

LifeCourse Across the Lifespan, Completely

Josh Kuznetsov and his parents, Judy and William Cohen, reside in suburban Pittsburgh, where the family are each active members of the local community. With the family's passion for volunteerism, Josh and his parents recently shared how their success in utilizing the LifeCourse Framework, has helped them to maintain their service-oriented lifestyle, as well as helped them to plan for their future.

The LifeCourse Framework helps individuals of all abilities and at all life stages, and those who support them, to develop a vision for a good life, to think about what they need to know and do, identify how to find or develop supports, and discover what it takes to create the lives they envision. LifeCourse also helps individuals keep an eye to future experiences that enable an inclusive and meaningful life in the community.

For the Cohen-Kuznetsov family, that vision includes a shared interest in volunteerism, which makes for an active schedule, as the family balances caring for its own needs along side caring for the needs of others.

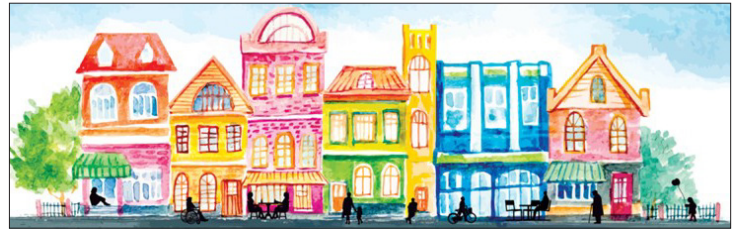
Josh has a diagnosis of cerebral palsy and a seizure disorder, and utilizes a wheelchair to help him remain mobile. He uses a Dynavox for conversations with friends and family, to email, and to change the channels on the television. The communication device also enables him to access his Amazon Alexa, which makes phone calls over the internet and enables him to socialize with friends. In addition, he is an active volunteer at the local library, and a volunteer for Rodef Shalom Synagogue and Friendship Circle. The Life-



Judy Cohen and her son Josh used the LifeCourse Framework to start the difficult conversations around succession planning.

Course Framework has helped him to maintain these activities, as they provide fulfillment of his vision for a good life, affording him work and social connections.

Similarly, Judy volunteers on the board of Jewish Residential Services, an agency that supports individuals with psychiatric, developmental, or intellectual disabilities, helping them to live, learn, work, and socialize as valued members of the community. She also serves on the Advisory Committee of the United Way's 21 & Able initiative and is the chair of its Committee for Individuals with Complex Medical and



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Behavioral Needs. The United Way's 21 & Able helps young adults with disabilities transition smoothly from the last day of high school to the first day of adult life by increasing employment, housing opportunities, and other support.

It was through her volunteer work at the United Way that Judy learned about the Community of Practice (CoP) LifeCourse Framework. Cathy Traini, ODP program specialist and certified Charting the LifeCourse trainer, spoke at a 21 & Able Complex Needs Committee meeting to present the LifeCourse. Afterward, Judy and Josh agreed to be a “test case” for the Framework.

Representatives from their county, Josh's supports coordination unit, and ODP staff met to assist, as the family developed its trajectory. Josh and his family were actively involved in the process. "It felt good to see how much everyone cares about me and my future," Josh noted.

The family met with the group three times and Josh was involved in two out of the three meetings. As they worked through the Framework, a variety of questions emerged regarding planning for Josh's future. Josh has complex medical needs and is at high risk for respiratory illness. He receives his nutritional needs through a g-tube. His parents provide him support, but Judy was concerned as to who would do this if she and William were no longer able to do so. She became aware of the need for succession planning. It is a difficult discussion for every family, but a necessary one.

During the second meeting the group used the Life-Course Framework to formulate a succession plan. “Not everyone may be comfortable with this,” Judy contends, “but I chose to use this as a time to talk about how Josh would be cared for if my husband

“The LifeCourse process focuses both on today and the future – what is the life we envision for Josh, and then what are the supports he will need to have that life?”

—Judy Cohen

and I are no longer here to do that. Josh's individual supports team has always been supportive and a great resource. Going through this process has deepened that relationship and given them a better understanding of Josh and what our family envisions for him."

Josh appreciated the planning.

