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House of Representatives
COMMONWEALTH OF PENNSYLVANIA
HARRISBURG

HOUSE DEMOCRATIC POLICY COMMITTEE HEARING
Topic: Human Services for Disabled Community
Lehigh Valley Hospital-Muhlenberg – Bethlehem, PA
July 24, 2018

AGENDA

2:00 p.m. Welcome and Opening Remarks

2:10 p.m. Sheila Theodorou
Director of Bureau of Supports for People with Intellectual Disabilities
Pennsylvania Department of Human Services

2:40 p.m. Panel from Lehigh County Human Services Department
- Josh Bridges, Administrator of Mental Health and Intellectual Disabilities
- Mike Paulik, Deputy Administrator for Mental Health

3:10 p.m. Panel of Providers:
- Ed Norris, MD, Department of Psychiatry Chair, Lehigh Valley Health Network
- Shane Adams, Supports Coordinator Supervisor, Service Access and Management

3:40 p.m. Panel from Pennsylvania Waiting List Campaign
- Ned Whitehead, Advisor
- Tom Carasiti, Advisor

4:00 p.m. Panel of Parents

4:20 p.m. Closing Remarks

Waiting List for Services

Sheila Theodorou, Bureau Director

Bureau of Supports for People with Intellectual Disabilities

Office of Developmental Programs

Representative McNeill's public hearing on Human Services for the Disabled Community

July 24, 2018

pennsylvania
DEPARTMENT OF HUMAN SERVICES

Good afternoon Representative McNeill, members, and staff. My name is Sheila Theodorou and I serve as director for the Department of Human Services (DHS), Office of Developmental Programs (ODP) Bureau of Supports for People with Intellectual Disabilities. On behalf of Secretary Miller, I would like to thank you for the opportunity to present testimony regarding DHS's efforts to support citizens of the commonwealth with intellectual disabilities (ID) and autism and their families achieve greater independence, choice, and opportunity in their lives.

DHS provides services for more than 56,000 people with ID and/or autism. The vast majority of the people DHS serves, over 74% or 45,400 individuals, live at home with their families. Services are funded primarily through federal Medical Assistance and with state and local funds through county government. There are four federally approved and funded home and community-based waiver programs for individuals with ID and/or autism, which currently serve 32,008 individuals. The four waiver programs are: the Person/Family Directed Supports (P/FDS) Waiver (12,659); the Consolidated Waiver (17,670); the Adult Autism Waiver (701); and the Community Living Waiver (978). In addition, DHS operates the Adult Community Autism Program (ACAP), which is a managed care program for individuals with autism (200). DHS also funds institutional services in private intermediate care facilities for individuals with an intellectual disability (ICF/ID) (1,906) and state-operated ICF/ID facilities (791). County programs provide services to approximately 20,000 additional individuals with state and county funds.

Services have evolved over the years. We have made tremendous progress from the 1970s when most individuals received services while living in an institution, away from their families and community. Today, most individuals are living with their family, or in supported homes in the community.

Our progress includes more than changing the location of services. Providing services to people in the community has changed the program's focus and goals. Our goal is not simply to provide care, but to create opportunities for growth and learning, help people get a job, practice their faith, join a health club, make friends and "hang out" with them, and become civically engaged –

in other words – to fully participate in their community and live an “everyday life,” like yours and mine.

While we provide services to more than 56,000 people in our service system, there is still a significant number of people and families who need, but do not receive, services.

The number of individuals waiting: As of May 2018, there are 13,499 individuals with ID who have requested services. For the ID waiting list, 5,238 people are listed as "emergency," which is defined as needing services in the next six months; 5,035 are listed as “critical,” which is defined as needing services within the next two years; and 3,226 are listed as “planning,” which is defined as needing services in more than two but fewer than five years.

The instrument used to collect information about people waiting for services provides basic demographic information about each person, but it does not provide a standardized assessment of each person’s clinical and support needs; nor does it provide information on each family’s situation, which would help us shape our program design and budget more accurately.

Waiting and receiving services: Of the 10,273 people who have reported that they will need services within the next two years (emergency and critical categories), 6,405 are getting some level of service while the remainder are not receiving any services. Of the 5,238 in the emergency group, 3,422 are receiving services, 1,867 are enrolled in one of our waivers and have expressed a need for additional services, and 1,555 are receiving some limited services from the county programs. While a large percentage of people in the emergency category are receiving some services, the services people are receiving are typically either through the P/FDS Waiver, which is capped at $33,000 per year, or through the county. The same pattern holds true for individuals on the critical list. Of the 5,035 individuals, 2,983 are receiving some type of service through the P/FDS Waiver or county. Among the planning group, of the 3,226 individuals listed as needing services in 2-5 years, 1,864 individuals are receiving some level of service.

The ages of individuals waiting: Individuals on the ID waiting list range in age between three and 88 years of age. Almost 50% of the individuals in the critical and emergency categories on the waiting list range between 15 and 27 years of age. A large number of these individuals are young adults who are beginning the transition from school to adulthood or have graduated from school and are home with a working or older adult.

To summarize the data: There are more than 10,273 people who have reported they will need services within the next two years (emergency and critical categories); 6,405 are getting some level of service and the remainder are not receiving any services. The majority are individuals in their late teens to mid-twenties whose parents work. The data suggests that our service expansion should focus on young adults who are transitioning or have transitioned from school as well as their families. The provision of adequate supports for these individuals would allow them to live at home and obtain work more easily. This additional support would allow parents to maintain their family member at home rather than seek more costly out-of-home services.

DHS actions to address the waiting list:

Service expansion:

With the support of Governor Wolf and the legislature, investments in the 2017-18 and 2018-19 budgets provided the most significant service expansions for individuals with ID and/or austism waiting for services. As a result of these expansions, resources have been allocated to serve every student 21 years of age graduating from school, and waiver services have expanded to include eligibility for individuals with autism. The 2017-18 budget included new resources for 1,870 people in three of our waivers, plus it expanded supports coordination for more than 2,000 people who are waiting for services. Every individual will receive support coordination to help plan and gain access to resources in their commmunities. The recently passed 2018-19 budget includes $74 million in new investments to assist individuals with ID and/or autism. Almost $16 million of these new funds will enable an additional 965 individuals with ID and/or autism to access waivers to provide supports and services so they can remain in their home and community and live an “everyday life.”

Improving supports to families:

Recognizing that a majority of people receiving services are living with families and that many families are looking for additional in-home supports, DHS is implementing program initiatives to improve supports to families.

Pennsylvania is joining the **National Supporting Families Collaborative** with 15 other states to explore together ways to transform state policies and programs to better support individuals and their families. DHS will invite six counties in Pennsylvania to participate in a statewide collaborative to redesign local programs and practices. Local collaboratives will include individuals and families, local community organizations, and relevant public entities to develop community solutions. Most importantly, the National Supporting Families Collaborative will focus on methods of supporting families of individuals on the waiting list.

As we prepare to launch this initiative, DHS has sponsored the **PA Family Network,** a family-operated program that will provide information and training to families across the commonwealth. The network's efforts will build the capacity of families to plan for the future and access resources throughout the community.

Planning for the future: DHS plans to improve the instruments and methodology used to identify and plan for people on the waiting list. DHS intends to maintain one list for people with ID and/or autism (while maintaining an indicator for each unique diagnoses) and to design a single assessment that will provide adequate information about each person's disability, the type and degree of support the individual needs, and his or her living situation including the needs of the family in order to improve our planning and budgeting. In addition, DHS is looking to standardize the criteria used to prioritize individuals on the waiting list for services.

Program expansion in the future will focus on two key principles, valuing what is important to people with ID and/or autism and their families, and acknowledging that people with ID and/or autism have a right to an "everyday life." An "everyday life" is about having opportunities, relationships, rights, and responsibilities. It is about being a member of the community, having a valued role, and making a contribution to society. Our services will focus on opportunities to use their skills to get a job, engage in society, and live an "everyday life" like any other Pennsylvanian.

Thank you for the opportunity to provide this information to you today and thank you for your continued support of Pennsylvanians with intellectual disabilities and autism. I will be happy to answer any questions you may have at this time.

Office of Developmental Programs (ODP) 2018

LEHIGH COUNTY OFFICE OF INTELLECTUAL DISABILITIES

Mission & Vision

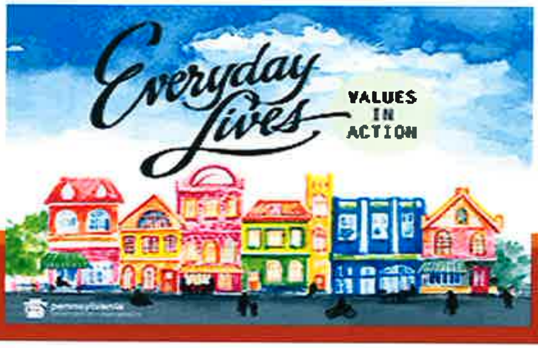
The mission of the Office of Developmental Programs (ODP) is to support Pennsylvanians with developmental (intellectual) disabilities to achieve greater independence,
choice and opportunity in their lives. The office seeks to continuously improve an effective system of accessible services and supports that are flexible, innovative and person-centered.

Everyday Lives

Everyday Lives is the core philosophy and framework of the State of Pennsylvania's Office of Developmental Programs (ODP). Originally introduced in 1991, Everyday Lives is deeply rooted in the concept of Self-Determination and Positive Approaches. In 2016, ODP revisited Everyday Lives, and involved 265 stakeholders to evaluate best practice and determine the most important steps for ODP to take to improve service delivery. The result was ***Everyday Lives, Values in Action.***

The fundamental concept of Everyday Lives is that, with the support of family and friends, individuals with disabilities decide how to live their lives and what supports they need. It also means that they are responsible for their decisions and actions.

ODP considers and ensures that the impact of every decision, rule or regulation of its staff or those working on its behalf, continues to support and promote the ideals of Everyday Lives.



Eligibility

- **Intellectual Disability**
  - IQ testing
  - Adaptive Functioning/skill Deficits
  - Onset before age 22

Autism

- Diagnosis of Autism Spectrum Disorder
- Adaptive Functioning/skill Deficits
- Onset before age 22

Developmental Disability

- Diagnosis of Developmental Disability
- Adaptive Functioning/skill Deficits
- Child is 8 years of age or younger.

ID Eligibility: IQ testing

A licensed psychologist, certified school psychologist, psychiatrist, or licensed physician who practices psychiatry certifies that the individual has significantly sub-average intellectual functioning which is documented by either:

- i. performance which is more than two standard deviations below the mean of a standardized general intelligence test; or
- ii. performance which is slightly above two standard deviations below the mean of a standardized general intelligence test during a period when the person manifests serious impairments of adaptive behavior. In such situations, the burden is on the examiner to avoid misdiagnosis and to rule out such factors as emotional disorder, social conditions, sensory impairment or other variables which might account more readily for observed deficits in adaptive behavior.

Autism Eligibility: Diagnosis of Autism Spectrum Disorder

A licensed psychologist, certified school psychologist, psychiatrist, developmental pediatrician, or licensed physician who practices psychiatry certifies that the individual has autism spectrum disorder as documented in a standardized diagnostic tool.

DD Eligibility:
Diagnosis of Developmental Disability

A licensed psychologist, certified school psychologist, psychiatrist, developmental pediatrician or licensed physician who practices psychiatry certifies that the individual has developmental disability which is defined as a condition of substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in an intellectual disability or autism likely to continue indefinitely as documented in a standardized diagnostic tool.

ID & Autism & DD Eligibility: Adaptive Functioning

A qualified intellectual disability professional (QIDP) who meets criteria established in 42 CRF 483.430 certifies that the individual has impairments in adaptive behavior based on the results of a standardized assessment of adaptive functioning which shows that the individual has either:

- significant limitation in meeting the standards of maturation, learning, personal independence, and/or social responsibility of his or her age and cultural group; or
- substantial functional limitation in three or more of the following areas of major life activity:
  - ☐ self-care
  - ☐ receptive and expressive language
  - ☐ learning
  - ☐ mobility
  - ☐ self-direction
  - ☐ capacity for living independently
  - ☐ economic self-sufficiency

ID & Autism Eligibility: Onset before age 22

Documentation substantiates that the individual has had these conditions of intellectual and adaptive functioning manifested during the developmental period which is from birth to the individual's 22nd birthday.

