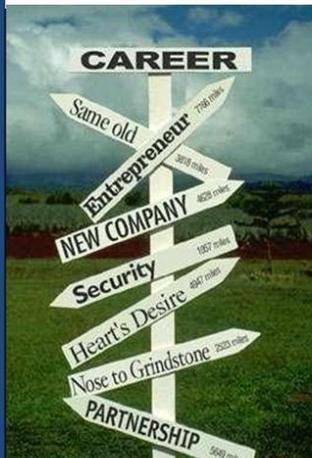


State Transition Task Force for Emerging Adults with Disabilities  
and Special Health Care Needs (SCR 34)

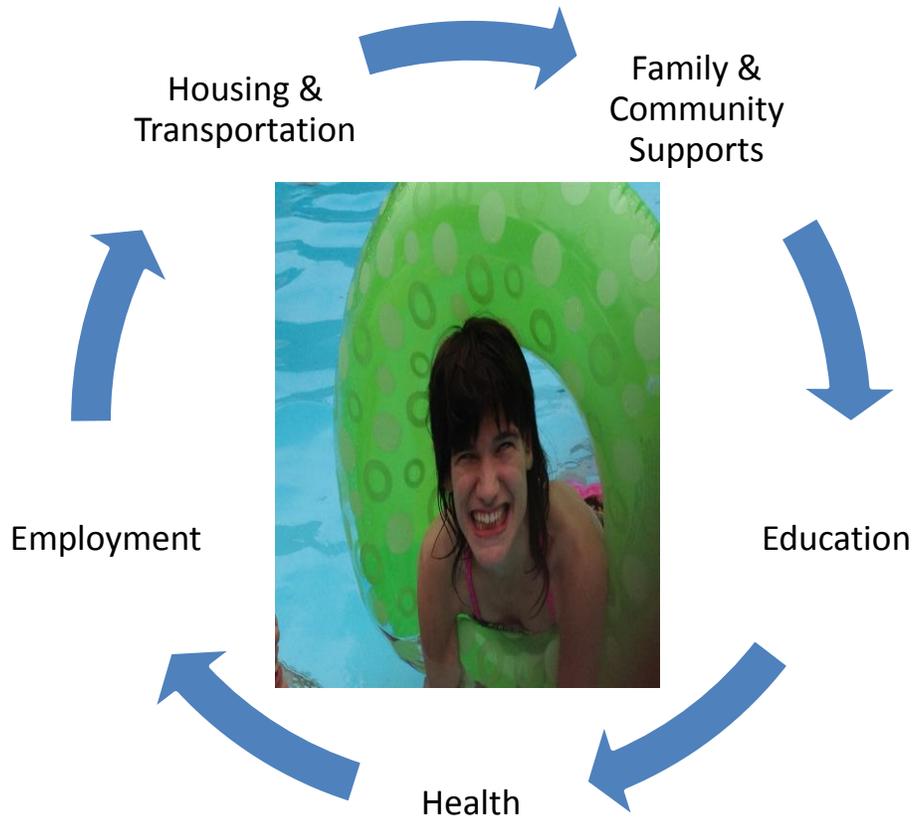


Final Report 2013

- ◆ Education ◆ Employment ◆ Health ◆
- ◆ Housing ◆ Transportation

TRANSITION





*“Individuals with disabilities should have, to the maximum extent possible, the same opportunities as all others do...”*

*-Governor Jack Markell*

## **Table of Contents**

<b>EXECUTIVE SUMMARY</b>	<b>1-2</b>
<b>FOREWORD</b>	<b>3-4</b>
<b><u>EDUCATION WORK GROUP</u></b>	
Education Work Group Executive Summary	<b>7-8</b>
Education Work Group Action Plan	<b>9-11</b>
Education Work Group Action Steps & Timeline	<b>12-20</b>
Education Work Group Recommendations	<b>21</b>
Education Work Group Members	<b>20</b>
Transition IEP Discussion Group Members	<b>21</b>
<b><u>EMPLOYMENT WORK GROUP</u></b>	
Employment Work Group Executive Summary	<b>27-29</b>
Employment Work Group Action Plan	<b>30-39</b>
Employment Work Group Action Steps and Timeline	<b>40-41</b>
Employment Work Group Recommendations	<b>42</b>
Employment Work Group Members	<b>43</b>

## **Table of Contents**

### **HEALTH WORK GROUP**

Health Work Group Executive Summary	<b>47-49</b>
Health Work Group Action Plan	<b>50-54</b>
Health Work Group Action Steps & Timeline	<b>55-59</b>
Health Work Group Recommendations	<b>60-65</b>
Health Work Group Members	<b>66-68</b>

### **HOUSING / TRANSPORTATION WORK GROUP**

Housing/Transportation Executive Summary	<b>72-74</b>
Housing Action Plan	<b>75-76</b>
Housing Recommendations	<b>77</b>
Housing Action Steps & Timeline	<b>78-80</b>
Transportation Action Plan	<b>81-82</b>
Transportation Action Steps & Timeline	<b>83-84</b>
Transportation Recommendations	<b>85</b>
Housing/Transportation Work Group Members	<b>86</b>

<b>ACRONYM LIST</b>	<b>88-97</b>
---------------------	--------------

<b>GLOSSARY OF TERMS</b>	<b>98-107</b>
--------------------------	---------------

## Table of Contents

<b>REFERENCE</b>	<b>108-110</b>
------------------	----------------

### APPENDIX

<b>POST-SCHOOL OUTCOME DATA</b>	<b>111-113</b>
---------------------------------	----------------

<b>SAMPLE -TRANSITION COORDINATOR JOB POSTING</b>	<b>114-117</b>
---	----------------

<b>HEALTH WORK GROUP POTENTIAL PARTNERS</b>	<b>118</b>
---	------------

<b>ESTIMATE OF ACCESSIBLE ASSISTED RENTAL UNITS, 2012</b>	<b>119</b>
---	------------

<b>HOUSING/TRANSPORTATION WORK GROUP INSIGHT ON TRANSITION FROM PROFESSIONALS</b>	<b>120</b>
---	------------

<b>AFTERWORD</b>	<b>121</b>
------------------	------------

<b>TASK FORCE MEMBERS</b>	<b>122-123</b>
---------------------------	----------------

#### **PROFILES IN PROGRESS**

Blake Bossert	87
Tara Bustard	44
Kurtis Cherry	26
Alyssa Cowin	71
Chris Coulston	24
Staci Forrest	6
Brigitte Hancharick	69
Brahmin Jackson	46

## **State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs Executive Summary**

“The difference between the ordinary and the extraordinary is the little extra.” This quote was the framework for discussions from which guided the State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs in making the recommendations you will read in this report. The State Transition Task Force was established by Senate Concurrent Resolution (SCR) 34, which was sponsored by Senator Bethany Hall-Long and Representative Rebecca Walker.

A seed was planted by former Center for Disabilities Studies (CDS) staff member Ilka Riddle to develop a Task Force on health and children with special health care needs. Terri Hancharick, Chairperson of the Governor’s Advisory Council for Exceptional Citizens (GACEC) and Wendy Strauss, Executive Director of the GACEC, felt that it would be best to go a step further and discuss forming a multifaceted Task Force. Terri and Wendy felt that the Task Force would be most effective if transition issues were addressed using a holistic approach. Terri and Wendy believed it would be possible to bring individuals from various backgrounds together to discuss services and programs for emerging adults with disabilities and special health care needs. As the founding members of the group, Ilka, Terri and Wendy felt there was a need as well as a desire for Delaware to address these issues.

All of the Task Force work groups included educators, state agency leaders, medical service providers, parents, self-advocates and community members (stakeholders) who recognized that a healthy home, school and agency culture existed and served to motivate all when carrying out their responsibilities within established guidelines. Each work group was afforded the opportunity to present successes and options to challenges within a safe and trusting environment.

At the heart of this Task Force there existed a culture of positive relationships with the process not operating in a vacuum. The quality of these relationships defined the collaborative climate and significantly impacted the productive discussions leading to agreed-upon priorities. Issues were discussed as part of a larger system that is impacted by (among other things) laws, regulations, community norms, values, attitudes and beliefs.

The work groups agreed that when obstacles which impeded the effectiveness of the process were evident, systems and resources were not always in place to provide the time, funding and clear channels of communication needed to plan, adjust and rectify student and family specific issues in a proactive and consistent manner.

These obstacles were presented and discussed by the work groups, who then came to consensus with their recommendations on how to best address these obstacles. Frustration among work group members about practices that worked contrary to those striving to enhance a culture of support in each student's individualized school program and transition to post-schooling and careers was reduced.

The work groups identified priorities which looked ahead not just in months, but in years. By taking the "long view", work group members agreed not to overestimate what can be done in a year, but rather what can be done over the course of multiple years.

It is a priority for all stakeholders to play a major role in communicating expectations, in addition to creating and maintaining a healthy culture. The Governor's Commission on Building Access to Community-Based Services (GCBACS) will assist in the implementation phase. The State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs will continue to meet every other month to receive updates on the progress being made in the suggested time frames. The State Transition Task Force will also actively assist in moving transition initiatives forward.

In the context of this report, the term "disabilities" refers to all physical, developmental, intellectual, behavioral, learning or mental health disabilities. Some examples of the "special health care needs" referred to in this report include conditions such as Diabetes, Asthma, Cystic Fibrosis, Epilepsy and/or cardiac conditions.

Throughout this report, you will notice Profiles in Progress featuring young adults with disabilities and/or special health care needs who are either currently receiving or have received special education services. These young adults share their stories of what they are doing now and of what or who assisted them in their own transition process.

We are confident that upon the review, approval, funding and implementation of the priorities detailed in this report, a consistent best practice approach will result in enhancing programming for all students and clients beyond basic compliancy measures.

## **State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs Foreword**

As Governor Jack Markell states in a report to the National Governors Association (NGA) on his initiative *A Better Bottom Line, Employing People with Disabilities*, “individuals with disabilities should have, to the maximum extent possible, the same opportunities as all others do; to live close to family and friends; to live independently and in safe communities; to engage in productive employment and to participate in community life.” In support of this ambitious initiative, the Task Force determined that critical changes were needed by individuals, case managers and organizations that support students in order to ensure a smooth transition from school to a productive and fulfilling life. The aforementioned critical changes need to be made in the following areas:

- Health Care
- Employment
- Education
- Housing & Transportation

The following is based on the federal definition of transition services as stated in the Individuals with Disabilities Education Act (IDEA).

***Transition services*** means a coordinated set of activities for a child with a disability that—

(1) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, (including post-secondary education), vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(2) Is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; including instruction, related services and community experiences, the development of employment and other post-school Adult living objectives, acquisition of daily living skills and provision of a functional vocational evaluation.

In spite of supportive legislation (e.g. IDEA, the Americans with Disabilities Act [ADA], and the Rehabilitation Act), as well as identified best practices, many students are not making an effective, productive transition into adulthood.

The Task Force’s essential question throughout this process was: “What are the gaps in our current system that prevent our students with disabilities from achieving the same opportunities as their peers without disabilities?”

This report highlights the strengths of the current systems and identifies challenges with suggested goals, action steps, and timelines that will facilitate the advancement of not only the Governor's initiative on employment, but also the implementation of effective transition services within the areas of education, employment, health, housing and transportation.

"I am going to learn more so I can help my friends

**LEARN MORE ABOUT TRANSITION**

They do not know the things I know and I am  
worried for them.

**EVERYONE SHOULD KNOW  
ABOUT TRANSITION**

but I don't think everyone

**UNDERSTANDS**

how

**BIG**

it is."

*-Chris Coulston, Age 14, Delaware Student*

**EDUCATION WORK GROUP**

# Staci Forrest



Staci is a student at Kutztown University in Pennsylvania majoring in Special Education. She aspires to obtain a Ph. D. in Disability Studies and an Ed. D. in Special Education. Forrest plans to use her education to help her become the Executive Director of a national non-profit focusing on disability issues.

**Q: What are you currently doing now that you have left high school?**

*A: Currently, I am a senior at Kutztown University of Pennsylvania. I am majoring in Special Education and Elementary Education with a minor in Women's & Gender Studies. I am involved in disability rights and awareness organization at both the national and state levels. Nationally, I served on the Board of Directors for the National youth Leadership Network (NYLN). Locally, I serve on the Family SHADE (Support and Health Care Alliance Delaware) Advisory Board. I have received a variety of national awards for my work within the disability community.*

**Q: What were your challenges and successes as you went through the transition process?**

*A: I think the main challenge I had when going through the transition process was actually believing that I could be on my own and be independent despite my disabilities ( I am partially sighted, have chronic illness and Post Traumatic Stress Disorder). Once I started to believe that, everything just seemed to fall into place.*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

*A: Specifically, I found the transition coordinator of my high school (Ms. Debbie Scott) to be extremely helpful in the transition process. She introduced me to the world of self-advocacy, self-determination and leadership for young people with disabilities when I was a junior in high school. During that time I had the opportunity to travel to and speak at a variety of transition conferences and to really learn what self-advocacy is all about and how I could apply it to my life. I think that all of these experiences played a role in helping me become a successful young adult and a budding professional focusing on youth leadership for students with disabilities.*

**Q: What is your anticipated path for the future?**

*A: In the future, I hope to continue my involvement in the disability community to the fullest extent possible. My future academic goal is to obtain a Ph.D. in Disability Studies and an Ed.D. in Special Education. I also hope to become the Executive Director of a national non-profit that focuses on disability issues.*

## **Education Work Group-Executive Summary**

Established under the State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs, the Education Work Group was charged with identifying gaps then recommending solutions for improving transition services within the current Delaware education system. The Action Plan and Timeline, as proposed by stakeholders, will weave together the following five broad areas of concern:

- I. School-based preparatory experiences and student empowerment
- II. Career preparation and multiple work-based learning experiences
- III. Youth development and leadership
- IV. Family involvement and supports
- V. Communication and professional development

Using these broad areas of concern as a guide, the Education Work Group prioritized concerns, developed recommendations for each concern and created a timeline and action plan. The Action Plan and Timeline utilize an organized data collection, planning, implementation and assessment process. The involvement of the Governor's Commission on Building Access to Community-Based Services(GCBACS), state and district administrators are critical to moving the plan forward.

Ultimately the State Transition Task Force has agreed that our objectives are to emphasize the absolute necessity of effective transition planning within the Delaware school system for students with disabilities and/or special health care needs and their families/caregivers, and to encourage change within the Delaware school system based upon the carefully considered recommendations of the Education Work Group.

## Education Work Group-Action Plan

### **I. School Based Preparatory Experiences and Student Empowerment:**

**1-** Improve Individualized Education Plan (IEP) transition practices and procedures in the Delaware school system to achieve the best post-secondary outcomes for students with disabilities and/or special health care needs.

**Rationale:** Student led IEPs will be research/evidence based best practice in Delaware. Early implementation of transition IEP planning, beginning in early childhood or at the age of identification will facilitate a more process-oriented, outcome-based mindset for educators, students, and their parents/caregivers during the student's entire school career. It is necessary to establish and implement uniform standards and research/evidence based best practice across school districts to ensure a smooth transition for students to other schools or programs they may attend. Uniform standards across districts and research/evidence based best practice will also ensure that district and school administrators and educators will have full access to a student's IEP regardless of educational placement. Student and parent/caregiver participation is necessary to provide valuable input on students' strengths, needs and interests toward the construction of meaningful and measurable IEP goals and the overall transition planning process.

**2-** A fully accessible Delaware State Transition Website (DSTW) must be developed, promoted and continuously updated in order to establish an effective and consistent means of collecting and disseminating key transition information to students, their families/caregivers and all interested parties.

**Rationale:** In order to be active, full participants in the transition process, students and their families/caregivers must first be empowered by knowledge that will allow them to understand the "who, what, when, where and why" of the process. A centralized website with key information from schools, agencies, health care systems, and other key participants in the transition process will facilitate a broad dispersion of information and promote further awareness of resources. To ensure high access to this website it is imperative that the public be made aware of its existence.

### **II. Career Preparation and Multiple Work-Based Learning Experiences:**

**1-** Develop a curriculum to cultivate knowledge and skills that includes a continuum of academic, employment and career goals and self-advocacy skills with agency collaboration to align with post-school outcome expectations.

## Education Work Group-Action Plan

**Rationale:** Participants in Key Informant Group meetings held by the State Transition Task Force in April 2012 indicated a need for the creation of collaborative and unified curriculum priorities that span academic, employment/career and independent living skills (such as driver's education) from ages 14-21.

**2-** Expand community experiences so that all students will have opportunities to practice real life daily skills in adult contexts (e.g., soft skills such as interviewing; as well as typical community experiences such as working, shopping, banking, accessing public services, using public transportation, etc...).

**Rationale:** There is great value in providing students early and frequent opportunities to engage in authentic interactions with the community.

**3-** Expand work-based learning opportunities (multiple paid and/or unpaid job shadowing/ job exploration opportunities).

**Rationale:** Individuals with disabilities and/or special health care needs need experience in authentic multiple work settings in order to gain skills necessary for successful employment.

**4-** Increase employment and volunteer opportunities and higher education supports for students with disabilities and/or special health care needs.

**Rationale:** Students will need a continuum of supports as they move into paid work or post-secondary education experiences. A few examples of persons who may provide these supports are the school's Transition Coordinator, a job coach or a family member/caregiver. While some students will need job development services based on relationships with employers, others will need intensive job coaching and mentoring to develop appropriate work behaviors.

Agencies in the state of Delaware should provide and promote internship and employment opportunities for young adults with disabilities and/or special health care needs.

## Education Work Group-Action Plan

### **III. Youth Development and Leadership**

- 1- Develop, implement, and assess self-advocacy, self-determination, and leadership curricula for students in all Delaware high schools, inclusive of special schools.
- 2- Support the continued development of a nationally-affiliated Youth Advocacy and Leadership Council.
- 3- Consider referring to the Virginia Department of Education Self-Determination Project's "I'm Determined" curriculum modules as a starting point for developing a similar curriculum for Delaware schools. Information can be found at: <http://www.imdetermined.org/modules/>

**Rationale:** Youth development is a process that prepares young people with and without disabilities to meet the challenges of adolescence and adulthood through a coordinated and progressive series of activities and experiences which help them gain leadership and self-determination skills and competencies.

### **IV. Family/Caregiver/Student/School/Agency Involvement and Supports**

- 1- Increase participation and involvement of family members/caregivers, students, schools, agencies and other support persons in the transition process.
- 2- Ensure that sufficient support is provided for parents/caregivers of a student with a disability and/or special health care need who may have a disability and/or special health care need themselves.

