



RECOMMENDATIONS FOR IMPROVING PENNSYLVANIA'S HCBS SYSTEM

*Prepared by the Home and Community Based Services
Shared Solutions Coalition*

November 2021

ABOUT THE HCBS SHARED SOLUTIONS COALITION

The Home and Community Based Services Shared Solutions Coalition is made up of a diverse stakeholder group that includes self-advocates, family members, direct support professionals (DSPs), and advocacy and provider organizations. As self-advocates, family members, and DSPs, more than half of the Coalition members are direct stakeholders with lived experience with the Home and Community Based Services system. Coalition members worked together to draft the following recommendations for the Office of Developmental Programs (ODP). Our goal is to build a path forward and create a sustainable system that is responsive to the needs of the people it serves.

This Coalition came together as a group to recommend solutions that ensure:

- The **QUALITY** of HCBS so that people with IDD get the supports that they want and need to live in the community
- The **SAFETY** of HCBS for people with IDD and the stability of providers of services
- The **RESPONSIVENESS** of HCBS to meet the needs of people with IDD, their families, and providers of services
- The **SUSTAINABILITY** of HCBS as an ongoing system of supports for people with IDD throughout their period of need for supports

November 1, 2021

Acting Secretary Meg Snead
Department of Human Services
625 Forster Street
Harrisburg, PA 17120

Dear Acting Secretary Snead:

We represent the Home and Community Based Services Shared Solutions Coalition, a group that was formed to identify solutions to many of the common problems experienced by Pennsylvanians with intellectual and developmental disabilities (IDD) and their families. Specifically, the Coalition aims to address the safety, quality, and staffing issues that currently plague the IDD service system, making it more difficult for people with IDD to live in the community.

Our Coalition represents a diverse stakeholder group which includes self-advocates, family members, and direct support professionals (DSPs), all of whom have lived experience with, and hold a direct stake in, the system. In addition, our Coalition's organizational stakeholders represent the perspectives of advocates and providers. From the outset, it has been our goal to build consensus on a path forward.

This summer, we engaged in a series of four in-depth meetings, in which we both identified problems with the current IDD service system and proposed solutions to address them. The vision was that The Arc of Pennsylvania would host a consensus-building process to engage stakeholders who would bring fresh perspectives from across the Commonwealth to frame recommendations for the Department. This initiative was stakeholder-driven, rather than government agency-driven. This was a very important undertaking that required many months of meeting, researching, and writing to craft our report and recommendations from leaders and individuals with lived experience from the field.

Our Coalition was formed with the goal of crafting solutions that the Department of Human Services, the Office of Developmental Programs (ODP), and other Commonwealth stakeholders, such as the General Assembly and Governor's Office, could implement collaboratively so that moving forward, the Commonwealth will have a sustainable, high-quality service system that is responsive to the needs of people with IDD.

Our efforts have culminated in the enclosed report, which offers truly shared solutions, as all the undersigned Coalition members are in agreement with the recommendations that follow. We believe these recommendations, if implemented by the Commonwealth, will lead to lasting and impactful change for Pennsylvanians with IDD. It is our hope that ODP and other government entities that share responsibility for the IDD service system will give serious consideration to our recommendations.

A failure to act on these recommendations could result in the continued collapse of the HCBS system, resulting in violation or abridgement of the rights of all people served by it. We welcome the opportunity to meet with you to discuss any questions or concerns you may have regarding the report and our recommendations. We look forward to working collaboratively with your office to improve the Commonwealth's services and supports for people with IDD. The Coalition emphasizes the importance and urgency of action on these recommendations.