Structural set up

- Office of Developmental Programs & Bureau of Autism Services
- State office part of DHS – Department of Human Services (formerly DPW)

- Administrative Entity – agent of the state
- Each county or county joinder has one

- Supports Coordination Organization
- “case workers”

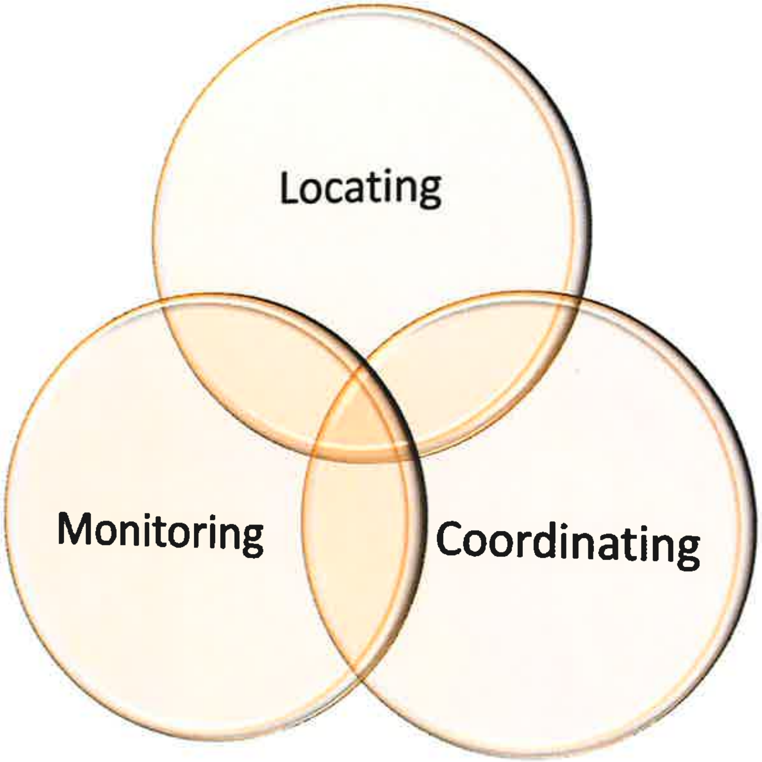
Role of Administrative Entity

An Administrative Entity (AE) is a county/joinder with an agreement/ contract with the Department to perform operational and administrative functions delegated by the Department, related to the Department's approved Consolidated, Community Living and Person/Family Directed Support (P/FDS) Waivers.

Role of the Administrative Entity Sample of tasks

- Determine Eligibility
- Manage Waiver Allocation
- Approve & Authorize Services for Individuals
- Qualify & Monitor Providers
- Oversee Support Coordination Organization
- Develop/Implement Quality Management Plans

Roles of the Supports Coordinator



Locating

Monitoring

Coordinating

Roles of the Supports Coordinator: Locating

Locating services and supports:

- Linking, arranging for, and obtaining services specified in the Individual Support Plan (ISP)
- Participate in the ODP standardized needs assessment process and facilitate completion of additional assessment
- Locate resources for the development of the ISP
- Identifying willing and qualified providers
- Assist in gaining access to needed services

Roles of the Supports Coordinator: Coordinating

Coordinating development & management of the ISP:

- Person centered planning
- Periodic review of the ISP and standardized needs assessment
- ISP planning
- Coordinating with entities, resources, programs, and individual's natural supports
- Facilitate resolution of barriers to service delivery
- Disseminate information and support

Roles of the Supports Coordinator: Monitoring

Monitoring of services per the ISP:

- Individual health and welfare
- Progress on outcomes
- Satisfaction with services
- Service modifications
- Advocacy

Funding

Base

- Administered by each county

Waiver

- Person/Family Directed Support (P/FDS)
  - Up to 33,000 dollars in services + up to 15,000 dollars for competitive integrated employment supports
  - Can not be used for residential placement
- Community Living Waiver
  - Up to 70,000 dollars in services
- Consolidated Waiver
  - Services to meet all needs of individual

Services that are available

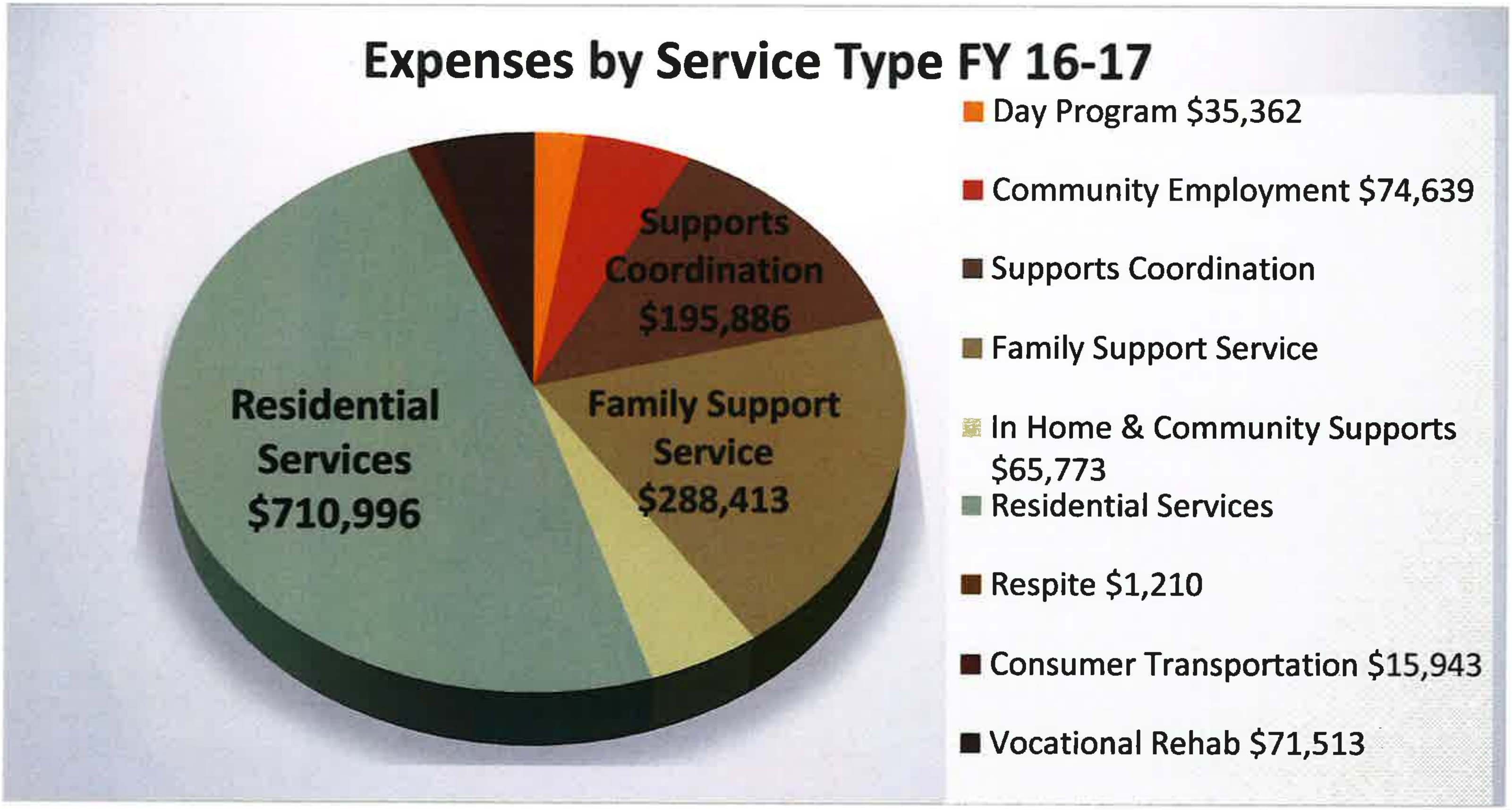
- Assistive Technology
- Behavior Support Services
- Benefits Counseling
- Companion Services
- Consultative Nutritional Services
- Community Participation Supports (CPS)
- Educational Support Services
- Family/Caregiver Training and Support
- Employment Services (expanded)
- Family Living
- Financial Management Services
- Home Accessibility Adaptations
- Homemaker/Chore
- Housing Transition and Tenancy Sustaining Services
- In Home and Community Support
- Nursing Services
- Older Adult Licensed Day Habilitation
- Residential Habilitation
- Respite
- Specialized Supplies
- Supported Employment Services
- Supported Living
- Supports Broker Services
- Supports Coordination
- Therapy Services (expanded)
- Transportation
- Vehicle Accessibility Adaptations

