



Exciting LifeCourse Initiatives from NE

The Northeast Region has eight active Regional Collaboratives covering 14 different County areas. Early on, the NE Region committed to being part of the Community of Practice and it shows! Each Collaborative has developed its own niche and there are exciting and innovative initiatives happening throughout the region.

A major focus area is an emphasis on the use of the LifeCourse framework with transition and employment. Wayne County Collaborative was an early adopter of the LifeCourse framework and easily incorporated it into its existing Quality Council meetings. This council already had a solid foundation of collaboration among the Human Service departments, providers and community. Wayne County quickly introduced students to the LifeCourse trajectory at its annual Transition event. It further involved a local school district where a LifeCourse presentation became part of a teacher in-service for the special education department.



A similar approach is occurring in the Carbon/Monroe/Pike Collaborative where a successful Spring Transition Fair was held. Students were offered assistance to dream about where they wanted to be once they graduated. It was an interactive session with the high school students. Teachers were amazed at their interest and attentiveness. Most recently, Carbon and Lehigh counties have worked together to introduce the LifeCourse Framework to the Carbon/Lehigh District Transition Council. The school districts have already committed to further trainings through 2019.

Another area with great emphasis is the introduction of LifeCourse concepts at Intake. Lackawanna/Susquehanna has taken the lead in this area and has a Lifecourse Specialist in its Independent Intake Unit, as well as a pilot position for a Community Specialist who has a caseload and works directly with individuals and their families Charting the LifeCourse. Other collaboratives also have started to provide individuals and families with LifeCourse materials and concepts as they go through the intake process. In Schuylkill County, individuals and families are also offered the opportunity to meet with a PA Family Network advisor shortly after intake to learn about the LifeCourse as well as possible mentoring

The third area of focus for the NE is the Community for All. We have seen, in particular, the Regional Collaborative of Bradford/Sullivan/Tioga put their efforts into helping individuals build social capital and to integrate into their communities. This same concept is emphasized in Luzerne/Wyoming and Northampton counties.

We look forward to more exciting and innovative initiatives happening elsewhere!



A Family ‘Reunion’ after Act 127

Note: Patti Middlemiss and daughter Michelle share details about their recent journey to find Michelle’s birth mother. Michelle is a member of the staff at *Pittverse*, a magazine written by adults with autism. She is also a member of the Office of Developmental Programs Information Sharing and Advisory Committee (ISAC).

PATTI’S STORY:

“When Governor Wolf’s Act 127 went into effect in November 2017, it turned our lives around. The Act allows an adopted person the right to obtain an unofficial copy of their original birth certificate. Until now, it was impossible for our daughter Michelle to know her original last name. That meant that she couldn’t search in any way for her birth mother, without going through the court. As Michelle got older, she realized that there was very little medical information given at the time of her adoption.



Pictured from left: Michelle Middlemiss, Patti Middlemiss, and Michelle’s birth mother.

With Michelle’s diagnosis of Autism and ADHD, along with other questions, she worried about not having enough medical information. So we sent for her original birth certificate, which arrived a few weeks later. We watched as Michelle opened the envelope and read her birth mother’s last name for the first time. We all had tears in our eyes as the sweetest expression came over Michelle’s face.

I knew that my husband Al and I had to find her birth mother. We used different websites and searched through Ancestry.com and newspapers from 30+ years ago. After collecting pages of information and possibly a trail to her family we took a chance and found success!

We are catching up on the last 37 years from both sides.

Five days later we met with Michelle’s birth mother, stepfather, grandmother, aunts, uncles, and cousins, discovering a new ‘family tree’ for Michelle. Since then, I have talked to Michelle’s birth mother every other day. We are catching up on the last 37 years from both sides. It’s gratifying to talk to her; answering each other’s questions and both being so proud of Michelle. We are grateful that they want to learn the best ways to accommodate Michelle.

In meeting her birth mother, Michelle has become more secure and gained a new perspective in her life. She knows with certainty that she has always been greatly loved. We all feel like this is a new and exciting chapter in all of our lives as we continue to float on Cloud 9.

Michelle had questions emailed to her for this interview. It was very interesting to me that Michelle wasn’t



A Family 'Reunion' after Act 127 continued

able to put answers to some of the questions. She told me that with autism the 'feelings about meeting her birth mother,' and 'how she reacted,' are emotions that she doesn't deal with easily. And explaining them is equally difficult. This was another insight Michelle has taught me about how she sees things in a different way sometimes."

