JOINT STATE GOVERNMENT COMMISSION

General Assembly of the Commonwealth of Pennsylvania

SERVICES TO INDIVIDUALS WITH INTELLECTUAL DISABILITY, DEVELOPMENTAL DISABILITY, OR AUTISM THROUGH THE PENNSYLVANIA OFFICE OF DEVELOPMENTAL PROGRAMS

Report of the Task Force and Advisory Committee

February 2024

Serving the General Assembly of the
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REPORT

House Resolution 212 of 2022
Report of the Task Force and Advisory Committee on
Services to Individuals with Intellectual Disability, Developmental Disability,
or Autism through the Pennsylvania Office of Developmental Programs

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The Joint State Government Commission was created in 1937 as the primary and central non-partisan, bicameral research and policy development agency for the General Assembly of Pennsylvania.[1]

A fourteen-member Executive Committee comprised of the leadership of both the House of Representatives and the Senate oversees the Commission. The seven Executive Committee members from the House of Representatives are the Speaker, the Majority and Minority Leaders, the Majority and Minority Whips, and the Majority and Minority Caucus Chairs. The seven Executive Committee members from the Senate are the President Pro Tempore, the Majority and Minority Leaders, the Majority and Minority Whips, and the Majority and Minority Caucus Chairs. By statute, the Executive Committee selects a chairman of the Commission from among the members of the General Assembly. Historically, the Executive Committee has also selected a Vice-Chair or Treasurer, or both, for the Commission.

The studies conducted by the Commission are authorized by statute or by a simple or joint resolution. In general, the Commission has the power to conduct investigations, study issues, and gather information as directed by the General Assembly. The Commission provides in-depth research on a variety of topics, crafts recommendations to improve public policy and statutory law, and works closely with legislators and their staff.

A Commission study may involve the appointment of a legislative task force, composed of a specified number of legislators from the House of Representatives or the Senate, or both, as set forth in the enabling statute or resolution. In addition to following the progress of a particular study, the principal role of a task force is to determine whether to authorize the publication of any report resulting from the study and the introduction of any proposed legislation contained in the report. However, task force authorization does not necessarily reflect endorsement of all the findings and recommendations contained in a report.

Some studies involve an appointed advisory committee of professionals or interested parties from across the Commonwealth with expertise in a particular topic; others are managed exclusively by Commission staff with the informal involvement of representatives of those entities that can provide insight and information regarding the particular topic. When a study involves an advisory committee, the Commission seeks consensus among the members.[2] Although an advisory committee member may represent a particular department, agency, association, or group, such representation does not necessarily reflect the endorsement of the department, agency, association, or group of all the findings and recommendations contained in a study report.

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[1] Act of July 1, 1937 (P.L.2460, No.459); 46 P.S. §§ 65–69.

[2] Consensus does not necessarily reflect unanimity among the advisory committee members on each individual policy or legislative recommendation. At a minimum, it reflects the views of a substantial majority of the advisory committee, gained after lengthy review and discussion.

Over the years, nearly one thousand individuals from across the Commonwealth have served as members of the Commission's numerous advisory committees or have assisted the Commission with its studies. Members of advisory committees bring a wide range of knowledge and experience to deliberations involving a particular study. Individuals from countless backgrounds have contributed to the work of the Commission, such as attorneys, judges, professors and other educators, state and local officials, physicians and other health care professionals, business and community leaders, service providers, administrators and other professionals, law enforcement personnel, and concerned citizens. In addition, members of advisory committees donate their time to serve the public good; they are not compensated for their service as members. Consequently, the Commonwealth receives the financial benefit of such volunteerism, along with their shared expertise in developing statutory language and public policy recommendations to improve the law in Pennsylvania.

The Commission periodically reports its findings and recommendations, along with any proposed legislation, to the General Assembly. Certain studies have specific timelines for the publication of a report, as in the case of a discrete or timely topic; other studies, given their complex or considerable nature, are ongoing and involve the publication of periodic reports. Completion of a study, or a particular aspect of an ongoing study, generally results in the publication of a report setting forth background material, policy recommendations, and proposed legislation. However, the release of a report by the Commission does not necessarily reflect the endorsement by the members of the Executive Committee, or the Chair or Vice-Chair of the Commission, of all the findings, recommendations, or conclusions contained in the report. A report containing proposed legislation may also contain official comments, which may be used to construe or apply its provisions.[3]

Since its inception, the Commission has published over 450 reports on a sweeping range of topics, including administrative law and procedure; agriculture; athletics and sports; banks and banking; commerce and trade; the commercial code; crimes and offenses; decedents, estates, and fiduciaries; detectives and private police; domestic relations; education; elections; eminent domain; environmental resources; escheats; fish; forests, waters, and state parks; game; health and safety; historical sites and museums; insolvency and assignments; insurance; the judiciary and judicial procedure; labor; law and justice; the legislature; liquor; mechanics' liens; mental health; military affairs; mines and mining; municipalities; prisons and parole; procurement; state-licensed professions and occupations; public utilities; public welfare; real and personal property; state government; taxation and fiscal affairs; transportation; vehicles; and workers' compensation.

Following the completion of a report, subsequent action on the part of the Commission may be required, and, as necessary, the Commission will draft legislation and statutory amendments, update research, track legislation through the legislative process, attend hearings, and answer questions from legislators, legislative staff, interest groups, and constituents.

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[3] 1 Pa.C.S. § 1939.

House Resolution 212 of 2022
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February 2024

To members of the General Assembly:

We are pleased to release *Services to Individuals with Intellectual Disability, Developmental Disability, or Autism through the Pennsylvania Office of Developmental Programs*, as directed by House Resolution 212 of 2021. The report was written with participation from a House of Representatives Task Force and an Advisory Committee representing a wide array of stakeholders. Included among them were individuals and family members of those who are receiving or are on waiting lists for home and community-based services, representatives of the Commonwealth's Office of Developmental Programs, the Office of Vocational Rehabilitation, and advocates, self-advocates, providers, the judiciary, a physician, and a representative of the Pennsylvania Association of County Administrators of Mental Health and Development Services, and others.

Participants reached general, but not unanimous, consensus on 24 recommendations that the commonwealth and providers should follow. Notably, it was recommended that the General Assembly consider a repeal and rewrite of the Mental Health and Intellectual Disability Act of 1966 to make it person-centered and reconcile terminology among the statute, regulations, waiver applications, manuals, and other materials. Further, the general consensus was that the overall system should have as its focus freedom of choice, wherein the paramount guide for decision making should be the desires and needs of the individual.

Significant fundamental disagreements exist among advisory committee members regarding how individuals' needs can be most appropriately supported. Members did, however, agree that the General Assembly must hear from all persons directly affected when it addresses these issues.

On behalf of the Joint State Government Commission, we thank the task force and advisory committee for their participation and for their continued efforts to improve the lives of those with intellectual disability, developmental disability, and autism.

The full report is available at http://jsg.legis.state.pa.us.

Respectfully submitted,

Glenn J. Pasewicz
Executive Director

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INTRODUCTION

House Resolution 212 (2021), Printer's No. 3330, adopted June 29, 2022, created a legislative task force on services provided to individuals with intellectual disability, developmental disability, and autism and directed the Joint State Government Commission to conduct a study on the impact of the Commonwealth's current needs and system capacity for providing opportunities for these individuals The Commission was further directed to establish an advisory committee to assist in its study. The Advisory Committee includes representatives from the Commonwealth agencies charged with responsibility for oversight of these services, the Office of Developmental Programs in the Department of Human Services and the Office of Vocational Rehabilitation in the Department of Labor and Industry. Other representatives include individuals and family members of individuals who are receiving home and community-based services, or on waiting lists for services. Service providers, advocates, self-advocates, a physician, and a representative of the Pennsylvania Association of County Administrators of Mental Health and Development Services, as well as other interested persons are also on the Advisory Committee.

HR 212 directs the Commission to examine and study a comprehensive list of issues that all ultimately relate to the efficiency, uniformity, and best practices of the administration of a system that's goal should be quality of life outcomes designed to assist individuals with various disabilities to function as independently as possible with proper supports that promote the ability of persons with disabilities to live everyday lives of their own choosing. The specific issues and areas of study are addressed in the body of this report and will not be reproduced at length in this introduction.

The advisory committee met eight times, either in person or via Internet conferencing, on October 27, 2022, January 26, 2023, February 24, 2023, April 6, 2023, July 14, 2023, August 24, 2023, October 5, 2023, and November 16, 2023. Further work on the project occurred via group emails. Additionally, task force member Representative Joe Hohenstein hosted a Disability Summit and Policy Hearing on September 14, 2023 at Temple University in Philadelphia, which focused on self-determination and independence. Commission staff attended the meeting and were able to gather much information.

Finally, it should be noted that the recommendations contained in this report represent the general consensus of the Advisory Committee. They are not unanimously endorsed and should not be considered the official position of all the organizations represented on the committee.