Intake Contact

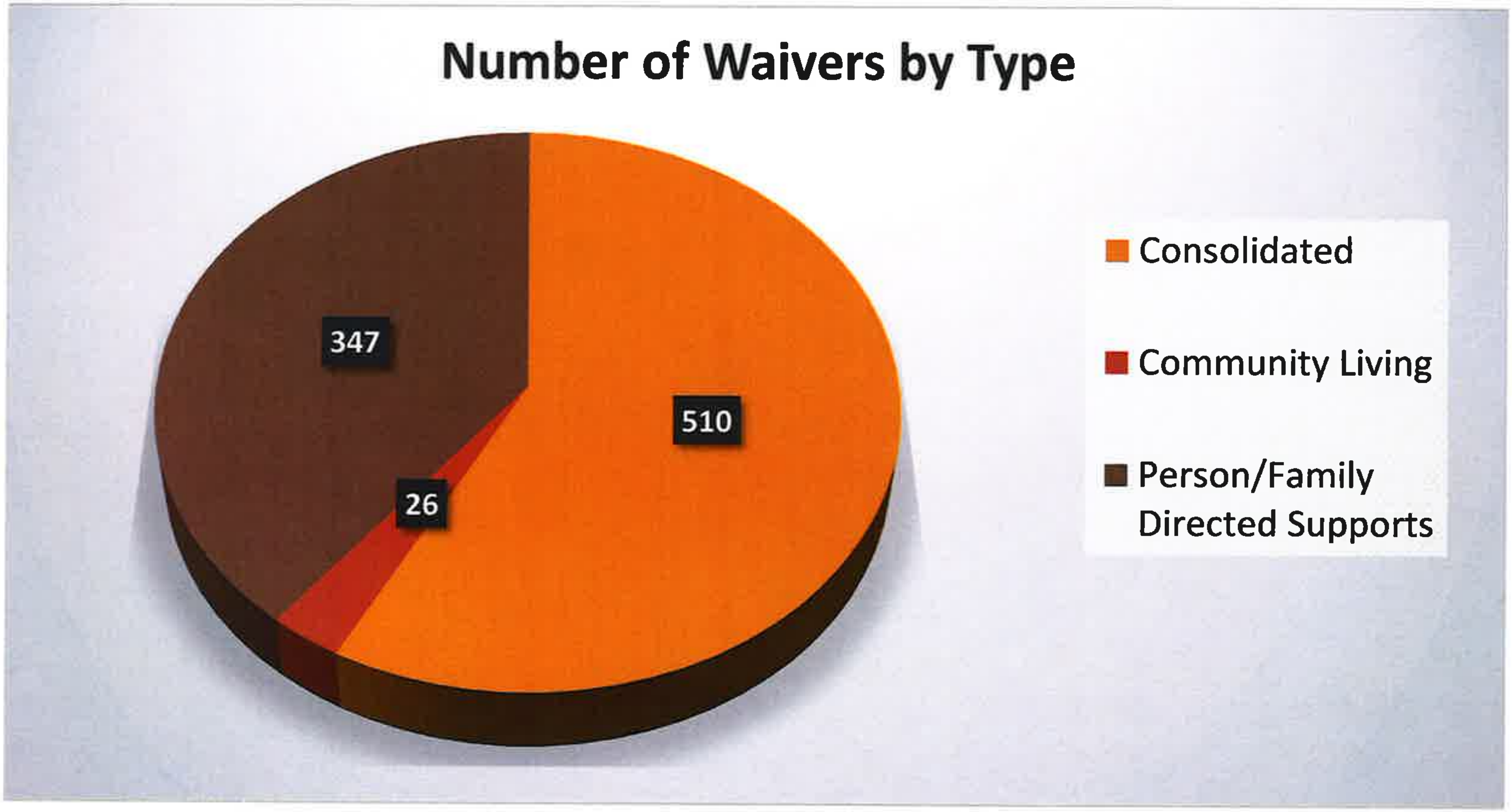
Lehigh County

Information & Referral
(610) 782-3200

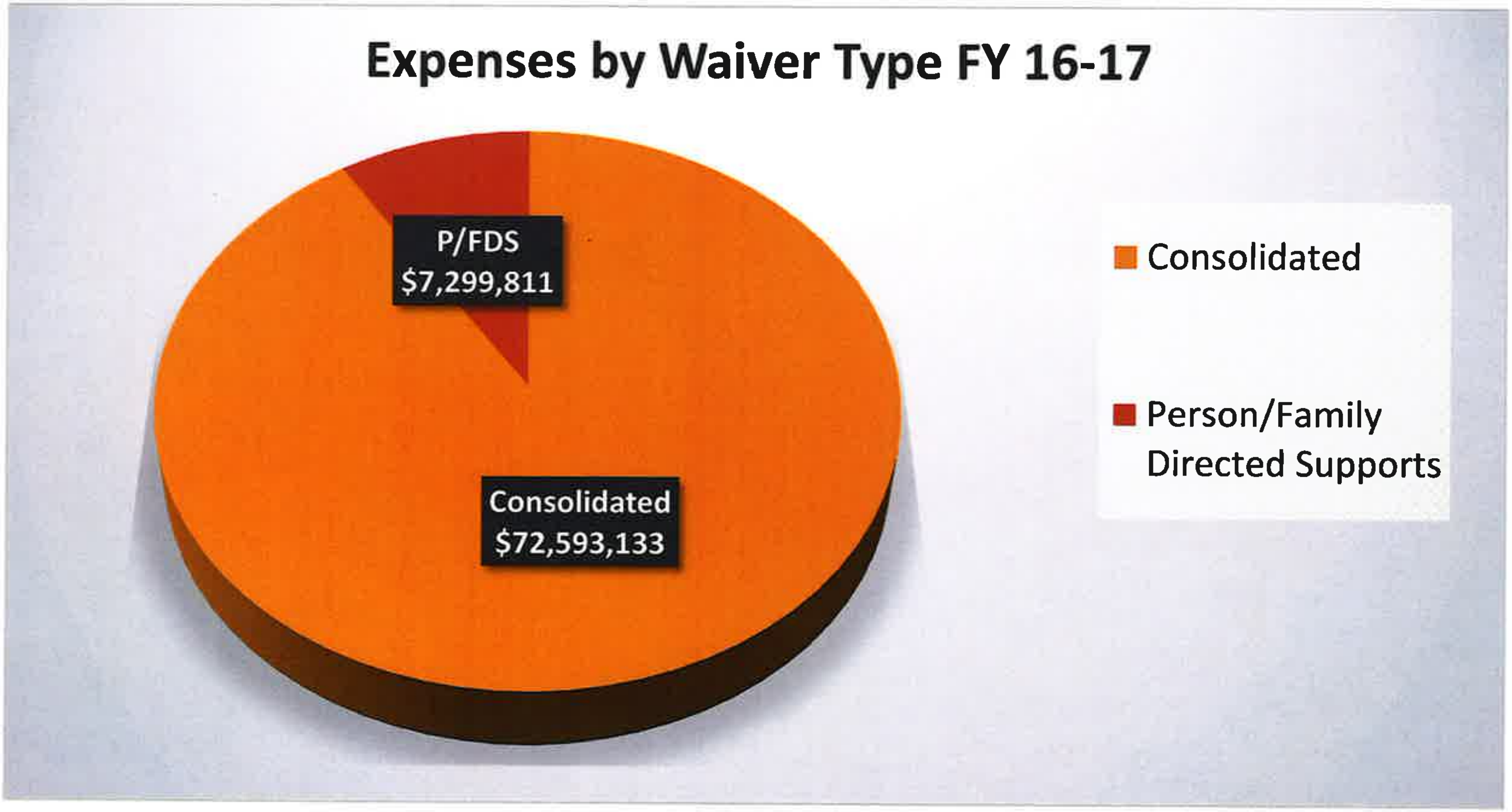
Base Funding



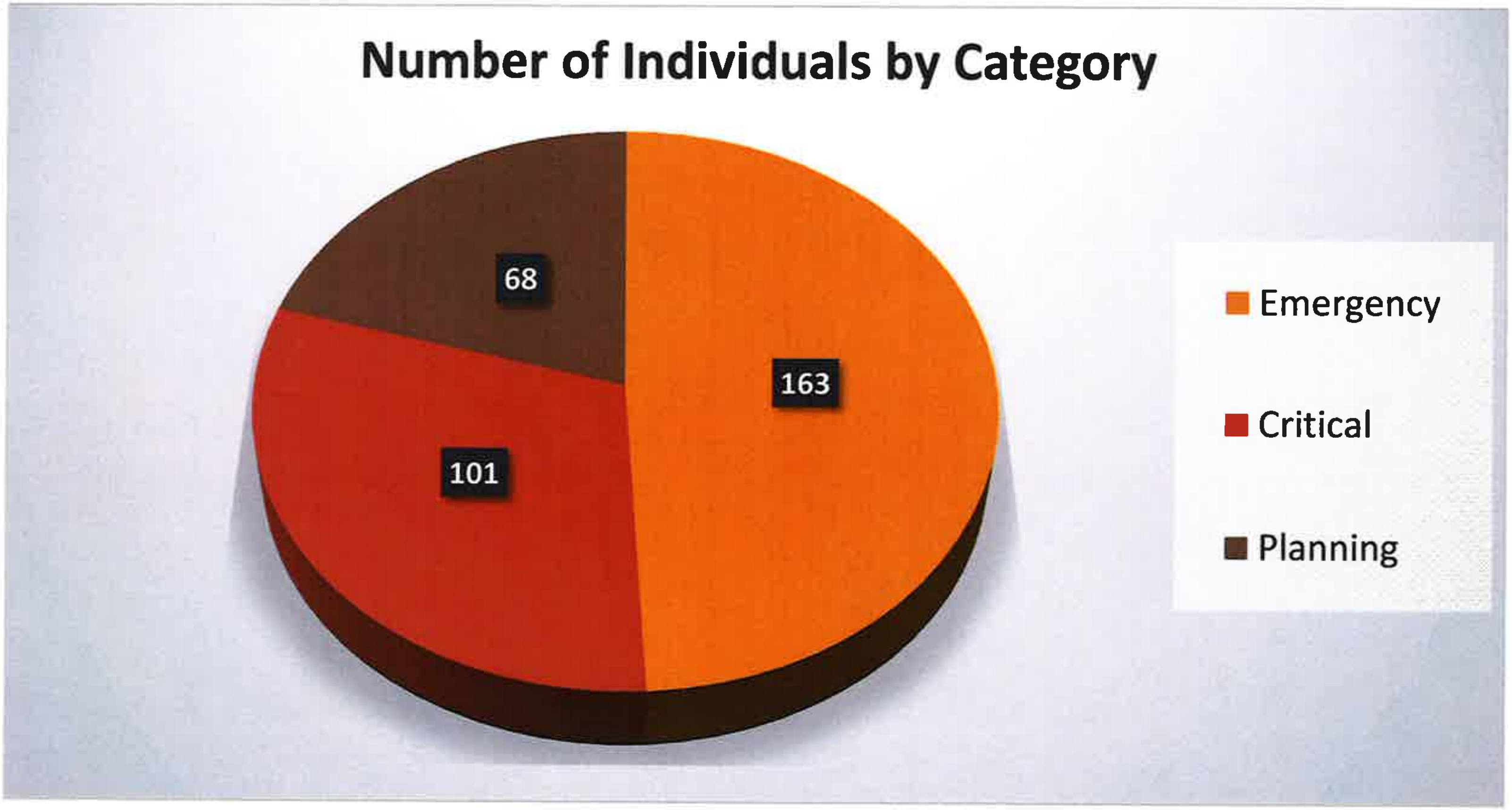
Waiver Funding



Waiver Funding



PUNS/Waiting List



Contact

Lehigh County Office of Intellectual Disabilities

- Michael Paulik

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Lehigh Valley
Health Network

Statement by Lehigh Valley Health Network

Presented by Edward Norris, MD
Chair, Department of Psychiatry

Pennsylvania House of Representatives
Democratic Policy Committee
July 24, 2018

Contact: Mary L. Tirrell
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Good afternoon, Chairman Sturla, and members of the Democratic Policy Committee. I appreciate the opportunity to speak with you today and want to thank Representative McNeill for inviting me to speak on this important topic of services for the intellectually disabled members of our community. It's also my pleasure to welcome you to Lehigh Valley Health Network (LVHN).

I am Edward Norris, Chair, Department of Psychiatry at Lehigh Valley Health Network, where I have worked for the past 15 years. I grew up in Seattle, Washington and Greenville, North Carolina and earned my undergraduate degree from the Massachusetts Institute of Technology. I attended Duke University for medical school and completed an internship in an internal medicine residency program at the Massachusetts General Hospital in Boston, Massachusetts followed by a residency in psychiatry at the Massachusetts General Hospital and McLean Hospital. I have also completed a fellowship program at Massachusetts General Hospital.

LVHN is very proud of the comprehensive behavioral health services we provide. A snapshot of those services and the conditions we treat can be found at the end of this statement.

For over 50 years, the Department of Psychiatry at Lehigh Valley Health Network has cared for, comforted and healed persons in our community suffering from mental illness. Much has changed in those years. After an explosion of research, especially on the linkages between mind and body, we can now offer children, adolescents, adults, and older adults a wider array of proven therapies to soften the burden of their illness and to help them regain their joy in living. Unlike years ago, when typical treatment involved lengthy hospitalization, most care today – even for more serious illnesses – can be provided on an outpatient basis.

What has not changed, is our dedication to providing a safe haven for patients, as we join them in finding ways to overcome their day to day challenges. Expertise and compassion extends to all our programs, in what we describe as our "full continuum" of care. By providing access to emergency, inpatient, ambulatory, and residential services – all linked together, supported by education and research, and integrated within the wider LVHN medical community – we can offer patients seamless transitions between different levels and types of care.

LVHN has one of the most comprehensive behavioral health programs in the area. In the past 12 months, we've treated well over 22,000 patients, in approximately 123,000 visits or days of treatment.

Whatever program they participate in, patients and families not only gain valuable insight into the nature of their illness and learn pragmatic skills of better coping, but are also nurtured by feeling respected, listened to, and valued as a whole person. Whatever the combination of serious clinical challenges, our goal is to educate patients that with proper treatment -- and the realization *they are not alone* -- they can survive, and even thrive.

Finally, undergirding all our treatment modalities and education to patients, their families, and the general community, is our recognition of the harmful effects of stigma. My colleagues are appreciative of the partnership of Representative Schlossberg in our efforts to bring awareness to the need to eliminate stigma.

Although mental illness -- whether depression, schizophrenia, or other disorders -- has been shown to be a brain disease, it nonetheless continues to be the target of unfortunate misunderstanding as well as hurtful scorn and mockery. Although the National Institutes of Mental Health has indicated that about 1 in 4 Americans will suffer from a diagnosable mental disorder, and other research shows that mental illness is eminently treatable, it can easily become the target of ridicule and unfounded fears which can lead to hopelessness and prevent people from seeking treatment.

Key to treatment at all levels of care in LVHN Psychiatry, including our intellectually disabled patients, is a commitment to educating patients and their families about their disorder, including how to explain their experiences to others and how to cope with the possible discrimination that they'll periodically face in the community.

A small subset of patients who present to our psychiatry department have been identified as having an intellectual disability (ID). An intellectual disability is defined as a "permanent condition that affects a person's ability to learn and function in daily life that occurs during the developmental period". A diagnosis of ID indicates that <u>both</u> a person's general intelligence and their ability to function in daily life are compromised. The two conditions may be present at birth, or occur in the developmental period, which is defined as prior to their 22nd birthday.

ID occurs in about 1 to 3 percent of the population, and in mild forms often goes unrecognized until middle childhood. There are multiple causes of ID that include genetic, developmental and acquired factors. There are often (about 50% of the time) psychiatric illnesses that also occur in these patients. Although the overall number of ID/MH patients fluctuates from day to day, we estimate that there are typically 5-8 patients at any given time that have ID/MH diagnosis in our emergency departments and/or receiving inpatient behavioral health treatment. In most cases of intellectual disability, the underlying intellectual impairment does not improve, yet the affected person's level of adaptation can be positively influenced by an enriched and supportive environment. Thus, individualized treatment is based upon the assessment of social, educational, psychiatric and environmental needs.

