Everyday Lives
VALUES IN ACTION
DEPUTY SECRETARY’S MESSAGE

John McKnight, an emeritus professor of education and social policy at Northwestern University, had a message in the first *Everyday Lives* publication in 1991 that is even more relevant today: “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* affirms our dedication to making it possible for everyone to live a life of meaning and joy.

— NANCY THALER, Deputy Secretary, Office of Developmental Programs
# CONTENTS

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>EVERYDAY LIVES, 1991</td>
<td>See how Everyday Lives looked in the beginning</td>
</tr>
<tr>
<td>6</td>
<td>VALUES IN ACTION</td>
<td>Learn about the values behind Everyday Lives</td>
</tr>
<tr>
<td>7</td>
<td>HISTORY</td>
<td>Accomplishments of the past raise expectations for the future</td>
</tr>
<tr>
<td>10</td>
<td>VALUES STATEMENTS</td>
<td>People with disabilities and their families say what is important to them</td>
</tr>
<tr>
<td>14</td>
<td>BY THE NUMBERS</td>
<td>Data sets show the importance of work, relationships, and more</td>
</tr>
<tr>
<td>16</td>
<td>RECOMMENDATIONS</td>
<td>Guidance for developing meaningful policy and programs</td>
</tr>
<tr>
<td>20</td>
<td>STORIES</td>
<td>Take a peek into the everyday lives of eight Pennsylvanians</td>
</tr>
<tr>
<td>25</td>
<td>RECOGNITION</td>
<td>Group of committee members who made this publication possible</td>
</tr>
</tbody>
</table>
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* told us what was important to people with disabilities and made recommendations about how the service system should increase opportunities for full community participation, provide individuals with more control over services, and improve the system’s accountability for assuring health, safety, and positive outcomes.

An illustration from the 1991 *Everyday Lives* publication shows what people with disabilities value in their lives.
In November 2014, ODP formed the Information Sharing and Advisory Committee (ISAC), an ongoing committee to discuss policies and practices and make recommendations to ODP.

More than 265 stakeholders conducted research and evaluated best practices to determine the most important steps for ODP to take to improve system delivery.

Recommendations were submitted by the Futures Planning Work Group and were further developed and explored by ISAC members, resulting in this edition of Everyday Lives.
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

• *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

• 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

• Futures Planning Work Group met, 2013-15

• Home and Community-Based Services (HCBS) Final Rule mandated inclusive settings and person-centered practices, 2015

• 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
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 wish to be identified in different ways. “Self advocate” is the preference for some people, “autistic” is preferred by others, and others prefer simply “people with disabilities.”

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.

<table>
<thead>
<tr>
<th>EVERYDAY LIVES IN ACTION: MY LIFE, MY WAY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CONTROL:</strong> 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.</td>
</tr>
<tr>
<td><strong>CHOICE:</strong> I decide everything about my life. My family, supporters, and community help me learn about opportunities and together we make them happen.</td>
</tr>
<tr>
<td><strong>FREEDOM:</strong> 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.</td>
</tr>
<tr>
<td><strong>EVERYDAY LIVES IN ACTION: MY LIFE, MY WAY</strong></td>
</tr>
<tr>
<td>------------------------------------------------</td>
</tr>
<tr>
<td><strong>STABILITY:</strong> 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.</td>
</tr>
<tr>
<td><strong>EMPLOYMENT/MEANINGFUL CONTRIBUTION:</strong> 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.</td>
</tr>
<tr>
<td><strong>HEALTH AND SAFETY:</strong> 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.</td>
</tr>
<tr>
<td><strong>INDIVIDUALITY:</strong> 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.</td>
</tr>
<tr>
<td><strong>CONNECTED:</strong> 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.</td>
</tr>
<tr>
<td><strong>RELATIONSHIPS:</strong> 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.</td>
</tr>
<tr>
<td><strong>RESPONSIBILITY:</strong> 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.</td>
</tr>
<tr>
<td><strong>PARTNERSHIP:</strong> 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.</td>
</tr>
<tr>
<td><strong>COMMUNICATION:</strong> 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.</td>
</tr>
<tr>
<td><strong>QUALITY:</strong> I want my life my way. I, my family, supporters, and the community make sure the services I choose are proved to be of high quality.</td>
</tr>
<tr>
<td><strong>SUCCESS:</strong> 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.</td>
</tr>
<tr>
<td><strong>ADVOCACY:</strong> 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.</td>
</tr>
</tbody>
</table>
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 Pennsylvania’s ODP’s policies and practices across the service system. By consistent consideration of the question, “Are we adhering to the 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.
<table>
<thead>
<tr>
<th><strong>EVERYDAY LIVES IN ACTION: WHAT FAMILIES VALUE</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>THE UNIQUE ROLE OF FAMILY:</strong> Families represent the very heart of life throughout the lifespan.</td>
</tr>
<tr>
<td><strong>SUPPORTING FAMILIES THROUGHOUT THE LIFESPAN:</strong> Our families must be encouraged and supported early on in their children’s lives to hope, dream, and reach for the future.</td>
</tr>
<tr>
<td><strong>KNOWLEDGE AND RESOURCES:</strong> Families want to feel strong so they can provide for and support their loved ones.</td>
</tr>
<tr>
<td><strong>MENTORING:</strong> Families value mentoring as a strong component to informing and supporting families.</td>
</tr>
<tr>
<td><strong>COMMUNICATION:</strong> Good communication involves everyone working toward common goals, respecting one another in partnership.</td>
</tr>
<tr>
<td><strong>RESPECT AND TRUST:</strong> Respect must be granted to families, their values and beliefs, homes, and privacy.</td>
</tr>
</tbody>
</table>
**BY THE NUMBERS: EVERYDAY LIVES TODAY**

