list system to ensure that people are able to move to community programs.

Nonetheless, the movement to community living is a work in progress. There are currently four state-run public intermediate care facilities for people with intellectual disabilities in Pennsylvania, and over the next three years two of those, Polk and White Haven, are expected to close. ODP’s goal is to move people to life in the community.

A Range of Service Options Are Available

The range of services provided through Home and Community Based Services (HCBS) is as varied as the people who receive them. Services are available to help people maintain their health, promote decision-making, manage their homes or personal resources, to augment their ability to communicate, or help meet their communication needs. Services are available to provide greater mobility and transportation, support the development of relationships and promote socialization. In addition, services can enable people to take part in community functions, to learn, to work, to grow. In short, the service system helps people with disabilities live an everyday life, just like anyone else.

But individuals and families demand more. They rightfully demand that we provide them tools to ensure the health, wellness, and safety of themselves and their loved ones, so that they are able to live safely within the community. We have provided a number of tools to facilitate this, such as:

Unjustified Segregation is Unlawful

By 1999, the debate regarding the appropriateness of care for people with disabilities reached the US Supreme Court. As a result of the Olmstead Act, the Supreme Court concluded that the unjustified segregation of people with disabilities is unlawful under the Americans with Disabilities Act. It further provided that states are responsible for providing community placement, if there are available resources for it, and established a waiting
President’s Message
Sarah Holland

I have followed and listened to many voices as Pennsylvanians debated over the closing of two state centers. I heard the messages following the announcement, at the public hearings, during the legislative process, and the discussions on social media, and in the papers. I was struck by so many emotions and thoughts.

I am the parent of two children. My adult son, who experiences many complex medical, communication, and mobility needs and my second son who has entered into his first year of high school, have always been my guides and teachers. What struck me and gave me pause is that after many years of research, policy, and success stories, we still are addressing the divergent voices that seek to keep institutional care open. We continue to hear counter arguments about this research and knowledge, and falsehoods about the outcomes of institutional care.

I can relate to the fear that was driving some of this rhetoric. I am first and foremost a parent - a parent of a young man with very complex needs and his brother, who enjoy a positive and loving relationship with each other. Our family continues to work with the system, the system of supports, and the providers that support my son. I want my son to thrive. And I must say I am, at times, not feeling as successful as I would like to. I understand the fear that drives families. We want to ensure that our loved ones have the best care.

And I was disappointed by some of our legislative voices. Some voices were suddenly concerned about a group of people, that previously, they hadn’t paid much attention. Some legislators who have supported people with disabilities in the past, didn’t find their path to support the closure of these two centers. Some voices became very involved in conversations around job losses and pay, yet, these same voices haven’t supported an increase in the minimum wage or taken action to address the pay of direct care staff.

I am so proud of the work of The Arc of Pa and its chapters. We actively and clearly articulated the voice that was needed at this time. Strong and clear, Institutions are not the answer. They are not the answer to fear. They are not the answer to ensuring everyday lives. They are not the answer for supporting individuals with complex needs. They are not the answer to ensuring those who care for people with disabilities are paid a living and fair wage. Institutions are not the answer!

As we move forward, I know I will continue to be struck by these divergent voices. But as a member of The Arc, I know that I am not on this journey alone. The Arc has been a voice in my head throughout my parenting journey. It gives me confidence and pushes me to not be led by fear. I am a believer that the community has incredible capacity, that both of my sons belong and that I, with the support of The Arc, will continue to address issues of provider capacity, ensuring that individuals with intellectual and developmental disabilities have an Everyday Life. I will continue the work to ensure that the supporters in this work are treated as the professionals that they are - both in status and pay. That is our work and I believe in the power of The Arc and the capacity of our communities. Our work continues and I am thankful for The Arc to help lead and guide us.