Examples:

- *A student with a disability may have a parent who also has a disability. This parent may require accommodations in order to communicate effectively with the school district and their child's educators.*
- *The parent of a child with a special health care need may have a visual impairment and need accommodations in order to communicate effectively with the school district and their child's educators.*

**Rationale:** All youth need parents/caregivers, family members and other caring adults in their lives who have high expectations, remain involved in their lives, have access to accurate information about transition planning including access to medical, professional, and peer support networks and take an active role in transition planning.

## Education Work Group-Action Plan

**3-** Ensure that parents/caregivers who are non-English speakers or readers are provided with translators and materials in their native language, or in alternate format (e.g. video, audio).

### **V. Communication/Dissemination/Professional Development/Relationships**

**1-** Plan ongoing professional development training for staff, district, state and school administrators and agencies.

**2-** Establish a dedicated Transition Coordinator position in every Delaware high school, inclusive of special schools, which shall have a state-standardized job description.

**3-** Standardize and improve credentialing for teachers and transition coordinators to assure they are sufficiently trained and qualified to work effectively with students with disabilities.

**Rationale:** Transition services are most successfully implemented in multiple settings and with the services of a dedicated Transition Coordinator. Collaborative relationships need to be established among students, families/caregivers, district personnel, community service agencies, state agencies and employers within the community in order to build a supportive network to ensure that there are successful outcomes for these students. Transition best practices must underscore the value of interagency collaboration, including all stakeholders.

**Education Work Group Action Steps and Timeline**

<b>School-Based Preparatory Experiences and Student Empowerment:</b>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
<p>Create, develop, and distribute state-standardized, fully accessible IEP Pre-Meeting Questionnaire Forms to all students and their families/ caregivers prior to IEP meetings. The goal of this form is to provide a means for student and parent/caregiver input. Such forms should be made available to persons who use alternate modes of communication and at reading levels commensurate with individual abilities.</p>	<p>Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, PIC, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW</p>	<p>2013-2014 School Year</p>
<p>Teach individuals to communicate their disability-related or special health care needs regarding work support and accommodation requirements and be able to find, request, and secure appropriate supports and reasonable accommodations in education, training and employment settings.</p>	<p>Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, PIC, Guidance Counselors, Business Owners, Community Service Providers</p>	<p>2013-2015 School Years</p>

**Education Work Group Action Steps and Timeline**

<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
<p>Establish transition services starting in early childhood or upon the identification of a disability and/or special health care need.</p>	<p>Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, CDW, DPH, GACEC, GCBACS, DHSS, EFI, DSTW, Related service Personnel [e.g. OT, PT, SLP]</p>	<p>2014 – 2015 School Year</p>
<p>Implement transition IEPs in a consistent format to facilitate effective planning of a student’s programs so that there is no loss of previously learned skills.</p> <p>Modify the current IEP Plus software to allow students, educators and district administrators to have access to the student’s IEP at all times. From a district perspective, this is useful when a student exits one program or school and enters another.</p>	<p>Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, Related service Personnel [e.g. OT, PT, SLP]</p>	<p>2014 – 2015 School Year</p>

**Education Work Group Action Steps and Timeline**

<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
<p>Create a curriculum for all students and professional development (PD) training for educators that provides an understanding of disability history, culture, disability public policy issues and the rights and responsibilities of all citizens. An example of such a curriculum is the “I’m Determined” curriculum modules developed by the Virginia Department of Education.</p>	<p>Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, SCC, PIC, Established Self-Advocates</p>	<p>2014-2015 School Years</p>
<p>Utilize multiple career assessments to help identify students’ school and post- school preferences and interests. Assessments should include but are not limited to Student Success Plans and Career Cruising.</p>	<p>Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW</p>	<p>2013-2014 School Year</p>
<p>Incorporate career assessment results with exploration and exposure to multiple career opportunities that ultimately lead to a living wage, including information about educational requirements, entry requirements, income and benefits potential and asset accumulation.</p>	<p>Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW</p>	<p>2014-2015 School Year</p>

**Education Work Group Action Steps and Timeline**

<b>Career Preparation and Multiple Work-Based Learning Experiences:</b>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Coach appropriate work-based employability skills including required documentation of work and life experiences, appropriate peer relations, conflict resolution skills with both co-workers and supervisors, and appropriate work communication skills, behaviors, expectations and responsibilities.	Students, All State Agencies, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, SSA, DMV	2013-2015 School Years
Engage in a range of work-based exploration activities such as site visits and job shadowing leading to multiple on-the-job experiences (paid or unpaid), including community service, that are specifically linked to the content of a program of study and school credit. State agencies should actively seek students with disabilities and/or special health care needs to fill open internship opportunities.	Students, Teachers, Transition Coordinators, Parents, EFI, Community Partners, DSTW, State Agencies	2013-2015 School Years

**Education Work Group Action Steps and Timeline**

<b>Youth Development and Leadership:</b>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Encourage strong relationships with adult mentors (both with and without disabilities) through activities in both formal and informal, social and work settings with exposure to role models in a variety of contexts. This could be accomplished through a youth leadership and development council with an adult advisory board.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, DYLI, Community Partners, Post-Secondary Programs	2013-2015 School Years
Expose youth to personal leadership and youth development activities, including community service and opportunities that allow youth to exercise leadership skills and build self-esteem.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, Community Partners, Post-Secondary Programs	2013-2015 School Years
Develop and maintain a fully accessible Delaware State Transition Website (DSTW) that would facilitate a more effective means of communication and dissemination of consistent key transition information and resources.	GACEC, CDS, DHSS, DVR, DelDOT, DHA, PIC of DE, DFV, DSTW, GIC	2013-2015 School Years

## Education Work Group Action Steps and Timeline

<b>Family Involvement and Supports:</b>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Provide access to information about employment, transportation, housing, education, community resources and improve access to medical, professional, and peer support networks.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, DFV, PIC	2013-2015 School Years
Provide opportunities for parents and caregivers to obtain a better understanding of available information regarding their child's disability and how it may affect their education, employment and community life options.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, DFV, PIC	2013-2015 School Years
When students reach the age of majority, prepare parents, caregivers, and students for the change of rights and responsibilities under IDEA to the rights and responsibilities under ADA as individuals transition from high school to a post- secondary program. Discussion should begin at the onset of transition planning. (Under proposed changes to IEP practices, we have recommended that discussions about transition begin upon the identification of a disability and or special health care need, with a refresher at age 14.)	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, DFV, PIC	2013-2015 School Years

**Education Work Group Action Steps and Timeline**

<b>Communication and Professional Development:</b>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Standardize and improve credentialing for teachers (special education and regular education) to assure they are sufficiently trained to work effectively with students with disabilities.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, Delaware General Assembly, Current Special Educators, Division on Career Development and Transition	2014-2015 School Years
Establish a dedicated Transition Coordinator position in every Delaware high school inclusive of special schools.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, Delaware General Assembly, Division on Career Development and Transition	2014-2015 School Years

**Education Work Group Action Steps and Timeline**

<b>Communication and Professional Development:</b>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Create a standardized job description of Transition Coordinator to ensure that the Transition Coordinator’s focus remains on best transition practices as defined by IDEA Indicator 13.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, Delaware General Assembly	2014-2015 School Years
Change the culture of transition by providing professional development training and education to key persons at the state, district and school administrative levels focusing on effective transition planning and its impact on the academic and functional outcomes for special education students.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, Delaware General Assembly	2013-2015 School Years
Design and implement educational and training opportunities for students, families, and caregivers in an effort to expand the success of the transition process.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, Delaware General Assembly	2013-2015 School Years

**Education Work Group Action Steps and Timeline**

<b>Communication and Professional Development:</b>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Develop a Delaware State Transition Website (DSTW) with the goal of empowering students with disabilities and/or special health care needs, their parents and caregivers and all other interested parties with up to date information on Transition resources, services, and networking opportunities.	Students, Parents/Caregivers, District Administrators, Educators, Transition Coordinators, DOE, DVR, DDDS, GACEC, GCBACS, DHSS, EFI, DSTW, CDS, DOL, DelDOT, DSHA, PIC, DFV, all state agencies	2013-2015 School Years

## **Education Work Group Recommendations**

1. Develop, support and maintain a fully accessible transition guide website to improve access to information about transition planning for students, parents/caregivers, and all interested parties.
2. Ensure that the State Transition Task Force's Action Plan and Action Steps are implemented within the suggested time frame and are sustained for the future.
3. Develop a Self-Advocacy and Leadership Curriculum, ensure that student-led IEPs are best practice, and provide an expansion of community experiences and exposure to multiple work-based learning and employment opportunities for students with disabilities and/or special health care needs.
4. Develop, incorporate and assess youth leadership curricula accessible to students at all Delaware high schools, inclusive of special schools.
5. Establish a dedicated Transition Coordinator position in every Delaware high school, inclusive of special schools.
6. Change the culture of transition by providing professional development training on transition planning for state, district and school administrators and staff.

## Education Work Group Members

*Chair- Wendy Strauss, Executive Director, Governor's Advisory Council for Exceptional Citizens (GACEC)*

*Co-Chair- Dale Matusевич, Delaware Department of Education, Transition Services*

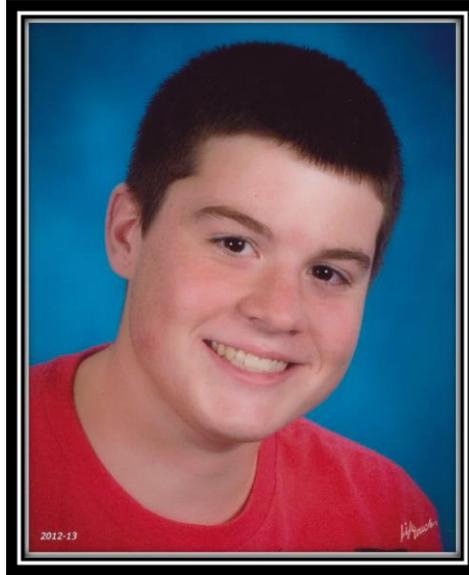
- **Marie-Anne Aghazadian**- Parent Information Center (PIC) of Delaware, GACEC
- **Ellen Coulston**- Parent Advocate
- **Cathy Cowin**- Parent Advocate, GACEC
- **Laura Eisenman**- University of Delaware Center For Disabilities Studies (CDS)
- **Staci Forrest**- Self-Advocate, Delaware Youth Leadership Initiative (DYLI)
- **Brian Freedman**- University of Delaware Center For Disabilities Studies (CDS)
- **Terri Hancharick**- Parent Advocate, GACEC
- **Amy Haughey**- Smyrna School District (SSD)
- **Kathryn Herel**- PIC of Delaware
- **Jen Holdsworth**- New Castle County Vo-Tech (NCCVT) School District
- **Jack Jadach**- Retired principal, John G. Leach School
- **Christopher McIntyre**- Division of Services for Children, Youth and Their Families (DSCYF), GACEC
- **Amy Pleet-Odle**- University of Delaware (UD)
- **Barbara Riley**- Division of Vocational Rehabilitation (DVR)
- **Debbie Scott**- NCCVT School District
- **Debbie Shiber**- Parent Advocate
- **Howard Shiber**- Parent Advocate, GACEC
- **Hailey Shiber**- Self-Advocate
- **Laurie Staz-Schulich**- Parent Advocate, Home Schooling Association of Delaware
- **Sybil White**- Parent Advocate

### **Transition IEP Discussion Group Members**

*Chair-Wendy Strauss, Executive Director, Governor's Advisory Council for Exceptional Citizens (GACEC)*

- **Marie-Anne Aghazadian**- Parent Information Center (PIC) of Delaware and GACEC
- **Marissa Band, Esq.**- Community Legal Aid Society, Disabilities Law Program (DLP)
- **Blake Bossert**-Self-Advocate
- **Ellen Coulston**- Parent Advocate
- **Cathy Cowin**- Parent Advocate, GACEC
- **Staci Forrest**- Self-Advocate, Delaware Youth Leadership Initiative (DYLI)
- **Terri Hancharick**- Parent Advocate, GACEC
- **Jack Jadach**- Retired principal, John G. Leach School
- **Christopher McIntyre**- Division of Services for Children, Youth and Their Families (DSCYF), GACEC
- **Amy Haughey**- Smyrna School District (SSD)
- **Kathryn Herel**- PIC of Delaware
- **Jen Holdsworth**- New Castle County Vo-Tech (NCCVT) School District
- **Dale Matusевич**- Delaware Department of Education, Transition Services
- **Megan Pell**- University of Delaware and Junior Partners in Policymaking
- **Debbie Scott**- NCCVT School District
- **Debbie Shiber**- Parent Advocate
- **Howard Shiber**- Parent Advocate, GACEC
- **Sybil White**- Parent Advocate

# Chris Coulston



**Q: What were your challenges and successes as you went through the transition process?**

*A: I started to attend transition conferences when I was in 6th grade. I was 12 years old. I wish I had started a little earlier because there is so much to learn about transition. These are important skills to learn that I use right now. I self-advocate for myself in school, I actively prepare and participate in my parent / teacher conferences and I prepare and co-lead my IEP meetings with my case manager. Self-determination is also an important part of transition. I need this skill now to complete high school and college and build my career!*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

*A: Kathie Herel is the main reason I started to learn about transition. She told my mom to go to the Transition Conference. My mom took me to the conference where I heard Jonathan Mooney and a group of students called the Blue Jays present. Jonathan Mooney gave me hope about transitioning to college and a career after I leave high school. He was young and he was a great presenter! The Blue Jays were a group of students who could talk about their strengths, their choices and the supports they need to reach their goals! I have also heard LeDerrick Horne. My favorite quote of his is, "I want to go to college and I need your help getting me there!" I was lucky to be invited to the Brandywine Special Needs Parent Teacher Association (BSNPTA) Delaware Kids Inspiring Kids program to learn more about Self-Determination. This program has made all the difference for me!*

**Q: What is your anticipated path for the future?**

*A: I am going to the Pennsylvania Transition Conference this summer to learn more about transition. I am going to learn more so I can help my friends learn about transition. They do not know the things I know and I am worried for them. Everyone should know about transition but I don't think everyone understands how big it is. I work on transition every day!*

*My goal is to be a Health Care Administrator. I became interested in the health care field after my volunteer experience at the Kutz Nursing Home. If I did not go to the Transition Conference, I would not understand how critical it is to gain work experience in high school. It's work but it's fun!*

“Stay

**WORKING**

at Bank of America,

be **RICH** ,

Find a nice boyfriend who

**LOVES ME**

and will

**SHARE MY LIFE.”**

~Tara Bustard, Bank of America employee for 14 years,  
when asked what her plans are for the future.

EMPLOYMENT WORK GROUP

# Kurtis Cherry



Kurtis Cherry, pictured with his 2011 Senator William Roth Achievement Award, is a Goodwill employee who enjoys travel and photography. Cherry hopes to live independently one day and move to Florida. Kurtis is a young man with Autism.

**Q: What are you currently doing now that you have left high school?**

*A: I work at Goodwill in Milford. I stock the books and housewares.*

**Q: What were your challenges and successes as you went through the transition process?**

*A: It was hard to find a job but Ms. Cheryl kept looking for me. I wanted to work at Wal-Mart but she thought it would be better for me to work somewhere smaller. I like Goodwill.*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

*A: The teachers and staff from the Charlton, DVR, DDDS and Ms. Cheryl from Kent-Sussex Industries (KSI) all worked together to make sure they knew what I wanted to do and how they could help me get the kind of job I wanted.*

**Q: What is your anticipated path for the future?**

*A: I want to keep working at Goodwill. I like to travel and take pictures. I want to move to Florida someday.*

## Employment Work Group Executive Summary

In July of 2012, Governor Markell signed House Bill (HB) 319 “Employment First Legislation”. HB 319 requires state agencies that provide services to persons with disabilities to consider, as their first option, employment in an integrated setting for persons with disabilities.

Sponsor and champion of HB 319 Representative Debra Heffernan said, “People with disabilities consistently demonstrate their abilities and value to our society. Often though, they don’t have the opportunity to choose where or whether they would like to work.” Heffernan continued, “People with disabilities want to be contributing members of society, and this new law will provide them the opportunity to gain employment. Folks going to work would not have to rely on government benefits like Medicaid and other social services programs. They would contribute to the economy both through taxes and by purchasing goods. It truly is a win-win situation for everyone.”

The Employment Work Group agrees with Rep. Heffernan’s assertion that gaining meaningful employment and establishing a career should be the first priority for students with disabilities and/or special health care needs when they leave school. However, students are not able to do this without assistance from their core support group of parents/caregivers, school districts, Transition Coordinators, health care providers and others. With these things in mind, the Employment Work Group established an Action Plan and Timeline with the following priorities as a guideline:

- I. Create a more responsive employment system for students with disabilities and/or special health care needs.
- II. Implement policies and programs that improve the transition process for students with disabilities and/or special health care needs as they transition from school to employment and/or careers.
- III. Foster a supportive employment and career environment for students with disabilities and/or special health care needs.
- IV. Build capacity, opportunities and resources for students with disabilities and/or special health care needs as they transition to employment and careers.

The need for the Employment First Initiative (EFI) becomes evident when current trends in employment of people with disabilities are considered. Individuals with disabilities are much less likely to be employed than individuals without disabilities. Furthermore, people with disabilities experienced even greater unemployment rates compared to people without disabilities between 2009 and 2010. Among working-age Americans, people with any disability are more likely to live in a household that is below the poverty line.

## **Employment Work Group Executive Summary**

The EFI starts preparing students with disabilities and/or special health care needs to transition out of high school. These individuals are, in many ways, in the best position for finding competitive employment. They have access to specialized services in school which can be specifically geared toward helping them identify competitive employment. However, in order to be successful in finding employment, we need to ensure that students with disabilities and/or special health care needs have access to a curriculum that will adequately prepare them for selecting career paths and train them in employability skills. This process should be led by a comprehensive and continuous assessment process which enables schools and other state systems to adequately take the appropriate next steps in allowing students with disabilities to advance toward successful employment. Finally, these experiences should culminate with relevant internship and/or multiple work experiences, which will ultimately place the student in the best position possible for exiting high school into the adult world.

Students with disabilities and/or special health care needs rely heavily on the support of the systems around them to help them understand their options, make appropriate connections, and learn relevant skills. However, school professionals and parents/caregivers are sometimes unaware of the most effective methods for preparing students for successful careers. Therefore, providing access to and relevant training for these support systems will also be critical for ensuring that students can achieve and maintain employment. A Delaware State Transition Website would be the ideal vehicle for disseminating consistent, correct and updated information regarding transition to students, their families/caregivers, and all other interested parties. Each student must also have clear access to a Transition Coordinator who can support them in navigating these complex systems and making educated decisions about next steps.

