for making therapeutic recommendations to families and relationship to the education system.



## IMPROVEMENT AREA II:

### Training & Technical Assistance

DELAWARE STRATEGIC PLAN  
TO IMPROVE SERVICES AND SUPPORTS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

#### OUTCOME A

All LEAs will make available to all sites an array of current evidence-based practices and models of service delivery regardless of a student's placement (e.g. within district specialized program, charter schools, etc.)

- 1) Create a sub-committee of the Interagency Committee for Autism in conjunction with the Monitoring Review Board that includes parents, the Department of Education, Local School Representatives, Content Experts and other stakeholders that will create a statewide Toolbox of special education strategies and practices that are peer-reviewed and/or meet the No Child Left Behind scientifically-based research parameters; and address issues of support to individuals with ASD and their families.
- 2) Disseminate the statewide Toolbox that clearly outlines the types of assessments, supports, services and understandings necessary to identify the needs of a wide range of students within the ASD category including the full range of abilities.
- 3) Develop local capacity within Local Education Agency (LEA) via LEA or school-based teams that can provide training and coaching (train the trainer model) in implementation of identified educational and habilitative strategies (teaching the Toolbox).

#### OUTCOME B

All LEAs, adult service agencies and providers have the skills and ability to provide high quality and equitable services and supports to individuals with ASD.

- 1) Design and implement a process for districts, district leadership, school boards, principals, supervisors of special education, agencies and adult service providers that reflects a self-assessment and improvement planning process which focuses on the provision of high quality and equitable services and support for individuals with ASD.
- 2) Create a statewide Education Technical Assistance Team within the Resource Center to work in collaboration with the Statewide Director with oversight from the Delaware Department of Education to address both district capacity and individualized student programming. This Education Technical Assistance Team will provide expertise across systems to ensure seamless services are provided across the state.
- 3) Review and revise, if necessary, the current system that routinely monitors LEA and approved programs for consistency in the delivery of evidence-based practices and educational outcomes.
- 4) Seek legislation resulting in requisite funding to support statewide plan initiatives and specifically the development of a Resource Center and associated Education Technical Assistance Team for autism.
- 5) Link to current professional mentoring programs where educators can be mentored by seasoned teachers or others in the approved DAP programs.
- 6) Expand the abilities and skills for LEAs inclusive of all the placements of youth with ASD (e.g. Statewide Program, In-District Programs, etc.) to provide inclusive community engagement with mixed groups of students with and without ASD.

#### OUTCOME C

School administrators, teachers and para-educators have access to an array of on-going professional development activities reflecting the education of students with ASD.

- 1) Develop or adapt a series of trainings (including web-based, didactic, coaching and performance management) targeted for teachers and para-educators on a variety of topics regarding the education of students with ASD. Trainings should include pre/post assessments and outcomes will be monitored to inform future professional development activities.
- 2) (See VIIA2- Resource Center)
- 3) Increase current DDOE capacity to train school administrators on specific best practices in ASD to be observed when implementing the evaluation and accountability process.



#### OUTCOME D

School administrators, teachers and para-educators have access to technical assistance anchored to their individualized school needs.

- 1) The Education Technical Assistance Team will establish protocols for individualized support to school administrators requesting support and assistance in the decision-making process for instructional program design.
- 2) (See IIB1- Improvement Process)

#### OUTCOME E

All medical providers, mental health providers and support staff will have access to information, knowledge and training to effectively serve individuals with ASD.

- 1) Develop and disseminate a series of one-page reference guides for physicians focusing on best medical standards in serving individuals with ASD, proper referral processes, understanding the educational system in Delaware, and the incidence of dual diagnosis and treatment.
- 2) Technical assistance will be provided through the Resource Center. (VIIA2)
- 3) Host an annual Interdisciplinary Conference on ASD.
- 4) Provide a mechanism to inform parents and providers of the status of evidence-based and emerging therapies in autism. (VIIA2- Resource Center and VIIA4-Medical Home)

## IMPROVEMENT AREA II:

### Training & Technical Assistance

continued

DELAWARE STRATEGIC PLAN  
TO IMPROVE SERVICES AND SUPPORTS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

#### OUTCOME F

There will be no shortage of highly-qualified practitioners, including but not limited to professionals trained in Applied Behavior Analysis and Speech Language Pathologists available in Delaware.

