



IRRC Approves 6100 Regulations

On October 18, 2018 the Pennsylvania Independent Regulatory Review Commission (IRRC) voted to approve the Office of Developmental Programs' Home and Community Based Services (HCBS) and Licensing Regulations (Pa Code 55 Chapter 6100). The vote was unanimous, with all five IRRC Commissioners voting in favor of the regulations. The IRRC approval, while significant, is not the last step in the regulatory process. The regulations will be reviewed by the Pennsylvania Office of the Attorney General, and then on to the Legislative Reference Bureau for final publication. Issuance of the final regulation in the Pennsylvania Bulletin is anticipated for mid-to late December 2018.

The Pa Code 55 Chapter 6100 regulations will replace Pa Code 55 Chapter 51 regulations. Major changes include strengthened requirements for individual rights, staff training, program planning, medication administration, restraint prohibitions, and incident reporting and investigation.

The regulations are the result of four years intensive public debate and comment with stakeholders representing individuals, families, county government, advocates, providers, and universities. More than 500 written comments were received throughout the regulatory process, and with the support and advice of the public stakeholders, each public comment was reviewed and considered. Interested parties can [view the ODP HCBS and Licensing Regulations online](#).

Comprehensive Employment Report Now Available

Governor Tom Wolf's administration is committed to connecting people with disabilities to meaningful employment opportunities. Pennsylvania became an Employment First State on March 10, 2016, when the governor signed Executive Order 2016-03, "Establishing 'Employment First' Policy and Increasing Competitive-Integrated Employment for Pennsylvanians with a Disability." As such, the Department of Human Services (DHS) must collect and publish data on program participants enrolled in programs that provide home and community based services and:

- a. Have employment as a goal in their service plan
- b. Are receiving employment services
- c. Are employed

As a program office under DHS, the Office of Developmental Programs (ODP) is pleased to announce the release of its comprehensive employment report for the Calendar Year 2017 and Quarters 1 and 2 of Calendar Year 2018. ODP anticipates completing this report on a yearly basis.

The full [comprehensive employment report can be found online](#).





Friendship Leads to Marriage for Pike Co. Couple

Nicole and Roger spent their first official date at a volunteer event in Honesdale, PA, on June 18, 2015. It was during a “Roots and Rhythm” fundraiser.

Because of their 12-year age difference and the protective nature of Nicole’s family, the two took their newfound friendship slowly. They were introduced through mutual support staff. Both Nicole and Roger are enrolled in the Consolidated Waiver.

As the months passed and the couple grew closer, Nicole’s family became more comfortable with Roger. Love developed.

On Sept. 23, 2016, Roger proposed during what Nicole thought was a surprise party, which she had planned for his birthday. When he opened his last gift, it was her ring. In front of family and friends, Roger knelt before her and popped the question. They exchanged wedding vows nearly two years later, in September 2018. When the officiant whispered to Nicole that she did an awesome job, she replied out loud, “Nailed It!”



When Nicole participated as a panelist at a large Communities of Practice event in July, Roger was by her side. They continue to support one another at work, at Special Olympic competitions, and in everyday life.

EDL: Personal Choice Over All Aspects of Life



41-year-old Michelle of Allegheny County has come a long way: from having to live as a young man with complex behavioral challenges who hated himself, to being a secure and confident transgender woman.

Michelle receives services through the Consolidated Waiver. She has an intellectual disability and autism and receives behavioral support services through Shawn and Valerie McGill of Shawn McGill Consulting, Inc.

Shawn, a licensed outpatient therapy provider, counseled Michelle for gender dysphoria. Gender dysphoria refers to “clinical significant distress” resulting from one’s physical and/or assigned gender differing from one’s actual gender identity. Not all people who are transgender have gender dysphoria, but those who do may experience significant emotional distress that can manifest in extreme behavioral challenges. For instance, at one point Michelle resorted to self-harming behavior.

Michelle’s family rejected her gender identity. She often heard that she was a freak and a disgrace.

