

DEPUTY SECRETARY'S MESSAGE

As we near the 30th anniversary of the adoption of Everyday Lives, the words of John McKnight included in the first Everyday Lives publication hold true: "Our goal should be clear. We are seeking nothing less than a life surrounded by the richness and diversity of community. A collective life. A common life. An everyday life. A powerful life that gains its joy from the creativity and connectedness that comes when we join in association as citizens to create an inclusive world."

Everyday Lives guides us in our commitment to help create a world that embraces and celebrates human differences, a world in which everyone can experience belonging.

- KRISTIN AHRENS, Deputy Secretary, Office of Developmental Programs



Everyday Lives: Values in Action, 2021. Pennsylvania Department of Human Services, Office of Developmental Programs

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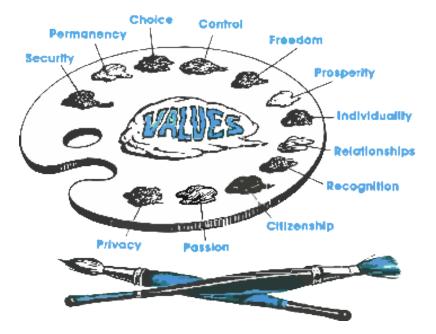
EVERYDAY LIVES, 1991

In 1989, the Pennsylvania Office of Developmental Programs (ODP) invited people with disabilities, families, advocates, governmental officials, and service providers to think about what the future should look like for *all* people with disabilities. Pennsylvania had been a national leader in creating community services as an alternative to institutional services, but it was time to think more deeply about what the purpose of community services should be — what kinds of experiences and opportunities people should have and what the overall outcome should be.

For months, participants conducted research about best practices and discussed their findings. Most importantly, the planning group asked people with intellectual disabilities what was important to them. The result was a list of *Everyday Lives* principles that has guided ODP and the service system since *Everyday Lives* was published in 1991.

Deeply rooted in the concept of self-determination, *Everyday Lives* promotes the belief that, with the support of family and friends, people with disabilities can and should decide how to live their lives.

The original *Everyday Lives* stated what was important to people with disabilities and recommended changes to the



An illustration from the 1991 *Everyday Lives* publication shows what people with disabilities value in their lives.

service system that increased opportunities for full community participation, provided individuals with more control over services, and improved system accountability in assuring health, safety, and positive outcomes.



CREATING EVERYDAY LIVES, 2021

In November 2014, ODP formed the Information Sharing and Advisory Committee (ISAC) to discuss policies and practices and make recommendations to ODP.

As part of a futures planning process, more than 265 stakeholders conducted research and evaluated best practices to determine the most important steps for ODP to take to improve service delivery. From this work, recommendations were adopted resulting in the 2016 edition of Everyday Lives.

Since 2016, ISAC has adopted a recommendation aimed at racial equity and identified strategies and performance measures to guide the Office of Developmental Programs (ODP) and gauge its progress in achieving the important goals put forth in Everyday Lives. The strategies and recommendations developed by the ISAC are intended to serve as a guide for everyone engaged in developing, providing, and advocating for services in the ODP system.



EVERYDAY LIVES: VALUES IN ACTION

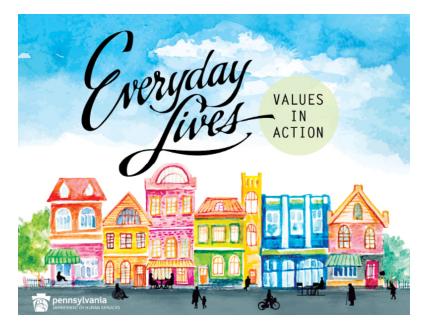
The foundation of *Everyday Lives: Values in Action* is two statements:

1. We value what is important to people with disabilities and their families, who are striving for an everyday life.

An everyday life is about opportunities, relationships, rights, and responsibilities. It is about being a member of the community, having a valued role, making a contribution to society, and having one's rights as a citizen fully respected. It is a vision that we should all be working toward together.

2. People with disabilities have a right to an everyday life; a life that is no different than that of all other citizens. This continues to be the truest statement on which we can build our work.

Everyday Lives will be a guide to ODP as it develops policy and designs programs. Providers of services will use the recommendations of *Everyday Lives* to support individuals and their families to achieve an everyday life. *Everyday Lives* will guide everyone toward the possibility of an everyday life.