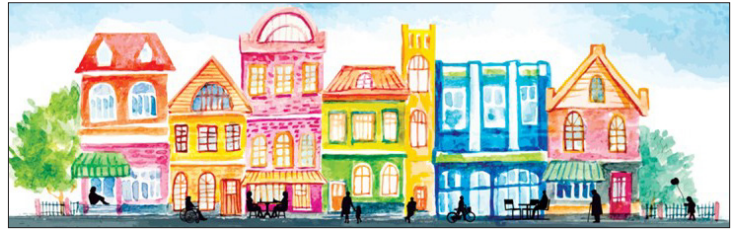
“The LifeCourse process focuses both on today and the future – what is the life we envision for Josh, and then what are the supports he will need to have that life?” Judy continued. “It is not a ‘services’-based process. It is strengths-based – in other words, we focused on Josh’s skills, personality and things he enjoys doing – not what he can’t do. This is an important distinction and completely changes the framework and dynamics of the conversation.”

Having a plan allows the family to continue to take part in the activities that have meaning for them, from volunteer work to shopping at the mall, to Josh using his Alexa to listen to the classical music, which he enjoys. It also helps afford peace of mind that the things that have value to Josh have a plan to continue in the event that she and William are not around to ensure them. Judy believes the value of the LifeCourse Framework is one that families should embrace. “My hope is that other families will benefit from the work we have been doing,” Judy said.

**To learn more about the CoP LifeCourse Framework
visit MyODP.org>Resources>Charting the LifeCourse.**

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Self-Advocates Stress Importance of a Healthy Life

Self-advocate leaders of The Arc of Washington County developed a series of meetings that focus on healthy choices, good nutrition, physical activity, positive thinking, and striving for an overall good life. It is entitled “Living A Healthy Life” and The Arc is available to present it.

Maria is the founder of “Living a Healthy Life.” At 9 months of age, she suffered a traumatic brain injury. She has cerebral palsy. She also suffered a stroke at age 16. After her mother passed away, Maria was placed in a nursing home. A strong self-advocate, Marie spoke out about her placement. She wanted to live on her own and be in the community. Her passion is to do the same for others.



Maria, a self-advocate, started “Living a Healthy Life” at The Arc of Washington County.

She now helps others understand the employment process, from how to find work, how to identify volunteer opportunities, and how to find the resources needed to establish more independence. Maria feels that staying healthy involves both physical and emotional health. “We have to know how to eat well, think well, and be well. It’s important to think positive, in order to move forward and not backwards,” she says.

The self-advocate leaders of The Arc of Washington County mentor and train other self-advocates who want to learn more about speaking up for themselves, as well as provide training for direct support professionals on understanding rights and responsibilities. If interested in scheduling a training, please contact Darrilyn McCreary at 724-745-3010, extension 109.

Bill Would Protect SSI Benefits for People with I/DD Who Marry

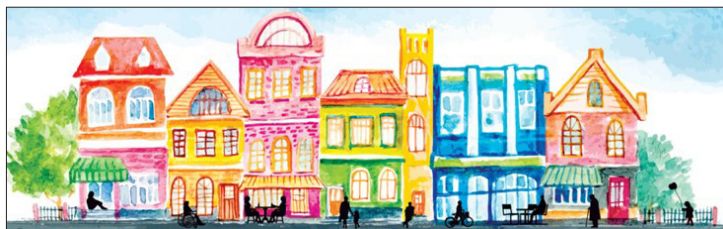
On March 5, 2019, U.S. Rep. Bill Keating (D—MA) and U.S. Rep. John Katko (R-NY) introduced [The Marriage Access for People with Special Abilities Act \(MAPSA\)](#). The intent of the legislation is to protect Supplemental Security Insurance (SSI) benefits for individuals with intellectual or developmental disabilities (ID/DD) who wish to legally marry.

When determining these benefits for an individual with ID/DD, only their own income and resources will be reviewed, and not those of their spouse. This helps to maintain Medicaid benefits.

“People with intellectual or developmental disabilities should not have to choose between marriage and their disability benefits,” Rep. John Katko said. “This bipartisan legislation protects the rights of individuals with disabilities and enables couples to pursue happiness without obstruction.”