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Dual Diagnosis Training Curriculum Now Online

People with Disabilities, Family Members, Supports Coordinators (SCs), SC Supervisors, Provider Staff, Administrative Entity Staff, and Organizational Leadership are encouraged and invited to participate in an ODP-approved Dual Diagnosis Training curriculum to help meet the needs of individuals with complex challenges.

Through the statewide Residential Strategic Thinking Workgroup, as well as the experience of Regional Clinical Directors and Benjamin Settlement implementation leads, ODP leadership has made training broadly available to support individuals with complex needs and greatly benefit the services our system provides. Also, ODP has strengthened the training standards for newly enrolled Residential Habilitation providers to expand the clinical capacity of Residential Habilitation services. Completion of this Dual Diagnosis Curriculum will ensure the ODP stakeholder community is more knowledgeable and equipped to meet the needs of individuals with complex challenges and ensure their ongoing health and safety.

The [Dual Diagnosis Curriculum](#) is part of a joint initiative of The Commonwealth of Pennsylvania, Office of Mental Health and Substance Abuse Services (OMHSAS) and ODP to address the needs of people who have an intellectual disability as well as mental health challenges. The curriculum contains 20 core training modules which provide the basic information that anyone would need to support an individual who has a dual diagnosis. Each module includes a knowledge test. A certificate is issued upon completion of each module and upon completion of the entire curriculum.

The Dual Diagnosis Curriculum can be found on MyODP.org at [the Dual Diagnosis Curriculum link](#).

Pittsburgh Tragedy Impacts ODP Community

Cecil and David Rosenthal, who died in the [Pittsburgh synagogue shooting](#), both received residential and employment services through ACHIEVA, whose staff shared details about Cecil's infectious laughter, David's gentle spirit, their commitment to their Squirrel Hill and Tree of Life communities, and their inseparable bond to each other. Another victim, Daniel Stein, a retired IM4Q monitor, was a member of the New Light Congregation, which held services in the same building as Tree of Life. It was reported that Daniel especially loved his role as a grandfather.



The Rosenthal family is pictured here. Cecil is in the front row, far left. David is in the back row, second from left.

Please join ODP in remembering the joy they brought to those who knew them. After a traumatic incident such as the shooting in Pittsburgh, taking steps to build resilience can help you manage distress and uncertainty. The American Psychological Association offers [tips for building resilience](#).



EDL: Personal Choice Over All Aspects of Life

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Nevertheless, having an Everyday Life means having personal choice and control over all aspects of life, including one's gender identity.

"It is not about our own morals. It is about the basic human dignity and rights that are everyone's basic rights in life,"

says Maryellen Chandler-Bosko, Program Manager at FamilyLinks, Inc., who worked with Shawn McGill Consulting to find behavioral support services for Michelle. "When people were depriving these rights to Michelle, Shawn gave them to her and helped us fight for her. Shawn and Shawn's staff never gave up."

"There is a need to help people be seen as a whole person and give them a life they envision."

"There is a need to help people be seen as a whole person and give them a life they envision," Shawn says. She and Valerie point out that a person with intellectual or developmental disabilities might be transgender, just as neurotypical people might be transgender, and this should be taken into account when determining how to support individuals.

"It's their truth," Valerie adds. Michelle's gender identity has remained constant and she needed to be supported as a female. She receives residential services, where she is living with an all-female staff. A service provider in Pittsburgh and the Shawn McGill Consulting team secured a pro bono attorney to help Michelle with her gender marker change and to get her birth certificate and state ID to reflect her gender identity.

Valerie recalls how Michelle proudly reached into her purse to pull out her birth certificate and license, which now reflect her true gender identity.

Michelle is undergoing hormone replacement therapy and hopes for gender reassignment surgery. She has a difficult time acknowledging how long this may take. Insurance will not cover the surgery and there are some goals and therapies she must complete beforehand. Valerie continues to work with Michelle on achieving goals of independence and responsibility for one's own health, hygiene, and wellness. But Michelle's behavior has significantly improved during this process. Valerie adds, "It gets better and better...she is so proud and thankful."