Sincerely,

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cc: Deputy Secretary Kristin Ahrens

EXECUTIVE SUMMARY

Throughout the summer of 2021, a group of self-advocates, advocates, family members, DSPs, supports coordinators, and providers met to discuss the issues facing Pennsylvania's Home and Community-Based Services (HCBS) system. During these meetings, the HCBS Shared Solutions Coalition discussed barriers that need to be resolved. These barriers include:

- Insufficient staffing and funding and a general lack of access to services and opportunities (resulting in people with IDD not having the freedom to live their lives as they choose)
- Lack of education and support for families
- Lack of understanding among the general public about the needs of people with IDD
- Lack of choice
- Complexity of system requirements

Once these barriers were identified, the Coalition drafted solutions to address the issues facing the system. This report is the culmination of these meetings and discussions, and it includes the Coalition's recommendations to improve ODP's HCBS system. The proposed solutions are the result of consensus, as all Coalition members agreed to their inclusion in the report. The recommendations aim to increase the quality, safety, responsiveness, and sustainability of the HCBS system.

In order to ensure that all Pennsylvanians with IDD are fully supported, and to ensure that the system is responsive to the people it serves, the Commonwealth must consider and implement the recommendations included in this report. The Coalition emphasizes the importance and urgency of government action on these recommendations. Without it, the HCBS system will be unable to meet the needs of the people it supports.

Key Recommendations

Increase the Voice of Self-Advocates and Families in Directing HCBS

- Increase voices of all people and families receiving services
- Increase self-advocate input over how they are supported and by whom
- Include robust, ongoing statewide opportunities for self-advocates and their families to learn about regulations and waiver definitions
- Make self-advocacy a required discussion at Individual Support Plan (ISP) meetings
- Increase understanding of the intersectionality of racial experience and disability experience, cultural competency, and an individual's support needs and desires

Increase Access to a Range of Home and Community-Based Services

- Modify the current structure to support community services, so that it allows individuals in residential services the freedom, autonomy, and choice for participation in the community
- Incentivize and support programs to serve individuals who have complex needs, mental health needs, and/or complex medical needs
- Address the needs of people enrolled in a waiver or on the waitlist who live at home and receive little to no services
- Increase individuals' and families' awareness and understanding of what is already available within waiver service definitions in order to help them make meaningful choices and get access to the supports they need from providers and the waivers

Expansion of Technology

- Expand definitions and increase funding for technology supports that can be covered under the waivers.
- Secure the knowledge, expertise, resources, and funding to provide technology training.
- Train Support Coordinators (SCs) and Administrative Entities (AEs) to ensure that technology supports are included in ISPs.

Increase Wages, Benefits, and Financial Stability of Services

- Increase rates for wages and benefits for DSPs, SCs, and other professionals supporting individuals in the waivers in recognition of the responsibilities of their work.
- Reinvest dollars from state center closures back into the HCBS system to decrease waiting list numbers and increase rates for wages and benefits for DSPs.

Improve Workforce Infrastructure and Professionalism

- Provide funding and develop a system of tiered pay based on certifications, continuing education requirements, and/or voluntary professional development, including a voluntary DSP certification program. Participation in the program would be voluntary by the DSP and mandatory by the agency. Training would be paid for and available through ODP, and the certification would be portable by the DSP.
- Promote career ladder and advancement opportunities for DSPs, so that they can work toward moving beyond front-line positions, and into management roles.

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INTRODUCTION

Everyone benefits when people with disabilities are a part of the fabric of our communities. Historically, people with disabilities were forced to live in institutions that limited their choices and forced them to live segregated lives away from their family, friends, and community. Though people with disabilities want to be served in the community, Pennsylvania's service system continues to treat access to the supports that help people with disabilities gain independence as optional, rather than a right to which they are entitled. As access to, and the variety of, HCBS has expanded, it remains important to regularly reassess the landscape of options and identify areas for improvement and innovation.

The pandemic has made the need for reassessment even more urgent, as it brought to light issues with the HCBS system. Congregate care settings such as intermediate care facilities and nursing homes have put people at much greater risk of contracting COVID-19.

At the same time, HCBS providers are facing unprecedented challenges because of the pandemic. Some have closed their doors and cannot provide services due to staffing shortages. As a result, people with disabilities are being restricted from accessing the services that help them remain safe and lead independent lives. For those who live at home with family, their relatives have had

to provide 24/7 care without relief, often at the expense of their jobs or worse yet, their physical and mental health.