Hospitals recognize that many of challenges of the intellectually disabled are better managed through the ID and MH systems in the community. However, to qualify for services through the tax-payer funded Waiver Program, one must have a diagnosis of ID based on the results of objective standardized testing. Unfortunately, both developmental pediatricians and neurologists who are qualified to administer and interpret these tests are in short supply. This is in part due to the lack of sufficient insurance reimbursement for neuropsychological testing and the frustrations specialists experience in trying to access services for these children and families once diagnosed, limiting the number of physicians who choose to work in these specialties.

Hospital emergency departments care for individuals with ID/MH that are brought in for services that may not meet a level of either acute health or psychiatric care. Unfortunately, emergency departments can seem to be the only safe place for outside caregivers to take individuals with ID that demonstrate behaviors such as:

- aggressive behaviors towards care takers or group home peers or staff,
- calling the police because they have conflict with peers, group home staff or caregivers,
- behaviors (including self-injury) that require caregivers or group home staff to call emergency services via police that result in emergency department visits, and
- medication refusal and/or inability for group home staff to provide medications to assist with managing individuals.

These behaviors are certainly not present in all patients with an ID diagnosis and do not always warrant any type of inpatient psychiatric treatment, yet some require evaluation by a physician before they can be returned to a group setting.

Individuals with ID that receive behavioral health inpatient treatment can have delays in discharge after being psychiatrically treated. Some examples of situations in which processes are long and require much time in order for the services to be put in place include:

- Individuals who do not have current ID services yet require an ID county service,
- Individuals who require obtaining waivers for services,
- Individuals who require housing,
- Care takers – whether family or professional - that refuse, or are unable to, accept the individual back to their original residence prior to admission and
- Situations when the MH system and ID system do not agree which system is responsible for the care of the individual.

LVHN-Psychiatry has identified a few ways to improve communication with community providers, better understand the community needs, and be proactive with the care that we provide to the ID community members. We have partnerships enabling us to discuss, problem-solve and educate one another so that we can improve care. In December 2017, we brought together many ID government and community based providers from Lehigh and Northampton Counties to discuss and identify challenges and obstacles within our systems. The community ID providers shared their regulations that they are governed by and the complexities of managing challenging patients in the community. I'm pleased to see some of them will also be addressing you today because it really does take community partnership to support our patients with ID.

Together, we've identified areas that we think would help us care for this special population.

1. Medication policies and regulatory requirements shape the current practice of community providers. There's a need to review regulations and practices, including the use of behavioral plans that are used in the community not being able to be utilized in inpatient behavioral health settings.
2. Individuals that have ID/MH issues have limited resources. This includes emergency services and respite opportunities. Identify more respite care areas.
3. Referral processes and funding responses require time. Streamline processes to access funds for individuals in restrictive settings such as inpatient hospitals.
4. Examine the reimbursement rates for pediatric developmental evaluation and management services.
5. If a patient does not have a medical or psychiatric symptom to treat, inpatient and emergency departments are not appropriate areas to reside while waiting for appropriate placements. These individuals are exposed to highly stimulating and sometimes frightening settings as well as exposed to infections and disease. They are treated in the most restrictive settings when they could function in less restrictive environments if resources were available. County and State ID staff need to identify more resources to assist with managing individuals in community.

Once again, thank you for inviting me to speak today. It's been my privilege to share these ideas with you.

Behavioral Health Services at LVHN:

- The *Psychiatric Evaluation Service* is available for those who require immediate evaluation in one of LVHN's 3 Emergency Departments in the Lehigh Valley, offering access to safe and compassionate evaluation and triage to an appropriate level of care.
- *Inpatient Behavioral Health* is available to adults and adolescents at the Behavioral Health Science Center, on the LVH-Muhlenberg campus.
- *Partial Hospital Programs,* for adults and adolescents, provide treatment typically for 6 hours per day Monday thru Friday. This is an especially valuable resource for helping avoid the need for inpatient care, or as an intermediate step between inpatient care and traditional outpatient visits.
- *Outpatient Behavioral Health* includes group practices at LVH-Muhlenberg and 1259 South Cedar Crest Blvd in Allentown, as well as mental health clinics at LVH-Muhlenberg and at LVH-17th Street.
- The *Consultation Liaison Service* utilizes specially trained Psychiatrists and other clinical staff to offer consultation services to LVHN medical units, along with providing outpatient treatment.
- The *Transitional Living Center* is a residential program for persons who can benefit from a safe and supported housing arrangement until they can return to independent living.
- *Behavioral Health Integration* offers behavioral health services fully integrated, under the same roof, with LVHN medical practices and Community Care Teams. This has been developed in collaboration with the Departments of Family & Internal Medicine, as well as with various LVHN specialties.

The following list includes *some* of the conditions and issues that we treat in our various levels of care. Regardless of the problem, by combining our skills and commitment with the person's strengths and self-knowledge, we work together to successfully overcome the stresses they are facing.

- Anger issues
- Anxiety & Panic disorders
- Attention Deficit Hyperactivity Disorder
- Bipolar disorders
- Childhood and adolescent problems
- Decision making capacity
- Depression / Mood Disorders
- Effects of trauma or abuse
- Families & relationships – including how to help a loved one with mental illness
- Loss & grieving

- Marriage, couples or family difficulties
- Obsessive Compulsive Disorder
- Personality disorders
- Post Traumatic Stress Disorder
- Problems of aging
- Relapse prevention
- Relationship between health & emotional wellness
- Schizophrenia & other Psychotic Disorders
- Stress Management
- Suicide issues
- Workplace issues

No matter what their discipline, training, or clinical specialty, or whether treating children, adolescents, adults or older adults, all our staff in all our programs have one common goal:

To provide treatment that blends the latest science with the richest compassion, as we partner with persons in our community to aid in their recovery from the challenges of mental illness.

About LVHN

Lehigh Valley Health Network includes eight hospital campuses - three in Allentown including the region's only facility dedicated to orthopedic surgery, one in Bethlehem, one in East Stroudsburg, one in Hazleton and two in Pottsville, Pa.; 22 health centers caring for communities in seven counties; numerous primary and specialty care physician practices and 19 ExpressCARE locations throughout the region including the area's only Children's ExpressCARE at the Health Center at Palmer Township; pharmacy, imaging, home health services and lab services; extensive inpatient and outpatient rehabilitation services; and preferred provider services through Valley Preferred. Specialty care includes: trauma care at the region's busiest, most-experienced trauma center treating adults and children, burn care at the regional Burn Center, kidney and pancreas transplants; perinatal/neonatal, cardiac, cancer care, orthopedics, and neurology and complex neurosurgery capabilities including national certification as a Comprehensive Stroke Center. The Lehigh Valley Cancer Institute, the Lehigh Valley Heart Institute and the Lehigh Valley Institute for Special Surgery give clinicians of the highest caliber the necessary infrastructure, programs and partnerships to help community members stay healthy and provide the most advanced treatment when needed. The Lehigh Valley Cancer Institute is a formal member of the Memorial Sloan Kettering (MSK) Cancer Alliance, a transformative initiative to improve the quality of care and outcomes for people with cancer in community health care settings, including access to key MSK clinical trials. Robotic surgery is offered in ten specialties across the health network with more than 10,000 procedures performed since 2007. Lehigh Valley Children's Hospital, the only children's hospital and Level 4 NICU in the region, provides care in more than 30 specialties and general pediatrics. Lehigh Valley Hospital–Cedar Crest has been recognized by *U.S. News & World Report* for 22 consecutive years as one of America's Best Hospitals. Lehigh Valley Hospital–Cedar Crest, Lehigh Valley Hospital–17th Street and Lehigh Valley Hospital–Muhlenberg are national Magnet hospitals for excellence in nursing. Additional information is available by visiting LVHN.org, or following us on Facebook and Twitter.

Edward R. Norris, MD, DFAPA, FAPM

Dr. Norris is the Chair of the Department of Psychiatry at Lehigh Valley Health Network in Allentown, PA. He is a Professor of Psychiatry at University of South Florida College of Medicine, LVHN's academic affiliate.

He received a B.S. degree in biology from Massachusetts Institute of Technology in Boston, MA, and his M.D. degree from Duke University School of Medicine in Durham, NC. Dr. Norris completed his internship in Internal Medicine residency training at the Massachusetts General Hospital in Boston, MA, and then his residency in Psychiatry at the Massachusetts General Hospital and McLean Hospital. He also completed a Psychosomatic/Consultation Psychiatry Fellowship Program at the Massachusetts General Hospital.

He is a Distinguished Fellow of the American Psychiatric Association and Fellow of the Academy of Psychosomatic Medicine.

He was recruited to Lehigh Valley Health Network from Emory University in 2003. He developed a highly successful research program, including 28 varied trials as principal investigator and receiving over $2 million in grant support for his research. He is the Chief Medical Director for our $1.59 million federal grant for reverse primary care co-location in our mental health clinic.

His research is especially notable for his investigator initiated trial for Ramelteon in bipolar disorder in which he recruited and enrolled 90 patients. Those results were so intriguing that Takeda Pharmaceuticals further investigated these findings with two large international trials. Takeda enlisted two national experts, Gary Sachs, MD and Joseph Calabrese, MD, and Dr. Norris to work together to design this trial.

Lehigh Valley Health Network then selected him to work on the joint operating committee for the design and creation of the USF-LVHN regional campus. Through this significant amount of critical work, the eventual USF Health Morsani College of Medicine SELECT program was created. At one point during this work, he was in Tampa every other week to ensure the successful partnership was created.

From December 2010 through May 2011 he served as Interim Chair of Psychiatry, while the Chair himself served as interim Chief Medical Officer of LVHN during an executive leadership search. In this role, he also served as a member of the Senior Management Council for LVHN.

Our over 1,000 member physician group then enlisted his work for four and a half years from

January 2012 through June 2016 as Chairman of the Compensation Committee. In this role, he was responsible for the design of our value based incentive program, which currently awards over $7 million in yearly incentives. He also helped to design the corridor compensation plan, and recently redesigned the primary care compensation plan to move the Lehigh Valley Physician Group into the next steps of value reimbursement.

He has been in charge of medical student education in psychiatry and was the Clerkship Director for the third year Psychiatry and Neurology clerkship. He was active in the design of the regional campuses innovative longitudinal curriculum that created a long term exposure to family medicine throughout the entire year. He served as Chair of our Clerkship Committee for over the last ten years, and in this role helped solidify all of the clerkship directors to work together in the creation of USF SELECT third and fourth year rotations.

Throughout all his time in the Lehigh Valley Health Network, he has maintained an active clinical role in the medical hospitals as a consultation psychiatrist and maintained an outpatient psychiatric practice.

In recognition of his efforts, he was nominated by our Chief Executive Officer and Chief Medical Officer as an applicant for a GE Healthcare Physician Fellow through the Health Management Academy. The Health Management Academy is comprised of executive members from the country's largest integrated health systems. Members exchange best practices and benchmark information on increasing the quality and efficiency of healthcare. This fellowship was a competitive selection for 10 people throughout the country for a two year program. As a fellow, he has peer-interactive programs and an action project to further develop his critical skills and strategic perspectives necessary to assume increasingly responsible positions in the network.

As chair of the Department of Psychiatry, he notes:

- We have a stable, experienced, and well organized team that provides a large scope of core services that bring the highest value to the people of the Lehigh Valley.
- The department is actively engaged in seeking efficiencies and new ways of delivering care to extend the delivery of mental health services and to prepare for new payment models.
- The department will seek strategic operational and financial support as it continues to innovate new care deliveries, to transition from inpatient care to increased ambulatory care, and to expand our workforce.
- We are very excited about our newly accredited psychiatry residency program – we will train and mentor the next generation of psychiatrists in the Lehigh Valley.

Service Access and Management, Inc.

A Guide to Supports Coordination

What Is Supports Coordination?

Supports coordination is a critical service that involves the primary functions of locating, coordinating, and monitoring needed services and supports for waiver participants.

What is the role of an SC?
The SC’s role is usually described in three ways:

Locating Services—Helping you find ways to meet your needs.

Coordinating Services—Helping you access services that will help you.

Monitoring Services—Making sure that you receive a service appropriately, safely and in the best way to meet your needs.