HISTORY

Accomplishments of the past raise expectations for the future

1940s

• Families across the commonwealth formalized their support and advocacy network with incorporation of the Pennsylvania Association for Retarded and Handicapped Children, 1949

1960s

- The Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L.88-164) provided money to build community facilities, 1963
- Social Security Act Amendments (P.L. 88-97) established Medicare and Medicaid, 1965

• The Pennsylvania MH/MR Act established a system of community services, 1966

1970s

- PARC vs. Commonwealth established the right to education with due process in Pennsylvania, 1971
- Pennsylvania funded Family Support Services for the first time, 1971
- Pennsylvania began funding Community Living Arrangements for the first time, 1971
- The Federal Education for All Handicapped Children Act (94-142) mandated free, appropriate, and individualized education for all children in the least restrictive environment, 1975
- Protection and Advocacy system was mandated (P.L. 94-103), 1975
- Federal court rules that institutionalization is a violation of constitutional rights to equal protection in the case of PARC vs. The Pennhurst State School and Hospital, 1977

1980s

- Lifesharing program began, 1982
- Self advocates in Pennsylvania formalized their peer support group and incorporate as *Speaking for Ourselves*, 1982
- Federal Fair Housing Act added disability as a protected class, 1988

1990s

• Americans with Disabilities Act (ADA) was passed, 1990

• Early Intervention Services System Act was signed by Gov. Robert P. Casey, 1990

- Everyday Lives was published by Gov. Casey, 1991
- Waiting list campaign: Individuals and families advocated for services for people and families who have been waiting for a long time, 1998
- *Multi-Year Plan* for Pennsylvania's system of services for people with disabilities and their families was published by Gov. Tom Ridge, 1997
- Pennsylvania included post-secondary education options in waiver services, 1997
- Five Year Plan to Address the Waiting List was adopted, Gov. Ridge, 1998



Cover of the 2001 publication, *Everyday Lives: Making It Happen.*

- *Self Determination* grant was awarded by the Robert Wood Johnson Foundation, 1999
- The Person/Family Directed Support Waiver was implemented, 1999
- U.S. Supreme Court ruled in Olmstead vs. L.C. that integration is for everyone, 1999



2000s

- Independent Monitoring for Quality (IM4Q) was established, 2000
- *Everyday Lives: Making It Happen*, was published by Gov. Ed Rendell, 2001
- Autism Task Force produced a report, 2004
- PA Act 62, Autism Insurance Act was established, 2008
- ODP initiated services to adults with autism, 2008

2010s

- Affordable Care Act passes providing further protections against disability discrimination, 2010.
- Pennsylvania State Senate Bill No. 458 was passed amending the Mental Health and Mental Retardation Act of 1966 by renaming it the Mental Health and Intellectual Disability Act, 2011
- Home and Community-Based Services (HCBS) Final Rule mandated inclusive settings and person-centered practices, 2014

- PA was accepted into the National Community of Practice: Supporting Families throughout the Lifespan, 2016
- Gov. Tom Wolf signed the Employment First Executive Order to increase competitive, integrated employment among people with disabilities, 2016
- Pennsylvania Department of Human Services officially updated language to remove outdated or offensive terms in 24 chapters of regulations, 2016
- Gov. Wolf signed into law the Pennsylvania Achieving a Better Life Experience (ABLE) Act so people with qualified disabilities and their families can open tax-exempt savings accounts to be used for disability-related expenses, 2016
- Governor Wolf signed into law, the Employment First Act, 2018
- The Community Living Waiver was implemented, 2018
- New regulations for home and community based services were established providing greater rights protections for people with disabilities, 2019.

VALUES STATEMENTS

WHAT IS IMPORTANT TO PEOPLE WITH DISABILITIES

Everyday Lives in Action; Value Statements is presented in two parts. The values statements on pages 10 and 11 are provided to help other people understand what is important to people with disabilities. Part two on pages 12 and 13 tells us what families value and what they need from supporters and the community to achieve the hopes and dreams of their family members.

People with disabilities may refer to themselves in different ways. "Self advocate" is the preference for some people. Others prefer "people with disabilities," and others prefer not to be identified by their disability at all.