In order to ensure successful career exploration and employment, employers in Delaware must also be reached and brought together. Coordinated efforts by existing organizations (such as the Delaware Workforce Investment Board [DWIB]) can ensure that the training young adults receive reflects the true needs of the work force. Furthermore, by establishing deeper connections with employers, greater opportunities can be developed and true culture shift can be impacted. As a result, employers will eventually understand that young adults with disabilities and/or special health care needs should be considered for positions in their organizations.

Finally, training and education for many individuals with disabilities and/or special health care needs does not end in high school. Many individuals have the capacity to pursue and succeed in college and other post-secondary training programs. The pursuit of post-secondary education allows an individual to move beyond qualifying for entry level jobs. This serves a critical importance in impacting a cultural shift in order to help others understand that young adults with disabilities and/or special health care needs can be successful in the same types of positions and

work environments as everyone else. Through the bolstering of current systems, significant gains can be made in ensuring that those students who can succeed in college are connected with these opportunities and afforded the appropriate level of supports. While the current trends in the employment of people with disabilities and/or special health care needs remains bleak, the State of Delaware has taken several positive steps toward ensuring greater employment. By continuing to move forward and ensure that individuals are connected with existing supports (e.g. families, agencies, employers, school, etc.) and expanding upon these supports, we can begin to make a true impact across the state.

## Employment Work Group Action Plan

### I. **Create a more responsive employment system for students with disabilities and/or special health care needs.**

**1- Employer Connections-**Since one key tenet of a successful transition process is ensuring that all transition-age youth have multiple work experiences in the community, it is critical to continue to develop and enhance relationships with employers to create employment opportunities.

**Rationale:** Employers can be successfully encouraged to utilize their employment sites for job shadowing, internships and mentoring transition students. The DWIB and the newly formed Delaware Business Leadership Network (DBLN) are entities comprised of business leaders that can serve to promote employment of people with disabilities and/or special health care needs.

The DWIB ensures the provision of occupational training and employment service opportunities to Delaware citizens, as well as communication with the business industry in order to connect them with prospective employees. The DWIB has made the employment of people with disabilities and/or special health care needs part of their strategic plan this year, and would be open to gaining information on transition services and how they can support the efforts of school-based work experiences.

The Delaware Business Leadership Network (DBLN) is a new group in Delaware which is part of the United States Business Leadership Network (US BLN). The national and local BLN's priority is increasing the employment of people with disabilities and/or special health care needs in the private sector. This organization may also provide a forum for school transition programs to partner with their communities to provide work experiences and future employment. Each of these organizations is a willing partner in supporting increased employment opportunities for youth with disabilities and/or special health care needs. The next step will be to formalize these connections, offer resources and training to community employers, and cultivate critical relationships with the business community. This could be done on a statewide level through the State Transition Task Force, as well as at a more local level within each school district. This will become an important aspect of the role of a Transition Coordinator in Delaware high schools.

## Employment Work Group Action Plan

### **II. Implement policies and programs that improve the transition process for students with disabilities and/or special health care needs as they transition from school to employment and/or careers.**

**1-Employment First and the “Better Bottom Line”-** When Governor Markell signed House Bill 319, creating the Employment First Act and the Employment First Oversight Commission (EFOC), it represented a huge step in signifying the importance of ensuring that all individuals, including those with significant disabilities and/or special health care needs, had the opportunity to pursue employment in an integrated setting. Employment First is a national movement. Governor Markell ensured that Delaware would take the lead nationally in promoting employment among people with disabilities and/or special health care needs by creating the “Better Bottom Line”, his lead initiative as chair of the NGA.

**Rationale:** The emphasis on employment for individuals with disabilities is quite relevant for transition-age youth, as the choices and decisions that are made regarding whether to pursue employment (versus selecting a sheltered workshop or day habilitation services) can impact their long-term options for career growth. For example, youth with Autism Spectrum Disorder (ASD) have been found to earn less money and cost more to state systems when they spend time in sheltered workshops before moving into supported employment services as opposed to beginning with supported employment services while the student is still in school (Cimera, Wehman, West, Burgess, 2012).

Therefore, the State Transition Task Force intends to collaborate with the EFOC work groups in order to ensure that students in high school who are preparing to exit are being provided with these options. This begins with having appropriate preparatory experiences in high school, including having community-based work and internship experiences being made available to all youth.

**2-Youth and Parent Training-** It is increasingly apparent that parent and youth education on disability benefits and systems can make an extraordinary impact on the long term career prospects for youth with disabilities and/or special health care needs.

#### **2 a. Education on Disability Benefits**

**Rationale:** Over the course of the past decade, the Social Security Administration (SSA) has developed a number of youth demonstration projects with the research backing of Mathematica (2009), which have identified several important findings.

## **Employment Work Group Action Plan**

For youth who enter the disability rolls when they are younger than 18, the average total duration of their enrollment in disability support services will be almost 27 years (Rupp and Scott, 1996). At the 2009 federal monthly payment amount of \$674, the net present value in current dollars of a 27-year Supplemental Security Income (SSI) stay is approximately \$150,000 (using a three percent discount rate), which does not include the even higher costs of concurrent participation in the Medicaid program. Thus, effective interventions, including disability benefits counseling for youth beneficiaries and their families, even interventions that produce only modest impacts, could substantially shorten the average duration of dependency and thereby create savings for SSA and other government agencies.

The need for benefits counseling for caregivers as well as students is a critical component of successful transition programs. Once family members/caregivers as well as the transition-age student understand the financial advantages that come with employment as opposed to full benefit assistance, they are more likely to pursue work as a real goal for adulthood.

### **2 b. Parent Training on How to Support a Young Adult with a Disability/Special Health Care Need**

**Rationale:** As children with disabilities and/or special health care needs grow into young adults, they are expected to become stronger self-advocates and decision-makers in different areas of their lives. This important shift lays the groundwork for developing greater independence as an adult.

Simultaneously, parental roles change as parents are expected to shift from being the main advocate and decision-maker to supporting their child in making the best decision for him/herself. This can be quite stressful and challenging, as many parents have served as the main advocate throughout that child's life. Parents also have understandable fears about their child having increased exposure to others who might mistreat or take advantage of them, and they worry that their child may not be ready or capable of making well-informed decisions. Unfortunately, parents/caregivers rarely receive guidance or instruction on how to help their young adult become more independent, or how to best adjust to their new parenting role. Therefore, parents would benefit from specific support and training. This might include:

## **Employment Work Group Action Plan**

- How to actively promote their child developing stronger self-advocacy skills in all environments.
- How to support their child in thinking through their options for solving problems in a variety of settings, including on-the-job, versus relying on others to solely determine solutions for them.
- How to actively and comprehensively fade back the supports they provide so that parents/caregivers are still able to support their child and help their child take their individual next steps toward becoming independent.
- How to support their child in becoming the main point of contact for employment and other areas of their life (e.g., having the child contact their employer if they will be late).
- How to develop communication systems with their child so that parents/caregivers are still kept well-informed of what's going on in their child's life, but without needing to serve in an inappropriate and potentially awkward role (e.g., asking a child's supervisor about their job performance).
- Understanding the differences between entitlement versus eligibility programs and IDEA versus ADA.

**3-Replication of Current Programs-**There are currently transition programs available across the state which could be accessed by more transition-age students. Unfortunately, a lack of student and parent awareness of the existence and benefits of these programs prevents more students from being able to access them.

These programs include:

### **3a.-Early Start to Supported Employment (ESSE)**

**Rationale:** Early Start to Supported Employment (ESSE) is a collaborative program sponsored by the Delaware Division of Vocational Rehabilitation (DVR), the Delaware Division of Developmental Disabilities Services (DDDS), the Delaware Department of Education (DOE) and Local Education Agencies (LEAs). The ESSE philosophy is that all persons, regardless of disability and/or special health care need, are able to be employed and be successful, active, participating members of their communities.

The ESSE program begins two years prior to the student exiting high school and is a way to connect transition-age youth with employment services and work opportunities.

Although ESSE started as a pilot in 2005, it quickly became recognized as a best practice

## Employment Work Group Action Plan

in Delaware. This program offers students an opportunity to gain exposure to work in the community, assists them with learning and retaining employment related skills and provides a more seamless transition to alleviate student and family stress during the difficult transition from school to an unknown adult life.

### 3 b. Project SEARCH

**Rationale-**This successful model is in its second year of operation at Christiana Care in partnership with the Red Clay School District. Approximately 10 students attend class at Christiana Hospital, where their teacher provides soft skills training and job coaches instruct the students at internship sites throughout the hospital. Project SEARCH began at Cincinnati Children's Hospital in Ohio and now operates over 200 sites throughout the United States and Europe. Hospitals, banks, as well as Federal and County government agencies have served as SEARCH sites. Project SEARCH gives transition-age students the opportunity to experience work in a real business outside of school and learn to meet the expectations of the host business for its employees. Through replication of this model in Delaware, it is hoped that there will be at least one Project SEARCH site in every school district. The more realistic work experiences we can provide students prior to their exit from school, the more likely they are to succeed as adults in the workplace.

### 3 c. Post-secondary education settings

**Rationale-** Many individuals with disabilities and/or special health care needs will choose to seek out post-secondary education after they complete high school. There are some programs and services in Delaware that can support an individual pursuing this option. Unfortunately, these opportunities are limited and do not reach all students who are eligible. However, they serve as important models for how a variety of services can be offered to individuals with different levels of need:

- Disability Support Services – All institutes of higher education legally must provide accommodations to individuals with disabilities. These accommodations allow the individual to access the academic curriculum. The level of accommodations provided can vary according to the college.
- Transition and Post-secondary Programs for Students with Intellectual Disabilities (TPSID) – the University of Delaware received a 5-year federal grant to create a model demonstration college program for students with intellectual disabilities. These are students who, due to their disability, would otherwise have significant difficulty being successful in college.

## **Employment Work Group Action Plan**

- Academic Coaching – these are services offered through university settings and by outside providers which help students develop successful study habits, organization, and social skills relevant to the post-secondary academic setting. This is typically provided through group and one-on-one support environments.

### **III. Foster a supportive employment and career environment for students with disabilities and/or special health care needs.**

#### **1- Transition Coordinators should be in all high schools, inclusive of special schools, and must have a uniform, state-standardized job description.**

**Rationale:** It is critical to have a Transition Coordinator in each high school, inclusive of special schools, because they synchronize all transition services for students. It is also imperative that a state-standardized job description be established for all Transition Coordinators, to ensure that uniform transition practices are taking place in all schools. Transition Coordinators act as the student’s advisor and facilitate standardized testing and training programs relevant to a student’s post-school plans. Emerging adults with disabilities and/or special health care needs leave the structured environment of school and confront a maze of public and private agencies in the community. Planning for this transition before leaving school helps students and their families/caregivers sort out the maze of resources, overcome the gaps in services and start on a productive path.

Transition planning is a lifeline to adulthood and should begin early. The Transition Coordinator is an essential member of a team of educators and others (e.g. agencies, service providers) who help students navigate this process. Early transition planning is important for many reasons. Transition from special education services and its entitlements is complicated. It will take time to put post-school services and supports in place for students with disabilities and/or special health care needs.

### **IV. Build capacity, opportunities and resources for students with disabilities and/or special health care needs as they transition to employment and careers.**

#### **1- Increase multiple work opportunities for students with disabilities and/or special health care needs prior to their exit from school.**

## Employment Work Group Action Plan

**Rationale:** Research indicates that work experiences during high school are one of the strongest predictors of successful post-school employment for students with disabilities and/or special health care needs (Landmark, Ju & Zang, 2010; Test et al., 2009). These work experiences can be either paid or unpaid, but the result is still the same: students are more likely to find a job after they finish school when they've had previous work experiences during school. There are critical skills that are learned in a work setting that cannot be replicated in the same fashion in the classroom. These include:

- Learning the skills for a particular job. Work experiences provide an opportunity for an individual to gain training, practice and receive supervision on a number of skills. The structure of this training and supervision is typically quite different from a school.
- Experience the expectations of an employment setting. Most employment settings have very different rules than a school or classroom. There is typically less tolerance for being late or being out sick or on vacation. This is particularly true of special education settings, where the general rules of the school may also be “flexed” in order to ensure that the student is able to progress.
- Learn the social rules of the workplace. There are very specific social skills that are important to learn and understand in order to be successful at work. Students with disabilities, regardless of level of disability, have been shown to exhibit significant deficits in social skills. By spending time in a work setting, students can begin to learn these rules, apply them and get feedback. There is also value in modeling other employees at the workplace.
- Develop networks. Most individuals rely upon their networks to help them connect with future steps in jobs and careers. However, most students enter the workforce with very limited networks; typically consisting of family and special education staff. As a result, they miss out on these critical variables which promote employment success. By participating in work during high school, they can begin to develop their networks.
- Educate the business community. By facilitating connections between students and community employers, this also provides the business community with an opportunity to dispel incorrect perceptions they may have about employing individuals with disabilities and/or special health care needs. Short-term work experiences or internships provide a low-cost opportunity to the employer to recognize the benefits of hiring an individual with a disability and/or special health care need.

## **Employment Work Group Action Plan**

In an age when academic success is highly valued and linked to funding for school systems, it becomes difficult to make a case for why school time should be spent in employment settings and not in the classroom. Therefore, we must creatively identify opportunities for students to gain work experiences in the context of the school curriculum and link the experiences to academic learning. Some options to pursue might include:

- Strengthen internship opportunities within ESSE.
- Replicate evidence-based best practice models currently being embedded within the context of the school environment, e.g., Project SEARCH and Customized Employment.
- Provision of services by agencies and adult service providers earlier in high school, particularly for those students not referred for ESSE.
- Emphasize access to DVR counselors prior to exit – identify individuals and support them in pursuing eligibility prior to start of last year (e.g., for students who have 504 plans).
- Enhance vocational technical school enrollment and participation. Students in special education who are enrolled in a vocational/technical school are in a good position to receive experiential opportunities and training that create a likelihood of post-school employment.

There are some best practice models for providing community work experiences in the state (e.g., Cape Henlopen). Technical assistance is required to ensure all districts are competent in providing support and education in this area.

### **2-Enhance employment-related assessments and outcomes.**

Research provides very little information about the factors that shape the employment outcomes of individuals with intellectual and/or developmental disabilities. As the Employment First agenda continues to be implemented in Delaware, professionals working with individuals with disabilities and/or special health care needs must take a more thorough look into the necessity of starting earlier with career education, employment skills assessments and integrated community-based experiences.

**Rationale:** Individuals who had earlier experiences that helped them determine not only the type of job they wished to obtain, but were exposed to a specific career they wanted to pursue, resulted in increased positive outcomes. Data has shown that individuals who had a previous work experience (either paid, internship, or volunteer) were more likely to retain

## **Employment Work Group Action Plan**

employment. Early employment experiences also impacted individuals' confidence in their abilities. Findings also reveal that school staff members are often the conduit to the early employment experiences which shape the student's choice and confidence. (Timmons, Hall, Bose, Wolfe, & Winsor, 2011).

Although the Employment First agenda is being emphasized, little is currently being done to ensure targeted assessments, interventions, community-based experience and appropriate accommodations are in place to maximize the chances for these individuals to achieve gainful and rewarding employment. This results in the continued underemployment of individuals with disabilities and a decrease in positive outcomes for students exiting our schools.

The transition planning process must include changing the mindsets of parents/caregivers and educators so that they recognize the importance of beginning transition planning for students with disabilities and/or special health care needs at an earlier age. By doing so, parents/caregivers and educators will begin to utilize the resources available within the school system. These resources include assessments to determine the level at which the child can succeed and exposing students to work-based opportunities.

It is the recommendation of the Task Force's Education Work Group to begin discussions of the exposure process and skill development in a student's educational career as early as possible (e.g., upon identification of a disability and/or special health care need). Until that happens, significant gains can be made by beginning the process in middle school. For example, in the fall of 8th grade, soft skills (i.e., social skills for the workplace), and barriers to employment, and preliminary discussions about life after high school can all be examined. IEP goals can then be created to assist school staff in helping a student and their families/caregivers incorporate areas of concern into everyday school life. Assessments could include looking at stamina, fine/gross motor skills, medical challenges, career interests and styles of learning. Positive attributes could be highlighted and praised, while areas of challenge may be addressed with well-defined, realistic, measurable and attainable goals.

These assessments could then be repeated in the fall of 10th grade. The individual could be introduced to *Career Cruising* and/or *Choose and Take Action: A Transition Employment Program* depending on the significance of their disability and/or special health care need. This would also be the beginning of the Student Success Plan (SSP). New IEP goals would then be developed incorporating the outcomes of these assessments. During their 10<sup>th</sup> grade year, individuals would be offered opportunities to visit various work sites, explore a variety of careers, begin to understand what skills are

## Employment Work Group Action Plan

required to be successful within those careers and determine what education or training may be required to reach their goal. Job shadowing and summer programs would be available to develop work and social skills, based upon the employability skills employers are looking for in entry-level positions, and to work on challenges and barriers in real life community-based experiences. In the spring of the 10th grade individuals would begin exploration of, and visits to, adult service providers and be empowered to make an informed choice prior to entering the 11th grade.

In the fall of their 12th grade year, individuals on a diploma track who have an IEP as well as individuals working toward a certificate of completion/attendance will be reassessed with the same instruments administered during their 10th grade year. Individuals would participate in a one year community-based employment experience, with potential to change sites between semesters if it is determined by the individual or the educator that the site is not a good match. An assessment tool will be developed to provide the individual with an Employability Skills Rating upon completion of their education. Results provided through individual self-assessments and site supervisor evaluations will be collected throughout the year. Adult Service Providers will attend all transition/IEP meetings, and would conduct community-based assessments in partnership with DVR. Should individuals continue to participate in an 18 to 21-year-old program post-exit from high school; the same assessment model would be administered at age 19 and again just prior to exit at age 21.

### **3-Internship opportunities for student's post-high school**

**Rationale:** For some students, the pursuit of a career may not begin during high school or may be unsuccessful. As a result, opportunities for individuals to pursue internships after they leave high school would also empower them to consider new potential career options, develop critical skills, and expand their business networks to facilitate gainful employment.

