2013

FINAL REPORT

Delaware Strategic Plan

TO IMPROVE SERVICES AND SUPPORTS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

Blueprint for Collective Action

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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 yours 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."

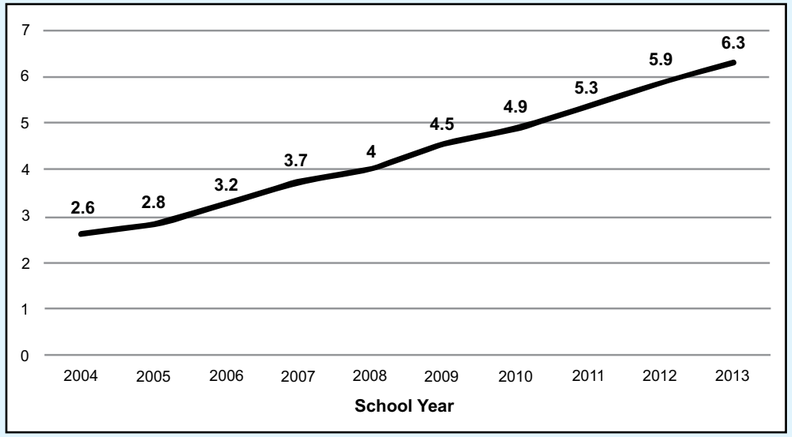
–Delaware Parent

Context of the Challenge

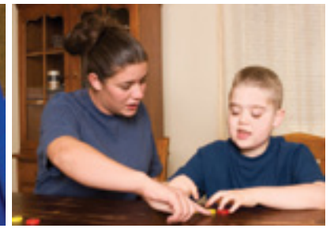
The Centers for Disease Control and Prevention characterizes the rise in ASD as an urgent public health concern. Although at this time it is difficult to know the exact number of individuals in Delaware who are diagnosed with ASD, the school-age classification rate offers some guidance. During the 2012–2013 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.[1] 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.[2] 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)



[1]Delaware Department of Education (2013)
[2]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

Figure 2: Statewide Planning Process

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 providers and how far families traveled to see a provider.

> "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*

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.

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. Participants were informed that their participation was voluntary, they did not have to answer any questions they did not want to, and they could chose 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.[3] 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

[3]Isaksen, 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 meeting 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

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 parent's 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

OUTCOME A

All LEAs will make available the same full array of current evidence-based practices and models of service delivery regardless of a student's placement (e.g. within district, specialized program, charter school, 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 for 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*

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 VIIA2- 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 (VIIA2).
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 their 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

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 to 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, specialized program, charter 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 without disabilities will be educated in avenues 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

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 service.
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 they need them 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 (DSANH) 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 must. This climate of crisis motivated the statewide ASD planning project, which in turn facilitated the development of the *Blueprint for Collective Action*.

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

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-unified 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*.

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