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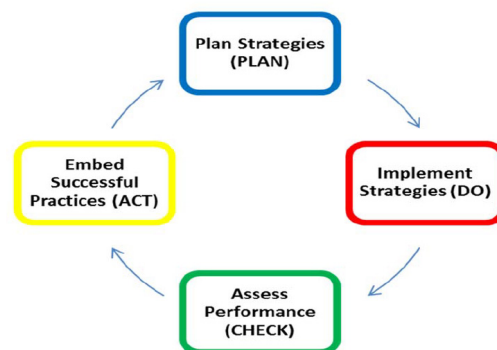
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ODP Reviews/Updates Everyday Lives Strategies

As part of ongoing quality management, the Information Sharing and Advisory Committee (ISAC) is in the process of reviewing, assessing, and updating the *Everyday Lives Recommendations, Strategies, and Performance Measures* put forth in 2016.

ODP and the ISAC are evaluating the effectiveness of strategies by using the Plan, Do, Check, Act (PDCA) Cycle. This four-step method allows for implementation of change, problem-solving, and continuous improvement of system processes. Review of data will be part of this re-evaluation. ISAC members will then amend strategies accordingly. Final publication of the updated version of *Everyday Lives Recommendations, Strategies, and Performance Measures* is expected in the fall of 2019.



WITF-FM radio presents “[Living with autism; improving awareness and inclusion](#),” featuring Dr. Michael Murray, child psychologist and director of Division of Autism Services at Penn State Health Milton S. Hershey Medical Center, and the director of the central region for ASERT (Autism Services, Education, Resources, and Training); and Melanie and Zach Hartzell, a parent and her 19-year-old son who is living with autism.

The power of early intervention is just one of the important messages conveyed in this report. Find an [Early Intervention Resource Collection](#) on [paaautism.org](#).

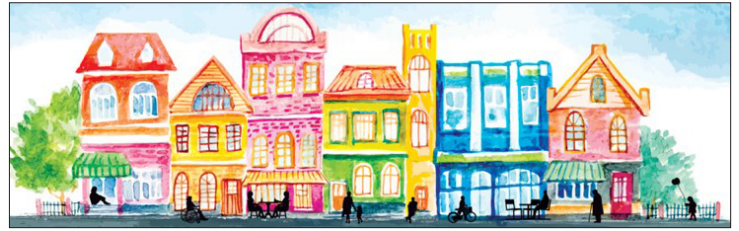


Recommendation #1 of Everyday Lives is to Assure Effective Communication. This section of the monthly newsletter will be devoted to promoting awareness and acceptance of nontraditional communication. Each month check this section of the newsletter for a quote, a fact, or a tip on communication. For any questions on the Communication Corner, please contact the Special Populations Unit at RA-ODPDeafServices@pa.gov

**Not being able to speak
is not the same as
not having anything to say.**

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Information, Upcoming Events, & Training



FUNDING GUIDE: Pennsylvania Assistive Technology Foundation (PATF) offers, "[Funding Your Assistive Technology: A Guide to Funding Resources in Pennsylvania](#)," to provide Pennsylvanians with disabilities, older Pennsylvanians, and their families help in navigating the complex web of funding options for AT devices and services.



NEW DOCUMENTARY: More than three decades ago, the groundbreaking documentary, *Suffer The Little Children*, was released, exposing the dehumanizing conditions at Pennhurst. A new documentary, *Pennhurst*, was released on Apple iTunes on March 26. View the trailer here: <https://vimeo.com/276776424>



THEATER: A sensory-friendly performance of "The Lion King," sponsored by Pittsburgh Cultural Trust, will take place at 2 p.m. Saturday, Sept. 14, at the Benedum Center, 237 Seventh Street, Pittsburgh. Tickets are \$19-\$49 and go on sale May 20 at 9 a.m. [Find more details on the event flyer.](#)



EMERGENCY PLANNING: The Administration for Community Living offers the [Capacity-Building Toolkit for Including Aging & Disability Networks in Emergency Planning](#), which presents a framework for a streamlined approach to address emergency planning for individuals with access and functional needs.



JUSTICE RESOURCES: Since 2014, the ASERT Collaborative has trained over 5,800 Justice System Professionals. In an effort to increase the knowledge base and awareness of ASD, ASERT offers free trainings that are tailored to the specific audience.

ASERT has also created various resources for Justice System Professionals that coincide with the training and [these justice resources can be found on paautism.org](#).