MICHELLE'S STORY:

"When I was in school and asked to do a family tree, I sometimes felt like I was from a different planet. I knew I belonged here but with my allergies and my disabilities, it felt that there was just enough to separate me from everybody else in my family. I didn't know where any of that came from.

I found out that my birth mother shares many of my disabilities and surgeries when she was young. I also went through many surgeries in younger years...Now I feel more connected to this planet because of her. And it helps that I look exactly like her.

Meeting her hasn't changed anything regarding my own adoptive family. It only adds to how I feel toward my mom and dad; it doesn't take away. They worked very hard to help find her for me. They wanted this to happen for me. What we didn't know was that my birth mother had tried ways to search for me, but didn't have my last name either!

When I first walked into the room where my birth mother was standing, I walked right over to her. Then I met many of my 'birth relatives.' I was amazed when I found out that my birth mom had made sure that before we arrived, my 'comfort zone and needed accommodations' would be in effect. Some of the family wanted to give me a hug and asked first. I knew that they were told ahead of time that I may not care for that, and I respected the planning that was done for me. It wasn't like meeting strangers. It was like a 'coming home' of sorts. What I found out from my birth mother is that I wasn't 'abandoned.' She had been much too young to raise me and was devastated to not be able to keep me. I was always in her heart and on her mind. I was told that was the way it was for her family also.

Especially on my birthday and around holidays...I was not forgotten. These were the times when I always had trouble sleeping at night and felt out of sorts. My birth mom told me how her not being able to sleep had been the same as mine! This Easter was the first holiday that I didn't feel this sadness. In fact I can now really sleep at night. Life is great and now I know, in words, what every adopted child wants to hear: I was always loved; then and now."



Michelle Middlemiss speaks with her birth mother at their first in-person introduction.

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‘Promoting Health & Wellness’ can be tasty

Members of the Milestone Health Care Quality Unit (HCQU) West Management Oversight Committee embraced the Everyday Lives: Values in Action recommendation No. 5, “Promote Health, Wellness, and Safety,” by holding their first cooking class in conjunction with Butler County Community College. Chef Molly Nasky-Creighan instructed Direct Support Professionals, Family Living Providers, and Self-Advocates on basic cooking skills.



Brady Neal, Brad McCutcheon, and Johnathan Blystone participate in a culinary class organized by the Milestone HCQU West Management Oversight Committee.

First, participants were instructed on sanitary food preparation, then they learned how to roast vegetables, make a salad dressing, and bake chicken.

They also learned how to make a healthier breakfast using granola, Greek yogurt, and berries. Lastly, they measured how much sugar is actually in a typical granola bar and other food items. This was really eye opening to many of them.

Class members learned ways they can help improve their own lives, or the lives of someone they support, through food choices and preparation.

The class will be held again in the fall, and it will be open to both self-advocates and staff. For more information, email DQuinn@milestonepa.org.

Will Your Service Animal Be Traveling?

Since March 15, 2011, only dogs are recognized as service animals under Titles II and III of the ADA. Emotional support animals, comfort animals, or therapy dogs are not. View the [ADA Requirements for Service Animals](#).

With that in mind, [this article from Anything Pawsable](#), an online magazine for service and working dog owners, may offer helpful advice for those planning to travel with a service dog this summer.



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Updates on Electronic Visit Verification

The 21st Century Cures Act requires states to implement Electronic Visit Verification (EVV) for all Medicaid personal care services (PCS) and home health care services (HHCS) that require an in-home visit by a provider. States must require EVV use for all Medicaid-funded PCS by January 1, 2019, and for HHCS by January 1, 2023. You can view additional guidance, issued by the Centers for Medicare and Medicaid Services (CMS), on [implementation of the Cures Act](#).



EVV applies to home and community-based services waivers such as the Consolidated, Community Living, Person/Family Directed Support (P/FDS), and Adult Autism waivers. EVV is not new. Some providers have been using it voluntarily for decades to save time in paperwork and payroll processing.

In the recent guidance, CMS has clarified that “in-home visit” excludes personal care services provided in congregate residential settings where 24-hour service is available. CMS defines personal care services as consisting of services supporting Activities of Daily Living (ADL), such as movement, bathing, dressing, toileting, and personal hygiene. Personal care services can also offer support for Instrumental Activities of Daily Living (IADL), such as meal preparation, money management, shopping, and telephone use.