The debate surrounding how to deliver services to individuals with intellectual disability, developmental disability, and autism is one in which consensus on policy recommendations is particularly hard to achieve. There are passionate opinions among self-advocates, family members, and advocacy groups. The voice of every stakeholder should be heard. To reach consensus a balance needs to be struck between those stakeholders who believe that all persons with disability, regardless of the degree, can happily live in their home and community and those stakeholders who believe that some persons with disability desire and thrive in in a more structured environment and would prefer not to be forced to participate in activities and environments that they have no interest in. The Americans with Disabilities Act, the Olmstead opinion and the federal Developmental Disabilities Assistance Act all promote and emphasize the ability of individuals with intellectual disability, developmental disability and/or autism to choose where they live and which services they receive. The statutes are designed to enable individuals to participate in their communities without discrimination. At no point do any of these statutes state that individuals must choose or accept the alternatives presented to them. Some individuals, given the choice, would not participate in every aspect of their communities, much as some people without disability pick and choose what activities they wish to engage in. These statutes are not meant to force an individual with a disability to act, but rather to prohibit anyone from preventing them from acting, or creating an environment where they would not feel welcome. Families, advocates, providers, and the Office of Developmental Programs should always be aware that while they are assisting individuals in determining how they can live everyday lives of integration and inclusion in their local communities, a person-centered system should treat the desires of the individual as primary, and not substitute their own judgment or preferences as what would "be for the person's own good."

Two areas in particular tend to create battle lines that may never be reconciled. These areas are living arrangements and employment. The debate flows from a fundamental difference of opinion on the support needs of individuals with disabilities. One camp firmly believes that with the right supports, regardless of level or degree of disability support needs, any person can live and work in the community alongside individuals without disability. The other camp, comprised mostly of family members, believes that there are levels of significant and profound needs that prohibit a small class of persons with disability from ever being fully integrated into their communities and that without some segregated environments, these individuals would be left with no opportunities to engage in any activities outside of their homes.

Part of this report is a historical review of how the Commonwealth has cared for and provided services to individuals with disability over time. This history, especially in its early days, is unpleasant for all and disturbing to some. It is included because it is critically important to remember where Pennsylvania has been and how it got to today's system. Memories of the inhumane treatment of individuals with disability in the past colors and drives current efforts. There are lessons to be learned from the Commonwealth's collective history. To paraphrase George Santayana, those who forget the past are condemned to repeat it.

RECOMMENDATIONS

The Commonwealth should …

- Promote freedom of choice. The desires and needs of the individual should be paramount in all decision-making.

- Ensure that the voices of individuals with more intensive needs are represented in all policy decision-making processes. While some individuals can and should self-advocate, there are individuals whose ability to self-advocate is limited by the nature of their disability, although all should be encouraged to self-advocate. While there are advocacy agencies that attempt to speak on behalf of these individuals, and self-advocates who advocate from their own personal perspectives, caution should be used in attempting to speak on behalf of those whose advocacy is not easily understood. Not everyone has the same needs nor is there a perfect way to meet those needs. Parents, siblings, or other family members who have lived with the individual with disability may be in a better position to represent and advocate for the individual's needs when their communication is limited.

- Provide individuals with real choices. Multiple alternatives for any and all services should be presented to the individual. Individuals with disability should be presented with comprehensive information about all options available and be able to make informed decisions. Services themselves should reflect the full spectrum of support needed and funding provided to make them sustainable. Diversity of choices must also be reflective of the needs and desires of the person receiving the services, and one type of service should not be given preference over another. Choice is illusory if the decision is between no service or the only one being presented to you. It should be noted that it is a choice of individuals and their families to apply for and receive waiver-funded services. If the conditions of the waiver are objectionable, the individual in principle has the right to refuse to accept the conditions of support and instead, where assistance is needed, recruit and privately pay for it. This option, such as it is, is not realistic for anyone other than the extremely wealthy.

- At a minimum, greater transparency regarding membership selection should be provided by ODP. ODP's Information Sharing and Advisory Committee (ISAC) is instrumental in developing policy for the office. ISAC serves as ODP's Stakeholder Quality Council. However, while the membership list of ISAC is available online, how it is composed, both from the perspective of who is selecting the members and what the criteria are for selection, are not readily apparent. Commission staff has been assured that the membership consistently includes a minimum of 51 percent members who are either individuals with disability or families of individuals with disability and that there is representation of family members of persons with complex needs.

Nonetheless, express concerns of some Advisory Committee members regarding whether there was adequate representation of family members of individuals with complex or high-acuity needs, as well as concern about a lack of term limits for membership.

- The General Assembly should consider the flexibility ODP has under state and federal law to shape policies and guidelines, and whether there should be legislative boundaries on those policies that exceed federal and state minimum requirements.

- ODP should improve communication between ODP and individuals and their designated support person (who might be family) and also between providers and individuals and their person – any changes that may impact the quality of life and services to the individual should be clearly communicated in plain language with opportunities for input by the individual.

- Direct care professionals should be included/consulted, at the individual's request, and especially if the person's ability to communicate is limited, by ODP, supports coordinators, providers, and families in determining the needs and desires of the individual with disability when evaluations are being performed and when service plans are being formulated.

- Supports coordinators should educate individuals and families on the importance of participation in evaluations such as Prioritization of Urgency of Needs for Services (PUNS), Individualized Support Plans (ISPs), and Supports Intensity Scale (SIS), and their potential impact on funding and service availability.

- Living arrangements should be needs-based. An individual should not be presented with a short menu to pick the least objectionable living arrangement but instead be offered all types of arrangements, in whatever setting meets the needs and desires of the individual. This includes counties and providers being open to creating new and innovative living arrangements and reviewing what arrangements have worked in other states.

- The Commonwealth should consider developing a more global permanency planning policy that is consistent across all agencies serving children with intellectual disability, developmental disability, or autism needs, who are at risk of institutionalization. Permanency should also be a guiding factor in determining if an individual's living arrangements should be changed. Creation of an express cross-agency policy could build upon work already undertaken by DHS. Permanency planning could also address concerns relating to disruption of persons' lives when transitioning across different levels of care and different programs.

- The Commonwealth should protect each person's right of refusal regarding living arrangements. The Olmstead opinion stated that one of the criteria for de-institutionalization is that "the transfer from institutional care to a less restrictive setting is not opposed by the affected individual." This protection of the right of refusal by the person in need of services should be applicable across all living settings, so that the individual has ability to decline a move to a different program level if the current level can meet their needs, or among similar programs within a provider organization when a transfer is to a different site or to a situation in which the person must adjust to unfamiliar people. It should be remembered that all residential settings, regardless of location or intensity, represent the individual's "home" and not the equivalent of a "placement."

- While there is a general consensus that the current fee-for-service reimbursement system as structured is not viable in the long term, and most of the advisory committee supports ODP's plan to move to a "performance contracting" reimbursement methodology, there is a difference of opinion on whether this move should occur as quickly as possible or be implemented slowly. Regardless of the speed with which these changes are made, many caution that care should be taken to ensure that individuals with disability are not displaced or have their living arrangement options narrowed.

- In some service definitions there is a reference to "fading," wherein support is lessened as the individual develops greater skills in the selected activity. While the definitions state that fading is to occur when appropriate and the supports coordinator is charged with ensuring that the fading is appropriate to the individual's needs, it is important to remember that while life-long learning and support to be as independent as possible is a significant and important goal, there will always be some individuals who will always need support to live their best life.

- ODP should track weekly man-hours worked during integrated employment activities to develop an average weekly hours worked by county and statewide. These data could be used by ODP and advocates to ensure adequate integration and socialization.

- ODP should evaluate how hourly rates paid to employees with disability impact their Social Security Income (SSI) income limitations and how to support individuals after they reach those limits.

- ODP should develop a multi-year plan to end waiting lists. The plan should be designed to provide services to all those currently on the waiting lists and predict needs in the future. Budget and waiver capacity limitations should be identified. A mechanism to provide funding for transitions between waivers should be established so that individuals who are enrolled in one waiver program who become eligible for another need not return to the waiting list until the new program has capacity.

- ODP should continue to expand reimbursement and support for transportation services, because some needs are still unmet. Individuals and their families still struggle with the costs of transportation, and larger annual allocations to capped waiver programs are needed.

- It may be beneficial to explore the possibility of requiring public transit employees, especially drivers, to be trained in interacting with individuals with a disability and addressing their needs. Drivers must also receive appropriate compensation to incentivize them to work in this industry.

- Services available to individuals with a disability should include travel training to assist them in navigating complicated public transportation systems (if they are able), so they do not have to rely on other alternative means. These services can already be found in Community Participation Supports and Supported Employment in the Adult Autism Waiver programs but should also be provided within other appropriate programs.

- School districts and intermediate units, as well as supports coordinators, should ensure that transition planning is thoroughly addressed in student individualized education plan meetings (IEPs) beginning at age 14. References and information about transition planning could be included on the school district's website and in the student handbook and should be incorporated into school college and career readiness programs.