PODCAST: Tera Girardin, a Minnesota Leadership Education in Neurodevelopmental Disabilities (MNLEND) Fellow, offers a podcast series for families with children who have been recently diagnosed with autism or other developmental disabilities. The podcast, "[Oxygen Mask](#)," will be hosted by Beth Dierker (MNLEND Fellow, 2018), Executive Director of Communities Engaging Autism. Girardin and Dierker are both parents of children with autism and the podcast series will provide useful information to families who are wading through the information and decisions that accompany a diagnosis of autism or other developmental disabilities.



EMPLOYMENT SUCCESS: Networks for Training and Development, Inc., a nonprofit dedicated to promoting inclusive communities, features a monthly #workitwednesday email regarding employment success stories which goes out on the first Wednesday of each month. In October, an entire month of daily employment success stories will be featured for National Disability Employment Awareness Month. View [employment profiles online at We're On the Job](#).

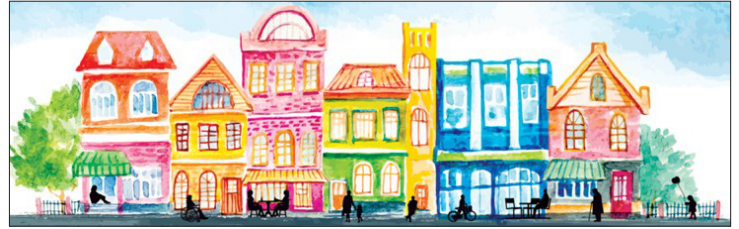


MEDICAID NEWS: Attorney General Josh Shapiro announces [Grand Jury Recommendations for the Pennsylvania Medicaid Program](#). The recommendations aim to assist the Pennsylvania Department of Human Services in identifying and preventing fraud from occurring in the program and provide law enforcement.

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ODP Relaunches Positive Approaches Journal

It is with great enthusiasm that the Office of Developmental Programs (ODP) and the Office of Mental Health and Substance Abuse Services (OMHSAS) announce the relaunching of the Positive Approaches Journal, written by and for professionals who provide supports and services to individuals with mental and behavioral health challenges, intellectual disabilities, autism, and other developmental disabilities.



The Positive Approaches Journal seeks to improve lives by increasing knowledge and capacity of professionals that provide supports and services to individuals currently utilizing services within the ODP and OMHSAS systems. The articles will be written using the guiding principles of Everyday Lives, Child and Adolescent Service System Program (CASSP), System of Care; and the Resilience and Recovery Movement in mind.

With this relaunching of the Positive Approaches Journal, we add Data Discoveries, useful data presented in ways that are interesting and customizable. Data presented will be focused on a topic related to each issue theme. [You can read the Positive Approaches Journal on MyODP.](https://www.moodp.org/course/view.php?id=1362)

HMJ Recognizes Businesses for Diverse Staffs

The Huntingdon-Mifflin-Juniata Employment Coalition, a committee of the HMJ Regional Collaborative, hosted an Employer Recognition Banquet at the Square One Clubhouse in Lewistown on April 24.

The coalition recognized 45 businesses, agencies and organizations who have successfully diversified their workforce by hiring persons of different abilities.

Pictured, from left: Beth Metz Gilmore-Kish Bank, Jeff Foltz of Joe's Original Italian Pizza; Shawn Laub, Weis Markets #35; Terry Knouse, NuVisions Center; Stacey Snook, Giant Food Store #6025; Adam Pfingstl, Huntingdon County Pride; Dan Tice, Service Access and Management; Charles Losak, guest speaker employed at Joe's Original Italian Pizza; Tammy Foltz, Joe's Original Italian Pizza, and PA Representative



Johnathan D. Hershey. (Missing from photo: Beth Zong, Compass Community Connections.)

For more information, email hmjemployment@gmail.com.

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ISAC Member Receives SARTAC Fellowship Award

Michelle Middlemiss, self-advocate and member of the ODP Information and Sharing Advisory Committee (ISAC), is among the 2019-2020 Self Advocacy Resource and Technical Assistance Center (SARTAC) Fellowship Award recipients.

Michelle is one of six fellows chosen through a competitive application process. The SARTAC Fellowship is a year-long opportunity for self-advocates to develop and grow their skills as leaders in the self-advocacy movement. Fellows work with a supporting host organization on policy issues or a project that can help develop their leadership skills. This is the third of four groups of SARTAC Fellows.