Family means both those related by birth and those chosen as family; supporters mean those who provide services and supports, including natural, public, and private resources; community means people interacting with whom they live, work, play, and worship. These values should guide every decision made by, for, and about people with an intellectual disability or autism.

EVERYDAY LIVES IN ACTION: MY LIFE, MY WAY

CONTROL: I have control over all areas of my life. My family, supporters, and community know these are my decisions and work with me to achieve greater control.

CHOICE: I decide everything about my life. My family, supporters, and community help me learn about opportunities and together we make them happen.

FREEDOM: I have the same rights as all other members of the community and I can fully use them. My family, supporters, and community respect my rights.

EVERYDAY LIVES IN ACTION: MY LIFE, MY WAY	
STABILITY: Changes to my life are made only with my permission and input. My family, supporters, and community do "nothing about me without me." They plan with me to meet my needs, now and for the future.	EMPLOYMENT/MEANINGFUL CONTRIBUTION: I want to work and/or have other ways to contribute to my community. My family, supporters, and community support me to find and keep a real job that I like with good wages and benefits or start and run my own business, and/or volunteer the way I want in my community.
HEALTH AND SAFETY: I am healthy and safe in all areas of my life. I, my family, supporters, and community balance health, safety, and risk according to my wants and needs.	INDIVIDUALITY: I am respected and valued for who I am and want to be. My family, supporters, and community treat me with dignity and support me in a person-centered way.
CONNECTED: I am a full member of my community with respect, dignity, and status. My family, supporters, and community know me as a person, welcome and accept me.	RELATIONSHIPS: I decide who is in my life: friends, family, partners, neighbors, pets, and others in the community. My family, supporters, and community respect the relationships I choose and support me to form new relationships.
RESPONSIBILITY: I am dependable and honor my commitments. I keep my word. My family, supporters, and community are honest and fair, do what they're supposed to do, and keep their word.	PARTNERSHIP: I need people in my life who will honor my life's journey. My family, supporters, and community work together with me to build bridges.
COMMUNICATION: I am listened to and understood; my input is valued. My family, supporters, and community listen to me and communicate in ways that work for me.	QUALITY: I want my life my way. I, my family, supporters, and the community make sure the services I choose are proven to be of high quality.
SUCCESS: I am the best I can be in the goals that I decide. My family, supporters, and community learn how to support me to achieve my goals.	ADVOCACY: I am the best person to let others know what I want and need. My family, supporters, and community listen to me and understand what I want and need, and assist me to be heard by others.

VALUES STATEMENTS

WHAT IS IMPORTANT TO FAMILIES

Families embrace and envision person-centered, family-supported, values-based everyday lives for their family members, regardless of changes in administrations, fiscal fluctuations, and unforeseeable influences. Families want these values adopted and embedded into ODP's policies and practices across the service system. By consistently asking if we are adhering to these values, these value statements can be utilized to bring about meaningful and enduring systemic changes.

Family is integral to an everyday life. We are born into families and we choose families. Families are the foundation of our early development and often our achievements as adults.

If people with disabilities are to enjoy the everyday life that all citizens should enjoy, families will play a key role beginning in the earliest years by having a positive and promising vision for their child. Families can do this by knowing how to facilitate their child's full inclusion into the school and community, by ensuring their child has all the experiences and opportunity needed to learn and grow toward independence, by having good advocacy skills, and by preparing for all of life's transitions into adulthood.

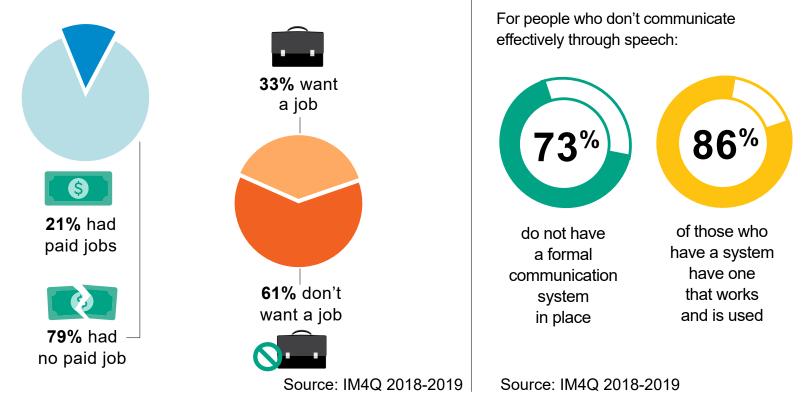
Families need support. Families need information, advocacy skills, and connections to other families. The realization of *Everyday Lives* is dependent on the service system successfully partnering with families to achieve the hopes and dreams of their family members.