-Sarah Holland
The Arc of Pennsylvania was started 70 years ago by parents of children with intellectual and developmental disabilities who fought against society’s expectation that their children be sent to state institutions. It was certainly not unusual at that time, and for years to come, for parents to hear that their son or daughter’s needs could best be met by living at one of Pennsylvania’s many large state institutions for children and adults with intellectual disabilities.

Our foremothers and forefathers worked tirelessly to change this reality. They created community services. They monitored state centers. They filed lawsuits, and worked with state governments to create a comprehensive community system of supports. Thanks to their work, and the movement they created, life for children and adults with intellectual and developmental disabilities and their families is far better than it was in the early 1950’s.

The Arc of PA continues to be governed by a volunteer board of people with disabilities and parents who care passionately. This past year, that passion was tested. Following the Governor’s announcement to close Polk Center in Venango County and White Haven Center in Luzerne County, two bills were introduced in the Pennsylvania legislature. If passed, these actions would have stopped the closure of these two centers.

The Arc of PA, along with other disability advocates, families, and professionals worked to stop the passage of these bills. With the Governor’s veto on February 12, the Department of Human Services will continue to work with individuals and families in the closing of Polk and White Haven over the next 3 years. We could sit back on our laurels and take a rest. But our work is NOT DONE! We still have much to do to assure that people with intellectual and developmental disabilities have the kind of life they deserve and want.

Our work continues in these important areas:
- Assure that people are safe wherever they choose to live, work, and play.
- Advocate for funding for home and community based services for people who are waiting for services, and in particular, the 5,000 people on the emergency waiting list.
- Assure that people receive the supports, including access to technology, to live as independently as they can and wish.
- Advocate for funding for Pennsylvania schools so that all students graduate with the skills they need to succeed in adult life.
- Support full implementation of Employment First which results in people with intellectual and developmental disabilities having life sustaining jobs.
- Advocate for funding and training for the professionals who are providing critical home and community based services, including our early intervention providers.

Please join The Arc of PA in this work. Regardless of how your legislator voted on Senate Bill 906, we need their support for people with disabilities. Reach out to them and all decision makers. Extend the olive branch! All of us are needed to make change.

Sincerely,

Sherri Landis
1. The Health Risk Screening Tool (HRST) to help assess health risks.
2. The 8 Health Care Quality Units (HCQUs) that work across the state to build capacity and competency within the physical and behavioral health care system.
3. The Community of Practice (CoP), which partners with individuals, families, and regional leaders to provide training, mentoring, and resources for individuals and families on topics such as LifeCourse, a set of tools to help people plan for their future and support decision making.

Why does ODP support and advocate for community life? Simply put, people do better when they live in a community, when they have the opportunity to take part as members of the community, when they belong, when they have the chance to work and earn a living like everyone else, and when they have the opportunity to continually learn and grow. The desire to belong to a community, to take an active part in it, and to grow along with it is something all Pennsylvanians have in common. Why does ODP support this? Because it is the best thing for the people we serve, for their friends and families, and for everyone.

Eileen Quinn is the Director of Training and Communications for the Office Developmental Programs.

LIFE SHARING: MEET PAUL NEWSOME

The Arc of Crawford County has had the honor and privilege of supporting Paul Newsome since 1992. Paul Newsome receives a residential service called Life Sharing with the Sommers Family in Cochranton, Pennsylvania.

Paul is a man with exceptional gifts and some significant needs. At the age of 13 months, Paul needed to leave his natural family’s care. He was placed into foster care with Merv and Lydia Sommers. When he turned 21 and needed to exit foster care, Paul and the Sommers entered The Arc of Crawford County’s Life Sharing program. That was about 26 years ago.

Paul is 47 years old and has led an extraordinary life with his family. What others see on the outside looking in is a man who has intensive support and medical needs (repositioning every 2 hours, track ceiling lift for transfers, and a person who needs assistance for all his needs). He uses eye blinks and a communication board to communicate his wants and wishes.