Currently, the DVR system in Delaware provides some support for individuals who would like to test out particular career paths or employment settings. By examining potential ways to expand on these services, in terms of both amount of time spent on internships and number of internships participated in, as well as by conducting an analysis of the Return on Investment (ROI) for participation in such activities, a system may be developed that can mirror the recommended supports prior to leaving high school.

**Employment Work Group-Action Plan and Timeline**

<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Enhance work opportunities prior to exit from high school.	EFI, GCBACS, DSTW, DOE, DVR, DDDS, DSAMH, DSAAPD, DVI Service Providers (DelARF)	2013-2014
Enable strategic partnerships with employers through training, organization, etc.	EFI, GCBACS, DSTW, DWIB, BLN, DDDS, DVR, DVI, Service Providers (DelARF)	2013-2015
Provide training for families/caregivers on critical areas related to enhancing employment outcomes (e.g., benefits counseling, increasing independence, etc.)	EFI, GCBACS, DSTW, DDDS, DVR, DSAMH, DSAAPD, DVI, DOE, CDS, PIC	2013-2014
Provide training and technical assistance for schools on the implementation of work experiences as part of the school day.	EFI, GCBACS, DSTW, DOE, DDDS, DVR, DSAMH, DVI, DSAAPD, CDS, Transcen Inc., NSTTAC	2013-2015

**Employment Work Group-Action Plan and Timeline**

<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Conduct thorough assessments of youth, preferably upon identification of disability and/or special health care need, in order to support them in understanding their strengths and weaknesses, and to develop curricula to enhance their career exploration and employment skills.	EFI, GCBACS, DSTW, DOE, DDDS, DVR, CDS, DSAMH, DSAAPD, DVI, Transcen Inc., NSTTAC	2013-2015 (for a pilot)

## **Employment Work Group Recommendations**

- 1.** Enhance multiple work opportunities, paid or unpaid, for students with disabilities and/or special health care needs prior to their exit from school. This may be accomplished through collaborative efforts with EFI, DOE, DVR and DDDS.
- 2.** Enable strategic partnerships with and between Delaware employers through coordinated education, training and technical assistance that promotes increased awareness, job development, job shadowing and job internship opportunities for students with disabilities and/or special health care needs.
- 3.** Provide training for families/caregivers on critical areas related to enhancing employment and career outcomes (e.g. benefits counseling and supporting increased student independence) for students with disabilities and/or special health care needs.
- 4.** Provide training and technical assistance for schools regarding the successful implementation of work experiences as part of a student's school day.
- 5.** Conduct thorough assessments of young adults with disabilities and/or special health care needs earlier in school in order to support them in understanding their employment-related strengths and weaknesses. Develop curricula to enhance their career exploration and employment skills.
- 6.** Enhance statewide support systems to enable more individuals with disabilities and/or special health care needs to access post-secondary education and training.

## **Employment Work Group Members and Contributors**

*Chair, Andrea Guest – Division of Vocational Rehabilitation (DVR)*

**Barbara Riley** – Division of Vocational Rehabilitation (DVR) /Division of Services for Children, Youth and their Families (DSCYF)

**Brian Freedman** – Center for Disabilities Studies (CDS) at the University of Delaware

**Cindy Sterling** – Service Source (an Employment Support Services Provider)

**Daniel Madrid** - Division of Vocational Rehabilitation (DVR)

**Donna Nacchia** – Parent Advocate

**Katie Howe** – Division of Developmental Disabilities Services (DDDS)

**Loretta Harper- Brown** – Division for the Visually Impaired (DVI)

**Margaret Haas** - Cape Henlopen School District (CHSD)

**Marissa Catalon** - Division of Developmental Disabilities Services (DDDS)

**Sandra Miller** – Division of Vocational Rehabilitation (DVR)

**Terri Hancharick** – Governor’s Advisory Council for Exceptional Citizens (GACEC) and Parent Advocate

**Wendy Claiser** – Center for Disabilities Studies (CDS) at the University of Delaware

# Tara Bustard



Tara Bustard, pictured second from left, is described by family and friends as “a really neat lady who just happens to have a disability”.

Bustard has enjoyed a successful career at Bank of America for 14 years, and is a competitor in three different sports with Special Olympics of Delaware.

**Q: What are you currently doing now that you have left high school?**

*A: I am working full time and have been at the same employer for almost 14 years. I do Special Olympics for 3 sports throughout the year. I walk every day for health and I don't drink sodas. I am losing weight.*

**Q: What were your challenges and successes as you went through the transition process?**

*A: The high school staff was a challenge for me in so many ways. I was told by the “vocational teacher” at my IEP meeting in front of everyone that I would never work, that I would always live in a group home, and that I would always be dependent on the state. She then asked my Mom why my Mom was “forcing them to teach me to get a job.” This sums up my transition help from the high school. My DMR Case Manager helped me get my job at MBNA and I love it. I left school when I was 18 to work and got educational tutoring from the result of a due process win. The best thing I did was decide to leave Middletown High School early and go to work. My Mother taught me how to live on my own and helped me get my own apartment where I lived for 4 years.*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

*A: DMR Case Manager, Janine Lamond, was the best. She believed in me and helped me get a job.*

**Q: What is your anticipated path for the future?**

*A: Stay working at Bank of America, be rich, find a nice boyfriend who loves me and will share my life.*

State Transition Task Force for Emerging Adults with Disabilities  
and Special Health Care Needs

“...I remember lying next to her on her bed and asking her

**WHAT SHE WANTED**

**TO DO WITH HER LIFE.**

Though she could not answer me

I thought to myself, of course,

**SHE WANTS WHAT ALL OF OUR  
OTHER KIDS WANTED.**

To be **FULLY INCLUDED** in her community

**JUST**

**LIKE**

**EVERYONE**

**ELSE**

**IS. “**

*Terri Hancharick, speaking of a conversation she had with her daughter, Brigitte*

**HEALTH WORK GROUP**

# Brahmin Jackson



Brahmin Jackson, pictured on set at WHYY television studios in Philadelphia, is a case manager and mentor for Jewish Family Services of Delaware. Jackson is pursuing a degree in Human Services and aspires to a career in politics.

**Q: What are you currently doing now that you have left high school?**

*A: I have been working in the field of Case Management/ Mentorship for almost 2 years under the guidance and employment of Jewish Family Services of Delaware. I am currently transferring from Wilmington University as a film/studio production major to Del Tech in pursuit of an associate degree in Human Services.*

**Q: What were your challenges and successes as you went through the transition process?**

*A: I had a very trying time finding my balance and becoming stable in my perspective, prospects and livelihood. I encompassed the motivation and ambition to sustain success, but I couldn't fathom the process or the opportunities available. I didn't begin to come into my own until I got out of my comfort zone. Once I became busy after being introduced to what to me was uncharted areas, I began retaining personal and financial gain growing accustomed to the new lifestyle and eager to move forward. With my new experiences and understandings possibilities were apparent and I could formulate a detailed plan to achievement.*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

*A: Staying in touch with Scott Michels of Jewish Family Services and Mrs. Allen-McIntyre (then Principal of Ferris School) is one of the greatest and most impactful decisions to my life that I've ever made, to this day. I was introduced to happenings beyond what my eyes could see and concepts that exploded my consciousness and competence.*

**Q: What is your anticipated path for the future?**

*A: I will continue to share my success with others of all ages, by implanting in them the guidance and knowledge I've gained. I will continue my education in human services and law while continuing a freelance career in media/ film production. As a man who has grown from one perspective to live in another, I will move forward in full preparation to be a career politician.*

## Health Work Group Executive Summary

*“A well-timed transition from child-oriented to adult-oriented health care allows young people to optimize their ability to assume adult roles and functioning.”-Pediatrics, 2002; 110; 1304*

What is meant by “health care transitions”? The journal *Pediatrics* defines health care transitions as follows:

“Transition in health care for young adults with special health care needs is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.”

With this definition in mind, the Health Work Group of the State Transition Task Force selected the following priorities from the many which were identified to be addressed in their report:

- I.** Create more responsive systems in Delaware for young adults with disabilities and/or special health care needs and their families/caregivers.
- II.** Implement policies and programs in Delaware that improve health for young adults with disabilities and/or special health care needs and their families/caregivers.
- III.** Lay the foundation for access to information to promote health literacy, transition readiness and success for young adults with disabilities and/or special health care needs and their families/caregivers.
- IV.** Build capacity for the individual health of young adults with disabilities and/or special health care needs and their families/caregivers.

Having access to consistent, correct and updated information will eliminate much of the confusion currently experienced by young adults with disabilities and/or special health care needs as they seek information and resources to assist them with their transition to adult life. Health care transitions are challenging for all young adults, but can be particularly complicated for young adults with disabilities and/or special health care needs. Communication, collaboration and coordination between health care systems (e.g. A.I. duPont/Nemours, Christiana Care), education systems (e.g. districts and high schools), and key agencies (e.g. the Division of Public Health [DPH], DVR, DDDS) is absolutely critical to the success of the health care transition process for young adults.

## **Health Work Group Executive Summary**

The education and health care systems are the natural settings to begin transition planning with young adults with disabilities and/or special health care needs and their families/caregivers, ideally with the collaboration of key state and private service agencies. Students with disabilities and/or special health care needs and their families/caregivers are often not aware that changes will occur in their health care once they reach the ages of 18-21. Therefore, it is imperative that all health systems, education agencies and state/service agencies distribute one cohesive set of consistent, correct, updated and readily available information regarding transition. This information would be available for distribution to anyone in need of information regarding the transition process, ideally through a Delaware State Transition Website. Such a website would be the ideal vehicle for dissemination of information, and will also provide a listing of valuable resources for those who are seeking guidance regarding the transition process.

The integration of the health care system, education system and state/service agencies are essential when planning the transition IEP of a young adult with a disability and/or special health care need. It is an absolute necessity that a young adult with a disability and/or special health care need be in their best possible health. Poor health leads to diminished functionality for all individuals. The transition IEP process is therefore an ideal time to set goals and expectations for a young adults' transition to the adult health care system.

During the transition IEP process, students must be made aware of their rights and responsibilities regarding their health care both while they are in school and when they leave school. An ongoing dialog must take place while the student is in school, not just during IEP meetings, regarding changes in guardianship, health insurance, eligibility for services and continuation of care from pediatric to adult health care systems. A registry for young adults with special health care needs who do not have an IEP must be created and maintained. This will provide the state with valuable data to utilize when developing state-standardized, data-driven transition best practices for students with special health care needs who do not have an IEP.

As previously stated, the Health Work Group feels that effective communication, collaboration and coordination between young adults with disabilities and/or special health care needs, their families/caregivers, and those who serve them is the key to ensuring a successful transition to adult life. A statement supporting this assertion is shared in the journal *Pediatrics*. In a consensus statement written by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine entitled "A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs" it states, "Clearly, no single approach will work equally well for all young people, and the health care sector cannot work in isolation from the other professionals and networks that impact these young people."

The Health Work Group has agreed that our objective is to emphasize the necessity of effective transition planning within the health care system for students with disabilities and/or special health care needs and their families/caregivers, and to encourage multiple systems change based upon the recommendations of the Health Work Group.

## Health Work Group Action Plan

### I. Create more responsive systems in Delaware for young adults with disabilities and/or special health care needs and their families/caregivers.

1- Create universal eligibility criteria across Delaware state agencies, so there is a seamless health care transition between systems and services.

**Rationale:** Communication and collaboration between agencies serving children and those serving adults is imperative when re-examining and redefining eligibility criteria, definitions, and transition plans.

- When communication and collaboration are carried out effectively, it ensures that the young adult does not experience a substantial gap in needed services.
- The many systems and services for young adults with disabilities and/or special health care needs are currently not communicating and sharing information effectively, and are not user-friendly.
- It is necessary to work together to create universal eligibility and a seamless transition will help to maintain the health of young adults with disabilities and/or special health care needs through their continued health care visits.
- Young adults with disabilities and/or special health care needs and their families/caregivers must be able to obtain all needed services without any gaps or delays in services.

2- Establish definition and reimbursement codes and rates for patient-centered medical homes (PCMH).

**Rationale:** This will create the opportunity for reimbursement for the extensive amount of time the PCMH spends coordinating care for patients. It will also encourage the PCMH to spend that amount of time coordinating care to decrease inappropriate utilization of health care services. The reimbursement codes will also broaden access to other providers to accept patients with disabilities and/or special health care needs into their practices.

3- Develop and assess online curricula for all levels of medical personnel, including physicians, nurses, therapists and all related-services personnel. The curricula must focus on transition health care issues.

## **Health Work Group-Action Plan**

**Rationale:** We need to develop culturally-responsible health care personnel so there are no disparities in patients' access to care. The creation of curricula will enforce equitable access to care across all disciplines.

**4-** Develop, update and maintain a fully-accessible Delaware State Transition Website which will contain consistent, correct and updated information for young adults with disabilities and/or special health care needs, their families/caregivers and all persons interested in transition issues.

**Rationale:** It is imperative that all health systems, education systems and state/service agencies distribute one fully accessible cohesive set of consistent, correct, updated and readily-available information regarding transition. The Delaware State Transition Website will contain information which is available for distribution to anyone in need of guidance regarding the transition process. A Delaware State Transition Website is also the ideal vehicle for dissemination of information, and will also provide a listing of valuable resources for those who are seeking information regarding the transition process. At a minimum, the website will include information about self-management, self-advocacy, education, employment, housing, health care (including provider office accessibility), transportation, legal, insurance, financial, emergency care, assistive technology, home health care and mental/behavioral health. Public Service Announcements (PSAs) will be used to disseminate transition information and promote the Delaware State Transition Website, through DPH. Young adults and their families/caregivers that do not have access to the internet should be in contact with agencies or other stakeholders who will assist with accessing and disseminating the appropriate information in a culturally and developmentally appropriate format.

## **II. Implement policies and programs that improve the health of young adults with disabilities and/or special health care needs in Delaware.**

**1-** Develop, assess and maintain a registry for students receiving 504 accommodations from their school. The 504 Registry will allow these students to take advantage of transition planning services offered to their peers who have an IEP.

**Rationale:** Currently students with IEPs are known and guaranteed supports through PL 94-142, but students with 504 plans are not tracked and therefore, schools and physicians may not know that the student needs accommodations. In keeping with the tenets of establishing a PCMH, developing registries helps identify high risk groups, which allows supports and services to be allocated appropriately.

## Health Work Group-Action Plan

2- Increase the age limit for Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services for young adults with disabilities and/or special health care needs, inclusive of mental health conditions, to avoid a gap in medical care and treatment necessary to maintain their health.

**Rationale:** Persons with mental health or chronic conditions need to have further supports so that they can apply for appropriate financing and/or program supports and continue with necessary care (treatments, therapy, and medications). An age extension will allow persons with mental health or chronic conditions more time to establish a transition plan.

3- Expose adult medical providers to transition issues and increase awareness of pediatric-onset conditions through Grand Rounds, Continuing Medical Education (CME), Medical Society of Delaware (MSD) journals, and the Delaware Chapter of the Society of General Internal Medicine (SGIM)/Family Medicine.

**Rationale:** “When adult medical care providers were exposed to the process of transitioning young adults in the context of their residency training experiences, they were much more likely to incorporate it in to their practices after residency.” (Okumura, 2008). Due to the advances in pediatric medicine, children with previously fatal pediatric-onset conditions are now surviving into adulthood. Therefore, it is likely that many adult health care providers were not exposed to information regarding these pediatric-onset diseases during training.

4- Expand the age of eligibility to “high school age” rather than age 18, so young adults who are receiving services from the Division of Prevention and Behavioral Health Services (DPBHS) can continue to receive services while they are still in school.

**Rationale:** Many young adults turn 18 while still in high school. To disrupt their access to services and continuity of care leads to poor outcomes and gaps in services. As the Executive Director of the Division of Substance Abuse and Mental Health (DSAMH) can attest, many young adults turn 18 and never proceed to enter the adult mental health system, due to the lack of having gone through an effective transition process. Many of these young adults return to care or enter the judicial system at the point of crisis in their early 20s. By extending coverage through high school for recipients of DPBHS services, gaps in services will decrease.

## Health Work Group-Action Plan

### III. Lay the foundation for access to information to promote health literacy, transition readiness and success for young adults with disabilities and/or special health care needs and their families/caregivers.

1-Health care planning must be made an integral part of the transition IEP process. If students are unable to maintain good health, they will not be able to make a successful transition to adult life.

**Rationale:** Currently life skills are addressed in all other domains except health care on the IEP. By adding health care goals to a student's IEP, young adults' life skills are optimized and they are better integrated into medical and wellness activities.

2- Develop and assess a life skills course, to include lessons plans on understanding one's condition, medication management, understanding insurance, how to interact with medical personnel and how to renew medication at the pharmacy, among other topics.

**Rationale:** Currently high school students enrolled in life skills classes are not included in the traditional health education curricula to which their typical peers are exposed. Students who have a disability and/or special health care need would benefit from the self-advocacy and self-management training learned in a life skills class.

3- Create an age-based milestone mailing/website posting/text message alert, which will define age parameters for each program, service and eligibility that the young adult is currently receiving.

**Rationale:** This serves to alert or remind young adults with disabilities and/or special health care needs and their families/caregivers about upcoming changes to expect through a mailing/Delaware State Transition Website posting/text message alert. Information about changes to guardianship, private insurance, Supplemental Security Income (SSI), etc. will be included, as well as information about changes in eligibility and types of coverage for ancillary services once covered through the IDEA.

These reminders should be provided at the young adult's IEP meeting and/or 504 meeting once they reach 16 years of age. Using the DPH "Text 4 Baby" model for newborn through 24-month-old outreach via telephone and text messaging, create a similar program for young adults in the 16-18-year-old age range which will contain information about transition. This letter/Delaware State Transition Website posting/text message should

contain information about age-based policies. The information contained therein is pertinent to any child receiving *any* service for which there is an age-restriction or

## Health Work Group-Action Plan

change. In addition to being readily available on the Delaware State Transition Website in letter format and in text message format, this information must also be available in schools, at state/service agency offices, etc. The letter will list the entire menu of services for each specific program (e.g. Adult Expansion Medicaid services and eligibility, Long Term Care Plus Medicaid services and eligibility). Notification of services which will *not* continue must also be included (e.g. dental care, hearing aids, EPSDT).

4- Every pediatric office will have a written policy on health care transition. The policy will be distributed to all patients and posted in the office.

**Rationale:** Pediatric physician's offices should assist young adults with disabilities and/or special health care needs and their families/caregivers in finding specialists necessary for the young adult's care, as well as a new adult primary-care physician, prior to the young adult aging out of their practice.