**EMPLOYMENT**
Of people interviewed by Independent Monitoring for Quality:

- **14%** had paid jobs
- **86%** had no paid job

- **38%** want a job
- **62%** don't want a job

- **23%** had job goal in plan
- **77%** no job goal in plan

Source: National Core Indicators, 2012-13

**COMMUNICATION**
PEOPLE NEED TO BE HEARD
For people who don’t communicate effectively through speech:

- **67%** do not have a formal communication system in place
- **83%** of those who have a system have one that works and is used

LEVEL OF CHOICE
WHERE PEOPLE LIVE MATTERS

The choice scale runs from zero to 100. A higher score indicates a greater level of choice-making. The statewide average score is 48.

<table>
<thead>
<tr>
<th>Location</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>State Intermediate Care Facility (ICF)</td>
<td>42</td>
</tr>
<tr>
<td>Lifeshare</td>
<td>61</td>
</tr>
<tr>
<td>Own Home</td>
<td>78</td>
</tr>
<tr>
<td>Relative’s Home</td>
<td>58</td>
</tr>
<tr>
<td>Private ICF</td>
<td>29</td>
</tr>
<tr>
<td>Community Home (1-4 People)</td>
<td>44</td>
</tr>
<tr>
<td>Community Home (5+ People)</td>
<td>38</td>
</tr>
</tbody>
</table>

RELATIONSHIPS
PEOPLE HAVE FRIENDS

In a National Core Indicators study:

- **78%** of people from Pennsylvania with an intellectual disability or autism said they have friends who are not family or staff.
- **76%** said the same nationally.

Source: National Core Indicators (NCI) and Pennsylvania IM4Q, 2013-14

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

4. SUPPORT FAMILIES THROUGHOUT THE LIFESPAN

The vast majority of people with disabilities in Pennsylvania live with their families. Families need support in order to make an everyday life possible. Families need information, resources, and training. They need connections with other families and support services. Listening to people with disabilities and their families is key to providing supports that help them 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.
STORIES: PEOPLE LIVING EVERYDAY LIVES

APRIL

Three years ago April began to realize her dream of being an artist. At an art studio, April immediately excelled with creating and designing. She enjoys combining her passion for art with her love of helping others. She is learning, creating, and expressing herself through her art, and recently became employed as an arts enrichment aide at the studio. She works four hours per week. She still has studio time for herself, which is important to her. April also shares her love and passion for animals by volunteering time at area shelters. April excels in basketball and track and is actively involved in Special Olympics.