- 1) Create a Workgroup of the Interagency Committee for Autism.

#### OUTCOME G

All employers of individuals with ASD and post-secondary institutions in the state will have access to adequate training on the characteristics, skills and needs of individuals with ASD.

- 1) Technical assistance will be provided through the Resource Center.
- 2) Provide adequate on-going technical assistance to businesses who employ individuals with ASD (See VIA2: Resource Center).

#### OUTCOME H

All agencies and human service providers will have access to adequate training to support life skills, employment, public safety and emergency management on behalf of individuals with ASD.

- 1) Technical assistance will be provided through the Resource Center (VIA2).
- 2) Provide enhancement of current training for direct support professionals to focus on the unique support needs of individuals with ASD.

#### OUTCOME I

All infants diagnosed with ASD will be provided transition planning and associated services to preschool and school-age programs that are appropriate for the specific individual needs.

- 1) The statewide Interagency Committee for Autism will include members from the Birth to Three and 619 programs and LEA representation to advise on the process of transition to the early childhood and school-age programs due to birth mandate.

#### OUTCOME J

All early childcare and preschool educators will demonstrate the skill and knowledge necessary to appropriately include and support children with ASD.

- 1) A series of professional development trainings will be developed and provided, focusing on developing core competencies in social emotional development, positive behavior supports, and supporting children with the communication and behavioral challenges common in ASD in early childhood settings.

#### OUTCOME K

All early intervention providers and early childcare/preschool educators will demonstrate the skills and knowledge necessary to appropriately transition children with ASD from early intervention programs to preschool and/or from preschool to school.

- 1) A series of professional development trainings will be developed and provided that are focused on the considerations for transition for children with ASD.



"There are so many other diseases where, when you receive the diagnosis, you would have a plan. This isn't the fault of conventional medicine, but we need a plan for autism."

—Middletown Parent

## IMPROVEMENT AREA III:

### Pre-Professional Training

DELAWARE STRATEGIC PLAN  
TO IMPROVE SERVICES AND SUPPORTS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

#### OUTCOME A

*There is a comprehensive pre-professional system that reflects both blended and on-site coursework which is designed to develop knowledge and skills in the education of students with ASD.*

- 1) Develop and submit a personnel preparation federal grant that addresses the preparation of teachers of students with ASD.
- 2) Establish a pre-service training workgroup of the Interagency Committee for Autism to address and positively influence the current teacher training programs across disciplines (e.g. general education).

#### OUTCOME B

*Professional certification standards for all teachers and para educators reflect the competencies necessary to effectively support students with ASD.*

- 1) Amend general and special education certification standards to reflect the core competencies needed to teach and support students with ASD in inclusive environments (e.g. social skills).

#### OUTCOME C

*Medical residency programs, allied health service training programs, rehabilitation professional training programs and mental health training programs will reflect training initiatives on identification, treatments and service delivery for individuals with ASD.*

- 1) (See VIIA2: Resource Center)
- 2) Develop and/or adopt a training curriculum on ASD and other related developmental disabilities to be infused into all pre-service training for medical and mental health professionals using a variety of approaches (simulation, web-based, etc.).



## IMPROVEMENT AREA IV:

### Self-Determination, Self-Advocacy and Social Network Development

#### OUTCOME A

*All individuals with ASD and their families, regardless of the placement (e.g. within district or specialized program, shelter, school, adult services, etc.) will have access to resources and knowledge/skills to make informed choices.*

- 1) Develop and implement a curriculum or model for supporting parent training in the approaches to promote development and education. This includes approaches to independence, social skills and communication.
- 2) Develop and implement a health and self-awareness curriculum including the topics of sexuality and intimacy.