### IV. Build capacity for individual health for young adults with disabilities and/or special health care needs and their families/caregivers.

1- Promote and provide incentives for physicians to have a PCMH for both pediatric and adult medicine.

**Rationale:** The amount of services provided through a PCMH is more extensive and thorough than traditional primary care. It has been shown to reduce redundancy, identify high risk groups and allocate services appropriately. Having a PCMH for both pediatric and adult care would also assist in communication of the patient's need across systems.

2- Allow physician reimbursement through insurance for shared visits between a young adult's pediatrician and adult care physician during the young adult's first year of transition.

**Rationale:** This would consist of one visit with the young adult's new adult care physician and one visit with their pediatrician. This allows the young adult and their family/caregivers to feel that there is a continuity of care. Pediatricians would also be sharing information with the young adult's selected adult care physician. Under this proposed plan, the adult care physician, the young adult and their family/caregivers would feel more comfortable with the transition, since the lines of communication will be kept open between the young adult's pediatrician and adult care physician. A similar model is also suggested for youth aging out of the child mental health system. Currently, the transition from pediatric care to adult care is limited to the forwarding of the patient's file from pediatrician to adult care physician.

### Health Work Group Action Steps and Timeline

<b>Goal I:</b> Implement policies and programs that improve the health of young adults with disabilities and/or special health care needs in Delaware.		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Create universal eligibility criteria across Delaware state agencies, to establish a seamless transition between systems and services.	Please see the list on page 118 for a complete listing of potential partners.	Beginning in 2013- Ongoing
Establish definition and reimbursement codes and rates for patient-centered medical homes (PCMH).	Please see the list on page 118 for a complete listing of potential partners.	Beginning in 2013- Ongoing
Develop, update and maintain a fully-accessible Delaware State Transition Website which will contain consistent, correct, updated information for young adults with disabilities and/or special health care needs, their families/caregivers and all persons interested in transition issues.	Please see the list on page 118 for a complete listing of potential partners.	Beginning in 2013- Ongoing

### Health Work Group Action Steps and Timeline

<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Develop, assess and maintain a registry for students receiving 504 accommodations from their school. The 504 Registry will allow these students to take advantage of transition planning services offered to their peers who have an IEP.	Please see the list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing
Increase the age limit for EPSDT services for young adults with disabilities and/or special health care needs, inclusive of mental health conditions, to avoid a gap in medical care and treatment necessary to maintain their health.	Please see the list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing
Expose adult medical providers to transition issues and increase awareness of pediatric-onset conditions through Grand Rounds, Continuing Medical Education (CME), Medical Society of Delaware (MSD) journals, and the Delaware Chapter of the Society of General Internal Medicine (SGIM)/Family Medicine.	Please see the list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing

### Health Work Group Action Steps and Timeline

<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Expand the age of eligibility to “high school age” rather than age18, so young adults who are receiving services from the Division of Prevention and Behavioral Health Services (DPBHS) can continue to receive services in school.	DPBHS, Legislators	Beginning in 2013- ongoing
<p>Continue with the five core strategies identified by the Delaware Youth Opportunity Initiative for successful transition out of foster care:</p> <ol style="list-style-type: none"> <li>1. Engage youth to become better decision-makers and self-advocates.</li> <li>2. Forge alliances and build a network of resources through partnerships and collaboration.</li> <li>3. Galvanize public will and policy to effect reforms in practices and policies that will bring about more successful transitions.</li> <li>4. Increase opportunities for economic success.</li> <li>5. Use data from research and evaluation to drive decision-making and shape communications.</li> </ol> <p>Judicial System- continue the work of Judge Jan Jurden’s transition task force.</p>	Delaware Youth Opportunities Initiative ( <a href="http://www.dyoi.org">www.dyoi.org</a> ) Judge Jan Jurden	Beginning in 2013- ongoing

## Health Work Group Action Steps and Timeline

<p><b>Goal II:</b> Lay the foundation for access to information to promote health literacy, transition readiness and success for young adults with disabilities and/or special health care needs and their families/caregivers.</p>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Create an age-based milestone mailing/website posting/text message alert, which will define age parameters for each program, service and eligibility that the young adult is currently receiving.	Please see the attached list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing
Make health care planning an integral part of the transition IEP process.	Please see the attached list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing
Develop and assess a life skills course, to include lesson plans on understanding one's condition, medication management, understanding insurance, how to interact with medical personnel, how to renew medication at the pharmacy, etc.	Please see the attached list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing
Ensure every pediatric office has a written policy on health care transition. Distribute the policy to all patients and post it in the office.	Please see the attached list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing

### Health Work Group Action Steps and Timeline

<p><b>Goal III:</b> Build capacity for individual health for young adults with disabilities and/or special health care needs and their families/caregivers.</p>		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Promote and provide incentives for physicians to have PCMH for both pediatric and adult medicine.	Please see the attached list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing
Allow physician reimbursement through insurance for shared visits between a young adult's pediatrician and adult care physician during the young adult's first year of transition.	Please see the attached list on page 118 for a complete listing of potential partners.	Beginning in 2013-Ongoing

## **Health Work Group- Primary Recommendations**

*The adult systems of education, mental health, Social Security, vocational rehabilitation, and workforce development all have different terminology, eligibility requirements, and service options than those of their corresponding youth systems. The lack of a seamless youth-to-adult system can result in young adults to losing access to these critical services and falling behind. The Health Work Group has the following recommendations to ensure that this is no longer the case.*

1. Create more responsive systems in Delaware for young adults with disabilities and/or special health care needs and their families/caregivers.
2. Implement policies and programs that improve the health of young adults with disabilities and/or special health care needs in Delaware.
3. Lay the foundation for access to information to promote health literacy, transition readiness and success for young adults with disabilities and/or special health care needs and their families/caregivers.
4. Build capacity for individual health for young adults with disabilities and/or special health care needs and their families/caregivers.

## **Health Work Group- Supporting Recommendations**

*The additional recommendations listed below are intended to add details to the primary priorities identified by the Health Work Group. The primary priorities and recommendations addressed thus far in this report were selected from a large group of recommendations shared by Health Work Group members and stakeholders. The inclusion of these high-view, overarching priorities is not intended to diminish the need and importance of the Health Work Group's additional recommendations regarding health care transition. These overarching priorities are intended to serve as the foundation of the Health Work Group's recommendations, and the details listed below should be considered the bricks and mortar to help build a strong structure of health care transition in Delaware.*

### **1. Create a Delaware State Transition Website:**

- A Delaware State Transition Website would be the ideal vehicle for dissemination of key, consistent and updated information regarding transition, and will serve as a valuable resource for anyone seeking information regarding the transition process.
- The website will include information about the following: self-management, self-advocacy, education, employment, housing, health care (including office accessibility), transportation, legal concerns, insurance, finance, emergency care, assistive technology, home health care and mental/behavioral health.
- Promotional and advertising strategies for making the public aware of the Delaware State Transition Website's existence are critical to its success as the go-to reference and resource tool for those seeking information and assistance with transition.
- It is necessary to ensure that young adults with disabilities and special health care needs and their families/caregivers, as well as state agencies, LEAs and physicians' offices are aware of the website as the go-to source of reliable transition information, so that they may assist in promoting the website through their interactions with young adults with disabilities and/or special health care needs and their families.

### **2. Create an age-based milestone mailing, which documents age parameters for each program, service, and eligibility, to alert or remind young adults with disabilities and/or special health care needs and their families/caregivers about the changes to services for a particular age.**

- This alert would serve to remind young adults with disabilities and/or special health care needs and their families/caregivers about what upcoming changes to expect through a mailing/Delaware State Transition Website posting/text message alert.

## **Health Work Group- Supporting Recommendations**

- Information about changes to guardianship, private insurance, SSI, etc. will be included, as well as information about changes in eligibility and types of coverage for ancillary services once covered through IDEA.

### **3. Create universal eligibility criteria across Delaware state agencies, so there is a seamless transition between systems and services.**

- Communication and collaboration between agencies serving children and those serving adults is imperative when re-examining and redefining eligibility criteria, definitions, and transition plans.
- When communication and collaboration are carried out effectively, it ensures that the young adult does not experience a substantial gap in needed services.
- The many systems and services for young adults with disabilities and/or special health care needs are currently not communicating and sharing information with one another, and are not user-friendly.
- Working together to create universal eligibility and a seamless transition will help to maintain the health of young adults with disabilities and/or special health care needs through their continued health care visits.
- This will also allow young adults and their families/caregivers to obtain all needed services without any gaps or delays.

### **4. Align and strengthen incentives in public and private health care programs to support coordinated care and transition planning**

- Delaware Institute of Medical Education and Research (DIMER) and Delaware Institute for Dental Education and Research (DIDER) recruitment should include specialties in medicine where there are shortages for young adults (e.g. orthopedics, urology and neurosurgery).
- Improve insurance reimbursement to physicians' offices through better coordination of care codes (see AAP PCMH section on coding).
- Provide incentives for practices that implement PCMH models.
- Work with the Delaware Health Care Commission (DE HCC) to ensure adequate and equitable reimbursement for the same chronic conditions in both the pediatric and adult systems.
- Establish incentives for medical practices that update their offices to be compliant with the Americans with Disabilities Act (ADA).

## **Health Work Group- Supporting Recommendations**

- Work with the DE HCC on the Delaware Health Information Network (DHIN) interconnected medical record system to improve the continuity of care and patient safety.
- Work with the DE HCC on the PCMH model to create a consistent definition of “Pediatrics” and “Adult Medicine”.
- Revisit definitions of “skilled nursing care” and “home health aides” as it relates to assisting young adults with medical needs in securing employment.
- Educate and inform the business community of the abilities and unique needs of young adults with medical needs (e.g. feeding tubes, Diabetes). Individuals who have not had frequent interactions with young adults with disabilities and/or special health care needs may initially feel uncertain of how to best work together. Education and awareness efforts can help to reduce employers’ concerns, and eliminate the gaps that may prevent young adults with disabilities and/or special health care needs from securing employment.
- Explore the state’s ability to blend and braid funding across agencies to support shared services as young adults with disabilities and/or special health care needs transition to a new system.
- Re-consider insurance reimbursement for the co-management of patients during their last year in pediatric practice – both the pediatric and adult providers should be able to bill for services as the primary doctor in order to deliver uninterrupted care and minimize gaps in services.
- Transition CME should be linked to the state’s licensure renewal process (similar to abuse).
- Add a “must-pass” element to the PCMH criteria based on NCQA standard 5c62.
- Increase access to HL7 data for electronic health records to have better continuity across systems for patients.
- Expand the use of integrated Electronic Medical Records (EMR) for chronic disease.
- Improve dissemination of key information in schools. Information from the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) and the Division of Substance Abuse and Mental Health (DSAMH) must be distributed at a young adult’s IEP and/or 504 meeting.
- Establish a team of transition personnel within state departments.

## **Health Work Group- Supporting Recommendations**

- Align and strengthen incentives in public and private health care programs to support coordinated care and transition planning.

### **5. Educate health care providers about the transition process from pediatric to adult centered care.**

- All health care providers including, but not limited to, physicians, Physician's Assistants (PA), Nurse Practitioners (NP), Registered Nurses (RN), Medical Administrators (MA), radiology and lab technicians, and ancillary service providers will receive education about facilitating health care for people with developmental, intellectual, and physical disabilities possibly through an online curriculum, CME or attendance at Grand Rounds.
- Incorporate and expand chronic care education and transition education in pediatric, internal medicine, and dental residency programs, and in nursing and NP programs in Delaware.
- Pediatric providers will be encouraged to discuss the transition to an adult provider with *all* adolescent patients, not only patients with disabilities and/or special health care needs.
- Providers will be encouraged to educate patients about self-management skills starting at age 12 as appropriate to the developmental level of the patient (will refer to appropriate ancillary services to provide this education – Speech Therapy [ST], Occupational Therapy [OT], Physical Therapy [PT], home health nursing).
- Pediatric providers will network with their adult counterparts so they know who to refer patients to.
- Providers will be encouraged to connect with pharmacists in order to ensure that important information is shared with patients/families.
- Pediatric providers will be encouraged to educate adult providers about pediatric-onset conditions and goals of care. Pediatric providers may provide guidance and suggestions for adult providers through best-practice handouts (Center for Youth and Adults with Conditions of Childhood [CYACC] handouts, New York Merger, Acquisition, and Collaboration Fund [NYMAC] grant handouts).
- Adult providers will be encouraged to implement a patient- centered approach, as opposed to a disease-centered approach.
- Transition Coordinators in schools will have a core competency in all aspects of health care transition.

## **Health Work Group- Supporting Recommendations**

### **6. Mental health:**

- Expand age eligibility to “high school age” rather than age 18, so people in high school can continue receiving services from the DPBHS.
- Encourage young adults who are receiving services from DPBHS to have an active dialog with their case worker about transition and timelines of their transfer to the adult mental health system. These young adults will also have received a letter explaining the transition between the systems.

### **7. Ancillary services:**

- Home health care agencies will be encouraged to provide information about their patients’ insurance changes to families and whether or not they can continue services.
- New staff may be utilized as youth age out of pediatric offices, to assist with developing a new home and community care plan.
- Medicaid must consider providing dental coverage beyond age 21.
- Extend EPSDT for persons with chronic conditions and mental health conditions beyond age 21.

## Health Work Group Members

*Chair, Ann Phillips*- Executive Director, Delaware Family Voices

*Chair, Cory Nourie*- Patient Transition Social Work Coordinator Nemours Alfred I. duPont Hospital for Children

*Chair, Dr. Jennifer LeComte, D.O.* - Christiana Care Health System

**Beth Macdonald**- Delaware Special Needs Alert Program (SNAP)

**Bettina Riveros**- Delaware Health Care Commission (DHCC)

**Beverly Weigand**- Diamond State Partners Program, Delaware Division of Medicaid and Medical Assistance (DMMA)

**Bhavana Viswanathan**- Children and Youth with Special Health Care Needs Program, Delaware Division of Public Health (DPH), Maternal and Child Health Bureau

**Bill Love**- Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)

**Carol Barnett**- Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)

**Carol Greblunas**- Delaware Physicians Care Initiative (DPCI)/ Aetna

**Cathy Cowin**- Parent Advocate, GACEC

**Chris Oakes**- Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)

**Colleen O'Brien**—Caesar Rodney School District (CRSD)

## **Health Work Group Members**

**Crystal English**- Delaware Division of Medicaid and Medical Assistance (DMMA)  
**Steven Yeatman**- Delaware Division of Prevention and Behavioral Health Services (DPBHS)  
**Dan Madrid**- Delaware Division of Vocational Rehabilitation (DVR)  
**Daniel Chappell**- Delaware Division of Medicaid and Medical Assistance (DMMA)  
**Dave Michalik**- Delaware Division of Medicaid and Medical Assistance (DMMA)  
**Dawne Estep**- Delaware Division of Medicaid and Medical Assistance (DMMA)  
**Deanee Moran**- Delaware Sexual Assault Network (DSAN)  
**Deb Jastrebski**- Practice without Pressure (PWP)  
**Deb Nock**- The Arc of Delaware  
**Deborah Scott**- New Castle County Vo-Tech School District (NCCVT)  
**Diann Jones**- Nationwide Special Needs Planning  
**Eric Burlingame**-Henrietta Johnson Federally Qualified Health Center  
**Estelle Whitney**-Christiana Care Health System (CCHS)  
**Gary Mears**- Parent Advocate and University of Delaware Center for Disabilities Studies (CDS)  
**Gerard Gallucci**- Delaware Department of Health and Social Services (DHSS)  
**Harvey Doppelt**- Delaware Division of Prevention and Behavioral Health Services (DPBHS)  
**Heidi Mizell**- Autism Delaware  
**Esther Curtis**- Brain Injury Association of Delaware (BIAD)  
**Henry Smith**- Delaware Department of Health and Social Services (DHSS)  
**Jeanine Carrio**- Parent Advocate  
**Jessica Hedden**- Medial Society of Delaware (MSD)  
**Julia Rawding**- Diamond State Partners Medicaid Office  
**Julie Leusner**- Delaware Division of Prevention and Behavioral Health Services (DPBHS)  
**Karen Stewart**- Insurance Commissioner of the State of Delaware  
**Katie Borrás**- University of Delaware Center for Disabilities Studies (CDS)  
**Katie Hamilton**- American Academy of Pediatrics (AAP) Delaware  
**Kelly A Dobrowolski**- Delaware Division of Prevention and Behavioral Health Services (DPBHS)

## **Health Work Group Members**

**Kim Marsh**-United Health Care (UHC)

**Larry Henderson**-Independent Resources, Inc.

**Linda Nemes**- Delaware Insurance Department

**Lisa Bond**- Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)

**Lisa Furber**-Brain Injury Association of DE (BIAD)

**Lori Jones** – Christiana Care Health Systems (CCHS)

**Marilyn Hollenbeck**-Delaware Division of Prevention and Behavioral Health Services (DPBHS)

**Marissa Band, Esq.**- DE Community Legal Aid Society (CLASI), Disabilities Law Program (DLP)

**Mary Anderson**- Division of Developmental Disabilities Services (DDDS)

**Nancy Ranalli**- Easter Seals

**Dr. Allen Friedland**- Christiana Care Health System (CCHS)

**Pat Maichle**- Delaware Developmental Disabilities Council (DDC)

**Staci Forrest**- Self-Advocate

**Stephanie Beard**- Delaware Physicians Care Initiative (DPCI)/ Aetna

**Stephen Groff**- Delaware Division of Medicaid and Medical Assistance (DMMA)

**Terri Hancharick**- Parent Advocate and Governor's Advisory Council for Exceptional Citizens (GACEC)

**Wendy Strauss**- Governor's Advisory Council for Exceptional Citizens (GACEC)

**Suzilene Board**- North East Treatment Delaware, Youth and Family Services

**Terry Olson**- The Arc of Delaware

**Tobi Montgomery**- Delaware Physicians Care Initiative (DPCI)/ Aetna

**Victoria Kelly**- Delaware Division of Prevention and Behavioral Health Services (DPBHS)

**William Weaver**- Dover Behavioral Health System

**Yolanda Jenkins**- Division of Services for Children, Youth and their Families (DSCYF)

# Brigitte Hancharick

(With Terri Hancharick)



Brigitte Hancharick, pictured smiling in style at home, is known for her sunny personality, gorgeous grin, infectious giggle and love of being around people. All of these things make Hancharick, a graduate of the John G. Leach School, a natural and frequent volunteer. Keep your eyes peeled for her bright smile while she is volunteering at the 2013 Firefly Music Festival in Dover. Hancharick has multiple disabilities and is nonverbal.