EVERYDAY LIVES IN ACTION: WHAT FAMILIES VALUE	
THE UNIQUE ROLE OF FAMILY: Families represent the very heart of life throughout the lifespan.	CHOICE AND CONTROL: Families seek freedom, on behalf of their family members, to make responsible and personal choices in all aspects of life.
SUPPORTING FAMILIES THROUGHOUT THE LIFESPAN: Our families must be encouraged and supported early on in their children's lives to hope, dream, and reach for the future.	HEALTH AND SAFETY: People should be safe at home, work, school, and in the community.
KNOWLEDGE AND RESOURCES: Families want to feel strong so they can provide for and support their loved ones.	SIMPLICITY AND FLEXIBILITY: Families value a simplified and transparent system that is easy to access, understand, and navigate.
MENTORING: Families value mentoring as a strong component to informing and supporting families.	QUALITY AND STABILITY: Families value quality supports and services that enable people to live everyday lives.
COMMUNICATION: Good communication involves everyone working toward common goals, respecting one another in partnership.	COLLABORATION: Along with self advocates, family members must be part of the discussion, planning, and creation of every element of the service system.
RESPECT AND TRUST: Respect must be granted to fami- lies, their values and beliefs, homes, and privacy.	OPPORTUNITY FOR INNOVATION: Families support innovative, creative approaches that can be the key to truly person-centered solutions and often offer the most cost-efficient solutions.

BY THE NUMBERS: EVERYDAY LIVES TODAY

EMPLOYMENT

21% Of people interviewed by Independent Monitoring for Quality:



COMMUNICATION

PEOPLE NEED TO BE HEARD



DAILY ACTIVITIES CHOICE MATTERS



of the individuals interviewed reported that someone else chose what they do during the day



of the people interviewed chose what they do during the day without assistance



of individuals reported that when they chose their work or day activity, they had an option to go where people without disabilities go



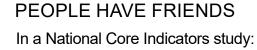
of the individuals surveyed chose their daily schedules without assistance



say they have enough choice about how they spend their free time

Source: IM4Q 2018-2019

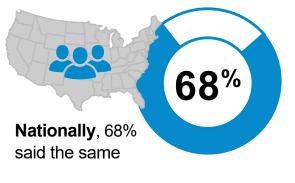
RELATIONSHIPS





77% of people from **Pennsylvania**

with an intellectual disability or autism said they have friends who are not family or staff



Source: National Core Indicators (NCI) 2018-2019

VALUES IN ACTION: RECOMMENDATIONS

SAC recommendations for *Values in Action* are built on the values, goals, expectations, and aspirations of people with disabilities and their families. The recommendations are a guide for ODP to develop policy and design programs for people with disabilities, families, providers of service, and advocates who support people to have an everyday life.

1. ASSURE EFFECTIVE COMMUNICATION

Every person has an effective way to communicate in order to express choice and ensure their health and safety. All forms of communication should consider and include the individual's language preferences and use of current technology.

2. PROMOTE SELF-DIRECTION, CHOICE, & CONTROL



Personal choice and control over all aspects of life must be supported for every person. Choice about where to live, whom to live with, what to do for a living, and how to have fun all are key choices in life, as are seemingly small choices, such as what to eat, what to wear, when to wake up in the morning, and when to go to bed. It is important to be able to trust the people who provide assistance, to feel confident that they respect you and your right to manage your life, and to enjoy each other's company.

Self-direction works when individuals have clear and understandable information, opportunities to exercise choice, and assistance with making decisions when needed. Self-direction is only possible when family, friends, and people who provide supports respect the individual's preferences and their right to make mistakes and facilitate the implementation of the individual's decisions.