What we see is a man who has been loved fiercely and supported intensively and who is living his best life. Paul is immersed in his church family; he is a greeter, an usher, and an elder. He is a prominent member of the Meadville & Cochranton community - attending sporting functions, bowling at the local lanes weekly, and enjoying ice cream at local parlors every chance he gets.

Paul is a friend to many. He meets his friends for iced coffee every week and enjoys rowdy discussions about his sports teams from Pittsburgh (Steelers, Pirates, and the Penguins). Paul is the beloved member of the Sommers’ family – a loving son, a supportive brother, and a fun uncle to his niece and nephews.

What people see on the outside as a really hard and challenging life, full of disability, needs, support and medical needs (repositioning every 2 hours, track ceiling lift for transfers, and a person who needs assistance for all his needs). He uses eye blinks and a communication board to communicate his wants and wishes.

What we see is a man who has been loved fiercely and supported intensively and who is living his best life. Paul is immersed in

Pictured: Paul Newsome, Merv & Lydia Sommers - Life Sharing Providers & JoAnn Lee, Life Sharing Program Manager.

For More Information about The Arc of Crawford County’s Life Sharing Program, contact: JoAnn Lee, Life Sharing Program Manager, The Arc of Crawford County, Inc.; 222 Chestnut Street, Meadville, PA 16335; jlee@arcofcrawfordcounty.org.
PEOPLE & SYSTEMS: WORKING TOGETHER FOR AN EVERYDAY LIFE

As parents of a child with severe autism and intellectual disabilities, Mike and Meg Eisert have had to face many challenging issues. One of the most difficult was dealing with their son’s insomnia. For several years, staff from the Barber National Institute’s Agency with Choice Program helped the couple care for Greg, now 23 years of age, in the Eisert’s home. “The staff would leave at midnight and then I would take over,” recalls Mike. “Sometimes, I would be up with him the entire night and then have to go into work in the morning.”

Both Meg and Mike began thinking about what would happen to their only child as they aged, and what will happen after they are not here to care for him. The Eisert’s came up with 14 different options that they closely reviewed before deciding on the one that changed their lives: turning their family home into a residential community group home for Greg. “It’s turned out much better than we ever expected,” said Mike. “When you have a child with a disability you’ll never have a perfect world. But we really are in a great place right now. And so is Greg.”

Mike points to many benefits from leasing their home to become a group home. There is the peace of mind knowing that staff who have been trained to meet Greg’s needs are there 24 hours day/seven days a week; nursing case management ensures Greg’s medical plan is followed and transportation is provided for all medical appointments; staff prepare well balanced meals for good nutrition and a structured schedule with activities in the community.

Over the past year, Mike said that the group home staff have “become like family.” They take him out to do activities that he likes, such as swimming at the YMCA. Mike and Meg are still involved, attending medical appointments and going on family outings such as a sailing program for persons with special needs.

Greg’s favorite activities include volunteering at the Salvation Army and a local food bank; going for walks at Presque Isle State Park and other area parks; visiting the local environmental center; attending sporting events such as hockey, baseball or basketball games; and enjoying lunch or snacks at various local eateries.

The efforts to provide Greg with the best opportunities to live in and be involved in his community have been successful for him and his family. “Greg has very complex needs, but this shows that those needs can be met, and the individual can successfully live in the community when everyone involved - the family, the provider, the county and the state – really work together to do what is best for that person,” said Pam Baker, vice president Program Development/Family Focused Services at the Barber National Institute.

For more information about the Barber National Institute, visit their website at: https://www.barberinstitute.org/.

NUMBER OF CHILDREN UNDER 21 RECEIVING HOME AND COMMUNITY BASED SERVICES

10,188*

*(DURING FY 2018-2019)
ROSE HAS FLOURISHED IN THE COMMUNITY

Rose has lived many places throughout her life. With one family, she found her home. Earlier in her life, she transitioned from a county home to Polk State Center in Venango County where she resided for over 23 years. After Polk, she spent over five years at a behavioral health inpatient facility. Finally, she transitioned to a community home operated by ACHIEVA. At that home, Rose met Elva, an ACHIEVA employee.