The Coalition wants a framework that meets the needs of all Pennsylvanians with IDD, and a system that allows for equitable access to the services that people with disabilities need to live in their communities.

This report aims to identify solutions to many of the common problems experienced by Pennsylvanians with IDD. The Coalition is focused on addressing the safety, quality, systems, and staffing issues that are eroding and leading to the collapse of the IDD service system, which in turn is making it difficult for Pennsylvanians with IDD to live and remain in the community.

The Coalition identified solutions that address the safety of individuals with IDD. We also explored solutions that assure that the HCBS system is sustainable, and at the same time, meets the needs of the people receiving services, the professionals providing the services, and the network of providers.

HCBS SHARED SOLUTIONS COALITION RECOMMENDATIONS

Increase the Voice of Self-Advocates and Families in Directing HCBS

It is essential that self-advocates and their families play a larger role in the HCBS system. Their lived experiences enable them to see what is or isn't working, and what must improve. In order to make the HCBS system work for all of the people it serves, and to increase the voices of self-advocates and their families in directing HCBS programs and supports, the Coalition makes the following recommendations:

- ***Increase voices of all people and families receiving services.***

Across Pennsylvania, there are self-advocates and families who zealously advocate for their rights, and the supports and services they need. ODP actively works with self-advocates and families to hear their perspectives and understand their needs. However, the next generation of self and family advocates must be cultivated, with a particular focus on those perspectives that have traditionally been marginalized. All voices, all perspectives, and all unique lived experiences must be heard and evaluated when implementing policies for supports and services to ensure that the HCBS system works for all people with IDD.

- ***Increase self-advocate input over how they are supported and by whom.***

For the HCBS system to truly succeed in supporting individuals with IDD, it must adapt to their unique needs, and provide them with a choice as to who provides services. A system that is built on choice is one that ensures quality and is responsive to people's needs. Self-advocates must be given increased opportunities to provide ODP and providers with input about how they are supported and what they need to lead an everyday life.

- ***Include robust, ongoing statewide opportunities for self-advocates and their families to learn about regulations and waiver definitions.***

All individuals with IDD and their families need access to clear, easy to understand information about the system. Specifically, they need information about their rights, the regulations which govern the system, and waiver definitions so that they can better advocate for themselves. This will enable self-advocates and their families to make informed decisions and be better prepared when

discussing service options with providers. ODP must prioritize training for self-advocates and families, similar to the Training Partnership program it used from 2004-2014, so that advocates can understand Pennsylvania's system changes, regulations, and waiver definitions. These trainings must be ongoing and offered both in person and virtually in order to adjust for any changes or amendments implemented by ODP.

- ***Make self-advocacy a required discussion at Individual Support Plan (ISP) meetings.***

Empowering people with IDD to become self-advocates is critical to elevating their voices in the decision-making process for the HCBS system. An ISP details what is most important to the individual, so that everyone involved in supporting him or her can focus on those areas. By prioritizing self-advocacy in an ISP plan, individuals will gain critical tools and supports to build and advance their self-advocacy skills.

- ***Increase understanding of the intersectionality of racial experience and disability experience, cultural competency, and an individual's support needs and desires.***

Recent reports and studies have shown how individuals with disabilities, particularly those who are people of color, face increased levels of bias and marginalization. ODP must devote time and resources to train direct support staff and individuals with IDD on the intersectionality of race and disability to raise the voices of those who have been historically marginalized. By using existing organizations and support structures, such as the National Association for the Advancement of Colored People (NAACP), ODP can elevate the voices of people of color with IDD, which will result in them receiving needed critical supports.