With the recent guidance from CMS, ODP has determined that the following services are subject to EVV requirements:

Consolidated, Community Living and P/FDS Waivers: Companion, In-Home and Community Support, Respite (unlicensed settings only), Homemaker/Chore (homemaker portion only)

Adult Autism Waiver: Community Support and Respite (unlicensed settings only)

To meet the January 1, 2019 deadlines, the Department of Human Services will use the existing PROMISe™ fiscal agent contract with DXC. This will be an open system that will receive information from existing EVV systems being used by providers and will supply EVV for PCS providers who do not have their own system.

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Archivists Preserve History of Disabilities Rights

Pennsylvania State Archives collaborated with statewide organizations to preserve the history of institutionalization and the experiences of people with intellectual disabilities in the state. An informational session about the project was presented at the April meeting of MARAC (Mid-Atlantic Regional Archivist Conference), a consortium of archivists who live and work in the states of Delaware, Maryland, New Jersey, New York, Pennsylvania, Virginia, and West Virginia, and in the District of Columbia.

The Western Pennsylvania Disability History and Action Consortium website provides a [detailed listing of presenters and their topics](#), including Margery Sly, Director of the Special Collections Research Center at Temple University, and personal collections of important activists such as Dennis Haggerty and Leona Fialkowski; J. Gregory Pirmann presenting “It’s important not to forget the story of Pennhurst”; and Lisa Sonneborn, Director of Media Arts and Culture at the Institute on Disabilities at Temple University, sharing how the Institute uses art in different forms to help people engage with disability history.



History Meets Disability Advocacy 2018

The consortium presents “Let’s Not Repeat the Past: History Meets Disability Advocacy 2018” in two half-day events, one took place May 31 and the next will take place October 18. The events focus on learning from the past— how the disability rights movement of the 1960s and 1970s informs present-day issues and advocacy. The October 18 event is free and open to the public. Register at this link: <https://bit.ly/2GBTJnx>.

Driver Safety and Transition Course Available

The National Aging and Disability Transportation Center will offer a new online course, “[Driver Safety and Transition: Understanding Shared Interests, Challenges, and Opportunities for Collaboration in Supporting Transportation Independence](#),” now through July 6, 2018. The course will provide an in-depth look at planning for transportation independence as age-related challenges make driving increasingly difficult. Participants will:

- Learn about mobility issues that need to be considered when providing support to older drivers and drivers who have disabilities.
- Gain a better understanding of the alternative transportation options available.
- Learn how to access information on community transportation services.
- Learn how to help older adults and people with disabilities create a "roadmap for independence" by taking advantage of services offered in the community.

Registration is open until June 15.

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Information, Upcoming Events, & Training

Light a Spark

The 6th Annual LifeSharing Conference, “Light a Spark, Start a LifeSharing Firestorm,” will be held on October 15 & 16 at the Seven Springs Mountain Resort in Champion, PA. More information to come in August. Please visit Palife-sharing.com for more details.

Students Strive to Make Sites Sensory-friendly

Fifth-graders at Ross Elementary School in Ross Township near Pittsburgh, PA, researched ways in which popular public event sites can be more welcoming to people with autism and sensory sensitivities. Read more: [Student Autism Awareness Project at Ross Elementary School](#)

Article: Inclusion is a Strength for Business

An article co-written by Jennifer Morgan, SAP Executive Board Member, and Bob Casey, U.S. Senator, Pennsylvania, was published on Forbes magazine’s digital market platform. SAP is an international provider of business software. The article summarized a theme explored at the recent Disability Employment Summit in Harrisburg. Access [“Workforce Inclusion Is A Strength For Any Company.”](#)

Drug May Lessen Autism Symptoms

Clinical trials of the drug Suramin reportedly show its ability to alleviate symptoms of autism. Find more details in [this article on the Suratin clinical trials](#).

Pittsburgh Joins Job Initiative

Pittsburgh plans to actively recruit workers with disabilities, joining an initiative through a program of the United Way of Southwestern Pennsylvania, reports the [Pittsburgh Business Times](#).

Grants Available To Institutions of Higher Education

Grant to help institutions of higher education collect data and conduct research pertaining to people with intellectual and developmental disabilities are available through the Administration for Community Living. Learn more about [“Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities.”](#) Application deadline is July 23, 2018.