PAMELA

If you live in Philadelphia and have visited a Home Depot store within the past decade, chances are you have met Pamela. Since 1998, Pam has been employed full-time as a store associate. She takes pride in her job and enjoys working within the community and has established a strong network of co-workers and friends who support her personally and professionally. Over the years, she has taken on new leadership roles and has received numerous employee of the month awards and gifts in recognition of her hard work. Outside of work, Pam lives in a Lifesharing family. She likes spending time with her Lifesharing family member Melva, eating at new restaurants and visiting local shops. People who know Pam say she is friendly, humorous, and a loved woman who likes being on the go. She gets along with everyone and always sees the best in people.
AUSTIN

Austin chooses not to let his disability define him. Through the power of an Agency with Choice program, Austin hires his sister, Tiffany, to be his support. This has proved to be a win-win situation for all involved. Austin gets the precise level of support he needs from someone who knows him intimately, and Tiffany has the satisfaction of helping her brother out while being gainfully employed. And Mom? Well, she’s thrilled by the entire arrangement.

ELYSIA

People who know Elysia would say that she is a prankster who likes to joke around and is an overall wonderful young lady with a very bright future. Since high school, Elysia has held a job at a local Walmart, doing janitorial work and whatever else is asked of her. The organization A Home of My Own helped Elysia obtain supports and services to help move outside of her family’s home. Elysia immediately knew what she wanted in an apartment. Staff worked with Elysia and showed her different apartments in Allegheny County, but only one place truly was a great fit. Now 21 years old, Elysia has many social interests beyond work and school. In her spare time, she helps young aspiring musicians, songwriters, and singers develop their musical abilities in a community program. Elysia enjoys writing poetry, and is getting help to coordinate her poetry into music.
ALINA (WRITTEN BY HER MOM)

Alina and her support person, Debbie, “grew up” together. Alina was 11 when Debbie came into our lives; she is now 23. Although I am part of a divorced couple, we share Debbie, who supports Alina at both of our homes. Who would have thought that for the past 12 years, Debbie would remain our constant, our sanity, best friend, and trusted supporter. She is our lifeline, the reason we can go to work knowing our daughter is loved and supported every day. Relationships change over time; that’s part of an everyday life. Alina and Debbie’s did. Initially, Debbie and Alina worked on after-school activities that developed skills while taking into consideration how tired Alina was from school. Alina needs total support and an understanding of her gestures, motions, and sounds to be happy, healthy, and safe. We taught Debbie to “notice what you notice” and, when in doubt, to talk to Alina and let her know what she didn’t understand. Some days, they would just hang out on the sofa, with Debbie reading to Alina. They went out to restaurants, parks, museums, movies; anything they decided to do that day. When Alina was in the hospital, Debbie came to see her on her own time. They have a relationship built on love, and love is what Debbie gets back from Alina and us. Health changes over time, too. Debbie is no longer physically able to care for Alina. We’ve explained to Alina in a way you would tell anyone, and we’ve taken her to the hospital several times to visit Debbie. We especially miss the interactions she and Alina once had, but we still keep in contact. A new chapter of our lives has begun. Debbie’s daughter, Jaime, now supports Alina. We are grateful for the everyday life we continue to share with Debbie and her family.
NAOMI & JUSTIN (WRITTEN BY THEIR MOM)

Twenty-two years ago, my husband Jose and I came here from Puerto Rico. We have a daughter and a son, Naomi (20) and Justin (14). After Naomi was born, the doctors told us that the best place for her would be an institution. This was not the life we wanted for our daughter. We wanted her to live at home with parents who love her. Through the years, Naomi’s needs have changed, but the severity of her condition (she needs medical care and round-the-clock supervision) has not. In spite of that, we take her everywhere. We buy the things she loves, like CDs and magazines. She loves to stay at hotels and go in the pool. We’ve traveled to Puerto Rico to visit with family. We work hard as a family so she can have a life filled with the same opportunities that everyone has. When Justin was 2, I realized something was different. He did not act like other children his age. He was diagnosed with autism. We were already supporting a daughter with severe disabilities, and Justin’s diagnosis was heartbreaking. He has come a long way. He is a wonderful young man who goes to school, loves computer games, and works hard to achieve success. Like other parents, we are worried about their futures. We want to stay together as a family for as long as we can. Our deep, abiding love keeps the four of us bound together. Our life is a labor of love, one that is full of challenges, but by far many more blessings.