- The General Assembly should consider establishing a funding stream that assists families of persons with disability to petition for guardianship where appropriate. There are members of the advisory committee who do not support guardianship in general, nor state funding for it. Others consider it a critical option in some instances.

- Spouses should be allowed to provide personal care services under those waivers that currently prohibit them from doing so. At a minimum, specific circumstances should be delineated in which this can occur.

- The General Assembly should repeal and re-write the Mental Health and Intellectual Disability Act of 1966 to make it person-centered and reflective of the current state of the law, current standards of care and common practice. Terminology between the statute, regulations, waiver applications and amendments, reimbursement methodology, manuals and announcements need to be reconciled so that the same terms are used consistently and equivalently throughout the documents.

- All support agencies, from the Commonwealth to local providers, should Eliminate alphabet soup; that is, the use of acronyms to describe individuals and programs. It makes it harder for individuals receiving services to understand and navigate the system. A glossary of acronyms on ODP's home page would be useful to many exploring ODP's website.

EVOLUTION OF A SYSTEM

In the beginning . . .

Pennsylvania has a long and uneasy history of how it has addressed the needs of individuals with intellectual disability, developmental disability or autism. In part, that flows from an initial simplistic view of those who are "defective" as a monolithic class of people, in need of care and supervision, but virtually indistinguishable from one another in their "defectiveness". With a growing understanding of neuroscience and psychology over the past 50 plus years, the individual nuances and capabilities of individuals with these diagnoses has led to the development and implementation of a more person-centered approach that encourages independence and freedom of choice. While the system in 2023 is not perfect, it is so much better than it used to be. But it can be better still.

Navigating Pennsylvania's system, where power and authority are divided between counties and the state, can be extremely confusing. Part of the labyrinthine nature of Pennsylvania's system is a function of the Commonwealth's form of government. It is composed of 67 counties, each with its own government and its own responsibilities to provide for its residents. The state government supports and assists county governments, but the balance of power is relatively evenly distributed between local and state governments, unlike many other states where the state government is the overall authority. There are those who would argue that in the field of services for individuals with disability, Pennsylvania's Office of Developmental Programs (ODP) has functioned as that overall authority imposing rules and restrictions on counties. Part of that argument may be true but lies not so much at the feet of ODP as it is a function of Pennsylvania's efforts to acquire federal funds and the General Assembly's delegation of power to do so in a way that has given the Department of Human Services greater flexibility and responsiveness to federal requirements but has minimized legislative input and oversight into ODP's decision-making processes.

It is important to consider the history of the system, in which efforts to provide care for individuals seen as incapable of caring for themselves evolved into a system of warehousing and neglect that led to litigation and a complete revamp of the system in the latter half of the 20th century. Horrific conditions and treatment led to a justifiable abandonment of a failing institutional system. The lessons of that era have not been forgotten and weigh heavily on the decisions regarding appropriate services and living settings for individuals with disability that occur every day in this new era.

In this chapter, when historical material has been referenced and cited, the language and terminology used to describe persons with intellectual disability, developmental disability or autism has been the terminology used at the time the materials were originally written. This is done because Commission staff believes it is important that the reader understand the attitudes toward persons who are different and how these attitudes colored the perspective of the persons writing laws governing how they lived their lives in that era under review. Throughout the remainder of this report, "intellectual disability" will occasionally be used as a short-hand means of referring to intellectual disability, developmental disability, and autism, in order to avoid lengthy repetition. Although there are those in the field who use the acronym "IDDA" or "ID/A" to reference such characteristics, Commission staff has heard from self-advocates that not all persons with intellectual disability appreciate acronyms and abbreviations and find the "alphabet soup" that tends to permeate social service programs to be confusing.

Growth of Institutions

Responsibility for the care of individuals with disability and autism has always been shared in varying proportions among family members, local government, and the Commonwealth. In the 18th and 19th centuries, most people with intellectual disability, developmental disability, or autism were kept at home or enrolled in private schools. Indigent adults who could not be maintained in their homes could be committed to poor district institutions and almshouses. Poor districts were purely local creations and could encompass as small an area as a township or as large as a county and could overlap municipalities. Poor districts were abolished in 1937 and care for the indigent was made the responsibility of the counties.[4]

Persons who were "insane" or mentally ill were frequently confined to institutions, with Pennsylvania establishing its first such facility as the Pennsylvania State Lunatic Hospital and Union Asylum in 1845, which ultimately became Harrisburg State Hospital.[5] While Pennsylvania's history of building state hospitals for the mentally ill is not critically relevant to this study, it should be noted that there were individuals with intellectual disability housed in hospitals for the insane, county care hospitals, and jails and penitentiaries from those earliest days.

In 1853, the Pennsylvania Training School for Idiotic and Feeble-Minded Children (now known as Elwyn) was incorporated to establish a school "for the mental, moral and physical education of children of idiotic and feeble mind."[6] The school, the first in Pennsylvania and one of the oldest in the country, received a $10,000 state grant toward the construction of the school and provision was made for the state to contribute money annually for the maintenance and instruction of indigent pupils.

Beginning in 1893, children with intellectual disability, developmental disability, and autism under the age of 20 could be committed to a state institution specifically dedicated to the care of children. The Western Pennsylvania State Institution for the Feeble-Minded (later renamed Polk State School) was established to provide as follows:

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[4] Act of June 24, 1937 (P.L. 2017, No. 396) known as The County Institution District Law. See also, *Poor District Case,* 329 Pa. 390, 197 A. 33 (Pa. 1938).
[5] Act of April 14, 1845 (P.L. 440, No. 288).
[6] Act of April 7, 1853 (P.L. 341, 224). Under Pennsylvania's Constitution at the time, every corporation could only be created by an act of the General Assembly.

> Section 10. That this institution shall be entirely and specially devoted to the reception, detention, care and training of idiotic and feeble-minded children, and shall be so planned in the beginning and construction as shall provide separate classification of the number groups embraced under the terms idiotic and imbecile or feeble-minded. Cases afflicted with either epilepsy or paralysis shall have a due proportion of space and care in the custodial department. [The institution was designed to have two departments – the education and industrial department and the custodial or asylum department.] It is specifically determined that the process of an agricultural training shall be primarily considered in the educational department, and that the employment of the inmates in the care and raising of stock and the cultivation of small fruits, vegetables, roots et cetera, shall be made largely tributary to the maintenance of the institution.[7]

Ten years later, the eastern part of the Commonwealth got its own state institution for children, known as The Eastern Pennsylvania State Institution for the Feeble-Minded and Epileptic. This institution would eventually become the infamous Pennhurst State School and Hospital. Section 10 of that act is a repetition of Section 10 of the 1893, with the following difference:

> Section 10. That this institution shall be entirely and specially devoted to the reception, detention, care and training of epileptics and of idiotic and feeble-minded persons, of either sex, and shall be so planned in the beginning and construction as shall provide separate classification of the number groups embraced under the terms "epileptics" and "idiotic" and "imbecile" or "feeble-minded."[8]

While both schools were designed and specifically authorized for children, both acts contain a proviso that would permit certain adults to also reside at the institutions. Sections 15 of the 1893 act and 14 of the 1903 act provide:

> Adults who may be determined to be feeble-minded and who are of such inoffensive habits as to make them proper subjects for classification and discipline in an institution for the feeble-minded, can be admitted on pursuing the same course of legal commitment as govern admission to the State Hospital for the Insane.

By 1913, the state institutions for disabled persons were Eastern/Pennhurst/Spring City, Western/Polk, and Elwyn. There were also two private institutions for epileptics that received state funding, one in Beaver County and one in Delaware County. The state institutions accounted for approximately 7,200 individuals.

During the height of the American eugenics movement (late 18th to early 19th century), the Pennsylvania General Assembly passed a joint resolution on June 14, 1911 to create the "Commission on the Segregation, Care and Treatment of Feeble-Minded and Epileptic Persons in the Commonwealth of Pennsylvania." That Commission issued its report in 1913 (1913 Commission Report), concluding, among other things, that disability is inherited, that individuals

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[7] Act of June 3, 1893 (P.L. 289, No. 256). Repealed in 1951.

[8] Act of May 15, 1903 (P.L. 446, N0. 424). Repealed in 1951.

with disability are for the most part potential delinquents and criminals, and "there are now at large in the Commonwealth more than 15,000 feeble-minded and epileptic persons, which number, by reason of the unrestrained propagation of such defectives, is rapidly increasing." The report concluded that while sterilization was cheaper and more permanent, legal obstacles to wholesale sterilization made it not practicable and therefore segregation of men and women with disability should be the predominate means of "controlling" the population.[9]

Large institutions were recommended for this segregation, with distinct sections designated for children, men, women, and various "types" of intellectual disability. The Pennsylvania Village for Feeble-Minded Women (later known as Laurelton State Village) was established in 1913 to serve women between the ages of 16 and 45 and was to be "entirely and specially devoted to the reception, segregation, detention, care and training of feeble-minded women of child-bearing age." In 1969, men began to be committed to the institution. It ultimately closed in 1998.