Locating

Locating services and supports:

- Linking, arranging for, and obtaining services specified in the Individual Support Plan (ISP)
- Participate in the ODP standardized needs assessment process and facilitate completion of additional assessment
- Locate resources for the development of the ISP
- Identifying willing and qualified providers
- Assist in gaining access to needed services

Coordinating

Coordinating development & management of the ISP:

- Person centered planning
- Periodic review of the ISP and standardized needs assessment
- ISP planning
- Coordinating with entities, resources, programs, and individual’s natural supports
- Facilitate resolution of barriers to service delivery
- Disseminate information and support

Monitoring

Monitoring of services per the ISP:

- Individual health and welfare
- Progress on outcomes
- Satisfaction with services
- Service modifications
- Advocacy

How often should my SC contact and/or visit me?

Everyone needs to meet with their SC once a year to develop an Individual Support Plan (ISP). This helps them get to know you and to plan better for your future. If you have needs for services, a Prioritization of Urgency of Need for Services (PUNS) will also be completed. Both of these documents need to be updated at least yearly.

Other contact and visit requirements will be based on your type of funding, other services you receive and your individual needs.

What else can my SC help me with?

Your SC will want to work with you to plan for your future and to help you overcome obstacles in your life. Some of the ways your SC may do this are:

- Attending a meeting with any agency involved in your life
- Assisting individuals and families in identifying natural supports and community resources available to them.
- Helping you find a social group or day program to attend
- If you have ID waiver funding, your SC will help you choose service providers
- If you begin to receive waiver, they will assist you in completing the paperwork
- Attending an IEP meeting
- Keeping you informed about changes in the ID system
- Giving you information about resources and supports
- Helping you to complete applications for services like Medical Assistance and SNAP

(Supplemental Nutrition Assistance—formerly Food Stamps)

What can my SC not do?

- Your SC is able to help you find services, but is not able to provide them for you. For example, your SC can refer you to an agency that will help with a job, but your SC cannot help you find or keep a job. Also, your SC is not able to guarantee funding for services you may want or need. The SC will complete a budget and a funding request, but does not decide if funding is available. The SC is not able to assign a waiver slot to you.

How and when should I contact my SC?

You can contact your SC by phone, email, or postal mail. You should stay in regular contact with your SC, so they get to know you. Some important things you should tell your SC right away include:

- New phone number or address
- If you or your caregiver become seriously ill, are hospitalized, or are away from home for a period of time.
- When your needs change or if you need help that your family and friends cannot provide for you
- If you have questions about services in your community
- If you get a letter about your benefits, especially letters you need help with or do not understand
- To invite them to a meeting with an agency involved in your life or an individualized Education Plan (IEP) meeting
- If there is a significant change in your financial situation

How Do I Obtain A Supports Coordinator? You will need to be determined eligible through the Administrative Entity in the county in which you reside.

Intake Contacts

Northampton County Information, Referral & Emergency Services
610-829-4800

Lehigh County Office of Intellectual Disabilities
610-782-3126

Tom Carasiti
Pike County
tcarasiti@visionforequality.org

My name is Tom Carasiti. My wife and I live in Pike County. We're the parents of 3 young men. Our youngest, age 27, has ID and Autism.

Governor Wolf's proposed 2018–2019 budget Waiting List initiative was passed into law late June. It includes about $16 million to add 800 new waiver enrollments for 2018 graduates and 1 month of 2019 graduates. The amount also includes 100 more from the emergency Waiting List, and 50 from the autism Waiting List. We supported the initiative and the focus to continue helping graduates transition from education to community supports. However, the amount only keeps the total Waiting List numbers flat and will not decrease overall those who are waiting.

Ideally we wanted the entire emergency list funded for approximately $63 million or adding just .2% more to the entire budget. Notwithstanding that amount, we should at the very least target all the aging caregivers which have been largely ignored for several years. The numbers of senior caregivers (over the age of 60) have almost doubled in the past 3 years. The parent or parents in this age group must be filled with worry not knowing what support their loved one will have after they pass on. There are over 750 elderly caregivers on the emergency list. It would only cost the state approximately $18.5 million, just .06% of the budget, to provide these families with the peace of mind they've been hoping for during many years on the Waiting List.

Keeping the Waiting List flat each year with minimum attention does not help us reach that critical mass. Currently on average 1000 waiver slots turn-over each year. We need to grow the number enrolled so that turn-over equals the number entering the system and eliminates those who wait. Besides helping our graduates' transition, we should also help our senior care-givers feel the certainty and peace that after their final life transition, their loved one's care will be sustained.

Lastly, we know there is only a small discretionary amount to be proportioned to many deserving causes. In the end it's about prioritizing state resources and your responsibility to the taxpayers of the Commonwealth to get the most for their dollar. So besides the human service need that I noted, the taxpayer dollar is absolutely maximized here. Each dollar gets a Federal match and both dollars only go to jobs in Pennsylvania. Money does not go to the individual, nor does it leave the state like some program dollars. It only goes to Pennsylvania jobs. One person supported off the Waiting List can help provide work for up to 3 or more people. For example, it may help the special needs individual keep a job, it pays for the support worker's job, and may help one or both parents retain their employment. It leverages a federal matching dollar and it only goes to Pennsylvania jobs.

Thank you for this opportunity to speak today. The PA Waiting List team will make a stronger push next budget season to ask you to help our senior care-givers. We want them to receive the same focus our legislatures have kindly extended to our graduates.

Ned Whitehead

The Pennsylvania Waiting List Campaign would like to thank Governor Wolf, his Administration and the Legislators for passing the Initiative to fund the June 2019 graduates. This initiative funds students with Intellectual Disabilities and Autism who will need Medicaid Home and Community based Waivers. With the implementation of these funds, transition from high school will be much easier for our families.

Millions of dollars and countless hours of time and energy are spent by parents, school personal and most importantly, the student, to get ready for the transition from school.

I like to use my son and one of his classmates as an example. My son Christian, is a typical student and his friend Andrew, has a dual diagnosis of Autism and Intellectual Disability. Christian and Andrew had been classmates since kindergarten. When Christian graduated, he walked across the stage to get his diploma, Christian, his mother and I knew what his future plans entailed. He had enrolled in Kutztown, applied for loans, purchased a used car, knew where he was staying and what meal plan he was going to have.

When Andrew walked across the stage to get his diploma, he was in a holding pattern. His parents were hoping that the funding for the initiative would be in the budget when it was voted on and that the budget would be passed on time.
Andrew had gotten some work experience through the school's transition program. He had been working at a local convenience store, doing various jobs around the store. He was very proud of his opportunity to work and was a real asset to the store and to his fellow employees. The services and supports for Andrew to maintain that job were provided by the school. A Home and Community based Waiver was needed for him to continue in that position at the store.

At that time, when the budget was finally passed and the funding for the Waiver was released, it took 3 to 6 months before Andrew can start working on his transition plan from high school. Students and families like Andrew's sat waiting, while valuable time went by. The skills that the students had mastered begin to fade or are lost.
Parents are forced to make decisions about work and caring for their son or daughter.

The Waiting List Campaign is very excited to see the new initiative become reality. With the passing of the initiative for the 2019 graduates to be funded for one month of June makes transition plans more meaningful. The work that educators, Office of Vocational Rehabilitation caseworkers, parents and student will have real purpose.

No longer will skills be lost and time wasted sitting for a budget to be passed and ultimately for the funding to be released. Transition from school to adult waiver services will be seamless and implemented as it was intended to be done in a way that benefits the individual. Graduation will be a time for real celebration of the accomplishments of all students.

THE PA WAITING LIST CAMPAIGN

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THE FACTS ARE ...

Pennsylvania Waiting List Campaign Fact Sheet
as of May 31, 2018

The Pennsylvania Waiting List Campaign's goal is to end the devastation of Waiting Lists for persons with intellectual disability (ID) and autism who are in need of services through the Pennsylvania Office of Developmental Programs (ODP). These people are entitled to institutional care but choose to wait for home and community based services through the ODP Waiver Programs.

HOW MANY PEOPLE WITH INTELLECTUAL DISABILITIES AND AUTISM ARE WAITING?

TOTAL ID WAITING LIST NOT RECEIVING ANY HCBS SERVICES = 3868 (emergency and critical only)	TOTAL AUTISM WAIVER INTEREST LIST = 2,625 (AAW and ACAP)
Emergency = 1816	Priority 1 (receiving no services) = 1,947
Critical = 2052	Priority 2 (receiving some services) = 644
Planning (need services within 5 years) = 1362	ACAP Interest List = 34

What do we know about the people with ID on the waiting list?

- Most people are living with and being cared for by their family (86%) and some are living with friends or on their own (7%).
- Of the 11,547 people living with families, only 2400 are waiting for a 24/7 staffed group home. Services most requested by people living with families are individual supports like In-home and Community Support, Transportation, Employment and Respite.
- There are 773 individuals in Emergency Need who have caregivers over 60 years old. There are 1643 in Critical Need who have caregivers over 60 years old.
- There are 709 individuals who are 21 years old and are losing EPSDT and School services. They need services to successfully transition from school to adult life in the community.

What do we know about the "interest list" for autism services?

- People are served on a first come, first served basis and the need for services for adults with autism will continue to grow. The Census numbers indicate dramatic increases over 15 years, from 17,075 people in 2015 to 73,592 in year 2030.

How do we address the crisis in the community?

Waiting List Initiative	Number of People Served	Estimated Cost in State Dollars for Community-Based Waiver Services First Year	State Cost for Public Institutional Placement per year (Entitlement)
Emergency & Critical with no HCBS	3868 people for 6 months	$59 Million	$623 Million
Priority 1 List for autism	1947 people for 6 months	$25 Million	$314 Million
High School Graduates 2018	800 students for 9 months	$14 Million	$129 Million
High School Graduates 2019	800 students for 1 month	**$.8 Million**	$129 Million

Each person on the Waiting List has waived their right to institutional care, saving the commonwealth and the taxpayers billions of dollars over their lifetime, yet they languish on long waiting lists for home and community based services. If they choose to exercise their entitlement, the state would be required to serve them immediately and at a much higher cost in both dollars and freedoms. We need to close our State Centers and reinvest the funding into a robust, flexible, and responsive Community Based system.

Individuals and their families need assurance and hope that their needs will be met in their homes, with meaningful work opportunities and the basic supports they need to experience and enjoy Everyday Lives in the community of their choosing.

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Transition Initiative to End the Wait for High School Graduates

The PA Waiting List Campaign proposed that, in addition to class of 2018, this year's budget pass a Special High School initiative to fund the June 2019 graduates with Intellectual Disabilities and Autism who will need Medicaid home and community based waivers. We thank Governor Wolf's administration and the legislature for approving this initiative.

We spend millions of dollars in special education funding starting with Early Intervention until the child graduates from the education system. Every child is entitled to a free and appropriate education. Educators work hard giving them the education they are entitled to and need to prepare them to transition to adult life and preparing them for employment.

In a normal budget process that passes on-time with a graduate initiative, the graduate experiences a gap before services can begin, typically four to six months. This gap causes hardships on the family wage earners, can lead to regression of skills for the ID or ASD individual, and those with jobs supported by school services will lose them during the service gap. Some budget years the services don't begin until spring of the following year.