#### OUTCOME B

*Students and others with our disabilities will be educated in venues to support the development of relationships with their peers with ASD and assist in building social networks that include the diversity of ability.*

- 1) Develop and implement a peer mentoring/tutoring program template that can be implemented within each district.
- 2) Develop a statewide training curriculum and disseminate resources that teach peers about the social inclusion of their classmates with ASD.
- 3) Develop a formalized youth-in-transition peer mentoring program in high school, college and post-school employment/independent living settings and other community members that is available to all youth with ASD.

#### OUTCOME C

*All individuals with ASD and their families will understand, identify and support skills of self-determination.*

- 1) Develop and implement a self-advocacy training program that would empower decision-making in youth with ASD so they can better understand adult services and agencies and understand the distinction between funding sources and service providers.
- 2) Disseminate existing web-based seminars designed to assist parents in understanding the differences between entitlements and eligibility based services.

## IMPROVEMENT AREA V:

### Transition to Adult Life

DELAWARE STRATEGIC PLAN  
TO IMPROVE SERVICES AND SUPPORTS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

#### OUTCOME A

*All youth and individuals with ASD will be provided appropriate and outcome oriented transition planning and associated services.*

- 1) Develop a guide for the preparation of 504 plans addressing students with ASD for high school, college and other youth-engaged systems that includes coordinated transition and connections to Vocational Rehabilitation.
- 2) Develop a checklist of important life skills and employment skills for individuals and provide in-person and web-based series of training to assist parents in the support of developing life and employment skills in their children/youth.

"And I've had a couple people tell me that maybe my goals are too high for my son. And, because I want him to go to college... and maybe he won't be able to do it, but God knows I'm going to push as much as I can until I cannot push anymore"

—Newark Parent



#### OUTCOME B

*All LEAs, adult service agencies and employers will demonstrate the skills and knowledge necessary to appropriately transition youth with ASD from school to adult life outcomes.*

- 1) Develop a series of professional development activities for teachers and adult service providers in the provision of quality community-based learning and community engagement activities.
- 2) Develop a series of trainings for adult service providers and employers on working with individuals with ASD in community based settings. (See VIIA2: Resource Center & IIB1-Improvement Process)
- 3) Develop a mechanism to gather feedback from families and self-advocates on services provided by adult service providers and that adult service providers are accountable for the provision of adequate services.
- 4) Develop a fact sheet for transition coordinators, directors of special education, families and individuals with ASD on the array of postsecondary options for youth with ASD and other developmental disabilities.
- 5) Develop an educational outreach and training program for recreational and socially-oriented community activities that focus on skills in meeting the inclusion needs of individuals with ASD.
- 6) Establish a routine forum to highlight programs for effective "real work" community-based experiences and provide mentoring opportunities to assist LEAs and agencies in the implementation of effective programming.

#### OUTCOME C

*There will be appropriate post-secondary program options in Delaware including college programs for youth with ASD.*

- 1) Develop and implement a project that will expand access to and opportunities for students with ASD to participate meaningfully in colleges and/or post-secondary education programs.
- 2) Expand the settings and availability of the Vocational Rehabilitation supported education program and identify potential participants with ASD during the middle school years.
- 3) Ensure that options and duration of employment support services and subsequent associated funding are flexible to the individuals needs.

#### OUTCOME D

*All students with ASD will present optimal skills in self-advocacy and self-determination as evidenced by maximum participation in school and community.*

- 1) Develop and implement a self-determination project, embedded in the context of curriculum, with the similar attributes to the "I'm Determined" model out of James Madison University.