**Q: What are you currently doing now that you have left high school?**

**A:** *When Brigitte left John G. Leach School in New Castle she started attending a day program. After about a year we realized that she was very bored. There was not very much community interaction, except for shopping trips. As of now we are doing some volunteer work and enjoying life in the community.*

**Q: What were your challenges and successes as you went through the transition process?**

**A:** *Looking back, it was a very smooth transition. Because students from special schools usually have multiple disabilities that severely affect their lives the expectations are that they go to day programs or sheltered workshops where they are "safe". As a parent I thought that I was doing what was best for my child by keeping her "safe". What I didn't realize is that I was not giving her the same opportunities that her brothers had been given. Because of her orthopedic issues Brigitte cannot spend a full day in the community. She needs to be positioned constantly during the day. But she can have pieces of what everyone else has, a few hours a day of a "typical" life in the community.*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

**A:** *As I stated before there was not an expectation of Brigitte doing anything other than a day program. We were not given options. DVR was never involved or at any of Brigitte's IEP meetings. The only agency involvement was through DDDS to fund the day program.*

**Q: What is your anticipated path for the future?**

**A:** *Because Brigitte is nonverbal I can only guess about what she wants for her future. When we removed her from the day program, I remember lying next to her on her bed and asking her what she wanted to do with her life. Though she could not answer me I thought to myself, of course, she wants what all of our other kids wanted. To be fully included in her community just like everyone else is. We are still piecing together a life for Brigitte. We would love to find a job where she worked about two hours a day for maybe two days a week. Brigitte has never cared what activity she is doing, as long as there are people around and lots of activity and she is a part of it all. She wants to belong. We are looking for work and volunteer opportunities. She has enjoyed taking a class at the University of Delaware. I dropped her off and she had natural supports from the other students in the class.*

*What Brigitte needs most in her future: FRIENDS and meaningful connections in her community. We are not asking for more than what is in reach for everyone else, but very difficult to attain for someone with disabilities.*

“Every day is a

JOURNEY

And the journey itself is

HOME.”

~Matsuo Basho

“My DREAM is to have a full-time job with benefits so that I can

LIVE INDEPENDENTLY.”

~Alyssa Cowin, 2012 Goodwill Graduate of the Year

HOUSING AND TRANSPORTATION  
WORK GROUP



## Alyssa Cowin

Alyssa Cowin is the recipient of the 2012 Goodwill Graduate of the Year Award. She recently began her career as an Operations Support Specialist at the Department of Health and Social Services (DHSS) in the Office of the Secretary. Cowin aspired to one day become a small business owner.

**Q: What are you currently doing now that you have left high school?**

*A: I am working as an Operations Support Specialist at DHSS in the office of Cabinet Secretary Rita Landgraf. I assist in the areas of Human Resources and Public Relations. A few of my responsibilities are to take photos at events, post pictures on the DHSS Facebook page, shred papers for various divisions, deliver mail, assemble information packets and help with organizing things in the office.*

**Q: What were your challenges and successes as you went through the transition process?**

*A: Well, my challenges when I started at DHSS came from not knowing all the people's names or where their offices were! My successes are my award from Goodwill. I'm in the newspaper. I also went to the Governor's Ball as a person with a disability. I feel one of my successes is being able to advocate for other people with disabilities.*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

*A: The specific programs, agencies or persons are DVR, DDDS, CIS/Renee, Project SEARCH, my parents, Meadowood Vocational, Goodwill and DHSS.*

**Q: What is your anticipated path for the future?**

*A: My dream is to have a full-time job with benefits so I can live independently. And also, I would like to have a small business selling the dog and cat toys that I make.*

## **Housing/Transportation Work Group Executive Summary**

The Housing/Transportation Work Group was established under the State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs. The State Transition Task Force decided to combine the functions of housing and transportation because they both had similar importance to an emerging adult with a disability and/or special health care need attempting to transition into the community. A diverse group of members with interests in both housing and transportation issues was established. The group included representatives from the disability community, the Delaware State Housing Authority (DSHA), the Delaware Department of Transportation (DelDOT), the Delaware Transit Corporation (DTC), the Department of Services for Children, Youth and Their Families (DSCYF) as well as self-advocates and parents of people with disabilities.

The Housing/Transportation Work Group was charged with identifying barriers in obtaining housing and transportation that would hamper the transition of young adults with disabilities and/or special health care needs into the community, and making recommendations to eliminate the barriers. A significant amount of information pertaining to housing in Delaware was gleaned from a report published in April 2012 entitled, “Community and Choice, Housing Needs for People with Disabilities in Delaware”. It was produced by the Housing Sub-Committee of the Governor’s Commission on Community Based Alternatives for People with Disabilities and the State Council for Persons with Disabilities (SCPD).

The Housing/Transportation Work Group met six times, with three meetings being devoted to housing and three devoted to transportation issues.

### **Concerning housing barriers, the Housing/Transportation Work Group considered the following areas:**

- Accessibility
- Affordability
- Community Based Services
- Housing Systems
- Consumer Education and Builder Reluctance

For emerging adults with physical disabilities, being able to find housing that is both affordable and accessible has proven to be a major problem. There is an insufficient supply of accessible housing in the state and, all too often, if a person with a disability and/or special health care need

## **Housing/Transportation Work Group Executive Summary**

finds accessible housing, they can't afford it. Housing that is considered affordable is still out of reach for many young adults with disabilities and/or special health care needs. Community services to support young adults with disabilities and/or special health care needs who want to move into the community are still not sufficient in many areas in the state.

Additionally, more work needs to be done to build and improve connections between and within the affordable housing and disabilities service systems. Also, more needs to be done to collect accurate data on the housing needs of emerging adults with disabilities and/or special health care needs. Finally, many people who can afford accessible universal design features are not always aware of what is available. Builders are often reluctant to offer accessible universal design features to potential buyers when building new housing developments. More incentives must be offered to builders, especially when building affordable housing developments, to build in universal design features, thus increasing the availability of accessible housing.

### **Concerning transportation barriers, the Housing/Transportation Work Group focused on:**

- Availability
- Accessibility
- Training
- Policies and Procedures

There is insufficient accessible transportation for people with disabilities and/or special health care needs in Delaware. The fixed route bus system does not currently provide coverage in many areas in Kent and Sussex Counties. This causes many people with disabilities and/or special health care needs to rely on Paratransit, which is overburdening that system.

Paratransit was designed to augment the fixed route bus system as a means of transportation for people with disabilities. Currently, the reverse is occurring in Delaware. The Housing/Transportation Work Group also determined that transportation training for students with and without disabilities should begin in the 7<sup>th</sup> grade. Students should be trained on how to use all transportation systems, including rail and air travel. Also, students both with and without disabilities and/or special health care needs should be provided the option to be trained either to obtain a driver's license or learn to use other transportation systems. This training could include development of skills such as how to read a bus schedule, how to read a fixed route bus map, or how to use a Global Positioning Service (GPS) device to cite a few examples.

Transportation providers should be required to have a certain percentage of their fleet consist of accessible taxis or vans. This is currently being done in other cities across the country and it would greatly increase the availability of accessible transportation in Delaware. Also, vehicles purchased under the 5310 Program and distributed to non-profit agencies should be pooled to better utilize that accessible vehicle resource.

## **Housing/Transportation Work Group- Housing Action Plan**

### **I. Increase the availability of accessible housing in Delaware that people with disabilities can afford.**

- 1-** Improve real-time availability and access to rental and home ownership opportunities. This can be accomplished by using the DSHA website [www.Delawaresearch.org](http://www.Delawaresearch.org) where people can do a very specific search for accessible features in the housing they need.
- 2-** Reduce Fair Housing barriers to affordable/accessible housing. Source of Income (e.g. SSI, Social Security Disability Insurance [SSDI] and housing assistance such as Housing Opportunities for Persons With AIDS [ HOPWA]) should be made a protected class under the state's Fair Housing laws, the same as race and sexual orientation.
- 3-** Establish a common vocabulary and set of standards for accessible features. People with disabilities looking for accessible housing frequently become confused due to agencies and developers using terms differently, and sometimes inconsistently, which causes the confusion. There needs to be a commonly accepted and utilized standard set of definitions for universal design, visitability, livability, accessibility and adaptability.
- 4-** The prevalence of basic accessibility features in all types of new housing must be increased. Incentives for builders to build in accessible features should be expanded and utilized as part of every Request for Proposals (RFP) issued by housing authorities to build affordable housing developments.
- 5-** Increase the availability of Low-Income Housing Tax Credit (LIHTC) properties to people with disabilities, especially those with extremely low incomes.
- 6-** Continue to invest in permanent supportive housing for young adults with disabilities and/or special health care needs. Programs such as the Tenant Based Rental Assistance Program which provides rental assistance to rental units in the private sector are critical for young adults with special needs who are transitioning into the community, because they often cannot afford the current market rates.
- 7-** Asset-building opportunities for people with disabilities must be improved. Individual Development Accounts (IDAs) should not be limited and should allow people with disabilities to save for major investments such as vehicle and home modifications, communication devices and other assistive technology. This is critical for many young adults with disabilities and/or special health care needs who transition into the community.

## Housing/Transportation Work Group- Housing Action Plan

### **II. Increase the availability of Community Based Services and Supports**

1- Changes to the Medicaid managed care and waiver programs such as “Money Follows the Person” are needed to increase community based services which are needed for young adults to successfully transition into the community, even if they can find affordable accessible housing.

### **III. Improve Housing Systems in Delaware**

1- Communication and connection between and within the affordable housing and disabilities service systems must be improved. Each system should fully understand the other. DSHA, DHSS and DSCYF also need to coordinate in the implementation of the state’s new rental assistance program (SRAP). When that happens, young adults with disabilities and special health care needs will have a much easier time finding affordable and accessible housing in the community

### **IV. Educate people with disabilities and/or special health care needs and the General Assembly about available accessible features/universal design**

1- Young adults with disabilities and/or special health care needs who want to move into the community need to understand what accessible universal design features are available to meet their specific needs and how to obtain them.

2- Preferably, the General Assembly should realize that it is cost effective and a prudent use of tax payers’ money to build basic universal design features into all housing, so taxpayers can age in place and not have to pay for costly renovations to meet their needs as they age.

3- At a minimum, the General Assembly must understand that, when building homes with taxpayers’ money, a certain percentage should be set aside with accessible universal design features so that people with disabilities can be included in the community.

**Housing/Transportation Work Group**  
**Housing Recommendations**

The following potential legislation would be instrumental in building capacity in housing for emerging adults with disabilities and/or special health care needs who are transitioning into the community:

1. Legislation to make Source of Income, (SSI, SSDI and housing assistance such as HOPWA) a protected class in the State's Fair Housing Laws similar to race and sexual orientation.
2. Legislation to standardize the state's building codes as they pertain to building accessibility features such as ramps, bathroom fixtures, lights and bells for people with sensory impairments, etc. Currently these standards vary from county to county and within municipalities, which impacts costs.
3. Legislation that would either provide incentives for developers or require them to set aside fully accessible and subsidized units in affordable housing developments and integrate them into typical housing in multi-family developments.

**Housing/Transportation Work Group Action Steps and Timeline- Housing**

<b>Objective:</b>		
Make “Source of Income” SSI, SSDI, and Housing Assistance (such as HOPWA) a protected class.		
<b>Action:</b>	<b>Potential Partners</b>	<b>Time Frame:</b>
Meet with legislators to discuss possible legislation.	DDC, DLP, SCPD, GACEC, DHC, DSHA, GCBACS, DSTW	Fall 2013 through Winter 2013
Introduce legislation to make “Source of Income” a protected class.	DDC, DLP, SCPD, GACEC, DHC, DSHA, GCBACS, DSTW and Selected Legislators	Winter 2014 through Summer 2014

<b>Objective:</b>		
Standardize building requirements for accessibility (e.g. ramps) between counties and municipalities.		
<b>Action</b>	<b>Potential Partners</b>	<b>Time Frame</b>
Review the state’s building requirements in different counties and municipalities as they pertain to accessible features such as ramps.	DLP, Steve Tull, DHC, DSHA, GCBACS, DSTW, New Castle, Kent and Sussex County Habitat for Humanity Organizations	Fall 2013 through Winter 2013
Develop a report on the findings for the Legislature.	DHC, DSHA, DDC, DSHA, GCBACS, DSTW, Selected Legislators	Winter 2014 through Summer 2014

**Housing/Transportation Work Group Action Steps and Timeline- Housing**

<b>Objective:</b>		
Standardize building requirements for accessibility (e.g. ramps) between counties and municipalities.		
<b>Action</b>	<b>Potential Partners:</b>	<b>Time Frame</b>
Meet with legislators about possible legislation.	DLP,DDC,SCPD, GACEC, DHC, GCBACS, DSTW	Fall 2013 through Winter 2013
Introduce legislation to standardize the state's building codes as they pertain to accessible features.	DLP, DDC, SCPD, GACEC, DHC, GCBACS, DSTW, Selected Legislators	Fall 2013 through Winter 2013

<b>Objective:</b>		
Develop a database of agencies that can assist with building accessible features (e.g. ramps, bathroom modifications, lights and bells for those with sensory impairments, etc.), and agencies that can help with sources of funding for those accessibility features.		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Research the agencies in Delaware that can assist with building accessible features such as ramps.	DDC, DATI, Easter Seals, GCBACS, DSTW, Steve Tull	Fall 2013 through Winter 2013

**Housing/Transportation Work Group Action Steps and Timeline- Housing**

<b>Objective:</b>		
Develop a database of agencies that can assist with building accessible features (e.g. ramps, bathroom modifications, lights and bells for those with sensory impairments, etc.), and agencies that can help with sources of funding for those accessibility features.		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Research the agencies in Delaware that can assist in funding accessible features.	DDC, DATI, Easter Seals, GCBACS, DSTW, Steve Tull	Fall 2013 through Winter 2013
Develop a data base with the information found by the aforementioned research.		Winter 2014 through Spring 2014
Provide disability organizations throughout Delaware a link to the database.	DATI, Easter Seals, DDC GCBACS, DSTW, GACEC	Spring 2014 through Summer 2014

<b>Objective:</b>		
Set aside units for people with disabilities and fully integrate them into typical housing found in multi-family developments.		
<b>Task/Action</b>	<b>Potential Partners</b>	<b>Time Line to Complete</b>
Enter into discussions with legislators, housing authorities and developers on the rationale and need for units to be set aside for people with disabilities, & how these units may be integrated into multi-family developments.	GACEC, DDC, SCPD, Housing Authorities, DSHA, DHC, GCBACS, DSTW, Delaware Builders' Association	Fall 2013 through Spring 2014
Research methods other states have utilized to integrate and subsidize fully accessible homes into multi-family developments.	GACEC, DDC, DSHA, DHC, SCPD, AARP, GCBACS, DSTW	Fall 2013 through Winter 2013

## **Housing/Transportation Work Group Action Plan- Transportation**

### **I. Increase transportation training in Delaware's public schools.**

**1-** Transportation training should begin for students with and without disabilities in the 7<sup>th</sup> grade. Students should be taken out on supported trips to experience transportation options.

**2-** Travel training for students with disabilities and/or special health care needs via the school's Transition Coordinator should be funded for each school district. Also, a driver's training instructor capable of training and testing children with various disabilities to get their driver's license should be funded for each school district.

**3-** Parents should be given a transition manual that has information on transportation at their first 7<sup>th</sup> Grade IEP meeting. The manual should also include information on transition issues related to employment, education and health care.

**4-** Delaware Transit Corporation (DTC) should partner with DVR and DVI to provide transportation training to their clients.

### **II. Improve the state's transportation policies and procedures.**

**1-** All housing agencies and developers that build affordable housing should be required to coordinate with and support local transit. Additionally, we need to improve and enhance communication between local partners, such as employers, housing providers and transportation providers that impact a person with a disability's ability to successfully live in the community.

**2-** Transportation options for people with disabilities, to include innovative options, should be increased. Fixed route buses and accessible taxis should be considered part of any transportation network for people with disabilities.

**3-** All transportation providers should be required to have a percentage of their fleet include accessible taxis and vans.

**4-** Vehicles purchased under the federal 5310 Program and provided to non-profit groups to assist in meeting the needs of the elderly and people with disabilities should be pooled and their use coordinated.

**5-** Ensure that all fixed route bus stops in the state and the pedestrian walkways to those bus stops are accessible.

## **Housing/Transportation Work Group Action Plan- Transportation**

- 6-** A cost analysis should be done to compare the cost of daily two-way Paratransit trips as opposed to providing a person with funds to purchase an accessible van. Innovative ideas such as several people sharing the van, similar to the state's Ride Share Program, should be studied.
- 7-** Incentives must be created for localities to include funding for public transportation and a review of how each county uses federal pass through funds.
- 8-** Fixed route and Paratransit routes must be better coordinated, especially in Sussex County.
- 9-** An impartial committee should be formed to monitor the implementation of the DelDOT Transition Plan throughout the state and report on a regular basis to the Delaware Legislature.