In 1921, the Public Welfare Code was enacted, creating the Department of Public Welfare, which was given supervision over all state institutions.[10] Pennsylvania enacted the Mental Health Act of 1923, which imposed licensing requirements on non-State institutional entities providing care for "mental patients," defined as a person who is" mentally ill, mentally defective, epileptic, or inebriate." The term "school" was adopted to mean "any hospital, institution, training school, school, or place, public or private, for the care, education, and training of mental defectives or epileptics." This act, the first of its kind in Pennsylvania, also established procedures for the commitment of individuals and set forth a rudimentary patient bill of rights.[11] Individuals could be committed to state institutions and licensed local or private institutions. By the time the Administrative Code of 1929 was adopted, the State Colony for Epileptics at Selinsgrove had been established.

While the Commonwealth had its own dedicated institutions in the 1920s and 1930s, several counties maintained their own mental hospitals that were operated under local government control, except as affected by the state licensure rules. The year after the abolition of poor districts and the creation of county institution districts in 1937,[12] the state took control of all county, city, and institutional district institutions for the "care and maintenance of indigent mentally ill persons, mental defectives and epileptics should be centralized in the State Government in order to insure their proper and uniform care, maintenance, custody, safety and welfare" and because "care for such persons in institutions operated exclusively by the State Government will effect great economies for municipal subdivisions." Each institution so acquired would be named "State Hospital" proceeded by the name of the political subdivision in which it was located.[13] Referred to as the Full State Care Act, Pennsylvania acquired 13 county mental hospitals, five of which

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[9] Report of the Commission on the Segregation, Care and Treatment of Feeble-Minded and Epileptic Persons in the Commonwealth of Pennsylvania, made to the Legislature pursuant to joint resolution of June 14, 1911, at 3-4.

[10] Act of May 25, 1921 (P.L. 1144, No. 425). The Department of Public Welfare had its name changed to the Department of Human Services via amendments enacted by the act of September 24, 2012 (P.L. 458, No. 132). The following year, the Public Welfare Code had its name changed to the Human Services Code via the act of December 28, 2015 (P.L.500, No. 92). DPW and DHS will be used in this report when appropriate to the time period under discussion.

[11] Act of July 11, 1923 (P.L. 998, No. 414).

[12] See note 4, supra.

[13] Act of September 29, 1938 (Sp. Sess. 1, P.L. 53, No. 21).

were closed and eight converted to state hospitals. Of those eight, Embreeville and Mayview are believed to have housed persons with mental illness as well as those with intellectual disability at the time of the 1938 transfer.

The Mental Health Act of 1951 supplanted the 1923 act, renewing the requirement of licensure of private institutions and expressly prohibiting political subdivisions from operating or maintaining any institution for the care of patients, except beds in general hospitals used for temporary care.[14] At that time, Pennsylvania state institutions dedicated solely for intellectually disabled and persons with epilepsy stood at four – Pennhurst, Polk, Laurelton, and Selinsgrove.

In 1951, the General Assembly also passed an act creating the School for Mental Defectives. This statute is still in place, though staff have been unable to find any information as to where it is located, what name it is operating under, or if it was even constructed in the first place. Additionally, the state budget for 1975-76 identifies an "institution for the mentally retarded" named Southeastern, which had a population of zero intellectually disabled persons listed in October 1973 and 97 in October 1974. By the 1968-69 budget, it was no longer listed.

The 1950s and 1960s saw the opening of additional state schools and hospitals that began to be called institutions for the mentally retarded. In 1956, Ebensburg State School and Hospital opened as an annex to the Selinsgrove facility and became an independent facility in 1961. White Haven, a former tuberculosis sanitorium became Pennhurst Annex #2 in 1956 as well. Hamburg State School and Hospital, another former tuberculosis hospital converted in 1960. Western State School and Hospital, originally established as the House of Refuge of Western Pennsylvania and also known as the Pennsylvania Reform School was converted in 1962. What became known as the Cresson Center, started as the Allegheny Tuberculosis Sanitorium, and became the Allegheny State School and Hospital in 1964. Yet another tuberculosis sanitorium, the Pittsburgh City Tuberculosis Sanitorium became a rehabilitation center for the mentally retarded in 1974 and was known as the Marcy Center. In the 1968-69 budget, more than 12,000 people were living in nine institutions. Media exposes and extensive litigation led to increased efforts to deinstitutionalize individuals with intellectual disability in the early and mid-1970s. According to the 1969-1970 Governor's Executive Budget, 14,000 people were receiving mental retardation services in nine state schools and hospitals, 43 private agencies were providing interim care for persons waiting on admission to state schools, and 577 people were housed at Elwyn Institute. Additionally, 32 sheltered workshops were supported. These programs were administered through the Office of Mental Retardation. The Office of Mental Health was responsible for a total of 20 state institutions for the mentally ill that were also in operation. By 1976, 11 state institutions were expressly dedicated to persons with intellectual disability, two had dedicated units, and there were 18 state hospitals for the mentally ill. The population of the state institutions for the mentally retarded in October 1974 was almost 11,000 people as reported in the 1975-76 budget. The 2000-2001 budget listed eight institutions, one dedicated unit at a state hospital, housing in total 2,200 people. Today, there are two state institutions remaining, Ebensburg and Selinsgrove, with fewer than 500 residents in total. Persons with mental illness were institutionalized in six state hospitals as well.[15]

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[14] Act of June 12, 1951 (P.L. 533, No. 141).

[15] Clarks Summit, Danville, Norristown, Torrance, Warren, and Wernersville.

In August 2023, the population of Pennsylvania's public intermediate care facilities was 461 persons. An additional 1,429 individuals resided in private intermediate care facilities.[16]

While societal acceptance of persons with disability has improved radically in the past 100 years, discrimination and prejudice can still be found. In acknowledgement of this, Senate Bill 771 (Printer's No. 871) was referred to the Senate Judiciary Committee on June 14, 2023. The bill renames the crime "ethnic intimidation" to the term "hate-based intimidation" and adds persons with intellectual or physical disability to the protections of the Crimes Code. In recognition of the fact that some people with intellectual disability or autism can be manipulated into false confessions, House Bill 934 (Printer's No. 921) was introduced and referred to the House Judiciary Committee on April 17, 2023. The bill would prohibit the use of deception during custodial interrogations of individuals with intellectual disability or autism. The use of deception in interrogations has generally been found constitutional.[17]

Federal Involvement

The United States federal government historically did not intervene significantly in the provision of public health and welfare services by the states. The first major exception to that rule was the adoption of the Social Security Act in 1935, in response to the economic disaster that was the Great Depression. Old-age pensions were established, funded by a payroll tax. A federal unemployment insurance program, and Aid to Dependent Children were also established, all of which made provision for people with no or low-income.

The federal Mental Health Study Act of 1955 (Public Law 84-182) called for "an objective, thorough, and nationwide analysis and reevaluation of the human and economic problems of mental illness." The resulting Joint Commission on Mental Illness and Health, composed of 36 organizations, issued a report called "Action for Mental Health." [18] This report led to the enactment of the Community Mental Health Act in 1963. The bulk of the proposal was dedicated to the construction of community mental health centers to assist persons with mental illness in living outside institutions. Additionally, however, grants were made for the construction of centers "for research on mental retardation and related aspects of human development.[19] This effort became the start of the deinstitutionalization movement, although the first beneficiaries of that process were persons with mental illness, not those with intellectual disability, developmental disability, or autism.

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[16] *Monthly Data Report* (Pennsylvania Department of Human Services, August 2023), https://www.dhs.pa.gov/about/Documents/DHS-Data-Report_August-2023.pdf, 19. This was the most recent report available on November 27, 2023, when the website was visited.

[17] See Joint State Government Report, "Report of the Advisory Committee on Wrongful Convictions," September 2011, http://jsg.legis.state.pa.us/resources/documents/ftp/publications/2011-212-9-15-11%20rpt%20-%20Wrongful%20Convictions.pdf.

[18] "Important Events in NIMH History," *United States Department of Health and Human Services, National Institute of Mental Health*, accessed October 19, 2023, https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-institute-mental-health-nimh.

[19] Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, Pub. L. 88-164, October 31, 1963.

Concomitant with the federal movement toward funding community mental services for the mentally ill, Pennsylvania revised its approach to providing services to persons with mental illness and intellectual/developmental disability. The Mental Health and Mental Retardation Act of 1966 again re-asserted the Commonwealth's supervision and responsibility for state institutions, but also mandated that counties, on their own or jointly with other counties, create a county mental health and mental retardation program for the prevention of mental disability, and for the diagnosis, care, treatment, rehabilitation, and detention of the mentally disabled. "Mental disability" was defined as

> . . . any mental illness, mental impairment, mental retardation, or mental deficiency, which so lessens the capacity of a person to use his customary self-control, judgement and discretion in the conduct of his affairs and social relations as to make it necessary or advisable for him to be under care as provided in this act. It shall include conditions and terms heretofore defined as "insanity," "unsoundness of mind," "lunacy," "mental disease," "mental disorder," "feebleminded," "moron," "idiot," and "imbecile." [20]

Mental retardation was defined as:

> . . . subaverage general intellectual functioning which originates during the developmental period and is associated with impairment of one or more of the following (1) maturation, (2) learning and (3) social adjustment.