Elva and Rose became close friends and were described as two peas in a pod. They shopped, traveled, and crafted together and ultimately, they lived together as a family when Elva became an ACHIEVA Life Sharing provider. Life Sharing connects families in the community who want to share their homes with a person with a disability. Life Sharing provided Rose the opportunity to reside in a nurturing and caring environment. Remarkably, she no longer needed the medications that were previously relied upon to manage her mood and behavior.

Rose lived with Elva for 17 years until Elva passed away in 2016. Again, something remarkable happened. Elva’s daughter, Michele, carried on her mother’s loving legacy; she brought Rose into her own family as a Life Sharing provider. Rose joined Michele and her family as they moved to a new home that would accommodate all of their needs. They could not be happier!

Thanks to Elva and Michele, Rose has learned the joy of community and perpetual love in a place she calls home.

ACHIEVA envisions a community where all people with disabilities lead lives of personal significance. Its services range from early intervention therapies and employment supports to special needs trusts and supports in the home and community. ACHIEVA advocates for, empowers, and supports people with disabilities and their families throughout their lives. For more information about ACHIEVA: https://www.achieva.info/.

NUMBER OF OLDER ADULTS RECEIVING HOME AND COMMUNITY BASED SERVICES

4,025*

*(DURING FY 2018-2019)

Join Us!

The Arc of Pennsylvania’s 2020 Advocacy & Policy Conference
June 1-2, 2020 - Crowne Plaza, Harrisburg, PA

Highlights include:

- The Arc of PA Board & Annual Membership Meetings
- Legislative Reception - Come visit with your local legislators!
- Disability Rally at the State Capitol
- Plenary Sessions: "Advancing Employment for People with Intellectual Disabilities: Making Connections for the 21st Century Workforce"

Check out The Arc of PA’s Website at www.thearcpa.org for details!

Note: We understand that these are uncertain times and will continue to monitor the situation with Covid-19. We will let you know of any changes to the event.
John and Milo live in Altoona, Pennsylvania. Milo, an orange tabby cat, adopted John when his previous owner passed away. He needed to find a new home. Milo knew John, and just moved down the hall into John’s apartment. Milo is quite satisfied with his life now. John says that he can be a bit ornery - he sits on the countertops in the kitchen where he is not allowed and he will knock things off the kitchen table, enjoying the sound of things falling on the floor.

John’s story is just as interesting. When he was just a toddler, his parents took him to live at the Selinsgrove State Center. He lived there for 20 years. His older brother and sister never knew he even existed. They came to meet him at Selinsgrove to tell him that their mother had died. After meeting John and learning about his life, they took him back to Altoona that very day. John remembers his brother saying, “I’m getting you out of here.”

He loved living back in his community and getting to see his family on a regular basis. At first, he lived in a group home, but later learned that he really wanted to live on his own. With his advocacy and “speaking out”, he moved into his own apartment.

John’s says that he has a great life. He lives in an apartment building that is funded through HUD (Housing and Urban Development) - that helps him afford his apartment. He has lots of friends that live in the building and they do lots of things together like bowling, listening to music, and just spending time together. The apartment building is centrally located to downtown Altoona so John and his friends can go to festivals, Sheetz, and the Dollar Store. He makes good money now at a variety of jobs and he can buy what he needs. With support of Skills of Central PA, John says, “I live the life I want.”

Source: John Knorr lives in Altoona, PA. Skills of Central PA is a human services organization that strives to help people living with behavioral health, intellectual or development challenges. Skills believes everybody has the capability of becoming the best version of themselves. Our supportive staff partners with individuals and families in their journey to overcome obstacles. https://www.skillsofcentralpa.org.