**Housing/Transportation Work Group Action Steps and Timeline-Transportation**

<b>Objective:</b>		
Begin transportation training for students with and without disabilities in the 7 <sup>th</sup> grade.		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Teach transportation options and transportation skills such as bus familiarization, reading and understanding bus schedules, fares and travelling from one place to another including bus transfers.	DTC, DOE, SCPD, DLP, DDC, GACEC, GCBACS, DSTW	2014-2015 School Year
Educate students on train transportation, including reading train schedules, etc.	DeIDOT, DTC, DTC, DOE, GCBACS, DSTW	2014-2015 School Year
Begin travel training in the 7 <sup>th</sup> grade and make it a regular part of the school year. This will most likely require legislation.	DeIDOT, DTC, DOE, GCBACS, DSTW	2014–2015 School Year
Take students on road trips to experience the various transportation options using travel training approaches.	DEIDOT, DTC, DOE, GCBACS, DSTW	2014 – 2015 School Year

<b>Objective:</b>		
Begin transportation training for students with and without disabilities in the 7 <sup>th</sup> grade.		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Advocate for appropriate funding for both DTC's Travel Training Program and a Transition Coordinator in each school that would also provide the travel training.	GACEC, DDC, DLP, SCPD, GCBACS, DSTW	January 1 – June 30, 2014

**Housing/Transportation Work Group Action Steps and Timeline-Transportation**

<b>Objective:</b>		
Fund a driver’s training instructor in each school district to train and test students with disabilities so they can obtain a driver’s license.		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Fund training for all students with disabilities and/or special health care needs to either learn to drive or learn to use other modes of transportation. This will require legislation.	DDC, DLP, SCPD, GACEC, DOE, DTC, DelDOT, GCBACS, DSTW	2014 – 2015 School Year
<b>Objective:</b>		
Mandate that all transportation providers have a percentage of their fleet include accessible taxi cabs and vans.		
<b>Action:</b>	<b>Potential Partners:</b>	<b>Time Frame:</b>
Mandate that all transportation providers set aside a percentage of their fleet as accessible taxis and vans. This will require legislation.	DLP, GACEC, DDC, SCPD, DTC, DelDOT, GCBACS, DSTW	Fall 2013 through Summer 2014
Require a percentage of accessible taxis and vans to be in service and adhere to ADA non-discrimination standards and vehicle design standards. This will require legislation.	GACEC, DDC, DLP, SCPD, DTC, DelDOT, GCBACS, DSTW	Fall 2013 through Summer 2014

## **Housing/Transportation Work Group Recommendations-Transportation**

The following potential legislation will be instrumental in building capacity in transportation for emerging adults with disabilities and special health care needs who are transitioning into the community:

- 1.** Legislation to require school districts to begin transportation training for students with and without disabilities in the 7<sup>th</sup> grade. Transportation options and transportation skills such as fixed route and Paratransit bus familiarization, reading and understanding bus, train and plane transfers and schedules should be taught. Also, appropriate funding should be included for both DTC's Travel Training Program and a Transition Coordinator in each school district who would also provide travel training.
- 2.** Legislation to fund a Driver's Training Instructor in each school district to train and test students with disabilities and/or special health care needs so they can obtain a driver's license. Also, for each student with a disability and/or special health care need who wants to learn to drive, fund the ability for school districts to contract with companies that can provide a vehicle that meets the student's individual needs. All students should be able to either learn to drive or learn to use the other modes of transportation.
- 3.** Legislation to mandate that transportation providers have a percentage of their fleet set aside as accessible vans and taxi cabs. The legislation should also require a percentage of the taxis and vans to be in service and adhere to the Americans with Disabilities Act (ADA) non-discrimination standards and vehicle design standards.

### **Housing/Transportation Work Group Members**

*Chair, Al Rose*, Developmental Disabilities Council (DDC)

*Vice-Chair, Christopher McIntyre*, Department of Services for Children, Youth and their Families (DSCYF)

**John Bates**- Department of Services for Children, Youth and Their Families (DSCYF)

**Kim Brokenbrough**- Delaware State Housing Authority (DSHA)

**Bonnie Hitch**- Delaware Transit Corporation (DTC))

**Terri Hancharick**- Parent Advocate and Governor's Advisory Council for Exceptional Citizens (GACEC)

**Kyle Hodges**- State Council for Persons with Disabilities (SCPD)

**Tony Horstman**- State Council for Persons with Disabilities (SCPD)

**Felicia Kellum**- Department of Services for Children, Youth and Their Families (DSCYF)

**John McNeal**- Delaware Department of Transportation (DelDOT)

**Don Moore**- United Cerebral Palsy (UCP)

# Blake Bossert



Blake Bossert, pictured about to participate in one of his favorite hobbies, is a volunteer firefighter who enjoys his job at the University of Delaware Center for Disabilities Studies. Bossert and his fiancée, Katie, are looking forward to their upcoming wedding. Bossert has Attention Deficit and Hyperactivity Disorder (ADHD), Dyslexia and Dyscalculia.

**Q: What are you currently doing now that you have left high school?**

*A: I work at the Center for Disabilities Studies at the University of Delaware as the front desk person and also do advocacy and outreach for Junior Partners in Policy Making.*

*I am a volunteer firefighter at Five Points Fire Company.*

**Q: What were your challenges and successes as you went through the transition process?**

*A: I think the top challenge I had was finding a workplace that I could fit in well and be able to do the work without the fear of my disabilities getting in the way. My successes are when I can find something I can do really well that sets me apart from others and gives me a job that everyone comes to me to do because they know it's one of my strengths.*

**Q: Were there any specific programs, agencies or persons which were helpful to you and your family/caregivers during your transition process?**

*A: I went to DVR and got hooked up with the computer training program at Goodwill. Finding the job at CDS was by luck and with help from a good friend.*

**Q: What is your anticipated path for the future?**

*A: I am getting married, buying a house, new car and so on.*

## Acronyms

### A

AAP- American Academy of Pediatrics

AARP- American Association of Retired Persons

ACA- Affordable Care Act

ADA- American Dental Association

ADA- Americans with Disabilities Act

AIDS- Acquired Immunodeficiency Syndrome

APE- Adapted Physical Education

ASD- Autism Spectrum Disorder

AT- Assistive Technology

### B

BSNPTA-Brandywine Special Needs Parent Teacher Association

### C

CDC- Center for Disease Control

CDS- Center for Disability Studies (at the University of Delaware)

CEC- Council for Exceptional Children

## Acronyms

### C

CHSD- Cape Henlopen School District

CLASI- Community Legal Aid Society Inc.

COTA- Certified Occupational Therapist Assistant

CYAAC- Center for Youth and Adults with Conditions of Childhood

### D

DART- Delaware Area Regional Transit

DATI- Delaware Assistive Technology Initiative

DBLN -Delaware Business Leadership Network

DCDT- Division of Career Development and Training

DDC- Developmental Disabilities Council

DDDS-Division of Developmental Disabilities Services

DE PTA- Delaware Parent Teacher Association

DelARF- Delaware Association of Rehabilitation Facilities

DelDOT- Delaware Department of Transportation

DFV- Delaware Family Voices

DHC- Delaware Housing Coalition

## Acronyms

# D

**DHIN**- Delaware Health Information Network

**DHSS**- Department of Health and Social Services

**DIDER**- Delaware Institute for Dental Education and Research

**DIMER**- Delaware Institute of Medical Education and Research

**DLP**- Disabilities Law Program

**DME**- Durable Medical Equipment

**DMMA**- Division of Medicaid and Medical Assistance

**DMV**- Department of Motor Vehicles

**DNASW**- Delaware National Association of Social Workers

**DelARF**- Delaware Association of Rehabilitation Facilities

**DOE**- Delaware Department of Education

**DOL**- Department of Labor

**DPBHS**- Division of Prevention and Behavioral Health Services

**DPCI**- Delaware Physicians Care Insurance

**DPH**- Department of Public Health

**DSAAPD**- Division of Services for Aging and Adults with Physical Disabilities

**DSAMH**- Division of Substance Abuse and Mental Health

**DSCYF**- Division of Services for Children, Youth and their Families

**DSEA**- Delaware State Education Association

## Acronyms

### D

DSHA- Delaware State Housing Authority

DSTW- Delaware State Transition Website

DTC- Delaware Transit Corporation

DVI – Division for the Visually Impaired

DVR – Division of Vocational Rehabilitation

DWIB – Delaware Workforce Investment Board

DYLI- Delaware Youth Leadership Initiative

### E

ED- Educational Diagnostician

EFI- Employment First Initiative

EFOIC- Employment First Oversight Commission

EFOC- Employment First Oversight Commission

EMR- Electronic Medical Records

EPSDT- Early Periodic Screening, Diagnosis and Treatment

ESR- Employability Skills Rating

ESSE - Early Start to Supported Employment

## Acronyms

### F

FAPE- Free and Appropriate Public Education

FQHC- Fully-Qualified Health Care Center

FTA- Federal Transit Administration

### G

GACEC- Governor's Advisory Council for Exceptional Citizens

GCBACS- Governor's Commission on Building Access to Community-Based Services

GIC- Government Information Center

### H

HB- House Bill

HCC (DE) - Health Care Commission

HCR- House Concurrent Resolution

HOPWA- Housing Opportunities for Persons with AIDS

## Acronyms

### I

IDA- Individual Development Account

IDEA- Individuals with Disabilities Education Act

IDEIA- Individuals with Disabilities Education Improvement Act

IEP- Individualized Education Plan

IFSP- Individualized Family Service Plan

IPE- Individualized Plan for Employment

### K

KSI- Kent-Sussex Industries

### L

LEA- Local Education Agency

LIHTC- Low Income Housing Tax Credits

LRE- Least Restrictive Environment

## Acronyms

### M

MA- Medical Administrator

MCHB- Maternal and Child Health Bureau

MCO- Managed Care Organization

MFP- Money Follows the Person

MOU- Memorandum of Understanding

MSD- Medical Society of Delaware

### N

NAMI (DE) - National Association on Mental Illness

NCC PA- New Castle County Pediatric Association

NCCVT- New Castle County Vo-Tech

NCQA- National Center for Quality Assurance

NGA- National Governor's Association

NP- Nurse Practitioner

NPO- Non-Profit Organization

NSTTAC- National Secondary Transition Technical Assistance Center

NYMAC- New York Merger, Acquisition and Collaboration Fund

## Acronyms

### O

OCR- Office of Civil Rights

OT- Occupational Therapy/Therapist

### P

PA- Physician's Assistant

PCMH- Patient-Centered Medical Home

PD- Professional Development

PIC (DE) - Parent Information Center of Delaware

PT- Physical Therapy/Therapist

PWD- Person with a Disability

### R

RFP- Request for Proposals

RN- Registered Nurse

ROI- Return on Investment

## Acronyms

### S

**SB-** Senate Bill

**SCC-** Statewide Curriculum Cadre

**SCR-** Senate Concurrent Resolution

**SCPD-** State Council for Persons with Disabilities

**SGIM (DE) -** Society of General Internal Medicine

**SHCN-** Special Health Care Need

**SLP-** Speech Language Pathologist

**SLPA-** Speech Language Pathologist Assistant

**SMD-** Significant Multiple Disabilities

**SRAP-** State Rental Assistance Program

**SSA-** Social Security Administration

**SSDI-** Social Security Disability Insurance

**SSI-** Supplemental Security Income

**SSP-** Student Success Plan

**ST-** Speech Therapy/Therapist

**SWD-** Student with a Disability

## Acronyms

### I

TC- Transition Coordinator

TPSID- Transition and Post-Secondary Programs for Students with Intellectual Disabilities

### U

UD- University of Delaware

USBLN- United States Business Leadership Network

## **Glossary of Terms**

**504** – The U.S. Department of Health and Social Services, Office for Civil Rights (OCR) defines 504 as follows: “Section 504 of the Rehabilitation Act of 1973 is a national law that protects qualified individuals from discrimination based on their disability. The nondiscrimination requirements of the law apply to employers and organizations that receive financial assistance from any Federal department or agency, including the U.S. Department of Health and Human Services (DHHS). These organizations and employers include many hospitals, nursing homes, mental health centers and human service programs.

Section 504 forbids organizations and employers from excluding or denying individuals with disabilities an equal opportunity to receive program benefits and services. It defines the rights of individuals with disabilities to participate in, and have access to, program benefits and services.”

**Accessibility**- Barrier-free programs, services, and buildings which are open to people of all disabilities, age, education-level etc.

**Adult Expansion Medicaid Services**- Through the Affordable Care Act (ACA), effective January 2014, eligibility will be expanded to include more childless adults who have no insurance.

**Adult Health Care System**- Where adults access medical care by providers trained in adult medical issues.

**Affordable Care Act (ACA)** - Legislation passed in 2011 which overhauled the current health insurance system in the United States of America.

**“Age in place”**- The Center for Disease Control (CDC) defines aging in place as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level."

**Age of Eligibility**- The age at which a person becomes eligible to receive a certain service or support.

## Glossary of Terms

**Age of Majority-** Delaware Code identifies the Age of Majority as follows:  
“TITLE 1, General Provisions, and CHAPTER 7. AGE OF MAJORITY, § 701.  
Age of majority.

‘A person of the age of 18 years or older on June 16, 1972, and any person who attains the age of 18 years thereafter, shall be deemed to be of full legal age for all purposes whatsoever and shall have the same duties, liabilities, responsibilities, rights and legal capacity as persons heretofore acquired at 21 years of age unless otherwise provided.’

1 Del. C. 1953, § 701; [58 Del. Laws, c. 439, § 1.](#)”

**Age out-** The age at which a person has to exit a particular service delivery system (typically at age 18 or 21, depending on the service).

**Americans with Disabilities Act (ADA)** - The U.S. Department of Education, Office for Civil Rights defines the ADA as follows: “The Americans with Disabilities Act (ADA) gives civil rights protections to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services and telecommunications.”

**Assistive Technology (AT)** - Devices or equipment that help a person function or complete tasks more independently.

**“Authentic Multiple Work Settings”-** Engagement of individuals completing real/relevant work activities in an array of settings in the community specific to improving job skills (including soft skills) needed to gain part/full time employment.

**Basic Access-** Includes the most basic features to allow someone with a mobility disability to enter and have basic use of a home: one no-step entrance; a 32 inch door clearance through the first floor and at least a half-bathroom on the first floor

## Glossary of Terms

with clearance for a wheelchair. This is also sometimes referred to as “**Visitability**”. Basic access features are far less costly when built into the design of a home when it is constructed. Basic access features make it easier to adapt homes for occupants to age in place.

**Caregiver**- A person who provides support for activities of daily living to an individual with a disability.

**Continuing Medical Education (CME)** - Unit of credit earned by health care professionals by participating in educational activities.

**Culturally Competent**- The ability to interact effectively with people with different cultures, abilities and socio-economic backgrounds.

**Developmental Disability (DD)** – A condition that occurs before the age of 22, that significantly impacts learning in several domains.

**Durable Medical Equipment (DME)** - Devices/equipment/supplies a person with a disability uses in the home to aid in better quality of life.

**Eligibility vs. Entitlement**- In Delaware, this occurs when a student is between 18 and 21 years of age. **Entitlement** (Individuals with Disabilities Education Improvement Act [IDEIA] 2014) and **Eligibility** (Rehabilitation Act/Section 504 and ADA) are different laws with different requirements for services. Whereas entitlement includes benefits for persons with disabilities based on law/statute (e.g. IDEA), eligibility refers to a set of benefits which are covered based on an individual with a disability meeting certain criteria.

**Emerging Adult**- A person between the ages of 12-30.

**Federal 5310 Program**- In this program, formally known as the Elderly and disabled Specialized Transit Program (5310), the Federal Transit Administration (FTA) provides capital grants to meet the transportation needs of the elderly and persons with disabilities in areas where public mass transportation services are

## Glossary of Terms

otherwise unavailable, insufficient or inappropriate. It enables non-profit organizations to obtain accessible vans and buses to provide those needed transportation services.

**Fixed Route-** Fixed route refers to a system of buses that are often wheelchair accessible and equipped with bike racks. Fixed route buses operate on specific routes at specified times during weekdays, and on selected routes and times during weekends and holidays. Fixed route buses pick up and drop off individuals at designated bus stops and offer different types of services such as major corridor routes, crosstown routes, limited stop routes and express routes.

**Free and Appropriate Public Education (FAPE)** - The U.S. Department of Education defines FAPE as follows:

“Statute: TITLE [I](#) / [B](#) / [612](#) / [a](#) / 1

(1) Free appropriate public education.--

(A) In general.--A free appropriate public education is available to all children with disabilities residing in the state between the ages of 3 and 21, inclusive, including children with disabilities who have been suspended or expelled from school.

(B) Limitation.--The obligation to make a free appropriate public education available to all children with disabilities does not apply with respect to children--

(i) aged 3 through 5 and 18 through 21 in a state to the extent that its application to those children would be inconsistent with state law or practice, or the order of any court, respecting the provision of public education to children in those age ranges; and

(ii) aged 18 through 21 to the extent that state law does not require that special education and related services under this part be provided to children with

## Glossary of Terms

disabilities who, in the educational placement prior to their incarceration in an adult correctional facility--

(I) were not actually identified as being a child with a disability under section 602; or

(II) did not have an individualized education program under this part.

(C) State flexibility.--A state that provides early intervention services in accordance with part C to a child who is eligible for services under section 619, is not required to provide such child with a free appropriate public education.”

**Full Accessibility-** A unit that is built to meet all requirements for an accessible unit as set by a national standard. These features should allow full use of a unit by most people with disabilities.

**Grand Rounds-** Lectures given in medical communities to provide continuing education to health care professionals.

**HL7 Data-** Data type that secures information so it can be transferred electronically between users.

**Individual Development Account (IDA) -** The IDA is an asset building tool designed to enable low-income families to save toward a targeted amount usually used for building assets in the form of home ownership, post-secondary education or small business ownership. In principal, IDAs work as matched savings accounts that supplement the savings of low-income households with matching funds drawn from a variety of private and public sources. Most IDA programs specify a maximum household income for eligibility which, depending on the program, can range from 200% below the poverty line to 80% of the area median income.

## **Glossary of Terms**

**Individuals with Disabilities Education Act (IDEA)** – The U.S. Department of Education defines IDEA as follows:

“The Individuals with Disabilities Education Act (IDEA) is the nation’s special education law. First enacted three decades ago, IDEA provides billions of dollars in federal funding to assist states and local communities in providing educational opportunities for approximately six million students with varying degrees of disability who participate in special education.

In exchange for federal funding, IDEA requires states to provide a free appropriate public education (FAPE) in the least restrictive environment (LRE). The statute also contains detailed due process provisions to ensure the provision of FAPE. Originally enacted in 1975, the Act responded to increased awareness of the need to educate children with disabilities and to judicial decisions requiring states to provide an education for children with disabilities if they provide an education for children without disabilities.

Part A of IDEA contains the general provisions, including the purposes of the Act and definitions. Part B, the most frequently discussed Part of the Act, contains provisions relating to the education of school-aged and preschool children, the funding formula, evaluations for services, eligibility determinations, Individualized Education Programs (IEPs) and educational placements. It also contains detailed requirements for procedural safeguards (including the discipline provisions) as well as withholding of funds and judicial review. Part B also includes the Section 619 program, which provides services to children aged 3 through 5 years old.

Part C of IDEA provides early intervention and other services for infants and toddlers with disabilities and their families (from birth through age 3). These early intervention and other services are provided in accordance with an Individualized Family Service Plan (IFSP) developed in consultation between families of infants and toddlers with disabilities and the appropriate state agency. Part C also provides grants to states to support these programs for infants and toddlers with disabilities.

## **Glossary of Terms**

Part D provides support for various national activities designed to improve the education of children with disabilities, including personnel preparation activities, technical assistance and special education research.”