Office for Civil Rights Launches Accessibility, Tech Help Initiative

The U.S. Department of Education’s Office for Civil Rights (OCR) launched a new technical assistance initiative to assist schools, districts, state education agencies, libraries, colleges and universities in making their websites and on-line programs accessible to individuals with disabilities. Information regarding the scheduling and registration for webinars is available on [OCR’s Disability Discrimination website page](#).

Self Advocacy Power Network for All Event

People with disabilities and their guests are invited to join Self Advocates United as 1 (SAU1) on Thursday, June 21, 10 am.-2 p.m., at the Coyle Free Library, 102 N. Main St., Chambersburg. Power Coach Sam “The Man” will speak on “Using Your Power to Learn New Things.” A lunch will be provided. Following lunch, a discussion will focus on getting ready to work, looking for and finding a job, applying and interviewing, supports and accommodations, and more. Reserve your spot by calling or texting Angie at 814-386-1826, or by emailing Angie@sau1.org.

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Help Available in Getting Assistive Technology

The Pennsylvania Assistive Technology Foundation (PATF) and the Pennsylvania's Initiative on Assistive Technology (PIAT) can help people with disabilities get the assistive technology they need to achieve greater independence, choice, and opportunity in their lives.

PATF is a statewide, nonprofit organization that provides financing opportunities to help individuals with disabilities, families, and older Pennsylvanians acquire assistive technology devices and services that improve the quality of their lives.

PATF provides loans at 0% interest for the purchase of assistive technology (AT) and durable medical equipment (DME). It also provides education and tips on how to access public and/or private resources. PATF is not a grant program. Learn more about PATF at dhs.pa.gov/provider/training/index.htm, or by reading through the PATF Frequently Asked Questions page at dhs.pa.gov/cs/groups/webcontent/documents/document/c_273015.pdf.



PIAT is a program of the Institute on Disabilities at Temple University, University Center for Excellence in Developmental Disabilities Education, Research, and Service.

PIAT provides training, technical assistance, resources, and a free service that loans assistive technology devices to people with disabilities. It's available to Pennsylvanians of all ages and disabilities. Learn more at <https://disabilities.temple.edu/programs/assistive/piat/>.

Conference Set to Help Transition Post-school Youth

The 2018 Pennsylvania Community on Transition Conference will take place July 25-27 at the Penn State Conference Center and Hotel, 215 Innovation Boulevard, State College.

The purpose of the conference is to expand the capacity of schools, agencies, and communities, in partnership with youth, young adults, and families, in promoting the successful transition of youth/young adults with disabilities to post-school outcomes of employment, post-secondary education and training, community participation, and healthy lifestyles. Participants will have the opportunity to learn about effective practices to assist youth/young adults with disabilities to explore possibilities, to take advantage of their opportunities, and to actively advocate for their future. Register online at [PA Community on Transition Conference](https://www.pennstate.edu/transition/conference) on or before July 13, 2018.



Summary of ODP Communications Issued May 2018, With Links



1. [PAEFLMP 2018 Community of Practice Webinar Series : Best Practices in Rural Areas Part 2 \(of a 3 part series\) The Martin TN Experience](#)
2. [The LifeSharing Coalition Presents the 6th Annual LifeSharing Conference](#)
3. [Money Follows the Person \(MFP\) Initiative Dual Diagnosis Professional Conference Series](#)
4. 044-18 : [Person-Centered Thinking Training--Adult Session Added](#)
5. [ODP News: May 2018](#)
6. [Certified Employment Support Professional \(CESP\) Informational Webinars Presented by Office of Long Term Living](#)
7. 045-18 : [College of Direct Support Informational Webinar-- Administrative Overview and Refresher](#) May 23rd 2018 2-3 pm
8. 047-18: [Webinar Recording Available Regarding Home & Community Based Services \(HCBS\) Provider Self Assessment](#)
9. 048-18: [Person Centered Thinking Training Reading and Somerset Sessions Added](#)
10. [EFSLMP Provider Transformation 2.0 Webinar Series](#)
11. 049-18: [2018 Supports Broker Certification Training](#)
12. MFP ConferenceSeries: [Behavioral Manifestations of Physical Pain and Illness](#)
13. 050-18: [Quality Assessment and Improvement Training Webinars](#) June 14 2018 & June 21, 2018
14. Informational Memo BAW18-14: [Adult Autism Waiver Support & Services Directory May 2018](#)
15. 051-18: [ODP Cost Report Information for Waiver Transportation Providers](#)

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If your organization is hosting webinars that anyone can attend,  
please send information to RA-PWODP\_OUTREACH@pa.gov  
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