This terminology was eliminated from the act by amendments made in 2011 and the term "intellectual disability" replaced "mental retardation" throughout the act and was defined as:

> . . . significantly subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social and interpersonal skills, use of community resources, self-direction, functional academic skills, work, health and safety. The onset must occur before the individual's twenty-second birthday.[21]

The Office of Mental Retardation in the Department of Public Welfare changed its name as well and is now known as the Office of Developmental Programs. County MH/MR programs changed their names as well, to become mental health/intellectual disability programs.

County programs, in cooperation with the department were charged with ensuring that the following mental health and intellectual disability services are available:

(1) Short term inpatient services other than those provided by the State.

(2) Outpatient services.

(3) Partial hospitalization services.

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[20] Act of October 20, 1966 (Sp. Sess. 3, P.L. 96, No.6).

[21] Act of November 22, 2011 (P.L. 420, No. 105).

(4) Emergency services twenty-four hours per day which shall be provided by, or available within at least one of the types of services specified heretofore in this paragraph.

(5) Consultation and education services to professional personnel and community agencies.

(6) Aftercare services for persons released from State and County facilities.

(7) Specialized rehabilitative and training services including sheltered workshops.

(8) Interim care of those with intellectual disability who have been removed from their homes and who having been accepted, are awaiting admission to a State operated facility.

(9) Unified procedures for intake for all county services and a central place providing referral services and information.

These local authorities also have the power to establish the following additional services or programs for the mentally disabled:

(1) Training of personnel.

(2) Research.

(3) Any other service or program designed to prevent mental disability or the necessity of admitting or committing the mentally disabled to a facility.

Services may be provided either directly or by purchase of such services, except that unified intake and referral services must be provided directly through the county administrator. The county was also required to establish a local mental health and intellectual disability board and appoint a county administrator.

The federal government became more involved in providing for indigent individuals with the advent of the War on Poverty in the 1960s. The hallmarks of the war included amendments to the Social Security Act in 1965 to create Medicare (national health insurance for the elderly) and Medicaid (national health insurance for the indigent). Pennsylvania adopted a new Public Welfare Code in 1967, confirming the role of the Commonwealth is supervising all state institutions and creating the Commonwealth Mental Health Research Foundation.[22] It additionally, and more importantly, recognized the potential influx of new federal dollars for services to the elderly and disabled, and the General Assembly directed the Department of Public Welfare to essentially do whatever was necessary to access these funds.

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[22] Act of June 13, 1967 (P.L. 31, No. 21), as originally enacted.

Authority of the Department of Human Services

The grant of authority to DPW in 1967 to take advantage of Medicaid moneys was broad, and is found as follows:

> Section 201. State Participation in Cooperative Federal Programs.—The department shall have the power and its duties shall be:
>
> > (1) With the approval of the Governor, to act as the sole agency of the State when applying for, receiving and using Federal funds for the financing in whole or in part of programs in fields in which the department has responsibility.
> >
> > (2) With the approval of the Governor, to develop and submit State plans or other proposals to the Federal government, to promulgate regulations, establish and enforce standards ***and to take such other measures as may be necessary to render the Commonwealth eligible for available Federal funds or other assistance.*** Notwithstanding anything to the contrary in the act of July 31, 1968 (P.L.769, No.240), referred to as the Commonwealth Documents Law [procedures for promulgating regulations], the department may omit notice of proposed rulemaking and promulgate regulations as final when a delay of thirty days or less in the final adoption of regulations will result in the loss of Federal funds or when a delay of thirty days or less in adoption would require the replacement of Federal funds with State funds. (Emphasis added).
>
> Section 403. Uniformity in Administration of Assistance; Regulations as to Assistance. —
>
> (a) The department is responsible for maintaining uniformity in the administration of public welfare, including general assistance, throughout the Commonwealth.
>
> (b) The department shall establish rules, regulations and standards, consistent with the law, as to eligibility for assistance and as to its nature and extent. The department is authorized to seek waivers from the Federal Government to enhance consistency between Federal program standards, requirements or procedures. This shall not be interpreted to require the department to seek waivers to achieve consistency among standards, requirements or procedures in Federal programs, except as specifically required under other provisions in this article. Whenever possible, except for residency requirements for general assistance, and consistent with State law, the department shall establish rules, regulations and standards for general assistance consistent with those established for aid to families with dependent children. In no instance shall the rules, regulations and standards established for general assistance provide for assistance greater than that provided for aid to families with dependent children. If three or more general assistance recipients reside together in the same household, their income eligibility and cash assistance shall be no greater than income eligibility and cash assistance from aid

> to families with dependent children for a household of the same size. The secretary or a written designee is the only person authorized to adopt regulations, orders, or standards of general application to implement, interpret, or make specific the law administered by the department. The secretary shall issue interim regulations whenever changes in Federal laws and regulations supersede existing statutes. In adopting regulations, orders, or standards of general application, the secretary shall strive for clarity of language which may be readily understood by those administering assistance and by those who apply for or receive assistance. For the purpose of this subsection, the term "household" does not include single-room occupancy residences, rooming houses, nonprofit residential programs or personal care facilities receiving charitable funding or Federal, State or local government funding.
>
> Section 403.1. Administration of Assistance Programs.—
>
> (a) The department is authorized to establish rules, regulations, procedures and standards consistent with law as to the administration of programs providing assistance, including regulations promulgated under subsection (d), that do any of the following:
>
> (1) Establish standards for determining eligibility and the nature and extent of assistance.
>
> (2) Authorize providers to condition the delivery of care or services on the payment of applicable copayments.
>
> (3) Modify existing benefits, establish benefit limits and exceptions to those limits, establish various benefit packages and offer different packages to different recipients, to meet the needs of the recipients.
>
> (4) Establish or revise provider payment rates or fee schedules, reimbursement models or payment methodologies for particular services.
>
> (5) Restrict or eliminate presumptive eligibility.
>
> (6) Establish provider qualifications.
>
> (b) The department is authorized to develop and submit State plans, waivers or other proposals to the Federal Government and to take such other measures as may be necessary to render the Commonwealth eligible for available Federal funds or other assistance.[23]

Initially, Medicaid funding could only be used for mental retardation services provided in intermediate care facilities for persons with mental retardation (ICF/MR – now identified as ICF/ID). Ebensburg and Selinsgrove, the Commonwealth's remaining two state centers are structured as ICF/ID. There are approximately 150 other private facilities that are licensed to serve as ICF/ID. That all changed in 1981 with amendments to the provisions of Medicaid law. The 1981 amendments allowed States to request waivers from the provisions limiting reimbursement to skilled nursing or intermediate care facilities and permitted state medical assistance plans to include home and community-based services (other than room and board) pursuant to an approved written plan of care to individuals who would otherwise require the level of care provided in a skilled nursing facility or intermediate care facility. Services could include case management services, homemaker/home-health services, habilitation services, personal care services, adult day

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[23] Act of June 13, 1967 (P.L. 31, No. 21), as amended by Act of June 30, 2011 (P.L.89, No.22).

health services, respite care, and other approved services requested by the State. Waivers were generally valid for three years.[24] These amendments became the transition to waiver funding for most services for individuals with intellectual disability, developmental disability, an autism, and were the beginning of the end of institutional segregation of persons with mental disability by the state.

The provisions of the Human Services Code (previously known as the Public Welfare Code), read individually or together, can be seen as giving the Department of Human Services (and consequently its program office, the Office of Developmental Programs) statutory *carte blanche* to implement federal funding opportunities. This has resulted in at least two situations recently where ODP's authority has been questioned – the HCBS settings rule and the establishment of reimbursement rates, both of which are discussed in more detail later in this report.

It should be clearly noted that while the statutory authority of ODP appears broad, there are substantial regulations in place that have been vetted through the Independent Regulatory Review Commission process, including periods for public comment and input from legislators. These regulations can be found in 55 Pa.Code Chapters 1101, 2380, 2390, 4300, 6100, 6400, and 6500. These are comprehensive regulations that primarily address the role and permissible activities of providers. They specifically provide for the rights of individuals receiving services. The regulations do not exist in a vacuum; they also are responsive to federal and state laws governing financial fraud and abuse, neglect and abuse of care-dependent persons, children, and the elderly, and discrimination.