Increase Access to a Range of Home and Community-Based Services

The Coalition discussed the need for the HCBS system to adapt in order to support all individuals with disabilities. People with IDD deserve to have the same opportunity to choose their social activities as do people without disabilities. Without accounting for the unique needs and desires of the people it supports, including those with medical complexities, the system cannot provide holistic care and services. In order to ensure quality care for every individual, no matter their level of need, the Coalition makes the following recommendations:

- ***Modify the current structure to support community services, so that it allows individuals in residential services the freedom, autonomy, and choice for participation in the community.***

The HCBS system allows individuals with IDD the opportunity to choose their living situation, living companions, and what they want to do in the community. However, the DSP workforce shortage has restricted the freedoms of individuals to lead the lives they choose—such as limiting their ability to attend church, engage in self-advocacy activities, go on bicycle rides, visit with family, and to take walks in the community. Individuals with IDD who reside in group homes must have the ability to choose their own social activities, and not be limited to participating only in those activities with which all other residents agree. There is a need for greater awareness of and use of Community Participation Support.

Companionship services, as a supplemented not supplanted service, would allow greater flexibility for people living in group homes. It is important that HCBS are adequately funded through a rate structure that supports meaningful community participation. By including companionship services in an ISP, individuals with IDD will have the freedom to be out in the community.

- ***Incentivize and support programs to serve individuals who have complex needs, mental health needs, and/or complex medical needs.***

The current HCBS system does not address the unique needs of individuals who have medical complexities, complex behavioral needs/diagnoses, and/or significant mental health concerns. Providers are reluctant to provide services to individuals with these needs. The lack of providers and staff willing to support individuals who are medically complex, have multiple diagnoses, and/or mental health needs raises concerns about whether the system can support all people with IDD. ODP must ensure there is provider competency and credentialing for staff who support individuals with more complex needs. The HCBS system must implement



changes to ensure it is inclusive of all individuals with IDD. More funding is needed to support providers who are willing to serve people with IDD who have complex needs.

It is more than providers not being trained and/or willing to take on complex individuals to serve. It is also that ODP policies and reimbursement rates specifically disincentivize providers from accepting these referrals and providing ongoing supports. Programs need more money for improved staffing ratios and to pay higher rates for people with specialized expertise to appropriately serve individuals with complex needs.

The system is skewed toward the payment of services in the community for individuals with less intensive support needs. ODP's rates are not commensurate with the staffing ratios needed to provide supports for people with complex, behavioral, and medical needs. Programs that worked with individuals with complex needs are closing or scaling back, and those individuals cannot find alternatives for community supports. Rather, they are left home without services or end up in institutional settings. The Coalition recommends that ODP incentivize and support programs to serve individuals who have complex needs, mental health needs, or complex medical needs.

- ***Address the needs of people enrolled in a waiver or on the waitlist who live at home and receive no services.***

The vast majority of individuals with IDD reside in their own homes and receive support from their families. As of July 2021, 12,357 Pennsylvanians with IDD remain on the waiting list for a waiver slot. Thousands more are enrolled in a waiver, yet because they live at home with the support of family, they receive few if any services. Therefore, the Coalition recognized the need to prioritize and invest in providing services and supports to those who reside in a private home.

Families' can rarely access respite services when they need them. Individuals enrolled in the Person Family Directed Services and Community Living Waivers are not eligible for residential placements, but this does not mean they do not require the assistance of DSPs. These individuals are just as impacted by the DSP staffing crisis as those who reside in community homes, and their families are left to fill in the gaps in services to ensure their health and safety. The Coalition recommends that the IDD service system be modified so that it provides increased support to those who reside in private homes and the families who are taking care of their needs. These supports should be available to those enrolled in base services, as well as those enrolled in the Person Family Directed Services and Community Living Waivers.

- ***Increase individuals' and families' awareness and understanding of what is already available within waiver service definitions in order to help them make meaningful choices and get access to the supports they need from providers and the waiver.***

Individuals and families are often unaware of the different types of supports and services they can receive under the waivers due to changing regulations and the complicated nature of the system. It is essential that all individuals and their families be educated about these services and provided with background resources about them; access to this information should not be dependent on who is working as your Supports Coordinator.