3. INCREASE EMPLOYMENT



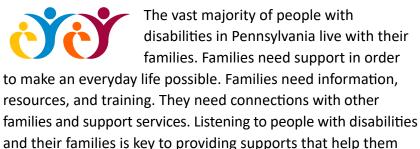
Employment is a centerpiece of adulthood and must be available for every person. The benefits of employment for people with disabilities are significant and are the same as for people without disabilities.

EMPLOYMENT IS:

Feeling proud

- Meeting new people
- Having self-confidence
- Building new skills
- Getting a paycheck
- Paying taxes

4. SUPPORT FAMILIES THROUGHOUT THE LIFESPAN



disabilities in Pennsylvania live with their

achieve an everyday life.

5. PROMOTE HEALTH, WELLNESS, AND SAFETY



Promote physical and mental health, wellness, and personal safety for every individual and their family. Promoting physical and mental health means providing information about health and

wellness, emotional support, and encouragement. Tools that help every individual adopt a healthy lifestyle — including good nutrition, healthy diets, physical activity, and strategies to reduce and manage stress and protect oneself from all types of abuse and exploitation — must be provided.

6. SUPPORT PEOPLE WITH COMPLEX NEEDS



People with disabilities who have both physical and behavioral health needs receive the medical treatment and supports needed throughout their lifespans. When individuals, families, and providers

plan and modify supports as people's needs change to meet these challenges, people are more able to live an everyday life. Opportunities for a full community life are dependent on adequate supports and the commitment to build capacity within the larger human service delivery system.

7. DEVELOP AND SUPPORT QUALIFIED STAFF



People with disabilities receiving services benefit when staff who support them are well trained. Values, ethics, and person-centered decision-making can be learned and used in daily practice through mentorship and training. Providing professional training that strengthens relationships and partnerships between individuals, families, and direct support professionals will improve the quality of support.

8. SIMPLIFY THE SYSTEM



The system of supports and funding of those supports must be as straightforward and uncomplicated as possible. This will allow for greater understanding and use of the system by everyone — most importantly the individual needing and receiving supports.

9. IMPROVE QUALITY

Together we must plan and deliver services and supports that adhere to our values, measure person-centered outcomes, and continuously improve an individual's quality of life. All stakeholders must be engaged in the process of measuring how well services assist people in achieving an everyday life.

10. EXPAND OPTIONS FOR COMMUNITY LIVING

Expand the range of housing options in the community so all people can live where and with whom they want to live. Listening to people with disabilities and their families, providers and support coordinators will help people locate affordable and accessible housing, find housemates, and identify housing resources/supports and other government benefits that, when blended with natural supports, will promote an everyday life.

11. INCREASE COMMUNITY PARTICIPATION

Being involved in community life creates opportunities for new experiences and interests, the potential to develop friendships, and the ability to make a contribution to the community. An interdependent life, where people with and without disabilities are connected, enriches all of our lives.



12. PROVIDE COMMUNITY SERVICES TO EVERYONE



Some people with disabilities — whether living on their own, with families, or in institutions — are waiting for community services. The goal is to build a system that has the capacity to provide services in a timely fashion for all people who need supports.

13. EVALUATE FUTURE INNOVATIONS BASED ON EVERYDAY LIVES PRINCIPLES

Future consideration of service models and reimbursement strategies must be based on the principles of person-centered planning, individual choice, control over who provides services and where, and full engagement in community life. Innovative approaches should be evaluated based on the recommendations of *Everyday Lives*, including: employment, recognizing and supporting the role of families, and meeting the diverse needs of all individuals. Stakeholders should be fully engaged in designing, implementing, and monitoring the outcomes and effectiveness of innovative service models and service delivery systems.

14. PROMOTE RACIAL EQUITY



Communities are richer, more just, and stronger when we honor and respect the whole of racial diversity. Access to a quality, person-centered, culturally competent system of supports and funding must be equally available regardless of race. Services must include planning over a lifespan and address racial disparities, including outcomes. The duty to ensure that racial diversity is promoted and supported, at all levels within the services system, must be embraced.

STORIES: PEOPLE LIVING EVERYDAY LIVES

GEORGE SHANDS

Gheorge Shands is a DJ and business owner from Southwest Philadelphia. George started his business, G-Fresh Emporium, with one mission in mind: "I want to make the world smell good." George's business produces and distributes car air fresheners, incense, bath bombs, and more. George started his business in order to be his own boss. In the 1980s, George lived in Embreeville State Hospital in Coatesville, but he was unhappy there. He wrote a letter to Governor Dick Thornburgh asking him to authorize his release from Embreeville. Governor Thornburgh answered his letter and George was released. George now lives with his friends Cliff and Rob.