## IMPROVEMENT AREA VI:

### Family Support & Stakeholder Engagement

#### ▶ OUTCOME A

*All families will have an understanding of the attributes and characteristics of ASD and the manner in which it affects human development and learning.*

- 1) Develop and implement a parent mentoring model with attributes of the "Guide by your Side" program which will be available to families of newly diagnosed individuals with ASD.
- 2) Develop and maintain a webinar series that assists parents in understanding the human development and learning characteristics of individuals with ASD and make available in hard copy.
- 3) A series of statewide sibling support and engagement activities will be developed and implemented to recognize value and needs of siblings with brothers/sisters who have been identified with ASD.

#### ▶ OUTCOME B

*There will be a continuum of residential options that will provide for adequate respite and out-of-home residential services for both short-term and long-term needs for both children and adults with ASD across the state.*

- 1) Develop and conduct a formal stakeholder advisory group that will provide planning for a continuum of services across the state. (This will be a workgroup of the Statewide Interagency Committee.)
- 2) Develop and implement clear guidelines for the use of residential programs based within our Delaware communities.
- 3) Advocate for a change in the system that will allow for creative residential options and services within the home.

#### ▶ OUTCOME C

*Dissemination - The initiatives reflected in this statewide plan include a wide range of information and avenues to provide information. Therefore, there will be an appropriate dissemination plan for all the stated initiatives.*

- 1) Develop a formal dissemination plan for each of the initiatives that are conducted within this plan and have the University of Delaware monitor to assure that information is being provided adequately in alternative formats and languages.

## IMPROVEMENT AREA VII:

### Systems Coordination

#### OUTCOME A

*There will be increased coordination between health, mental health and education services for all individuals with ASD.*

- 1) An Interagency Committee for Autism will be established as a statewide collaborative and representative group to provide input into programs and to ensure systems coordination across educational, mental health, medical and adult services and to implement this strategic plan.
- 2) Develop and implement a Statewide Centralized Resource Center as a comprehensive resource, training and technical assistance center for families and professionals around education, diagnosis, healthcare, employment and Independent living of individuals with ASD.
- 3) A system of care model for autism will be developed based on the medical home model (CDS, Nemours, CCHS, AAP, Health Care Commission, and Medicaid).
- 4) Collaboration among advocacy groups to support autism as a topic of research and study in the Delaware Health Science Alliance.
- 5) Develop and implement a webinar series to assist individuals, their families, support systems and others in understanding and navigating systems and provide in hard copy.

#### OUTCOME B

*All state systems will work together with and for families and self-advocates to support their choices.*

- 1) Work collaboratively with the Delaware Department of Transportation to gauge Delaware Paratransit users for satisfaction and develop a plan to improve services and educate families.
- 2) Explore the appropriateness of the Inventory for Client and Agency Planning (ICAP) for funding individuals with ASD and develop a collaborative process to enhance the ICAP to accurately assess and support individual needs.

#### OUTCOME C

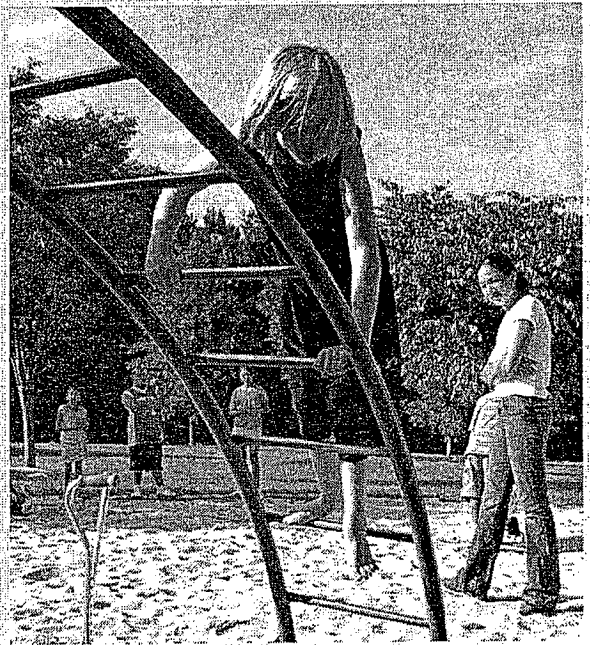
*All individuals with ASD will receive appropriate mental health services and crisis support services when, how, and where they need them.*