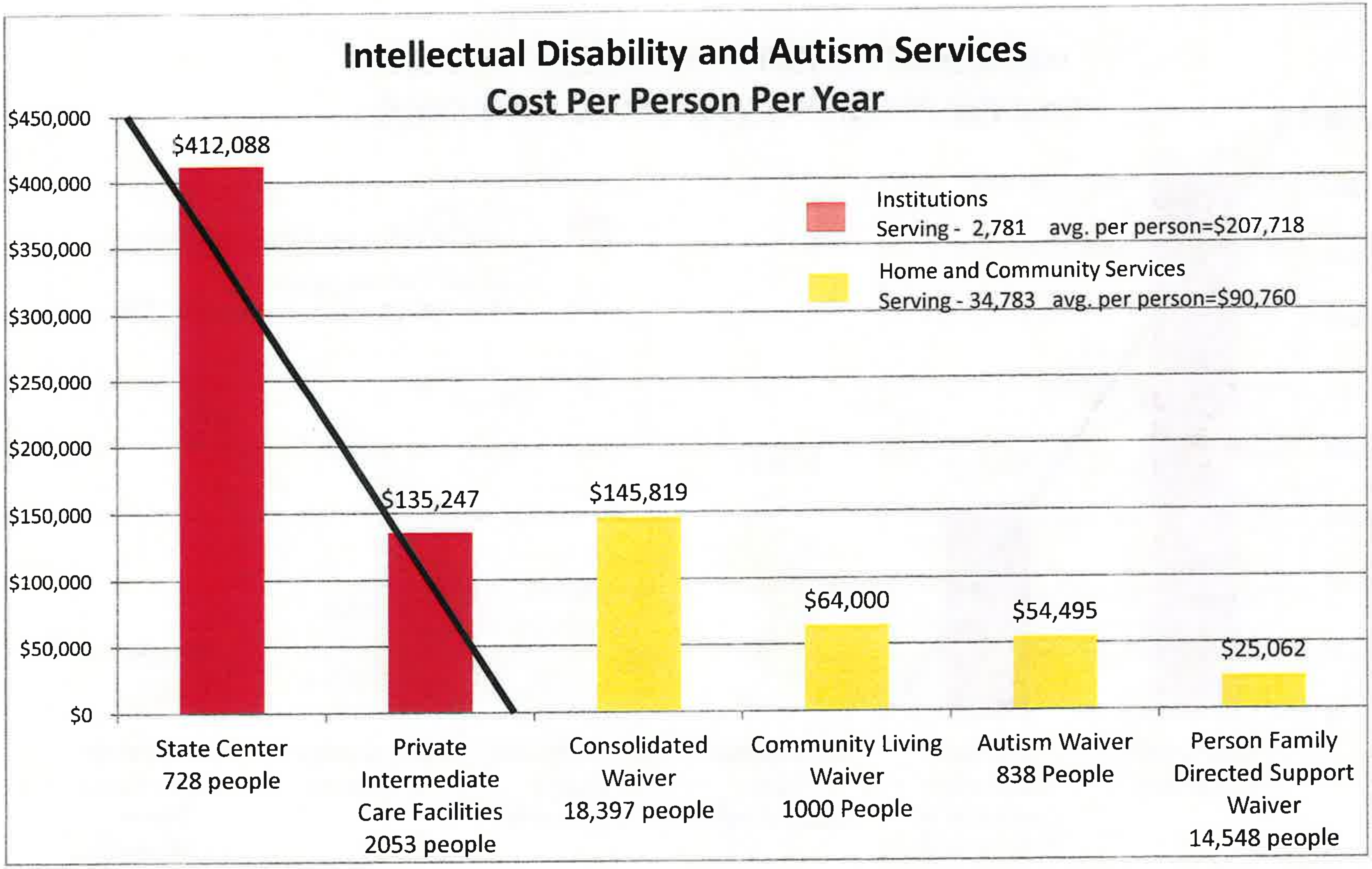
This extremely small initiative for June 2019 graduates for 1 month at a cost of a $770,000 dollars has the capacity to move young adults into the system and have their services begin immediately at graduation without worry should an extended budget process take place in June 2019. There will be no loss of continuity for the graduate. The services provided by OVR and the school system continue until graduation day, and then the adult waiver services seamlessly begin. There's no regression of developed skills, the care-givers can plan their family member's future in advance, just like what any typical high school graduate enjoys.

The June 2019 graduates will be, we hope, the first of many Pennsylvania classes to begin adult services once school services end. Then, each subsequent budget year, funds for new Waiting List initiatives can go directly to reducing overall numbers. We would be planning ahead for graduates and making real progress to when enrollment numbers create annual turnover that sustains the system without new initiatives.

We thank the PA General Assembly for passing this small amount of money to fund this group of individuals in their final year of school enabling them an easy transition into services immediately at graduation. We look forward to this becoming the standard our special needs graduates can anticipate from their legislatures. They and their families can plan their futures like any typical graduate. You have, and will, improve the lives of large numbers of families by keeping this graduate line moving into adult services without interruptions.

PUNS as of May 31, 2018
By Region, County Joinder and Urgency of Needs
Urgency of need of 'Fully Served' was excluded.
Source: EDW HCSIS PUNS Monthly Report Fact
Data Extraction Date: 6/25/2018

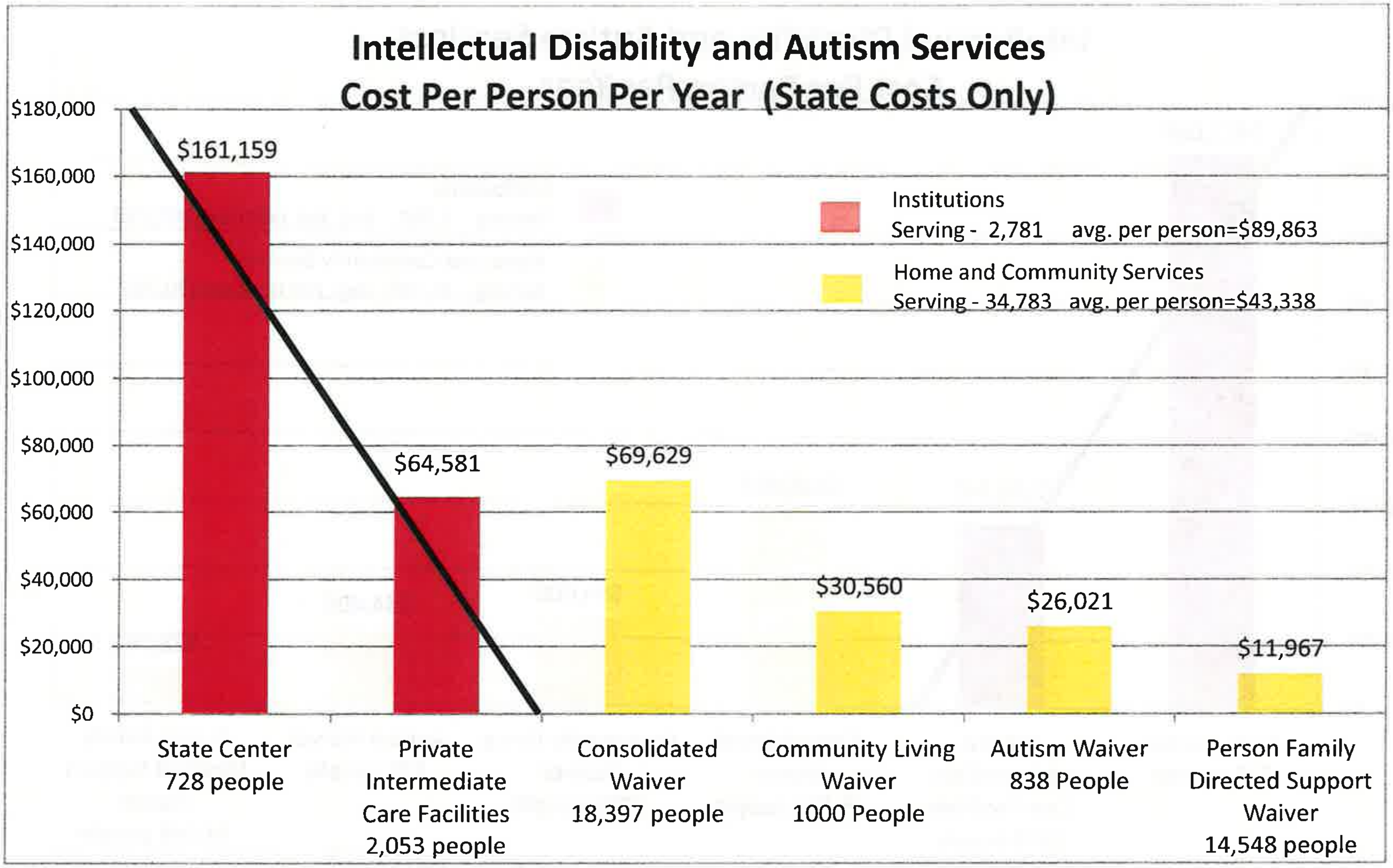
		Urgency of Need			
Region	**County/Joinder**	**Emergency**	**Critical**	**Planning**	**Grand Total**
Central	Bedford/Somerset	55	58	32	**145**
	Blair	58	66	13	**137**
	Cambria	20	35	31	**86**
	Centre	48	32	29	**109**
	Columbia/Montour/Snyder/Union	56	38	28	**122**
	Cumberland/Perry	73	98	77	**248**
	Dauphin	116	104	72	**292**
	Franklin/Fulton	39	63	22	**124**
	Huntingdon/Mifflin/Juniata	35	21	18	**74**
	Lancaster	214	175	80	**469**
	Lebanon	80	95	39	**214**
	Lycoming/Clinton	54	26	20	**100**
	Northumberland	13	70	32	**115**
	York/Adams	192	202	66	**460**
	Central Total	**1,053**	**1,083**	**559**	**2,695**
Northeast	Berks	375	102	111	**588**
	Bradford/Sullivan	19	26	11	**56**
	Carbon/Monroe/Pike	181	114	49	**344**
	Lackawanna/Susquehanna	70	103	174	**347**
	Lehigh	152	116	83	**351**
	Luzerne/Wyoming	232	99	54	**385**
	Northampton	95	107	70	**272**
	Schuylkill	120	51	38	**209**
	Tioga	13	11	6	**30**
	Wayne	12	23	11	**46**
	Northeast Total	**1,269**	**752**	**607**	**2,628**
Southeast	Bucks	140	168	224	**532**
	Chester	199	160	175	**534**
	Delaware	136	188	75	**399**
	Montgomery	324	283	201	**808**
	Philadelphia	818	821	462	**2,101**
	Southeast Total	**1,617**	**1,620**	**1,137**	**4,374**
West	Allegheny	278	524	323	**1,125**
	Armstrong/Indiana	80	33	46	**159**
	Beaver	116	73	51	**240**
	Butler	41	73	59	**173**
	Cameron/Elk	6	19	13	**38**
	Clarion	4	11	2	**17**
	Clearfield/Jefferson	19	22	29	**70**
	Crawford	44	40	39	**123**
	Erie	332	226	122	**680**
	Fayette	62	54	38	**154**
	Forest/Warren	8	16	23	**47**
	Greene	7	7		**14**
	Lawrence	70	34	45	**149**
	McKean	17	8	12	**37**
	Mercer	22	21	12	**55**
	Potter	3			**3**
	Venango	14	14	12	**40**
	Washington	93	88	38	**219**
	Westmoreland	83	317	59	**459**
	West Total	**1,299**	**1,580**	**923**	**3,802**
Statewide Total		**5,238**	**5,035**	**3,226**	**13,499**



State and Federal Funding for Intellectual Disability and Autism Services

Developed by the PA Waiting List Campaign

Source: Governor's Proposed Budget 2018/2019



State Only Funding for Intellectual Disability and Autism Services

Developed by the PA Waiting List Campaign

Source: Governor's Executive Budget 2018/2019

THE PA WAITING LIST CAMPAIGN

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What is the Pennsylvania Waiting List Campaign and what do we do?

Through Vision for EQuality, the Pennsylvania Waiting List Campaign was established in 1997 in response to the outcry of people in crisis across the Commonwealth to address the systemic problem of individuals with intellectual disabilities on waiting lists in PA.

Vision for Equality and the PAWL has an established Steering Committee who advise and direct our work. Steering Committee members consist of parents of child(ren) with Intellectual Disabilities and Autism as well as self-advocates. We include representatives from all parts of the state who are passionate about ending the wait for services.

Over the past 18 years, the Waiting List Campaign has been educating families, government officials, the public and the legislators about the impact of waiting lists on the health, safety and welfare of people with intellectual disabilities and autism.

Our Mission: To end waiting lists for community supports and services for people with intellectual disabilities, autism and their families.

We have influenced positive system change since our inception and have embraced the concept of self-advocates and families working together with other stakeholders to achieve our goals.

Through continuous education and advocacy we have brought the interests of people with Intellectual Disabilities and Autism, and their families to the forefront. We have contributed to several publications about the issues relating to the intellectual disabilities and autism system as well as the waiting list for home and community supports and services. We have served on numerous committees and workgroups representing the intellectual disability and autism communities. We have provided testimony for the House Human Service Committee Hearing alongside families and self-advocates as well as spoke at rallies about the lack of community supports and services.

- We have been instrumental in the development of the House Intellectual Disabilities Caucus
- We continue to encourage families by Empowering People them to Share their Story about what their life has been like and the challenges they face by being on the waiting list.
- We have been successful in securing a High School Graduate Initiative and The Elderly Caregiver Initiative for the past three years that has helped to target specific areas to help reduce the waiting list.
- We have been instrumental in House Intellectual Disabilities Caucus
- We helped development of the Prioritization of Urgency of Need for Services (PUNS)- to accurately count the number of individuals waiting for services in Pennsylvania

Our Plan to End the Wait

Our approach to education and advocacy is based on our key principles.