Governor Supports Pressure Injury Prevention Day

Governor Tom Wolf has issued an official proclamation in support of Pressure Injury Prevention Day on Nov. 15. Pressure injuries, also referred to as bed sores, decubiti, pressure ulcers, or skin breakdown, can develop into ulcers and become extremely painful. In addition to life-threatening complications, serious pressure injuries can lead to death. The Health Care Quality Units have launched a Pressure Injury Prevention Day campaign, which entails reaching out to providers and the community to increase prevention of pressure injuries (bed-sores) and promote awareness of their risk.

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Lifesharing Option Reunites Carbon County Family

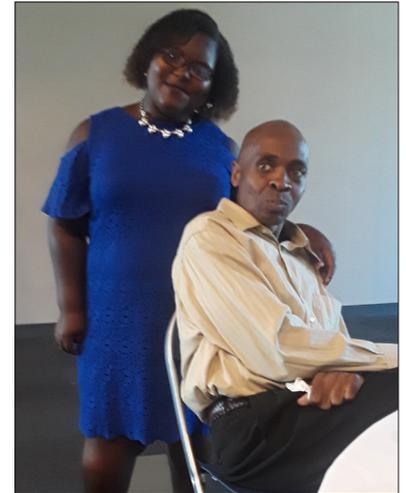
Carla J is a wonderful example of someone who applied herself to a goal and made a change to better her life. For several years, Carla struggled with poor health and depression caused by poor eating habits, limited exercise, and estranged familial relationships. She needed daily medications and 24-hour residential care to complete basic tasks, such as cooking meals.

Although she struggled, Carla remained friendly and enjoyed spending time with others. In 2017, her father and stepmother re-entered her life and Carla began spending more time at their Palmerton-based self-sustaining farm, helping to care for the chickens and cows.

The positive effect time spent with family had on Carla soon became obvious. She smiled more and appeared energized and motivated.

In September 2017, she and her family decided to try Lifesharing. Since doing so, Carla has lost 107 pounds, still enjoys two hours of alone time each day, prepares her own meals, helps out on the farm, and enjoys being with her parents. Carla also enjoys taking care of the pigs and cats on the farm.

It has to do with being a part of something bigger than herself, she says.



Carla is shown with her father, Carl. Carla spoke on a Community of Practice panel at an event arranged by Carbon-Monroe-Pike Mental Health & Development Services in Stroudsburg and held this summer.

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

DHS Announces Heating Assistance Program

Department of Human Services Secretary Teresa Miller, Pennsylvania Public Utility Commission (PUC) Chairman Gladys M. Brown, LIHEAP Advisory Committee Chairman Patrick Cicero, and representatives from local utility companies recently announced the start of the Low-Income Home Energy Assistance Program (LIHEAP) application process for the 2018-19 season. LIHEAP provides assistance for home heating bills to keep low-income Pennsylvanians warm and safe during the winter months. Assistance is available for renters and homeowners. Crisis and regular LIHEAP applications begin November 1, 2018 and end April 12, 2019. Eligibility for the 2018-19 LIHEAP season is set at 150 percent of the federal poverty income guidelines. Online applications for LIHEAP can be completed at www.compass.state.pa.us. Paper applications are available through local county assistance offices, or interested applicants can download and print an application from Benefits.gov.

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Lifesharing Provider Spotlight: Western Region

In the next few newsletters, ODP News will be highlighting winners of the Excellence in Lifesharing Awards, featuring providers from our four regions. This month we highlight Dorothy (Dot) Linton from Western Region, nominated by Kelly Young, Erie Homes for Children and Adults, Inc.

“Dot has exemplified everything that a lifesharing provider should be: she provided care and support above and beyond what would traditionally be expected or required of a lifesharing provider,” said Kelly. Through Mary Beth’s illness and in her last days, “Dot always made it be known that she was going to be there for Mary Beth, no matter what happened, for the duration of her life, and she certainly showed, by her actions, that she was sincere,” said Kelly. Dot was honored at the 6th Annual Lifesharing Conference in October, held at the Seven Springs Mountain Resort, in Champion, PA.