MICHAEL

Michael is a lifelong resident of Philadelphia. He is a graduate of a public high school and a four-year university’s post-secondary education program. During his two years as a university student, Michael took undergraduate academic courses and completed an internship working with the university’s police department monitoring activities throughout the main campus. Michael was the first recipient of the annual Spirit of Pride award, distinguishing him as a well-rounded student excelling in his academic and career development pursuits. Michael says he loves a challenge because it shows what he can do with his abilities. While attending school, he took an acting class, which is where he gained an interest in performing. Michael made his professional acting debut April 2016 in the Philadelphia play, “A Fierce Kind of Love,” which depicts the Pennsylvania disability rights movement. When not performing, Michael works as an office assistant at Temple University. He enjoys relaxing at home and watching Netflix with his fiancée, Charlene. Their wedding is planned for October 2016.
My husband and I have five children, and our youngest are five-year-old identical twins, Susan and Meredith. All five have attended the same private preschool, and all five will attend our local public school. This sounds like any family story, except that our twin girls have Down syndrome. When we received the prenatal diagnosis, we were overwhelmed by all of the ways we were told that our girls would be different from other children. They are different, but we have learned that they are so much like our other kids and our neighbors’ kids and all other kids. We choose to focus on the similarities, and have pushed to involve our girls in the same experiences their siblings have had in our community. What was important for Rory, Michael, and John is just as important for Susan and Meredith. We have been supported by the teachers in our preschool and therapists in working through the differences. Having our girls in the local preschool has taught their classmates about differences, the teachers about different learning styles, and families about including kids with all abilities in a meaningful and fun way. We live our life as a family, not just as “that family” with the twins with Down syndrome.
RECOGNITION

INFORMATION SHARING AND ADVISORY COMMITTEE MEMBERS (APRIL 2016)

ABOARD
Luciana Randall

ACHIEVA
Nancy Murray

ADVOCATE
Cindi Lashinsky

AUTISTIC
SELF ADVOCACY NETWORK
Savannah Logsdon-Breakstone

AUTISM SOCIETY
OF AMERICA (PITTSBURGH)
Tom Flynn

DISABILITY RIGHTS
PENNYSylvANIA
Jacqueline Beilharz

HEALTH CARE QUALITY UNITS
Dina McFalls

OFFICE OF DEVELOPMENTAL
PROGRAMS
Kevin Dressler
Dolores Frantz
Patricia McCool
Julie Mochon
Rick Smith

Nancy Thaler
Nina Wall

PARENT
AND LATINO COMMUNITIES
Marisol Ramos

PARENT
AND RURAL COMMUNITIES
Mary Saunders

PA FAMILY NETWORK
Lisa Tesler
PENNSYLVANIA ADVOCACY AND RESOURCES FOR AUTISM AND INTELLECTUAL DISABILITY
Shirley Walker

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
Lindsay Shea

PENNSYLVANIA DEVELOPMENTAL DISABILITIES COUNCIL
Graham Mulholland

PENNSYLVANIA LEAGUE OF CONCERNED CITIZENS
John Bastek

PENNSYLVANIA WAITING LIST CAMPAIGN
Sheila Stasko

REHABILITATION AND COMMUNITY PROVIDERS ASSOCIATION
Richard Edley

SELF ADVOCATE FOR ID SERVICES
Elise Westcott

SELF ADVOCATES UNITED AS 1
Francie Keeney

SPEAKING FOR OURSELVES
Debbie Robinson

SUPPORTS COORDINATION ORGANIZATIONS
James Schu

INSTITUTE ON DISABILITIES, TEMPLE UNIVERSITY
Celia S. Feinstein

THE ARC OF PENNSYLVANIA
Maureen Cronin

THE ALLIANCE OF COMMUNITY SERVICE PROVIDERS
Cherie Brummans

THE PROVIDER ALLIANCE
Edward Picchiarini

UNITED CEREBRAL PALSY OF PENNSYLVANIA
Jeffrey W. Cooper

VISION FOR EQUALITY
Audrey Coccia

FACILITATORS
Robin M. Levine, The Columbus Organization
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.

Find us online
www.dhs.pa.gov

Get up-to-the minute updates by following us on social media!