- We believe individuals with disabilities and their family members need to share their story and their life experiences with leaders in the administration and legislature. Our stories of life in the community and the barriers to accessing services are powerful, and we are most successful when key policy makers truly see and understand real people.
- Intellectual disability services are a core function of government and should not be fodder for political gamesmanship or partisan politics. PAWL is non-partisan and educates all elected officials on the impact of waiting lists on Pennsylvanians from all parts of the Commonwealth.
- People with disabilities deserve the supports and services they need in the community of their choosing. Home and Community Based Waiver services need to be available to prevent institutionalization and be provided to all citizens who qualify to assure their health and safety.
- Nursing homes, boarding homes, ICFs and State Centers are not acceptable community settings.

Debbie's Story

Debbie was born with Downs Syndrome to loving parents who not only accepted and understood her disability, but also extended it by adopting another disabled child, Susan. Susan, just like Debbie had Downs Syndrome, and in addition, a heart condition that required care.

Following the heartbreaking passing of both of Debbie and Susan's parents, their new caretaker was Debbie's birth sister, Terri, her husband Ed, and their children. Living in their care Debbie and Susan were introduced to a new life that no one ever should ever experience. In the home of their sister, Debbie and Susan were locked in a basement while Terri and Ed were often high on drugs. The sisters lived in fear of their new caretakers, terrified of Ed's gun and temper.

While locked in the basement, they were surrounded by dirty clothes and trash, and slept on hospital beds. They were given sparse amounts of food and did not receive any of the medication or professional care they required. Susan suffered significantly due to her heart condition, requiring oxygen she would never receive. She wasn't bathed, and couldn't feed herself. These responsibilities fell to Debbie, who also needed help and care. It was a sister's love that allowed Debbie to care for Susan, sharing what little food she had, exhausting all her energy to clean her, often injuring herself struggling to get to the basement door.

Her young niece, seeing the pain they endured, offered to remove them from the basement, but was told "no" by her parents, removing them would mean the end of the social security checks they received in Debbie's and Susan's name. On November 14, Debbie faced her next trial, the passing of her sister Susan. In the dark, dirty basement of their sister, Susan passed away with Debbie by her side. For three weeks the sisters were together side by side, one dead and the other just barely alive. When Terri and Ed lost their house due to their drug abuse causing financial problems it was the first time the serious issues came out in the open. For over a year Terri and her husband used Susan's and Debbie's social security checks to feed their drug abuse. People in Debbie's and Susan's surrounding knew the situation was bad, but it was little they could do with no legal backing. On Christmas, when the house was entered for repossession and Terri, her husband and their children were long gone, Susan finally after three weeks, received a proper burial.

It is now seven years later, and Debbie is able to share her story with the world, but it is not without regret that we listen. She is a strong incredible woman, and after many, many years of support she has moved on. She now is happily living in a group home, once again surrounded by people who loves and cares about her.

Brian's Story

Brian is 54 years old and has always lived with his mom. His mother's care is all he knows and all he has ever experienced. Brian is fully verbal and for the most part can take care of himself despite his intellectual disability. Brian and his mother did not receive any support from the city. No one stopped by the house to check on him and his elderly mother.

Living in the same house his whole life he knows the neighbors and he knows where the neighboring funeral home is. Brian knows that when someone dies you need to go to a funeral home. What Brian does not know is to call 911 when someone falls, or how to arrange a funeral or how much it costs.

We received the following information from a medical examiner.

On October 6th, 2011 Brian's elderly mother fell down the stairs. She landed at the end of the stairs and could not move. Brian did what his mother has done for him many times before; he made her food and tried to feed her for days. It's estimated his mother passed away on October 9th still at the bottom of the stairs. Brian sat with his deceased mother at the bottom of the stairs for 8 days. On October 14th Brian walked to the local Funeral Home one block from his house to inform the proprietor his mother died. The undertaker contacted the medical examiner's office. The forensics unit carried the decomposed body of Brian's mother from the home.

There is no family involvement whatsoever. Brian doesn't have any contact information to any relatives. He said his mother has a phonebook somewhere in the house, but he is not sure where. The only individuals who are aware of her passing are the police, medical examiners and a few neighbors. This left Brian alone, without help or services and support.

Father, disabled son found dead; friends call killing an 'act of love'

Pittsburgh Post-Gazette

By: Molly Born and Robert Zullo

Dec 17, 2013, 11:17 PM

When police found 78-year-old Richard Liposchok and his mentally disabled son, Mickey, 52, dead of apparent gunshot wounds inside their Port Vue home Tuesday morning, the news was a jolt.

"I got all teary-eyed and upset. It bothered me," said Marshall Black, a friend and Port Vue Borough Council member who knew the elder Mr. Liposchok through the borough's Vigilant Hose Company No. 1, where both men were longtime volunteers. "I know it bothers everybody in the fire company."

It was not, however, wholly unexpected.

"A lot of people assumed that something was going to take place here because of his son," Mr. Black said.

Police would not say Tuesday whether Mr. Liposchok killed his son before taking his own life, though the involvement of third person is not being contemplated.

Mickey Liposchok's body was found on the living-room floor in the house in the 1900 block of New York Avenue after a housekeeper couldn't get anyone to answer the door or reach them by phone. The woman summoned a neighbor, Frank Cortazzo, who looked through a window, spotted the body lying in a pool of blood and called police.

Richard Liposchok, known to his friends as "Lippy," was found in the bedroom with a rifle, borough police Chief Bryan R. Myers said.

Both men suffered at least one gunshot wound, he said. The Allegheny County medical examiner's office expects to release autopsy results today. Allegheny County police are in charge of the investigation and did not return calls Tuesday seeking additional information.

However, Mr. Black and Port Vue Mayor Brien A. Hranics, who also knew the elder Mr. Liposchok and went to school with his son, said the death of his wife, Gail, last year, failing health and assuming the role of sole caregiver for his son were taking a toll. Chief Myers, also a family friend, said Mr. Liposchok had been depressed since his wife's death in November 2012.

"It's an act of love is what it was," Mr. Hranics said. "It was definitely an act of love."

Mr. Black said Mr. Liposchok, a retired steel worker, worried about what would happen to his son when he died and was not the type to seek help for his own problems.

"When she passed, it was a lot on Rich. His health was deteriorating, it was getting bad. ... He was a very big guy. He whittled down to nothing," Mr. Black said."He's a strong-minded person. He's always done for himself."

Mr. Cortazzo has lived across the street from the family for nine years and helped officers break into the Liposchok home Tuesday morning.

Gail Liposchok "was the one that took care of everybody," he said, though both she and her husband cared for their son.

"You'd always see the father and the son riding together to the store," Mr. Cortazzo said.

Reached by phone, Bruce Michnowicz, Richard Liposchok's nephew, would not speak with a reporter Tuesday evening. A relative of Mrs. Liposchok who asked not to be named also declined an interview.

"It's very sad," she said.

Tuesday's grim discovery was the second time this month that police were called to the home.

According to 911 records, the elder Mr. Liposchok had left his vehicle running in the garage for an unknown amount of time Dec. 5 and officers responded for possible carbon-monoxide poisoning.

The incident was reported to have been accidental, those records show. Mr. Cortazzo said his family helped rid the home of fumes by lending a box fan.

"As far as him intentionally doing that on [Dec. 5], I personally would have probably said, 'No,' " Chief Myers said. "But, then again, who knows what's in people's minds?"

Mayor Hranics said Gail Liposchok was Mickey's primary caregiver, and she and her husband worked hard to give their son as normal an upbringing as possible.

"That boy was their life," he said.

The nature of Mickey Liposchok's disability wasn't entirely clear, but Chief Myers said he was born with the condition. Several people who knew the family said he was unable to care for himself.

After his wife's death, Richard Liposchok was seen around town less. The mayor wasn't sure if he was having trouble caring for his son, but said the family was private.

Mr. Black said Mickey was usually kept upstairs when he went to visit the home.

A longtime member of Vigilant Hose Company No. 1 who held various positions, including president and recording secretary, Richard Liposchok compiled the company's history through meeting minutes, newspaper clippings and photographs and was known as the town's historian.

"He's going to be missed. He was a very good guy. He was always fun to get in a conversation. He was up on everything. He was well liked," Mr. Black said.

First Published December 17, 2013, 2:41pm

MY STORY and MY STRUGGLE

My name is Sherri Kelly, I am the parent and legal guardian of two acutely disabled adult sons. Each son has been diagnosed with a different disability. My oldest son Justin, age 34, has Cerebral Palsy/Seizure disorder. My youngest son Jordan, age 24, has Autism/ADD. I have a middle son who went to college despite a learning disability and now works with the disabled. I have spent 34 years taking care of my eldest son and seeing to his needs. As a result of having him in my life, I became a disability advocate. I have helped people learn how to advocate for their disabled loved ones in a more effective manner. For the last ten plus years, my struggle has intensified because my youngest son went from having Autism/ADD to developing symptoms of Schizophrenia and Bipolar as well as OCD. When this occurred in the beginning of 2009, my world was turned upside down. I could not imagine what awaited me and my family. Because my husband has always had a long commute to his work, I have been the primary care giver when he is not around. When my son developed the dual-diagnosis, he did not respond well to most medications and became violent, especially towards me, as well as the rest of his family. Medicines made things worse and we didn't know what to do. We spent a lot of time and money having tests done to determine what course of action we could take. We decided to try transcranial magnetic stimulation to be performed on his brain in California. This therapy was not totally successful. It helped him to act and think normally for a little while. Unfortunately his behavior began to fluctuate and at times he seemed to be about 70 percent better. His medication was streamlined and reduced plus the most profound outcome was that he was no longer violent. He was still difficult at times but, we had achieved all that was possible and so we returned to our home in Pennsylvania. From 2014 until now I/we have tried to transition the boys to a different life. We changed our will, received guardianship over them and tried to get them in programs with aides. Justin was assigned an aide for five hours for five days a week and for Jordan a day program was provided for 3-4 hours for five days a week. These times are reduced by holidays, illness of my son or the aide, inclement weather and weekends. The waivers provided for resource allocation are not easily assigned. I was told I was lucky to receive them. I was told that they could also pay me to care for them for the rest of my life. I knew this was impossible. I had already faced my spouse nearly dying in 2013 and I had never had a life, or the opportunity to heal from the violence and struggle I had faced with my youngest. It is hard to work; I basically run a hospital 24/7 and have to lift my eldest son who weighs 100 lbs compared to my weight of 115 lbs. I contacted many legislators on both sides of the aisle including the late Daniel McNeill. Every agency and the county I lived in turned a deaf ear. Thus 2016 turned into 2017 and in late 2017 I met Representative Jeanne McNeill as she was campaigning for her late husband's seat. I knew nothing of her yet we seemed to click and we are still battling the bureaucracy and red tape so that I might place both my son's in a different location/facility. The battle has been intense, no room for multiple plans or facilities to be chosen. Thus far I have "Good Shepherd," for my eldest and "New Vitae," for my youngest. I usually have plan A, B, C but that's impossible now. I have watched this fierce battle destroy my life and can't believe this happens to many families. In fact many homeless are disabled or mentally ill and are bereft of any place to stay or have services provided for their needs. The problem is huge and can't all be fixed but, not addressing it is making it worse! Well, as for me, my life has been hurt and I need a chance to possibly learn to live differently and NOT as a hand- on caregiver every day of my life. My finances have been hurt from medical trips and supporting my two adult son's. I would like to work to assist with our financial burden but until my son's can be placed, that is not possible. I hope my battle can help others receive the needed assistance. As for my family we need answers/help as of yesterday. I continue to wait to transition my son's into their "new" life. I'm hoping this information will help to get the ball rolling so possible solutions can be found or more resources allocated for the people in need. Thank you.