In the wake of the DSP staffing crisis, it is even more imperative that waiver services are not eliminated on the basis they are underutilized, as this is often because people simply do not know they are available, there are no providers of individualized services in their area, or there are staffing shortages. Often, people with IDD who need more individualized supports face barriers to accessing these supports because the system takes a “one-size-fits-all” approach to service delivery. By increasing education and waiver recipients’ knowledge of the range of supports and services that are available, more individuals with IDD will be able to access services in their communities and live the everyday lives they want.

Expansion of Technology

New and emerging technologies can support the independence of individuals with IDD in their own communities. The Coalition affirms the need for people with IDD to be able to access the technology they want through the HCBS system, ensure funding is made available to acquire that technology, and provide ongoing training to individuals, families, and staff on using technology. The Coalition makes the following recommendations:

- ***Expand definitions and increase funding for technology supports that can be covered under the waivers.***

The ability to access technology enables individuals with IDD to live more independently and connect with their friends, families, and caregivers. With the pandemic, there has been increased reliance on technology. To build on that momentum, the waivers must allow for greater choice and access to both enabling technology and technology that all people use, such as iPhones, Alexa, and Google Home, so that across settings, people with IDD can live as independently as possible. It is not enough to only provide access to technology. The Department must prioritize funding to purchase technology and provide ongoing opportunities for individuals, their families, and staff to learn how to use the technology.

- ***Secure the knowledge, expertise, resources, and funding to provide technology training.***

Merely providing individuals with IDD, their families, and staff access to technology is not enough to make it a useful tool. Without ongoing training on how to use technology, especially newly emerging technologies, people with IDD will not be able to build their capacity or utilize all available tools to support their everyday lives. The Coalition recommends that ODP build partnerships with public and private companies that have expertise in these technologies to better support those in the HCBS system.

- ***Train Support Coordinators (SCs) and Administrative Entities (AEs) to ensure technology supports are included in ISPs.***

ISPs set the priorities for individuals' lives in order to ensure they receive the full supports and services they need. Including technology in a person's ISP enables those who are supporting him/her to understand how different forms of enabling technology can help the individual become more independent in his/her community. SCs and AEs must be educated on the importance of including technology in ISP planning meetings.



Increase Wages, Benefits, and Financial Stability of Services

There is a critical need for ODP to invest funding in increased rates for staff wages and benefits to ensure the sustainability of the HCBS system. Without qualified and experienced staff, the system will collapse, and it will no longer be able to support individuals with IDD in their own communities. By investing in the HCBS system and increasing rates, the Department will ensure the quality of supports and services for Pennsylvanians with IDD. The Coalition makes the following recommendations:

- ***Increase rates for wages and benefits for DSPs, SCs, and other professionals supporting individuals in the waivers in recognition of the responsibilities of their work.***

The work that DSPs, SCs, and other professionals in the HCBS system perform is critical to supporting individuals with IDD, allowing them to live in the community. These professionals are entrusted with the health and safety of the individuals they support, but the wages they receive are not commensurate with the responsibility of their work. The lack of recognition for this work and the



corresponding low pay has caused massive turnover and a high vacancy rate for the positions. This directly affects the health and safety of individuals with IDD across the Commonwealth. ODP must immediately refresh the rates used to set the salaries of DSPs, SCs, and other professionals in the HCBS field to ensure providers can recruit and retain staff and continue to support individuals with IDD in their communities.

- ***Reinvest dollars from state center closures back into the HCBS system to decrease waiting list numbers and increase rates for wages and benefits for DSPs.***

Historically, society has marginalized people with IDD and placed them in segregated institutions instead of supporting them to live in their communities. Individuals with IDD deserve to live an everyday and meaningful life in their own communities. As Pennsylvania continues to prioritize supporting individuals with IDD in the community and closing state institutions, it must reinvest the savings from those closures back into the HCBS system. Without increased support for HCBS as individuals are moved out of state centers and into the community, more pressure will be placed on the limited supports and services that are available. Also, by reinvesting the money from state center closures into HCBS, the Department will be able to support more individuals in the community and reduce the number of people on the waiting list.