Michelle's project is titled, "My Safety, My Rights." She is hosted by Youth Advocate Programs, Inc., a nationally recognized, nonprofit organization exclusively committed to the provision of community-based alternatives to out-of-home care through direct service, advocacy and policy change. Learn more about this year's [SARTAC Fellows and Michelle's project](#).



**MICHELLE
MIDDLEMISS**

PA ABLE Turns 2, Hits \$15 Million Mark in Savings



Since the Pennsylvania Treasury Department launched the PA ABLE Savings Program two years ago, Pennsylvanians have saved more than \$15 million for their current and future disability-related expenses. PA ABLE is now helping more than 2,100 people save and has grown by more than \$4 million since the beginning of 2019. A PA ABLE account gives individuals with qualified disabilities (eligible individuals), and their families and friends, a tax-free way to save for disability-related expenses, while maintaining government benefits.

To help you learn about the important features and benefits of the PA ABLE Savings, the Pennsylvania Treasury Department hosts free webinars each month.

Some of the topics that Treasury will discuss include: eligibility requirements for opening a PA ABLE account, the federal and state tax benefits of PA ABLE, and how PA ABLE account interacts with current benefits. Register today for an upcoming webinar:

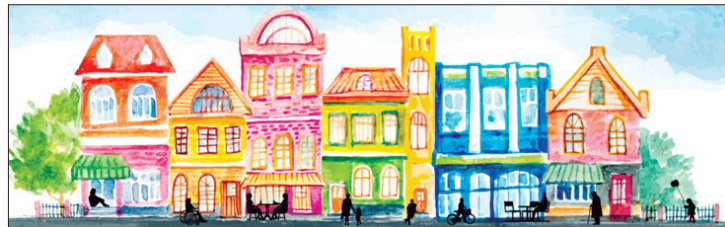
- [Thursday, May 16, 2019 12:00 PM - 1:00 PM](#)
- [Wednesday, June 12, 2019 1:00 PM - 2:00 PM](#)

Individuals, families and advocates can learn more about the PA ABLE Savings Program at PAABLE.gov or by calling 855-529-ABLE (2253).

Visit PAABLE.gov to learn more about PA ABLE and to enroll, or to access your account.

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Summary of ODP Communications Issued April 2019, With Links



1. ODP 19-040: [CAPS-- Peer Specialist Training Program for Individuals with Autism](#)
2. ODP 19-041: [ODP Releases Quality Assessment & Improvement Annual Statewide Report of Self-Assessments for Fiscal Year \(FY\) 2018-2019](#)
3. ODP 19-042: [Generation of EIM Notifications for Supports Coordinators and Supports Coordination Supervisors](#)
4. ODP 19-043: [EIM Alerts for Incidents not submitted within 72 hours of Creation](#)
5. ODP 19-044: [Qualification Process for New Providers UPDATE](#)
6. Money Follows The Person (MFP) Initiative: [Recognizing and Addressing Mental Health Factors when Providing Behavior Supports May 21, 2019](#)
7. ODP 19-045: [Updated Employment Resources Page on MyODP](#)
8. ODP 19-025: Now Available-- [Updated ID/Waiver Employment Service Definition Question and Answer Document and ID/A Waiver Employment Service Definition Quick Guide](#)
9. ODP 19-046: [Person Centered Thinking--Registration Available for Philadelphia and Harrisburg Sessions](#)
10. ODP 19-047: [Quality Assurance Analyst Employment Positions through Autism2Work](#)
11. [ODP Newsletter April 2019](#)
12. [Human Services Secretary Celebrates Autism Awareness Month, Highlights Resources and Services to Live An Everyday Life](#)
13. ODP 19-047: [PA Family Network Offers Statewide Training Sessions](#)
14. ODP 19-048: [Office of Vocational Rehabilitation \(OVR\) Contact Information for ID/Autism Coordinators--Updated 4/10/19](#)
15. [7th Annual Lifesharing Conference Call for Presenters - October 21-22 2019](#)
16. ODP 19-049: ["Getting Connected to the Community" Training Available](#)
17. Pennsylvania [APSE Statewide Day On Employment 2019](#)
18. Save the Dates! [2019 Dual Diagnosis Conference](#)
19. ODPANN 19-050: [Important Information Regarding the Medication Administration Training Program](#)
20. ODPANN 19-051: [Additional \(2nd\) FY19-20 Renewal Guidance](#)

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