Mrs. Sherri Kelly, Disability Advocate 829

March 3, 2018

TO: Congressman C. Dent, Senator P. Toomey, Senator P. Browne, Senator Lisa Boscola,
Representatives, Jeanne McNeil, Representative S. Samuelson

FR: Sherri Kelly

RE: Solutions to Ongoing Placement Dilemma

I am writing this letter to address the issues that I and everyone else nationwide have been battling with a couple of decades. Numerous letters have been written plus I met with various legislators regarding the placement of my two acutely disabled sons in a permanent facility/home. I have had countless phone conversations; most of it yielded absolutely ZERO results causing me great anguish and frustration. The realization I came to was, that we currently have next to nothing available for disabled individuals needing complex care. Therefore, parents/caregivers are highly encouraged to keep their charges for a lifetime or share them with another family etc. The second (so-called) solution is to have them be on their own in an apartment or room with some assistance, or none at all. I certainly was told that these were my best options. However, these options do not fulfill the hands-on needs that my sons require and we cannot assume that the parents will live a healthy life and all eventually die. At that juncture, the disabled individual will flounder through the system since there was no arrangement put in place.

There appears to be an understanding that some of the elderly cannot care for themselves. Nevertheless, we do not understand that many (NOT All) disabled or mentally ill fall into the same category. Many closures of facilities over the years have created huge gaps and a crisis for all families/caretakers. We have to negotiate with what is available in order to create future facilities. This all takes time and effort. I personally knew that it would not be easy, but I NEVER thought it would be this difficult. This has created chaos and emotional distress for me. The future is precarious for both my sons and that is unacceptable. I have discovered that many other Lehigh Valley families are in the same dilemma as I am. In order to bring change, the healthcare community, legislators/politicians, and families have to work together to create a better future for individuals with physical and mental disabilities.

In the following paragraphs, I will attempt to address some of the short term solutions that can be implemented and work with what we currently have in place:

The waiver issue has become a nightmare for our family. Therefore, if an emergency arises, the waivers should be able to be changed within a 60-90 day (or less) period to accommodate the special requirements of the individual. Currently, "supports coordinators," the Office of Long Term living, the county Mental Health/Intellectual Disabilities do little or NOTHING in regards to adapting or changing waivers. Legislators can set in motion appeals, emergency waiver changes etc. It would have to be on a case by case basis. On the other hand, the meetings and assessments done by supports coordinating staff should always look at future needs, while respecting the wishes of each of their consumers and their families. However, a 'one size fits all' approach with minimal solutions serves no one. Whether a waiver is needed, MA funds, Social Security, or Megellan funding; whatever is needed should be negotiated and implemented. The only suggestion I was given was private payment unless covered by insurance. Private payments are not always possible depending on the family's situation.

Perhaps in the future, tax incentives can be implemented for private and semi private agencies or facilities to be on board to fill the need that defunct facilities have created. Therefore, families can't be tossed around from place to place just because there isn't any facility or money available. If the only solution is a senior home, then a special wing or area has to be formed for individuals with similar issues to be served together. Senior homes are NOT the place for physical, mental or developmental issues to be addressed properly. Persons in their 20's and 30's should be with others like them, not with elderly. We seem to understand the issues facing the elderly, but not the disabled or mentally ill! There has been an increase in homeless disabled/mentally ill people. The problems are massive and may not be fixed rapidly. However, we can start by conversing and coming up with solutions. Everything has to start somewhere.

If a hospital or private facility is desired, new measures and incentives should be created to fulfill some of the needs. While we cannot force facilities to accept every consumer, we can have various agencies work together to come up with solutions when space is limited. As mentioned earlier, 'one size fits all' solutions do not work for every individual, whether it is staying home, lifesharing, living alone etc. We need to differentiate the mildly disabled individuals and the more chronic/acute situations. Forcing families to remain in the same situation is only prolonging the inevitable. People get sick and we all die. Then, the person flounders in the system with no clear direction or future with no one to solve all the problems. Obviously, it will be on a case by case basis based on the available resources, while attempting to construct some future property's; we can still have persons living in the community.

Recently, I learned of grants for microboarding, which is essentially starting one's own home. This may work for some, but not everyone. However, those homes sometimes take on extra tenants and that might help some but not all. Bottom line: I and many other families need help now! I originally told both supports coordinating agencies (Caring Heart and Quality Progressions) that I needed to look to both my son's future in case something happened to me or my spouse or both. (I already had faced that scenario in 2013 when my spouse nearly died.) I have been attempting to change every part of our future ever since. But, I do not want to spend years just trying to find the proper placement for both my sons. I have brought this issue up with legislators because it is a nationwide problem and we need to address it now. I really hope answers are forthcoming for our family and at least some others. I appreciate your efforts in helping our family. We really need to step up the actions and truly treat this and other situations as an emergency. The time for action has come. Many thanks to you all.

LETTER SUBMITTED INTO THE HEARING'S RECORD

January 4, 2018

Senator Lisa Baker
c/o Mike Cortez, Esquire
Senator Bob Mensch
c/o Mark Fetzko

508 Main Capitol Building
Harrisburg, PA 17120

RE: Disabled v Corporations "Blossom": Department of Human Services (DHS) and the Office of Attorney General (OAG) set precedent criminalizing civil procedures, defying rules, procedures to Social Security Act 1915 c, The Deficit Reduction Act (DRA) of 2005 for Participant Direct Services (PDS) and ignoring all Bulletins, PACODES including Developmental Program Bulletin Numbers 00-08-08 and Center of Medicare Services (CMS) Waiver Assurances CFR §441.464(a)(1)

Dear Honorable Senator Baker c/o Mike Cortez and Senator Mensch c/o Mark Fetzko;

Pennsylvania has adopted the participant-driven model (PDS) see 42 CFR §441.300 to 310, as an option under its 1915 C Consolidated Waiver PDS and the OBRA Waiver to protect the disabled and the elderly, but the Commonwealth has not followed Corrective action procedures before criminalizing families violating 55 Pa. Code § 51.45. Therefore, we ask that you commute my sentence and the sentence of the other family in Chester County. We made mistakes and should have been given training, guidance and corrective action, but we were sent over to the Attorney General's office. Please reference Section 1915(j)(2) of the Deficit Reduction Act sets forth six assurances that States must provide for the Secretary to approve self-directed PDS under this State Plan option to be in compliance with CMS.

Given the complexity and stringency of Medicaid requirements and the lack of clear guidance from the Commonwealth and the County, how can families be sent to TRIAL and convicted? As the Supreme Court noted in *Schweiker v. Gray Panthers,* 453 U.S. 34, 43, 69 L. Ed. 2d 450, 101 S. Ct. 2633 (1981), Title XIX of the Social Security Act, or Medicaid, is "one of the most complex statutes Congress has ever enacted."

Administrative Entities (AEs) under the Administrative Entity Agreement are r***esponsible to follow*** CFRs, Pa Code and Waiver regulations; See Developmental Program Bulletin Numbers 00-08-08. ***They cannot simply ignore the rights of families but follow them for Providers (Example "Blossom of Philadelphia).*** AEs used the Medicaid Fraud Unit for my family and another family without providing training, or corrective action, despite Pennsylvania's promise to the Center for Medicare and Medicaid Services (CMS) in return for CMS' approval of Pennsylvania's home and community-based waiver, to provide this support see 42 CFR 430.25., and 42 CFR 441.302. The policies and procedures in place with the Department of Human Services, ODP, and OLTL, are there to protect the disabled and their families. The discretionary use of corrective action will continue to harm families who are trying to care for their family members; see Pa Code§ 51.17. Incident management

Additionally, Pennsylvania Bulleting from Developmental Program **Number 00-08-08** states families are required to be notified of any problems that include Corrective Action. It states;

"Ensure corrective action occurs for significant and recurring failure to perform the AWC FMS requirements, for example, gross over and underutilization (utilization determined by the utilization criteria in the agreements), fraud, and ongoing and unresolved health and safety issues"

These failures by AEs and the state to follow codes and procedures have now set a precedent that other families will be harmed criminally while only trying to care for their severely disabled children. Families will have to choose their loved ones being provided care by Providers who can neglect participants/ individuals to protect themselves from prosecution; We should not have to sacrifice our loved ones to Providers for protection from Prosecution while knowing they can be seriously injured and killed (eating a slice of pizza) in a group home. Under the Pennhurst Agreement, Home Based Services are supposed to be in place to protect our families. Now that the Attorney General's office has criminalized families for the care of their loved ones it puts a dire spotlight on the reality of this situation. Additionally, in the context of our Federal Political motivations to strip the most basic needs from the disabled, I implore you to create legislation that will protect our loved ones by enabling families to live in peace while caring for their family members; We ask that you afford families what DHS has neglected, and they follow:

- Neglected to provide training to families who were providers of Participant-Directed Service (PDS) failing to provide correct procedures, see: Pa CODE 55§ 51.23. Developmental Program Bulletin Numbers 00-08-08

- Failed to follow Incident Management Procedures for the Disabled and criminalized civil actions failing to provide correct procedures as per 55 Pa. Code § 51.45 Developmental Program Bulletin Numbers 00-08-08

- Criminalized Families who became providers and common law employers without notification and Corrective Action Plan (CAP) failing to provide correct procedures as per 55 Pa. Code § 51.45 § 51.24.

- Failed to implement and develop policies with provisions for reporting and recording incidents in the Consumer file failing to provide correct procedures as per 55 Pa. Code § 51.15.

· Retaliated against family members who complained about services and policy adherence failing to provide correct procedures see Pa Code§ 51.27

Failed to properly investigate and report serious incidents, refusals to inform families and participants of the investigations that were initiated by concerned family members or staff failing to provide correct procedures as per 55 Pa. Code § 51.17.

· Imposed restrictions (Hab workers cleaning, job descriptions, and checklists) on the use of services and did not provide training, orientation, policy or information on what is billable v non-billable to PDS families failing to provide correct procedures. See Developmental Program Bulletin Numbers 00-08-08, 42 CFR 440.180

· Neglected to inform families of any errors in delivering services, instead called the Medicaid Fraud Unit failing to provide correct procedures. See Developmental Program Bulletin Numbers 00-08-08

· Neglected to inform families that they could follow hearing and grievance procedures when services were reduced or terminated failing to provide correct procedures including 38 CFR 3.103 and Developmental Program Bulletin Numbers 00-08-05 and Pennsylvania Local Public Agency Law 2 Pa.C.S. §§ 551-555

· SCOs and AEs unilaterally Changed ISPs and put Critical Revisions into HCSIS without a family signature, due process notice or participant consent and evidenced with signatures failing to provide correct procedures. Developmental Program Bulletin Numbers 00-08-05, and 42 CFR 431.992

· Failed to provide guardians and families consent to change services in the ISP See Developmental Program Bulletin Numbers 00-08-08 and 42 CFR 441.302 and 42 CFR 431.992

· Failed to provide service directory of services for the deaf that are home and community-based See Developmental Program Bulletin Numbers 00-08-08

· Failed to provide policy and procedures in consumer records and forced families to receive records through the “Right to Know” See Developmental Program Bulletin Numbers 00-08-08 and 42 CFR 431.992

· Used law enforcement against families to cover up agency and provider mistakes including all the above which was brought to the AE's attention. See Developmental Program Bulletin Numbers 00-08-08 and 42 CFR 431.992

In conclusion, I implore you to create legislation to protect families and create protections including a document Handbook for Participant-Directed Services of what is billable vs. nonbillable to make a clear distinction of civil v criminal penalties under DHS because families caring for their loved ones have been criminalized, and providers are afforded “Corporate Integrity Agreements”, and civil action for remediation. Families are being Criminalized against procedures and regulations outlined in the Developmental Program Bulletin Numbers 00-08-08, and 42 CFR 431.992. We ask that you commute the sentences, expunge our records and assure that regulations are followed.

Sincerely,
Angela Biesecker

Harold Brubaker, Philadelphia Inquirer
Ronnie Polaneczky, Philadelphia Inquirer
Senator Bob Casey
Michael Gamel-McCormick
Senator Elizabeth Warren
Pennsylvania Governor Wolf
Josh Shapiro, Attorney General Office of the Attorney General
Eugene DePasquale, Pennsylvania Auditor General
CMS Francis McCullough
CMS Daphne Hicks
CMS Sabrina Tillman Boyd
Laval Miller-Wilson, PA Health Law Project
Secretary DHS Teresa Miller
Executive Sec Leesa Allen
ODP Deputy Nancy Thaler
OLTL Deputy Jen Burnett
Vickie Stillman Toomey,ODP
Mary Citko, ODP
Marguerite Peashock, ODP
Bridget Thrash, Administrative Entity for Chester County
Terrence Farrell, Chester County Commissioner
Kathi Cozzone, Chester County Commissioner
Michele Kichline, Chester County Commissioner
Margaret Reif, Chester County Controller
Mark Rupsis, Chester County Chief Operating Officer