George started working in a sheltered workshop, however the work was not fulfilling, and he wanted to make more money. Since starting G-Fresh Emporium in 2015, George has increased his earnings one-hundred and ninety-nine percent. Ninety percent of his earnings are split between the business and his own



personal savings. George has limited mobility in his arms, so he found donors to help him purchase a robotic arm that assists him in the production and packaging of his air fresheners. George uses a Playstation controller to move the arm. This allows him to stir scents, dip fresheners, package goods, and punch holes. To sell his product, George has distribution deals with local shops and his own kiosk at the mall. For fun, George DJs at events around his area under the name DJ G-Fresh, which is where the name for his business originated. He creates party mixes that he gives to friends and family. George loves Motown hits and classic hip-hop like *The Sugarhill Gang*.



MAURA KEGG



Maura Kegg began singing at the age of 13. Her mother signed her up for the Woodlands Music Camp in Wexword, PA. Maura was convinced that she did not want to go, and she expressed this vehemently to her mother. Maura was quick to backtrack that sentiment after her first day at camp. Five years later, she would join a group of her Woodlands peers to advocate for an age limit extension on the camp. Like many others, Maura wished to continue attending Woodlands Music Camp past the age of 18. That year, Maura and her friends were able to speak up and create change. Maura, who hails from Ross Township, uses her voice to make music and to speak up wherever she goes. Maura lives with three roommates in a community home run by Achieva. Maura loves her roommates like sisters. On Sundays they watch *Golden Girls* and assign each other roles from the show – she proudly claims the role of Dorothy. She likes living with her friends because they can help each other both emotionally and with everyday tasks.

Maura, who is a wheelchair user, has always been a helper. Her mother is blind and hearing impaired, so Maura is used to mutually helping her loved ones. "I would be her eyes and she would be my legs." Maura's friends and family are very important to her. She loves her job at UPMC Vocational Center because she gets to see friends she met back in high school. Maura, now 31, makes sure to exercise every day. She tries to get to her bicycle exercises that help strengthen her legs every day, except on those days when she's really tired. Maura assists with the Western Pennsylvania Disability History & Action Consortium where she uses her voice to let the consortium know what issues in history are important to people with disabilities and what events to chronical. Maura can still be caught singing at community events to this day. Her rendition of "Where are you Christmas" truly captures audiences.

ERIN GANNON

Erin Gannon is an award-winning audio journalist and a proud native of Pittsburgh. Growing up the youngest of six, Erin has always known what it means to be a part of a community. For her, learning from other people's lived experience is crucial for a functioning society. Her friend Jennifer feels the same way. Erin and Jennifer met on the bus in 2015 and quickly realized they had similar aspirations: Erin was looking to start a career in journalism - a 15-year career Jennifer had just left to work as a direct support professional. The two quickly teamed up, Jennifer working as Erin's DSP to help her realize potential as a journalist. The two came up with the idea of starting a media center for people with disabilities that would give them the tools necessary to work in media. However, they needed funding. Jennifer knew the director of Point Park's Center for Media Innovation named Andy. The two arrived for their meeting and Erin was greeted by a



welcome surprise. Andy and Erin already knew each other. Andy was a good friend of one of Erin's sisters. As Erin and Jennifer saw it, the stars were aligning for something special to occur. With support from the Center for Media Innovation, Erin and Jennifer founded the All-Abilities Media Project.

In 2017, Erin started her podcast *Look Who's Here!* and she quickly gained attention. During the episode "She Set Them Free: Retiring Exec's Role in Improving Life for Disabled" Erin interviewed retired Achieva CEO Marsha Blanco to discuss her role in deinstitutionalization activism in Pennsylvania. For her reporting, Erin won the Press Club of Western Pennsylvania's 2018 Golden Quill award in the "Community Service, Radio and Podcasts" category beating out veteran NPR reporters. Erin would continue to win yet another Golden Quill the following year in the "Excellence in Audio Journalism – Lifestyle" category for her story "A Wonderful Life': Raising a Child With Down Syndrome" in which she interviewed her own parents about what their experience was like raising Erin. Erin lives in a community home run by Emmaus Communities. She has two roommates, her best friends Marisa and Cici – the former of whom she's been friends with for 25 years. On top of her impressive resume, Erin has worked for Achieva's early intervention program for 15 years. In light of her work in media, Achieva recruited Erin for their communications team as well. Erin now takes to Achieva's social media platforms each day to offer "Erin's Tip of the Day." The day ODP spoke with Erin she left us with this tip, "Be who you are, learn a little bit about everything and stick together."