The primary area where concern has been expressed regarding ODPs flexibility in making rules and guidelines relates to the Medicaid waiver programs. When a state wants to create a new waiver, it must provide at least a 30-day public notice and comment period to be completed prior to submission of the waiver application to CMS. CMS has 90 days to approve or deny an initial waiver. Waivers must be renewed every five years, but they can be amended at any time, subject to the public comment period and CMS waiting period. A quick review of the DHS website indicates that each waiver has tended to be amended at least once a year since 2017. This ability to be able to change an active waiver as often as the state desires can have the effect of creating relatively rapid change and a sense of instability. This is compounded by the fact that DHS and ODP have at least two websites, making Internet searches more challenging, and the website pages are not always updated contemporaneously with the effective date of new changes. Further, waiver applications can approach 500 pages in length, and even the summaries of changes for waiver applications run to 40 pages long.

The ability of the Department to be flexible and responsive to sudden changes at the federal level is important. However, the relative rapidity with which changes are sometimes made can be seen as capricious. Providers, advocates, and family members may feel their input is minimalized. There are four primary informative considerations behind a waiver program change: (1) community engagement; (2) evidence; (3) quality and risk management structure; and (4) state and federal law (regulations and litigation).

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[24] The Omnibus Budget Reconciliation Act of 1981, Title XXI, §§ 2175 and 2176, adding § 1915 to the Social Security Act. Pub.L. 97-35 (August 13, 1981).

For community engagement considerations, DHS must hear from several advisory bodies. Some advisory bodies are required pursuant to statute. Standing advisory committees required by statute or regulation include the following: Medical Assistance Advisory Committee (MAAC) (this is considered a consumer committee and is pursuant to a federal regulation); Employment First Oversight Commission (EFOC) (this committee issues an annual report with recommendations and is pursuant to a federal regulation); Special Education Advisory Panel (SEAP) (many concepts from SEAP have influenced DHS and ODP policies); and Information Sharing and Advisory Committee (ISAC) (which has three subcommittees – Racial Equity, Housing, and Provider Oversight). Another standing committee that informs DHS regarding program changes is the Independent Monitoring for Quality (IM4Q) Steering Committee. This committee is not explicitly required by statute or regulation. All these bodies have professionals who collaborate and help provide information to DHS when it is in the process of adopting changes to waivers or new waivers.

ISAC has the most influence on DHS policy. ISAC was formed in 2012, replacing a previous advisory body, but is not organized under any statutory authority. In 1989, ODP convened numerous stakeholders to discuss what services in Pennsylvania should look like, and then Governor Casey released "Everyday Lives: Values in Action" which has been ODPs "bible" ever since. In 2012, ODP formally established the Information Sharing and Advisory Committee (ISAC) as an ongoing committee to discuss policies and practices and make recommendations to ODP. ISAC consists of 35 members, most of whom are providers or members of advocacy or self-advocacy groups. The members are appointed by ODP and do not appear to have term limits.[25]

DHS also holds workgroups and taskforces. Some examples include Residential Strategic Thinking Group: Supports Coordination Strategic Thinking Group; Technology Taskforce; Fiscal Workgroup; Waiting List Workgroup; and multiple ad hoc groups on various topics (CPS, Residential Staffing Ratio, Conference Planning, and Incident Management). Ad hoc groups bring a collaboration of shareholders together to help discuss these topics specific to each group. They are often short-term.

Another form of DHS's community engagement comes in the form of public comment. DHS holds public comment through listening sessions prior to its 5-year renewals of a waiver program. The holding of listening sessions by DHS is by practice, not statutory mandate. In addition, there are also ad hoc listening sessions held by DHS for new leadership and responses to trends or complaints. When DHS submits a new application for a § 1915 waiver program, proposed amendments, or a program renewal, it is required to allow for a public comment. DHS also provides a Record of Change for each comment. DHS also holds live sessions for major stakeholder groups, as well as for general audiences, which provides specific, broken-down details of a proposed change. Some sessions scheduled for targeted stakeholder groups include individuals, families, providers, supports coordination, and administrative entities. They are often in-person and scheduled regionally. There is also a written comment period. DHS then summarizes and publishes the waiver application.

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[25] "The ISAC Hub," *MyODP Training Resource Center*, accessed February 14, 2024, https://home.myodp.org/resources/the-information-sharing-and-advisory-committee-hub/.

Evidence-based considerations behind waiver program changes are data-rich. DHS allows for the review of extensive sets of reports and dashboards. DHS also contracts with numerous consulting firms to provide research and analytics, technical assistance, and general consultation. DHS also utilizes its PeopleSTAT division, while ODP participates in national studies including longitudinal (comparative) data. These studies include staff data reports, national core data, residential information programs, and Coleman Institute State of the State surveys.

In 2018, DHS/ODP began a project to "Simplify the System" to implement Everyday Lives Recommendation No. 8, "The system of supports and funding of those supports must be as straightforward and uncomplicated as possible." The project is ongoing.[26] ISAC releases annual reports, and ODP recently released the third edition of the Office's "Gold Book: Understanding the Office of Development Programs" in July 2023. The Gold Book is intended to be a comprehensive guide for families as they enter and navigate the ODP service system.[27]

The Centers for Medicare & Medicaid Services (CMS) has made it clear that rules governing waivers give states a great deal of latitude in how the waiver programs are structured, so long as they meet minimum federal standards. For purposes of considering ODP's authority to establish standards for the number of persons who can attend any given program, and the settings in which programs can be held, CMS responded to inquiries with two letters that affirm that the federal rules set a minimum standard that states can exceed, and that the degree of interaction with the community is the determinant of an appropriate setting, not a numerical cap. Specifically, living arrangements such as farmsteads, intentional communities, and campus settings are not prohibited settings. Beginning in 2019, there has been an on-going dispute between several providers and ODP regarding reimbursement rate setting notices by ODP. The providers have argued that the authority of ODP was an unconstitutional delegation of legislative authority. The Supreme Court did not opine on that theory, and instead found that the providers needed to exhaust their administrative remedies before bringing suit. The case was remanded to the Commonwealth Court for review of the remaining issues.[28]

Least Restrictive Environment

In 1975, the U.S. Congress passed the All Handicapped Children Act of 1975 to require public schools to evaluate children with disability, create an educational plan with parental input that would allow students to experience their education in the least restrictive environment possible, where inclusion and interaction with non-disabled children can be optimized. Due process proceedings are put into place so that disputes as to the appropriate educational setting and instruction between parents and schools can be impartially resolved.[29] This statute was reenacted

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[26] Microsoft PowerPoint - DHS OSTA BSPS Project Activities Summary Options Text ISAC Deck_NRT. Revised.2 (myodp.org).

[27] "ODP Reissues the Gold Book," *My ODP Training Resource Center*, accessed February 14, 2024, https://home.myodp.org/2023/07/14/odp-reissues-the-gold-book/.

[28] *Rehabilitation and Community Providers Association et al. v. Department of Human Services Office of Developmental Programs,* 283 A.3d 260 (2022). Lower court opinion found at 250 A.3d 544 (Pa. Cmwlth.2021, opinion not reported.

[29] All Handicapped Children Act, Pub.L. 94-142 (November 20, 1975).

as the Individuals with Disabilities Education Act of 1990, and specifically provides for an individualized education plan (IEP), a free and appropriate public education in the least restrictive environment determined by an appropriate evaluation and parent and teacher participation.[30] This concept of the least restrictive environment for students with disability was expanded to persons with intellectual and physical disability as well.

The adoption of the Americans with Disabilities Act of 1990 (ADA) established civil rights for persons with intellectual or physical disability.[31] Enforcement of this act involved not only actions by state and local governments to ensure that public accommodations were not discriminatory, but litigation as well. In the *Olmstead* decision of the U.S. Supreme Court, that court found that unnecessary institutionalization was a civil rights violation and that services to the individuals with mental disability must be provided in the least restrictive environment.[32] The court in Olmstead specifically cited provisions of the ADA's findings and purpose that directly address the history of segregation of individuals with mental disability:

> § 12101. Findings and purpose
> (a) Findings
>
> The Congress finds that –
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> * * *
>
> (2) historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
>
> (3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;
>
> * * *
>
> (5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;[33]

The court found that the ADA's prohibition against discrimination could require placement of persons with mental disability in community settings rather than institutions. The court stated that:

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[30] Individuals with Disabilities Education Act, Pub.L. 101-476 (October 30, 1990).
[31] Americans with Disabilities Act of 1990, Pub.L. 101-336 (July 26, 1990).
[32] Olmstead v. L.C. 527 U.S. 581 (1999).
[33] *Ibid*, p. 588.

> Such action is in order when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.[34]

It is important to note two of these criteria that will become relevant in further discussions within this report: the requirement that the transfer is not opposed by the affected individual and that the placement can be reasonably accommodated taking into account the resources available to the state and the need of others with disability. The first is important to the discussion of the freedom of choice of the individual and the second relates to what can reasonably be expected of the state and its impact on waiting lists.

The ADA and its interpretation through the Olmstead case helped stimulate and promote the use of waivers to provide home and community-based services.