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PROTECTING HEALTH, SAFETY, AND RIGHTS

The mission of the Pennsylvania Department of Human Services, Office of Developmental Programs (Department) is to support Pennsylvanians with intellectual disabilities, developmental disabilities, and autism to achieve greater independence, choice, and opportunity in their everyday lives.

The Department is committed to protecting the basic human rights of individuals with disabilities, including the right to be protected from mistreatment and preventable harm. There are numerous oversight and quality controls in place to achieve this goal, which include:

- **Human Services Regulatory Administration**
  Regulatory administration is the application and enforcement of rules and regulations that govern service providers’ operations.

Human services regulatory administration, also known as human services licensing, involves measuring compliance with the minimum requirements to support individuals with an intellectual disability or autism in a day or residential setting.

These standards provide for protections in areas such as physical site and fire safety, staffing requirements, medication administration, restrictive procedures, and service provision. When regulatory violations are found, the Department ensures that providers develop and fully implement plans to correct the violations and prevent them from happening again.

The Department also provides technical assistance to providers to help them understand and better comply with regulatory requirements.

- **Programmatic Regulatory Administration**
  Programmatic regulatory administration involves ensuring that providers comply with state and federal rules and regulations relating to the delivery of Medicaid Home and Community-Based Waiver Services. These rules and regulations go beyond the standards established by human services licensing to ensure that services are delivered in a safe, effective, and high-quality manner.

The Department’s primary method for ensuring programmatic compliance is the Quality Assessment and Improvement (QA&I) process. The process includes mandatory provider self-assessments and on and offsite reviews by Department staff.

continued on page 8
Like human services licensing, providers must develop and fully implement corrective action plans in response to identified noncompliances.

The Department compiles all data collected from the QA&I Process into an Annual Statewide Quality Assessment and Improvement Report. Among other things, this report represents statewide provider performance relating to quality of services and supports and person-centered promising practices.

Incident Management

Incident management is a type of risk mitigation strategy that requires providers to:

• Report incidents to the Department;
• Investigate incidents using a Department-certified investigator;
• Take immediate action to protect impacted individuals’ health, safety, and rights;
• Take corrective action in response to incidents that both mitigate risk(s) and decrease the chance of a future occurrence of a similar incident;
• Build organizational policies and structures to support incident management; and
• Implement quality and risk management processes for the analysis and interpretation of individual and aggregate incident data.

Both human services and program regulations require providers to adhere to incident management requirements. The Department reviews incidents both individually and in the aggregate to ensure that providers are adhering to all incident management requirements. In some cases, reported incidents trigger an investigation by the Department to ensure overall rule compliance.

Sanctions and Enforcement

Sanctions, also called “adverse actions” or “enforcement actions,” are penalties used to provide incentives for compliance with law, rules, and regulations. The Department may implement an array of sanctions in response to noncompliance with rules. These include, but are not limited to:

• Issuing a provisional (warning) license;
• Revoking a license to operate;
• Recouping, suspending or disallowing payment for services not rendered or rendered improperly;
• Terminating a provider agreement for participation in the Department’s Home and Community-Based Waiver programs;
• Prohibiting the provision of services at a specified service location;
• Prohibiting the enrollment of a new service location; and
• Removing an individual from a service location.

If a provider complies with the rules, the provider will not be subject to penalties. If a provider does not comply with the rules, the provider may be subject to penalties. Sanctions are not punishment or retribution for wrongdoing; the primary benefit of sanctions is to compel compliance. Sanctions also give the Department the authority to take immediate steps to protect participant health and safety in crisis situations.

For More Information: Additional information about the Department’s measures for protecting individual rights is available at www.MyODP.org. MyODP also contains information about other Departmental programs and initiatives. Human services regulations (55 Pa.Code Chapters 20, 2380, 2390, 6400, and 6500) and program regulations (55 Pa.Code Chapter 6100) can be found at www.pacodeandbulletin.gov.

LEARN MORE, DO MORE

Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc Pennsylvania manages PIE for the PA Developmental Disabilities Council. Email us at pie@thearcpa.org to receive electronic alerts and the quarterly newsletter.