JORDON ROSS WEINHOLD



Jordon Ross Weinhold is a music arranger and actor from Lancaster, Pennsylvania. His passion for musical theater started when he was young. In elementary school, Jordon was diagnosed with autism. Jordon graduated high school and continued to pursue his career in musical theater by attending Point Park University. While there, Jordon focused on acting and directing, but when one of his colleagues needed a reduced orchestration for the musical *Into the Woods*, Jordon offered to take a shot at it despite having only dabbled in music arrangement in the past. For the reduced orchestration Jordon needed to take the original music written for 30 instruments and compress it to be played by only eight instruments. The resulting musical score was lauded by his well-connected peers and, as a result, Jordon received more and more offers to arrange original and sourced music.

Jordon is now a full-time music composer/arranger whose work ranges from local community theaters to Broadway shows. Jordon's latest project is creating a film score for a documentary produced by Steven Spielberg. Jordon is heavily involved with his local community theater where he stars in shows and assists with marketing ventures through promotional video editing.

ERIKA TAYLOR

Erika is an 11-year-old fifth grade student at E.H. Phillips Elementary. Erika is diagnosed with an intellectual disability and autism. At the age of six, Erika joined her foster family. At that time her communication abilities were limited, including some vocalizations and gestures. It was difficult for Erika to complete many daily activities, as her past experiences made it difficult for her to trust others. As she became more comfortable with her new family and began receiving the proper services and supports, she began to blossom. Erika now can communicate using a combination of small sentences and knows over 100 American Sign Language signs. Erika uses her voice to speak her mind with confidence. She loves to cook, swim, and rock climb. Erika loves spending time with her family and playing with her five brothers. In 2019, Erika was officially adopted by her loving foster family.



MALCOLM CORELY

Malcolm Corely is a visual artist currently residing in Lancaster, Pennsylvania. From an early age, Malcolm loved drawing. During his formative years he would draw pictures of *Dr. Seuss* and *Blues Clues* characters. It was around that time that Malcolm's grandmother, a child psychologist, suggested the family have Malcolm tested for autism spectrum disorder after observing his tendency to organize objects. He was diagnosed with PDD-NOS (now under the ASD definition) at the age of three. When Malcolm reached elementary school, his artistic talent was quickly embraced by his art teachers, and by the fourth grade Malcolm was receiving district-wide acclaim for his work. A pastel work of his was hung in the school's district office. In the nineth grade, Malcolm won the Scholastic Silver Medal for his painting of his sister, Kiana. The training and recognition he received as a child recently led up to a spectacular jumping off point for any young artist's career.

At twenty years old, Malcolm was selected to have his work displayed in the Kennedy Center's International Organization on Arts and Disability 2019 Emerging Young Artists program. The travelling exhibit, *Connected*, featured Malcolm's piece "Untitled #1" (pictured right). Malcolm is limited in his verbal



communication, so he communicates with some speech and writing, however Malcolm prefers to express himself through his art. Malcolm completed his graduation requirements for high school at the age of 18 in 2018, but he continued to attend high school to further his art education. Along the way, Malcolm has set up a website called MalcolmsTiles.com where he sells prints of his art. The site was originally created to hand painted tiles, but as Malcolm's artistic medium grew, so did his store. Three years after launch, Malcolm's Tiles had sold well enough to afford Malcolm a long-coveted trip to Europe where he was able to visit Julianatoren, an amusement park he had been longing to go to. Malcolm finished high school in 2020 and continues to live with his mother Maria in Lancaster.