In a similar vein, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act of 2000, updating its 1963 act and finding that " disability is a natural part of the human experience that does not diminish the right of individuals with developmental disability to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society."[35] "Developmental disability" was further defined to mean:

> A severe, chronic disability of an individual that –
>
> (i) is attributable to a mental or physical impairment or combination of mental and physical impairments:
>
> (ii) is manifested before the individual attains age 22;
>
> (iii) is likely to continue indefinitely;
>
> (iv) result in substantial functional limitations in 3 or more of the following areas of major life activity:
>
> (I) Self-care.
> (II) Receptive and expressive language.
> (III) Learning.
> (IV) Mobility.
> (V) Self-direction.
> (VI) Capacity for independent living.
> (VII) Economic self-sufficiency; and
>
> (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic service, individualized supports, or other forms of assistance that are lifelong or extended duration and are individually planned and coordinated.[36]

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[34] *Ibid*.
[35] 42 U.S.C. § 15001(a)(1).
[36] 42 U.S.C. § 15002(8)(A).

With respect to infants and young children, the definition reads:

> An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.[37]

The term "inclusion"

> means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to-
>
> (A) have friendships and relationships with individuals and families of their own choice;
>
> (B) live in homes close to community resources, with regular contact with individuals without disabilities in their communities;
>
> (C) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and
>
> (D) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.[38]

Further, the term "integration" "means exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals."[39]

In 2003, the Pennsylvania Secretary of Public Welfare convened an Autism Task Force that released a report in 2004 that sparked major changes in Pennsylvania's provision of services to persons with autism. Among other things, it led to amendments in 2008 to the Pennsylvania Insurance Law to mandate coverage of autism services in health insurance policies.[40] In 2008, the Office of Developmental Programs initiated services specifically for adults with autism.

In 2014, the Centers for Medicare and Medicaid Services announced that new rules were being proposed that would govern home and community-based services waivers (HCBS Rule). The rules would require States to ensure that plans of care are person-centered, define the

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[37] 42 U.S.C. § 15002(8)(B).

[38] 42 U.S.C. § 15002(15).

[39] 42 USC § 15002(17).

[40] *Pennsylvania Autism Task Force, Executive Summary* (2014), https://paautism.org/wp-content/uploads/2019/06/Pennsylvania-Autism-Task-Force-Report-.pdf.

characteristics of home and community-based settings, with the intent of insuring that individuals receiving services and supports through Medicaid waivers receive those services in settings that are integrated in and support full access to the greater community. Some waiver approvals would be subject to a five-year renewal period.[41]

In order for settings where services are provided to be considered home and community-based, they must meet specific criteria:

- It is integrated in and supports full access to the greater community.
- It is selected by the individual from among a variety of setting options.
- It optimizes autonomy and independence in making life choices.
- It facilitates individual choice in selecting both services and service providers.
- It ensures individuals rights of privacy, dignity, respect, and freedom from coercion and restraint.

Significantly, four of these criteria are focused on the individual's freedom of choice.

The rule required states to make a statewide transition plan to determine their compliance with the HCBS Rule.[42] Seven of Pennsylvania's HCBS waivers fall under the Rule: the Infants, Toddlers and Families Waiver, the Adult Autism Waiver, the Community Living Waiver, the Consolidated Waiver, the Person/Family Directed Support Waiver, the Community HealthChoices Waiver, and the OBRA Waiver. These waivers will be discussed in detail later in the report.

The Centers for Medicare and Medicaid released proposed new regulations governing HCBS in March 2023.

> . . . we are proposing new Federal requirements in this proposed rule to improve access to care, quality of care, and health and quality of life outcomes; promote health equity for people receiving Medicaid-covered HCBS; and ensure that there are safeguards in place for beneficiaries who receive HCBS through FFS [fee-for-service] delivery systems. . . . The proposed requirements are also intended to promote public transparency related to the administration of Medicaid HCBS program.[43]

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[41] Center for Medicare and Medicaid Services, *Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS Waivers)* (January 16, 2014), 79 Fed.R. 2948-3039, www.govinfo.gove/content/packg/FR-2014-10-16/pdf/2014-00487.pdf.

[42] Pennsylvania Department of Human Services, *Pennsylvania's Home and Community-Based Services (HCBS) Centers for Medicare and Medicaid Services (CMS) Final Rule Statewide Transition Plan (STP)* (August 2023), PA-Final-Approved-Statewide-Transition-Plan.pdf.

[43] The Medicaid Program; Ensuring Access to Medicaid Services (CMS-2442-P), 88 Fed. R. 27960, 27965. May 3, 2023. Comment period ended July 3, 2023.

A bill was introduced in the U.S. Congress in March 2023 that would enact the HCBS Access Act. The bill would make HCBS a mandatory benefit under Medicaid (waivers would no longer be needed), create a grant program to allow states to expand capacity to meet the needs of persons seeking HCBS, and help address the workforce shortage. The bill would also establish the presumption that "each eligible individual, regardless of type or level of disability or service need, can be served in the individual's own home and community; and at the option of the individual, that services may be self-directed."[44] Residential habilitation, which provides for individuals to live in group homes and facilities, is not listed as a benefit under this proposed program. The presumption and the lack of any reference to residential habilitation seems to indicate that this statute is designed to eliminate these living arrangements and narrow the choices of individuals with disability in determining the environment in which they wish to reside. This potential change is of concern to family members of person individuals with substantial and acute disability, some of whom find group settings the most appropriate and desirable living arrangement. The bill was initially introduced on March 9, 2023 and referred to the House Committees on Energy and Commerce, Education and the Workforce, and Oversight and Accountability for their respective perspectives on the bill. On March 17, 2023, the bill was referred to the Subcommittee on Health of the Committee on Energy and Commerce. No further legislative actions have been taken.

Senate Bill 452 (Printer's No. 434) was referred to the Senate State Government Committee on March 14, 2023. The bill would establish the Office for Individuals with Disabilities within the Governor's Office. The powers and duties of the office are broad, and it is not clear if this entity is meant to be a replacement for the Office of Disability Programs within the Department of Human Services.

Guardianship

Some individuals with intellectual disability, developmental disability, or autism have a legal guardian who has been appointed by the court to protect their interests. As is the case for individuals who receive services who have not been declared legally incapacitated, managing the ability to restrict or control an individual's autonomy is and should be paramount. Pennsylvania's guardianship law expresses a preference for the least restrictive alternative and limited guardianships are preferred over full guardianships. Substituted decision-making for an incapacitated person under the guardianship law must be tailored to the abilities and needs of the person over whom guardianship is sought. 20 Pa.C.S. § 5501 defines an incapacitated person as "an adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or to meet essential requirements for his physical health and safety." As so defined, guardianship may be granted over an individual who does not meet the criteria to receive waiver services.

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[44] S.762 — 118th Congress (2023-2024); https://www.congress.gov/bill/118th-congress/senate-bill/762/text?s=1&r=143.

20 Pa.C.S. § 5512.1 details how the type of guardianship needed is determined:

Determination of incapacity and appointment of guardian.

(a) Determination of incapacity.—In all cases, the court shall consider and make specific findings of fact concerning:

(1) The nature of any condition or disability which impairs the individual's capacity to make and communicate decisions.

(2) The extent of the individual's capacity to make and communicate decisions.

(3) The need for guardianship services, if any, in light of such factors as the availability of family, friends and other supports to assist the individual in making decisions and in light of the existence, if any, less restrictive alternatives. The court shall make specific findings of fact based on the evidentiary record of the absence of sufficient family, friends or other supports and of the insufficiency of each less restrictive alternative before ordering guardianship. Less restrictive alternatives include, but are not limited to:

(i) Advance directives such as durable powers of attorney or trusts.

(ii) Living wills.

(iii) Health care powers of attorney.

(iv) Health care representatives.

(v) Financial powers of attorney.

(vi) Trusts, including special needs trusts.

(vii) Representative payees for individuals receiving Social Security benefits.

(viii) Pennsylvania Achieving Better Life Experiences accounts.

(ix) Mental health advance directives.

(4) The type of guardian, limited or plenary, of the person or estate needed based on the nature of any condition or disability and the capacity to make and communicate decisions.

(5) The duration of the guardianship.

(6) The court shall prefer less restrictive alternatives to guardianship and, if no less restrictive alternatives are available and sufficient, limited guardianship. The following apply:

(i) A determination of incapacity is separate from a determination of where a guardian should be appointed.

(ii) The court may not use a determination of incapacity alone to justify a guardianship.

(iii) The court may not appoint a guardian if a less restrictive alternative exists that is sufficient to support the needs of an incapacitated person.

(iv) When entering an order denying a petition for guardianship in whole or in part, the court shall identify the less restrictive alternatives that are available and sufficient to enable the alleged incapacitated person to manage personal financial resources or to meet essential requirements of personal physical health and safety. An order may assist the respondent and any supportive and substitute decision makers involved to effectuate the respondent's decisions with third parties.