From left, ODP Acting Deputy Secretary Kristin Ahrens congratulates Dot Linton on winning an Excellence in Lifesharing Award.

Information, Upcoming Events, & Training

Website Ranks Best Cities for People With Special Needs

WalletHub, a personal finance website, recently ranked the “Best Cities For People With Special Needs,” reports Disability Scoops. Overland Park, Kansas, tops the list, followed by South Burlington, Vt., Sioux Falls, S.D., Scottsdale, Ariz., and Columbia, Md.

Survey: Employment and Leave for Caregivers

In 2017, the Research and Training Center on Community Living (RTC/CL) at the University of Minnesota and The Arc of the United States (The Arc) conducted an online survey, the Family and Individual Needs for Disability Supports

(FINDS) survey. The purpose of FINDS is to better understand the experiences of families who provide supports to a family member with intellectual and/or developmental disabilities (IDD). Read [“Employment outcomes and paid leave for caregivers of children with intellectual or developmental disabilities”](#) online, which examines a FINDS subsample of 388 caregivers of minor children with I/DD, ages 0-17.

Lecture Series Announced The Institute on Disabilities

Mini Course Lecture Series Fall 2018 presents “Out of the Shadows: The Disability Civil Rights Movement from NO PITY to ME

TOO,” featuring Joseph Shapiro National Public Radio News Investigations Correspondent, creator of NPR’s Abused and Betrayed series and author of “No Pity: People with Disabilities Forging a New Civil Rights Movement,” in Pittsburgh Tuesday, Dec. 4, and in Philadelphia, Wednesday, Dec. 5. Get more [details regarding “Out of the Shadows”](#) and [register online](#).

Dating Resources For Individuals With Autism

Find resources, developed by ASERT for ASDNext, with [information and tips for individuals with autism on topics related to dating](#).

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Summary of ODP Communications Issued October 2018, With Links



1. 087-18: [ODP Announces KEPRO's New SIS Scheduling Portal](#)
2. [KEPRO's SIS Scheduling Portal](#)
3. 088-18: [Home and Community Based Services Provider Settings Self-Assessment Update 2](#)
4. 089-18: [New Course Available: Dual Diagnosis Training](#)
5. BAW 18-23: [October, November, December 2018 Schedule of Virtual Trainings Presented by the BAS Clinical Team](#)
6. [PADES 2018 Registration is Open](#): October 31 and November 1st 2018
7. [PADES 2018 Conference Agenda Now Available](#)
8. [ODP News: October 2018](#)
9. [2018-2019 PA Community on Transition Webinar Series Planning for the LifeCourse](#)
10. 2018-2019 [Flu Season Health Alert Correction](#)
11. 090-18: [College of Employment Services ACRE Update Unlimited Seats Available](#)
12. 091-18: [Additional Waiver Amendment Webinar Available](#)
13. [Dual Diagnosis Conference 2018](#) : Broadening Understanding, Strengthening Support Nov. 13, 14, & 15
14. 092-18: [Clarification on Declining a Communication Assessment Report](#)
15. 093-18: [Claim and Service Documentation Requirements Webcast and Webinars](#)
16. [Health and Safety in Residential Services: What ODP is Doing to Improve Services](#)
17. [Dr. Cherpes Report: "The Fatal Four" Major Health Issues](#)
18. 095-18: [Now Available Version 2 of the Community Participation Supports Q&A Document](#)
19. BAW 18-24 : [AAW Supports & Services Directory \(October 2018\)](#)
20. 096-18: [Office of Developmental Program's First Comprehensive Employment Report](#)
21. [Final Comprehensive Employment Report-Pennsylvania Office of Developmental Programs 2018](#)
22. 097-18: [Listening Sessions](#)
23. [Listening Sessions for Families and Self-Advocates Flyer](#)
23. 098-18: Now Available on MyODP, [Waiver Amendment Webinar Recording](#)

We'd love to hear from you.
Email us at RA-PWODP_OUTREACH@pa.gov
with news or suggestions!