RECOGNITION

INFORMATION SHARING AND ADVISORY COMMITTEE MEMBERS (FEBRUARY 2021)

ABOARD Luciana Randall	DISABILITY RIGHTS PENNSYLVANIA
	Peri Jude Radecic
ACHIEVA	
Nancy Murray	HEALTH CARE QUALITY UNITS
	Kevin McElligott
BLAIR COUNTY SOCIAL	Ũ
SERVICES	DIRECT SUPPORT
James Hudack	PROFESSIONALS
	Nicholas Smith
BRADFORD COUNTY MH/ID	
Mayme Carter	OFFICE OF CHILD
	DEVELOPMENT AND EARLY

CASE MANAGEMENT UNIT Karen Wolf OFFICE OF CHILD DEVELOPMENT AND EARLY INTERVENTION Lisa Parker

OFFICE OF DEVELOPMENTAL PROGRAMS

Kristin Ahrens

Kevin Dressler Sheila Theodorou

Nina Wall

Rick Smith

Jeremy Yale

Dr. Gregory Cherpes

PARENT AND LATINO COMMUNITIES Marisol Ramos

PARENT AND RURAL COMMUNITIES Mary Saunders

PA FAMILY NETWORK

Francine Hogan

PENNSYLVANIA ADVOCACY AND RESOURCES FOR AUTISM AND INTELLECTUAL DISABILITY Mark Davis

PENNSYLVANIA ASSOCIATION OF COUNTY ADMINISTRATORS OF MENTAL HEALTH AND DEVELOPMENTAL SERVICES Lucy Mullis Kitner

PENNSYLVANIA ASSOCIATION OF PEOPLE SUPPORTING EMPLOYMENT FIRST

Julia Barol

PENNSYLVANIA AUTISM SERVICES, EDUCATION, RESOURCES AND TRAINING (ASERT) COLLABORATIVE Andrea Layton

PENNSYLVANIA DEVELOPMENTAL DISABILITIES COUNCIL Lisa Tesler

PENNSYLVANIA HEALTH LAW PROJECT David Gates

PENNSYLVANIA LEAGUE OF CONCERNED CITIZENS John Bastek

PENNSYLVANIA WAITING LIST CAMPAIGN Sheila Stasko

PITTSBURGH CENTER FOR AUTISTIC ADVOCACY Cori Frazer REHABILITATION AND COMMUNITY PROVIDERS ASSOCIATION Richard Edley

SELF ADVOCATE FOR ID SERVICES Joshua Stranix

SELF ADVOCATES UNITED AS 1 Oscar Drummond

SELF ADVOCATE – ADULT COMMUNITY AUTISM PROGRAM Michael Bomberger

SELF ADVOCATE – ADULT AUTISM WAIVER Michelle Middlemiss

SELF-ADVOCATE – POWER NETWORK FOR ALL (SAPNA) Chris Moore

SPEAKING FOR OURSELVES Debbie Robinson



SERVICE ACCESS & MANAGEMENT, INC.

James Schu

INSTITUTE ON DISABILITIES, TEMPLE UNIVERSITY Sally Gould-Taylor

THE ARC OF PENNSYLVANIA Sherri Landis

THE ALLIANCE OF COMMUNITY SERVICE PROVIDERS

Michael Donovan

THE PROVIDER ALLIANCE Marisol Valentin

VALUES INTO ACTION Marian Saulino

VISION FOR EQUALITY Audrey Coccia **FACILITATORS** Robin M. Levine, The Columbus Organization

ODP LEADS/SUPPORT

Julie Mochon Tara Giberga Ronald Melusky Laura Cipriani Lea Sheffield Samer Abdelhadi Candi Walton Angela Fortney Marlinda Smith Jennifer Fraker Lisa Wagner

ABOUT THE PENNSYLVANIA DEPARTMENT OF HUMAN SERVICES

The Pennsylvania Department of Human Services' program offices administer services that provide care and support to Pennsylvania's most vulnerable citizens. Our mission is to improve the quality



of life for Pennsylvania's individuals and families. We promote opportunities for independence through services and supports while demonstrating accountability for taxpayer resources.

ABOUT THE OFFICE OF DEVELOPMENTAL PROGRAMS

ODP supports Pennsylvanians with developmental disabilities to achieve greater independence, choice, and opportunity in their lives. ODP's vision is to continuously improve an effective system of accessible services and supports that are flexible, innovative, and person-centered.