**Individualized Education Plan (IEP)** - The U.S. Department of Education defines “IEP” as follows:

“Regulations: Part [300](#) / [D](#) / 300.320

Sec. 300.320 Definition of individualized education program.

**(a) General.** As used in this part, the term individualized education program or IEP means a written statement for each child with a disability that is developed, reviewed, and revised in a meeting in accordance with Sec. Sec. 300.320 through 300.324”

**Intellectual Disability (ID)** - Disability that impacts an individual’s ability to learn in a similar way to their peers.

**Jitney-** A jitney is a small and sometimes open bus that carries passengers over a regular route on a flexible schedule.

**Learning Disability (LD)** - A condition which impacts a person’s ability to learn or retain information, and which requires additional support beyond a peer who does not have those needs.

**Legal Guardianship-** The process by which a person is determined to be incompetent to make their own decisions and has another adult appointed to make decisions on their behalf.

**“Livability”-** Livability means a home has several additional features beyond what would be considered Basic Access. A “livable” home also has at least one no-step entry and 32 inch door clearance on the first floor. In addition, it has a full bathroom and a bedroom (or a room that can be used as a bedroom) on the first

## **Glossary of Terms**

floor so a person who has mobility impairment can live comfortably on the first floor.

**Long Term Care (LTC) Plus Medicaid Services-** State Medicaid services which includes reimbursement for additional supports such as home nursing and private duty nursing or aides.

**Medicaid Managed Care Organization (MCO) -** An insurance company contracted with the state Medicaid office to provide insurance following the Medicaid guidelines, but using the insurance company's staff for implementation to Medicaid-eligible individuals.

**Mental Health Condition-** A condition that impacts a person's emotional and/or behavioral state and requires support or management by a physician.

**Mobility Manager-** This is a person who can train students on transportation options and transportation skills including the use of various modes of travel such as fixed route buses, Paratransit, rail, air and taxi.

**Money Follows the Person (MFP) -** This program is part of a comprehensive, coordinated strategy, in collaboration with stakeholders, to make widespread changes to long-term care support systems. It assists states in their efforts to reduce their reliance on institutional care, while developing community-based long-term care opportunities, enabling the elderly and persons with disabilities and/or special health care needs to fully participate in their communities.

**NCQA Standard 5c62-** The National Committee for Quality Assurance's standard addressing health care transition outcomes.

**Non-profit-** A non-profit organization (NPO) is an organization that uses surplus revenue to achieve goals rather than distributing them as profits or dividends. NPOs are governed by boards or controlling members. Many have paid staff and management, but some operate with volunteers and unpaid executives who receive a nominal amount. While non-profit organizations are permitted to generate

## **Glossary of Terms**

surplus revenue, that revenue must be retained by the organization for self-preservation, expansion or to accomplish goals.

**Paratransit-** Paratransit is an alternative mode of flexible passenger transportation for people with disabilities and the elderly that does not follow fixed routes or schedules. Typically, minibuses are used to provide paratransit services, but accessible taxis and jitneys can also be important providers.

**Patient Centered Medical Home (PCMH) -** A team-based health care delivery model led by a physician that provides comprehensive and continuous medical care to patients with the goal of obtaining maximized health outcomes.

**Pediatrician/Pediatric Care-** A physician trained to work with children from birth through 22 years old.

**Physical Disability-** A condition which impacts a person's body and causes limitations as compared to a peer without that condition.

**Protected Class-** A protected class is a term used in United States anti-discrimination law. It describes characteristics or factors that cannot be targeted for discrimination and/or harassment. Some examples are race, ethnicity, sex, color, age, disability status and religion.

**Sensory Impairment-** A sensory impairment occurs when one of a person's senses (sight, hearing, smell, touch, taste) or spatial awareness is no longer typical.

**Special Health Care Need (SHCN) -** A health condition that requires health care professionals' management beyond that of a typical person's medical needs.

**“Special School”-** A school designed for children with complex educational needs. Students may have learning difficulties, physical disabilities, etc. Special schools provide specialized supports and modifications for these students which are not commonly available in a typical school setting.

## **Glossary of Terms**

**Text 4 Baby-** A DPH campaign which uses text messages to alert pregnant women and new mothers about health-related information, for both themselves and for their babies.

**Transition-** The purposeful, planned movement between one system to another system.

**Transition Coordinator (TC)** – An individual who plans, coordinates, delivers, and evaluates transition education and services at a school or system level, in conjunction with other educators, families, students and representatives of community organizations.

**Universal Design-** An approach to design that incorporates products, building features and elements which, to the greatest extent possible, can be used by everyone. This may include features such as lever door handles, faucets and switch plates, and a covered no-step entry for example.

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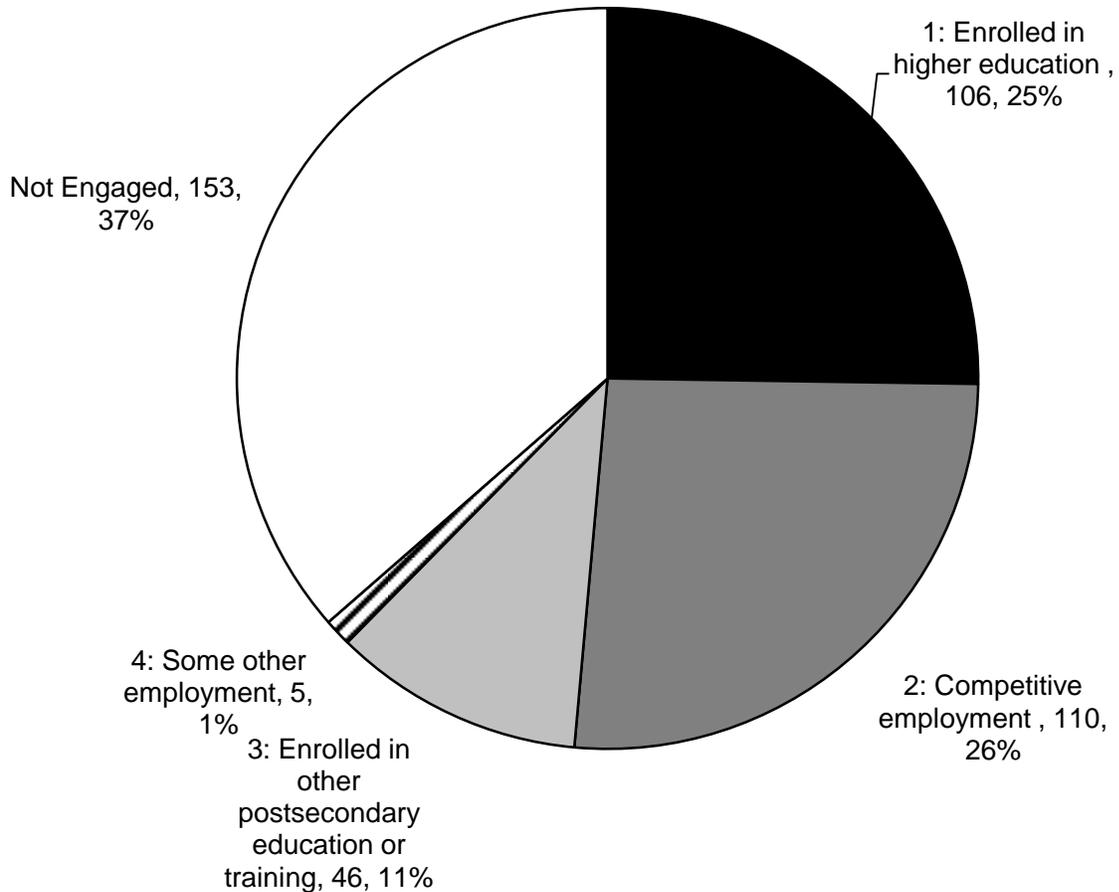
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## Appendix: Post-School Outcome Data

**Delaware IDEA Part B SPP/APR Indicator #14: Post-School Outcomes for 2010-11 School Year Exiters**



- 1: Enrolled in higher education
- 2: Competitive employment
- 3: Enrolled in other postsecondary education or training
- 4: Some other employment
- Not Engaged

Source: Delaware Department of Education

## Appendix-Post School Outcome Data, continued

<b>Statewide Response Rate</b>	<b>Percent</b>	
Statewide Response Rate	35%	
<b>Characteristic</b>	<b>Count</b>	
Statewide Respondents	420	
<b>Respondents by Type of Disability</b>	<b>Count</b>	
Specific Learning Disability	225	53%
Emotional Disturbance	19	5%
Cognitive/Intellectual Disability	65	15%
Other Health Impairment	59	14%
Multiple Disabilities	0	
Speech or Language Impairment	4	1%
Autism	19	5%
Hearing Impairments	10	2%
Traumatic Brain Injury	1	<1%
Orthopedic Impairment	15	4%
Visual Impairment including blindness	2	<1%
Deafness	0	
Deaf-Blindness	1	<1%
Unknown: Disability Type	0	
	<b>420</b>	<b><i>totals match</i></b>

<b>Statewide Non-Response Rate</b>	<b>65%</b>
------------------------------------	------------

<b>Characteristic</b>	<b>Count</b>	
Statewide Non-Respondents	794	
<b>Non-Respondents by Type of Disability</b>	<b>Count</b>	<b>%</b>
Specific Learning Disability	454	57%
Emotional Disturbance	59	7%
Cognitive/Intellectual Disability	106	13%
Other Health Impairment	113	14%
Multiple Disabilities	0	0%
Speech or Language Impairment	4	1%
Autism	29	4%

Source: Delaware Department of Education

### Appendix-Post School Outcome Data, continued

Hearing Impairments	7	1%
Traumatic Brain Injury	5	1%
Orthopedic Impairment	12	2%
Visual Impairment including blindness	1	0%
Deafness	0	0%
Deaf-Blindness	2	0%
Unknown: Disability Type	2	0%
Total	<b>794</b>	<b>100%</b>

Source: Delaware Department of Education

## **Appendix- Sample Transition Coordinator Job Posting**

### **Transition Specialist**

#### **Job Description/Core Competencies**

#### **Education Requirements**

Bachelor's degree, Master's Degree preferred, in education or a related field. Three years' experience working with secondary students with disabilities in the area of transition.

#### **Philosophical, Historical & Legal Foundations of Special Education**

Knowledge of:

- Theoretical and applied models of transition.
- Transition-related legislation in the fields of special and vocational education, rehabilitation, labor and civil rights.
- Roles of federal, state, provincial and local legislation and implications providing transition at all local levels.
- Basic history and current initiatives regarding transition.

#### **Characteristics of Learners**

Knowledge of:

- Implications of student characteristics with respect to post-school outcomes, environments, and support needs.
- School and post-school services available to specific populations of individuals with exceptional learning needs.

## **Appendix- Sample Transition Coordinator Job Posting, continued**

### **Assessment, Diagnostic, and Evaluation**

Knowledge of:

- Formal and informal career and vocational assessment approaches.
- Formal and informal approaches for identifying students' interests and preferences related to post-school goals and educational experiences.

Skills to:

- Match skills and interests of the student to skills and demands required in vocational and employment settings, community residential situations and other community participation options.
- Interpret results of career and vocational assessments for individuals, families and other professionals.
- In collaboration with individuals with exceptional learning needs, families, and agencies design, implement and use program evaluation procedures to assess and improve the effectiveness of transition education services, including evaluation of students' post-school outcomes.
- Use a variety of formal and informal career transition and vocational assessment procedures.

### **Instructional Content and Practice**

Knowledge of:

- Job seeking and job retention skills identified by employers as essential for successful employment.

## **Appendix- Sample Transition Coordinator Job Posting, continued**

Skills to:

- Assist teachers to identify, in conjunction with the student, appropriate educational program planning team members.
- Evaluate student's educational program with respect to measurable post-school goals and alignment of those goals with instructional activities.
- Monitor student, family and agency participation in transition planning and implementation.
- Evaluate and modify transition goals on an ongoing basis.
- Use interest and preferences of the individual with exceptional learning needs to develop post-school goals and educational objectives.

### **Planning and Managing the Teaching and Learning Environment**

Knowledge of:

- Methods for providing work-based and other community-based education experiences for individuals with exceptional learning needs.
- Methods for linking appropriate academic content to transition-related goals.

Skills to:

- Identify and facilitate appropriate modifications within work, residential, vocational training and other community environments.
- Assess and develop natural support systems to facilitate transition to specific post-school environments.
- Develop residential, work-based and other community-based educational programs for individuals with exceptional learning needs.

### **Communication and Collaborative Partnerships**

## **Appendix- Sample Transition Coordinator Job Posting, continued**

Knowledge of:

- Methods and strategies for increasing families' knowledge and skills about transition-related education and services, and post-school options in specific outcome areas.
- Systematically identify family services needs related to transition outcomes and assist the families to connect with support networks.
- Provide transition-focused technical assistance and professional development in collaboration with family members for educators, community agency personnel and other relevant transition stakeholders.

Source: provided by Brian Freedman, University of Delaware Center for Disabilities Studies, 2013

## **Appendix- Health Work Group-Potential Partners**

- Aging and Disabilities Resource Center (ADRC)
- American Academy of Pediatrics- Delaware Chapter (AAP)
- Center for Disabilities Studies at University of Delaware (CDS)
- College/University Health Centers
- Delaware Department of Health and Social Services (DHSS)
- Delaware Division of Developmental Disabilities Services (DDDS)
- Delaware Family Voices Family to Family Health Information Center (DFV)
- Delaware National Association of Social Workers (DE NASW)
- Delaware Society for Mental Health (DSMH)
- Delaware State Parent Teacher Association (PTA)
- Delaware State Teachers Association (DSTA)
- Delaware Youth Opportunities Initiative (DYOI)
- Dental Society of Delaware (DSD)
- Department of Education (DOE)
- Department of Education (DOE)
- Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)
- Division of Substance Abuse and Mental Health (DSAMH)
- Division of Services for Children Youth and Families (DSCYF)
- Durable Medical Equipment (DME) companies
- Federally Qualified Health Centers (FQHC)
- Home health agencies
- Limited English proficiency groups
- Medical Society of Delaware (MSD)
- Mental Health Society (MHS)
- National Alliance on Mental Illness-DE (NAMI-DE)
- New Castle County Pediatric Association
- Nursing Associations
- Pharmacies
- Safe Link
- School Nurses
- School Radio Stations
- School Wellness Centers
- Southern Delaware Consortium
- Training Programs (medical residents, nursing schools)

Source: State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs Health Work Group, 2013

## Appendix

### Estimate of Accessible Assisted Rental Units, Delaware 2012

	<b>Accessible Units</b>	<b>Units</b>	<b>Percent</b>
<b>Fully Accessible Units</b>			
Public Housing – Fully Accessible Units (Actual Units)	119	2,702	4.4
Assisted Rental Housing – Fully Accessible Units (Estimate)	234	11,331	2.1
Subtotal- Fully Accessible Units	353	14,033	2.5
<b>Units with Some Accessibility Features</b>			
Assisted Rental Housing – Some Accessibility Features (Estimate)	854	11,331	7.5
<b>Total – Fully Accessible Units and Units with Some Accessibility Features</b>	<b>1,207</b>	<b>14,033</b>	<b>8.6</b>

Sources: Analysis of Impediments to Fair Housing Choice, July 2011, and Delaware State Housing Authority

## Appendix

### Housing/Transportation Work Group Insight on Transition from Professionals

**Transition:** “To see true transformation, we start working on transition the very day the student is enrolled in our school.” *Delores Allen-McIntyre, Ferris School Principal, May 23, 2011.*

“Transition is a process that is best completed when all parties are knowledgeable of the pathway forward.” *Delores Allen-McIntyre, Ferris School Principal, May 23, 2011.*

**Housing:** “62% of extremely low-income households in Delaware (12,845) are severely cost-burdened: paying more than 50% of their income for housing.” *US Department of Housing and Urban Development, 2006-2008 Comprehensive Housing Affordability Strategy Data, compiled by the Delaware State Housing Authority, <http://www.huduser.org/portal/datasets/cp.html>*

“Citizens with developmental disabilities should live in inclusive, safe, accessible and affordable communities of their choice with people they choose to live with and be provided with the needed individualized supports and accommodations.” *National Association of Councils on Developmental Disabilities Statement on Housing, 2012.*

**Transportation:** “All publicly funded and/or regulated transportation service systems must be: seamlessly coordinated among all modes of transportation; expanded in suburban, urban, rural and unincorporated areas to connect places people live with places they work, shop, socialize, worship, attend school, access health care, etc.; incorporated with mobility management and training services for individuals with disabilities; designed to appropriately address insurance and liability of vehicles and operators who serve in a coordinated transportation environment, (including non-profit providers); based on principals of universal design; supported by stable and adequate funding; and fully accessible to all people with disabilities.” *National Association of Councils on Developmental Disabilities Statement on Public Transportation Systems, 2012*

## Afterword

When the State Transition Task Force for Emerging Adults with Disabilities and Special Health Care Needs recommendations are fully implemented, we will see the differences in every aspect of our community. We will have more individuals with disabilities and/or special health care needs completing high school and going on to attend vocational and secondary schools. We will also see these individuals achieve meaningful employment and careers. Our businesses will be stronger because we will have a more productive work force. Our Medicaid and Medicare costs will be lower because individuals with disabilities and/or special health care needs will be working and contributing to their own health care. As individuals with disabilities and/or special health care needs obtain jobs, they will become more independent by renting properties or buying homes. They will be active contributing members of society. Our community will reflect the value that we put into the early transition process.

A personal thank you to all those who contributed their time to bring our vision into existence. Our effort to move to a culture that truly understands the process of transition and its importance is the result of your many countless hours and your dedication. Volunteering your time by attending the Key Informant Group meetings, serving as an editor, being a Design Team member, a Work Group member or a Task Force member has helped lay a solid foundation for change. We are proud of the work and the accomplishment each of you have made. Your spirit of collaboration means so much to us. We thank you for working with us as it has been a pleasure working with all of you.

None of this could have been possible without the support of the prime sponsors of SCR 34. Many thanks to Senator Bethany Hall-Long and Representative Rebecca Walker for helping us begin this important work.

A special thank you to our GACEC staff support, Kristin Cosden.

Again, thank you all for the great work!

**Terri A. Hancharick**, Co-Chair, State Transition Task Force, Chair GACEC

**Wendy S. Strauss**, Co-Chair, State Transition Task Force, Executive Director, GACEC

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***Co-Chair- Wendy Strauss***, Executive Director of the Governor's Advisory Council for Exceptional Citizens (GACEC)

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**Diann Jones**- Parent Advocate

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