- 1) Study and respond to the current and needed options including a continuum of mental health options and the need for recruitment, retention and appropriate training of mental health professionals serving individuals with ASD.
- 2) Develop a plan within Division of Prevention and Behavioral Health Services (DPBHS) and Division of Substance Abuse and Mental Health (DSAMH) to service individuals with ASD in mental health and/or behavior health crisis situations.
- 3) Implement a system of reciprocal supports between Division of Developmental Disability Services (DDDS) and DSAMH.

#### OUTCOME D

*All individuals with ASD will have medical insurance that allows for access to all needed services to lead healthy and productive lives.*

- 1) Advocate within DDDS for the implementation of the Family Support Waivers and coverage by Medicaid for care coordination, family support and dental services.
- 2) Expand insurance coverage to individuals with ASD across the lifespan.



## Moving Forward

The dramatic increase in the number of individuals diagnosed with ASD has created significant difficulties for schools, social agencies, hospitals, clinics and families across Delaware. Systems have not been designed for or prepared to address the needs of this growing population, and medical, educational and social service agencies currently are not collaborating as effectively as they

The number of children in the United States diagnosed with autism has skyrocketed in the past decade, causing widespread concern and confusion.

—MSN

In 2000 and 2002, the autism estimate was about 1 in 150 children. Two years later, 1 in 125 8-year-olds had autism. In 2006, the number was 1 in 110, and the newest data — from 2008 — suggests 1 in 88 children have autism.

—Centers for Disease Control and Prevention

must. This climate of crisis motivated the statewide ASD planning project, which in turn facilitated the development of the *Blueprint for Collective Action*.

This project has been 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 practice and action has evolved within Delaware. Representing hundreds of voices and positions from every conceivable constituency group interested in the lives of people with ASD, the resulting strategic plan outlines the following fundamental assumptions and foundational activities:

- This *Blueprint for Collective Action* has been realized from the collective actions of the statewide ASD planning process and assumes that ALL stakeholders will dedicate fiscal and other resources for the purposes of achieving the stated outcomes.
- An Interagency Committee for Autism will be charged with identifying a unified plan for advocacy and will assume responsibility for leveraging resources across the membership organizations and agencies.
- An autism resource center will address the provision of training and technical assistance identified within the *Blueprint for Collective Action* and will be funded through the joint resources of the agencies and organizations involved.

