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## **System for individuals with intellectual disabilities, autism will collapse without increased state aid, advocates say**

*Health, human services organizations ask General Assembly for \$430 million increase to stop further termination of programs, closure of facilities*

**HARRISBURG, Pa. (May 3, 2023)** – Advocates for and providers of services for individuals with intellectual disabilities and autism (ID/A) today urged the Pennsylvania General Assembly to increase state aid by \$430 million to prevent a full collapse of the system. Prominent health and human services organizations gathered in the Capitol rotunda and said chronic underfunding and staffing shortages are forcing them to end programs and turn away individuals.

The \$430 million funding request would generate a federal match that would allow providers to resume service to the 4,029 individuals who lost care in recent years. Without the 20-percent increase, providers say that 60,000 Pennsylvanians with ID/A would be at risk of losing or experiencing a reduction of essential services.

“Make no mistake: the ID/A system is in crisis,” said Sherri Landis, Executive Director of The Arc Pennsylvania. “But, with \$430 million in additional state aid, providers will be able to improve the wage rates for direct support professionals to ensure that individuals continue to receive the care and support they need. If this request is ignored, then families and caretakers will continue to be strained and it will take much more for the system to recover.”

The Arc Pennsylvania was joined by the Rehabilitation and Community Providers Association (RCPA), Pennsylvania Advocacy and Resources for Autism and Intellectual Disability (PAR), The Provider Alliance, The Alliance of Community Service Providers and MAX Association in advocating for additional state assistance. They said that years of underfunding, the COVID-19 pandemic, staffing shortages and inflation impacts have put the ID/A network on the brink of

collapse. Providers have worked tirelessly to maintain the same level of service with fewer resources, but advocates say they are at a breaking point with little left to cut.

“If providers are forced to continue to downsize services and close programs, individuals and families will be left without needed, critical resources,” said Richard S. Edley, PhD, RCPA president and CEO. “This is already happening with wait lists, lost services, and individuals approved for services who can find none. Families have become the de facto safety net in place of providers. This is not sustainable.”

A recent survey by RCPA, PAR and The Provider Alliance of more than 130 providers found that the number of individuals served dropped by 4,029, or 11 percent, from March 2020 through February 2023. The reasons for the decline include underfunding and staff shortages which are leading to the elimination or downsizing of programs, closure of facilities or limitations on the number of people being served.

“The data shows that the decline in system capacity is directly related to workforce,” said Patrick DeMico of The Provider Alliance. “Direct support professionals (DSPs) provide essential care for everyone served and without them we don’t have a community system. We are on a fixed income from a single-payer and as inflation increases our system falls farther behind every day.”

Further stressing the ID/A network of care is the Pennsylvania waiting list backlog for ID/A services. More than 12,000 individuals remain on the list, and 5,400 of those are categorized as emergency need, indicating that they are at risk and require services immediately.

“This funding request would allow the ID/A network to resume services and resources to the 4,029 individuals that lost care in recent years, and to begin to assist those waiting for services,” said Cherie Brummans, The Alliance of Community Service Providers executive director. “While there is more work to be done, the increase in state aid would allow our providers to stop the bleeding and allow programs to resume and individuals in need to receive care.”

Providers are unable to raise wages by raising prices, as human services like ID/A are funded primarily by Medicaid. Inadequate rate fees imposed by the state do not cover the true cost of care and exacerbate operational challenges.

“The majority of the DSP workforce is comprised of female and minority workers, and the economic impact of DSP underinvestment has disproportionately affected them,” said Diane Conway, CEO of MAX Association. “This shortage has led to Pennsylvanians with complex needs and multiple diagnoses to be put at even greater risk, and also puts the families taking care of these individuals at a higher risk. The increase in state aid would mitigate these risks, and create a safer, more sustainable environment for our DSP workforce.”

“The healthcare system has been stressed to the max by staffing shortages, and our network has not been immune,” said Mark Davis, PAR president and CEO. “By increasing funding, we can be more competitive in recruiting DSPs, and serve more individuals without putting additional burdens of care on families. Without it, the system will collapse and families across Pennsylvania will continue to feel the burden.”

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**About The Arc Pennsylvania:**

The Arc of Pennsylvania is the state's leading advocacy organization promoting the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. More at <https://thearcpa.org>.

**About the Rehabilitation and Community Providers Association (RCPA):**

With well over 350 members, the majority of who serve over one million Pennsylvanians annually, Rehabilitation and Community Providers Association (RCPA) is among the largest and most diverse state health and human services trade associations in the nation. RCPA provider members offer mental health, substance use disorder, intellectual and developmental disabilities, children's, brain injury, medical rehabilitation, and physical disabilities and aging services, across all settings and levels of care. Visit <https://paproviders.org> for more information.

**About Pennsylvania Advocacy and Resources for Autism and Intellectual Disability (PAR):**

PAR proudly represents provider organizations whose mission is to serve and support Pennsylvania's children and adults with autism or intellectual disability. With a workforce of over 50,000 Pennsylvanians supporting tens of thousands of individuals and their families, the association promotes the highest standards of service through advocacy, information, training and education, and the resources provided by our members. Visit <https://par.net> for more information.

**About The Provider Alliance:**

TPA supports agencies that serve people with intellectual disability and autism across Pennsylvania. We do this through collaboration, advocacy, innovation and information-sharing across its membership. TPA promotes best practices and workforce development to help members deliver safe, supportive, and compassionate services that are part of the fabric of local communities. More at <https://provideralliance.org>.

**About The Alliance of Community Service Providers:**

The Alliance of Community Service Providers is a non-profit association of organizations who provide service to children and adults with mental health conditions, substance use disorders, and/or intellectual disabilities. The Alliance works to improve the quality and sustainability of services, provide a voice for our agencies and the people they serve at the city and state levels, and create a venue for collaboration, problem solving, and information sharing. Find out more at <https://thealliancecsp.org>.

**About MAX Association:**

MAX seeks to be the leading association of human service providers in the counties of Bucks, Chester, Delaware and Montgomery by supporting them to secure the necessary resources to fulfill their individual missions. We strive to create a cooperative organization among the community service providers for people with behavioral health disorders, developmental disabilities, and drug and alcohol involvement and their families in order to promote continuing quality improvement of supports and needs-based allocation of resources. Learn more at <https://maxassociation.org>.