Improve Workforce Infrastructure and Professionalism

To ensure the sustainability of the system, there is a critical need to elevate the position of DSPs, so that they view it as a career. DSPs do not receive the recognition they deserve for the level of responsibility that is required. To improve the workforce infrastructure and support those who enter this essential field, the Coalition makes the following recommendations:

- ***Provide funding and develop a system of tiered pay based on certifications, continuing education requirements and/or voluntary professional development, including a voluntary DSP certification program. Participation in the program would be voluntary by the DSP and mandatory by the agency. Training would be paid for and available through ODP, and the certification would be portable by the DSP.***

DSPs are a critical component of the HCBS system, and they support individuals with IDD in the community. However, their position is not valued by society. Providers not only have to constantly recruit new candidates, but also they must invest in the long-term retainment of experienced staff. DSPs deserve to have the opportunity for career development and advancement, and see their work elevated so that it receives the respect it deserves. By instituting a voluntary program that supports DSPs who want to advance their career and attain a level of certification, the Department will be investing in the long-term sustainability of HCBS by ensuring there are qualified staff to provide essential services.

- ***Promote career ladder and advancement opportunities for DSPs, so that they can work towards moving beyond front-line positions, and into management roles.***

Historically, people who worked as DSPs could climb the rungs of the career ladder to become supervisors, house managers, or serve in other more advanced roles. Their ability to advance was dependent on years of service and relevant work experience. Having this opportunity to move through the ranks helped to ensure the sustainability and quality of the system.

Today, there is a lack of staff with hands-on experience who remain in the job long-term due to low salaries and stress from staffing shortages. This crisis is exacerbated by the lack of advancement opportunities, as DSPs are less likely to remain in the job if they feel there is no chance of growth or possibility of advancement. The system must recognize DSPs' hands-on experience and acknowledge the relationships they regularly build with the people they serve by professionalizing their positions, because they are truly the backbone of the service system.

While it is important that senior level staff and management have education, it is just as important that they have practical, on the ground experience working in the HCBS system. In order to retain DSP staff, the Coalition recommends that ODP share best practices among providers that incentivize career advancement for those who start in front-line positions, and that the system receives enough annual funding to provide advancement opportunities.

CONCLUSION AND ACKNOWLEDGMENTS

Conclusion

The Coalition shares the same goals as the Department, ODP, and other concerned parties: *to ensure that individuals with IDD live an everyday life, surrounded by their friends and family, and included in their communities.*

We believe that by implementing these recommendations, the Commonwealth will enable all individuals who receive services through the HCBS system to have the supports and services they need to realize all the promises of the system. We welcome the opportunity to work together to implement these recommendations.

Acknowledgments

This Coalition was created and brought to fruition by The Arc of Pennsylvania. Many thanks to Sherri Landis and the staff at The Arc of Pennsylvania for the time, funding, and resources that they devoted to this project. Gratitude is also expressed to Disability Rights Pennsylvania for the staff time and funding they contributed to the development of this report.

In addition, we wish to acknowledge the steering committee members who have also devoted significant time to moving this project forward.

Steering committee members include:

Rhonda Beach Tyree, Facilitator

Joe Chandler, Self-advocate

Nancy Murray, Family member

Peri Jude Radevic, Disability Rights Pennsylvania

Shaleea Shields, Merakey

This project is supported by a grant from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, DC 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.



“I think about the word freedom and I don’t like to use it because it doesn’t apply to me. They ask what they can do for me, but now it’s like I was forgotten. Individuals are members of society. We are people too. Just because we live in a certain type of setting doesn’t mean we should be accounted as our community.”

*LIZ HUMPHREY
SELF-ADVOCATE*