Please visit our website at
BUILDING A LIFE IN THE COMMUNITY

Derek Gardner doesn’t have just one football player that he likes, he loves the entire Steelers team. It’s hard to live in Western Pennsylvania and NOT love the Steelers, of course! He also loves puzzles, especially crossword puzzles and going to the movies. Derek describes himself as a good worker, a believer in God, a lover, and a person who always wants to help others.

Derek first began working for Arc Human Services under the small group employment program in 2017 at Supply One in Washington, PA. Supply One is a leader in packaging solutions. Derek did so well at Supply One, he was offered a full time position with the company. The company appreciates that he completes all his work, he is reliable, and has such a great work ethic.

Derek really likes his job with Supply One. He makes boxes and prepares them to be sold to companies for packaging their products. His full time job includes the same benefits enjoyed by other workers such vacation and sick days. Most importantly, Derek likes the people he sees every day at work. He enjoys talking to his colleagues about sports and other topics of interest.

Arc Human Services is a nonprofit provider of employment and training as well as housing and support services to individuals with intellectual and developmental disabilities and mental health challenges in southwestern Pennsylvania. For more information check out their website at: http://www.archumanservices.org/.

NUMBER RECEIVING LICENSED/UNLICENSED RESIDENTIAL SERVICES 14,714* *(DURING FY 2018-2019)

NUMBER RECEIVING COMMUNITY-BASED EMPLOYMENT SERVICES 5,515* *(DURING FY 2018-2019)

NUMBER RECEIVING LIFE SHARING SERVICES 1,491* *(AS OF 2/29/2020)

In Touch is an electronic newsletter that is emailed every 2 weeks. It shares the most up to date information about legislative and governmental actions, resources, and events. If you’d like to receive it, email Shirley Keith Knox at skeithknox@thearcpa.org.

In Touch
Census 2020
YOU COUNT! BE COUNTED!

WHAT IS THE CENSUS?
Every 10 years, the government counts every person in the country. They ask them questions on where they live and who lives in their home. Only 1 person in each home needs to fill out the Census.

How will I get a Census paper?
The Government will mail you a census letter in March 2020. It will have instructions on how to fill it in.

How do I fill out the Census?
You can fill out the census three ways: on paper; by phone; or online.

Is the Census accessible?
There are guides to help people with disabilities fill out the census. There are large print guides and braille guides. If you have questions, you can call: 1-800-923-8282 or go to 2020census.gov.

For more resources, visit: thearc.org/census

#2020Census
"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.” - Margaret Mead
I met Eleanor Elkin when I was a sophomore in college, 45 years ago. I was the president of The Youth Arc of Erie County, PA, and she was already a legend.

That summer, The Youth Arc of Pennsylvania held our annual conference. Eleanor was the dinner speaker and I was most fortunate to sit next to her that evening. While I don’t remember what she spoke of that night, I do recall the feeling of knowing that I was in the presence of someone very special. It would be many years until I knew just how special she was.

Throughout my work with The Arc, I sat with Eleanor on occasion. Each time she would share about the early Arc battles, President Kennedy, Eunice Shriver, Pennhurst, The Right to Education, and how The Arc works to make positive change for people with disabilities

I can think of only one word that best describes Eleanor Elkin. ADVOCATE. ADVOCATE is one of those words that can be both a noun and a verb. Eleanor was an advocate, who would advocate for countless people with intellectual and developmental disabilities and their families. This kind, small, but powerful woman gave everything so that our brothers and sisters with intellectual disabilities could have everything.

Eleanor died at the age of 103 on December 4, 2019. She was a leader in The Arc movement, serving as President of The Arc of PA from 1957-1959 and as President of The Arc U.S. from 1967 -1968. Ken Oakes is a Past President of The Arc of Pennsylvania, Past President of The Arc of Philadelphia, and serves on the Board of Directors of The U.S.