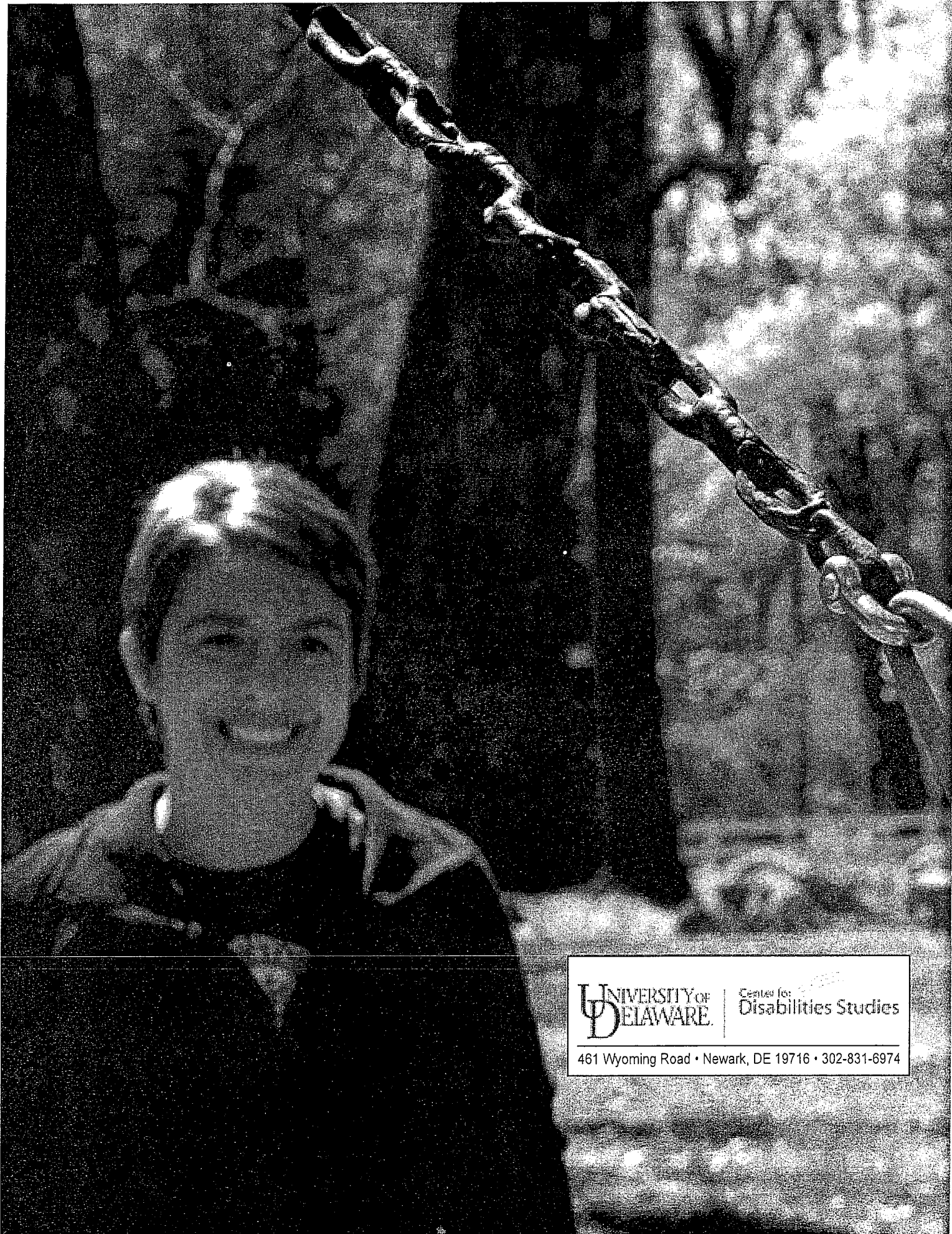
The *Blueprint for Collective Action* reflects the common vision of the now-united community of agencies, organizations and families of individuals with ASD. This community recognizes the importance of working together to maintain the forward momentum created by the energized planning group. The next phase of this initiative requires the dedication and commitment of the community so that all Delawareans with ASD can achieve the goals expressed by Dr. Temple Grandin, a woman with autism:

*"I don't want my thoughts to die with me — I want to have done something. I'm not interested in power, or piles of money. I want to leave something behind. I want to make a positive contribution — know that my life has meaning."*

— Temple Grandin

In summary, there is a climate of optimism within the community of organizations, agencies and families as it embarks on the creation of systems ensuring promising futures for Delaware's children and adults with ASD. This sense of shared responsibility is embodied in the *Blueprint for Collective Action*.





UNIVERSITY OF  
DELAWARE.

Center for  
Disabilities Studies

461 Wyoming Road • Newark, DE 19716 • 302-831-6974

[cid:image009.jpg@01D097CA.CA0900C0]

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  
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](mailto:tstevens24_2000@yahoo.com) <[mailto:tstevens24\\_2000@yahoo.com](mailto:tstevens24_2000@yahoo.com)>.

\* \* \* \* \*

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.

[cid:image010.jpg@01D097CA.CA0900C0]