> (b) Limited guardian of the person.—Upon a finding that the person is partially incapacitated and in need of guardianship services, the court shall enter an order appointing a limited guardian of the person with powers consistent with the court's findings of limitations, which may include:
>
> (1) General care, maintenance and custody of the incapacitated person.
>
> (2) Designating the place for the incapacitated person to live.
>
> (3) Assuring that the incapacitated person receives such training, education, medical and psychological services and social and vocational opportunities, as appropriate, as well as assisting the incapacitated person in the development of maximum self-reliance and independence.
>
> (4) Providing required consents or approvals on behalf of the incapacitated person.
>
> (c) Plenary guardian of the person.—The court may appoint a plenary guardian of the person only upon a finding that the person is totally incapacitated and in need of plenary guardianship services.
>
> (d) Limited guardian of the estate.—Upon a finding that the person is partially incapacitated and in need of guardianship services, the court shall enter an order appointing a limited guardian of the estate with powers consistent with the court's finding of limitations, which shall specify the portion of assets or income over which the guardian of the estate is assigned powers and duties.
>
> (e) Plenary guardian of the estate.—A court may appoint a plenary guardian of the estate only upon a finding that the person is totally incapacitated and in need of plenary guardianship services.
>
> (f) No presumption.—No presumption of incapacity shall be raised from the alleged incapacitated person's institutionalization.
>
> (g) Legal rights retained.—Except in those areas designated by court order as areas over which the limited guardian has power, a partially incapacitated person shall retain all legal rights.
>
> (h) Information as to rights.—At the conclusion of a proceeding in which the person has been adjudicated incapacitated, the court shall assure that the person is informed of his right to appeal and to petition to modify or terminate the guardianship.[45]

One common concern associated with guardianship has been the fact that the role is sometimes ignored or minimized by service or healthcare providers. This occurs partially because not all guardians fully understand their rights as guardians.[46] After the effective date of Act 61 of 2023, persons seeking to become guardian of three or more incapacitated persons will be required to meet competency and licensure requirements. Another common concern is the costly and lengthy legal process associated with appointing guardianships. In Pennsylvania, the process can cost thousands of dollars in legal fees and court costs, making guardianship an unaffordable option for many Pennsylvanians.

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[45] This section as presented as amended by the act of December 14, 2023 (P.L. 446 No. 61), which amended Title 20 of the Pennsylvania Consolidated Statutes. The amendments are effective June 13, 2024.

[46] Discussion in the Advisory Committee Meeting held on November 16, 2023.

Group Home Oversight

Following some reports of suspected abuse and neglect contributing to deaths of individuals residing in group homes, a Congressional request was made to the U.S. Department of Health and Human Services Office of Inspector General (OIG) to investigate whether group homes were complying with federal waiver and state requirements for reporting and monitoring critical incidents involving Medicaid beneficiaries with developmental disability. The OIG began meeting with the DHS Administration for Community Living and Office for Civil Rights to discuss how to address the concerns raised by these audits. The U.S. Department of Justice Civil Rights Division was also consulted. The result was a report released in 2018 that was intended to protect Medicaid beneficiary health and safety by recommending that states provide greater compliance oversight. The report proposed model practices that have the effect of requiring ODP to assert greater compliance oversight systems for group homes and impose greater uniformity of practices among the county mental health/intellectual disability programs.[47] Prior to OIG's report release, Pennsylvania had begun revising and re-visiting its supervision of residential services in 2017 and released a report outlining an improvement plan in 2019.[48] OIG audited Pennsylvania, but reviewed the years 2015-2016, which predated ODPs improvement activities. The report, released in 2020, found that Pennsylvania had not been fully compliant with the then existing rules.[49] As ODP had already begun an improvement process, it was not surprising that a subsequent OIG audit of fiscal year 2021 found that Pennsylvania had complied or was in the process of complying with its recommendations.[50]

House 1002 (Printer's No. 1155) was referred to the House Human Services Committee on May 5, 2023. The bill would require annual inspections of mental health establishments to ensure continuing conformity to the facility's license. If a facility is found to be operating outside the scope of its license, its license will be revoked.

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[47] *U.S. Department of Health and Human Services Office of Inspector General, Administration for Community Living and the Office for Civil Rights, Joint Report: Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight* (January 2018), https://www.oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf; See also, CMCS Informational Bulletin, "Health and Welfare Home and Community Services (HCBS) Waiver Recipients," June 28, 2018.

[48] *Improving the Quality of Residential Services* (DHS, ODP, January 2019), https://www.dhs.pa.gov/Services/DisabilitiesAging/Documents/Everyday%20Lives/Improving%20the%20Quality%20of%20Residential%20Services%20Report%20(c_287989).pdf.

[49] U.S. Department of Human Services, Office of Inspector General, "Pennsylvania Did Not Fully Comply With Federal and State Requirements for Reporting and Monitoring Critical Incidents Involving Medicaid Beneficiaries With Developmental Disabilities," Report No. A-03-17-00202, January 17, 2020, https://oig.hhs.gov/oas/reports/region3/31700202.asp.

[50] US DHS, OIG, "Pennsylvania Implemented Our Prior Audit Recommendations for Critical Incidents Involving Medicaid Enrollees With Developmental Disabilities but Should Continue To Take Action To Reduce Unreported Incidents," Report No. A-03-22-00202, November 30, 2023.

ODP oversees the Community Living Waiver, the Consolidated Waiver, and the Person/Family-Directed Support Waiver which provide services to adults and children with intellectual disability, developmental disability, and autism. It also oversees the Adult Autism Waiver which is available for all adults over age 21 with a diagnosis of autism who meet specific criteria. Pennsylvania received approval for its first Consolidated Waiver in 1990. The Person/Family Directed Support Waiver was first approved in 1999. Adult Autism Waiver was approved in 2008. The Community Living Waiver was approved in 2017.

Adults with developmental physical disability that result in at least three substantial functional limitations that are expected to endure indefinitely are covered under OBRA Waivers (The Omnibus Budget Reconciliation Act of 1987). Community Health Choices is a managed care program for adults who are nursing facility clinically eligible. OBRA and Community Health Choices are overseen by the Office of Long-Term Living. The Infants, Toddlers and Families Waiver provides services for children in need of early intervention services who are under the age of three and is administered by the Office of Child Development and Early Learning.

While there are a total of 10 HCBS waivers in effect in Pennsylvania, the remaining three overseen by ODP relate to different groups of individuals: older adults aged 55-plus who are nursing home eligible but who can safely live in the community with support (LIFE – Living Independence for the Elderly Program); adults aged 18-59 with a medically determinable physical impairment (Act 150 – State-Funded Program); and the Adult Community Autism Program (ACAP), a managed care program for adults with autism spectrum disorders who have fewer intensive behavioral needs, and is capable of serving up to 200 people in Chester, Cumberland, Dauphin, and Lancaster Counties.

In total, seven waiver programs exist under ODP. ACAP and LIFE waivers are not listed on the following table, as ACAP has a very limited geographic coverage area, and LIFE is essentially a managed care program. The following table lists the five waivers that provide services to individuals with intellectual disability, developmental disability and/or autism under ODP, the number enrolled in August 2022 versus August 2023 and the percentage change in enrollment over that period.

Table 1

ODP Waiver Programs for
Intellectual Disability, Developmental Disability, and Autism Services
August 2022 versus August 2023

Waiver	# Enrolled August 2022	# Enrolled August 2023	% Change
Consolidated	18,166	18.369	1.0 percent increase
Person and Family Directed	12,275	11,797	3.9 percent decrease
Community Living	4,408	5,509	25.0 percent increase
Act 150	1.019	1,090	7.0 percent decrease
Adult Autism	714	715	0.1 percent increase
TOTALS	36,582	37,480	0.25 percent increase

Source: Pennsylvania Department of Human Services, Monthly Data Report (August 2023), https://www.dhs.pa.gov/about/Documents/DHS-Data-Report_August-2023.pdf, 15, 17-18.

In August 2023, 37,480 individuals with intellectual disability, developmental disability, and/or autism received services through Pennsylvania's Medicaid waivers, an increase of 898 individuals over the prior year. Within those categories, the greatest increase in terms of raw numbers was the community living waiver, which is consistent with the stated ODP goal of moving individuals into more inclusive environments. This increase, however, has not kept pace with the waiting list, which as of March 2023, included over 12,000 persons.[51] Clearly, capacity needs to grow significantly.[52]

In April 2023, the Shapiro Administration announced the launch of The Pennsylvania Autism Surveillance Project (PASP). It is a cross-agency collaboration between the Pennsylvania departments of Human Services (DHS), Education (PDE), and Health (DOH). PASP is conducting public health surveillance as part of the Autism Developmental Disabilities Monitoring (ADDM) Network, under funding provided by the Centers for Disease Control and Prevention (CDC). The ASERT Collaborative will provide support and partner with DHS throughout this collaboration.[53] The project will provide a snapshot of the prevalence of autism in Pennsylvania by reviewing the educational and health records of four- and eight- years old children in Chester and Delaware Counties.[54] House Bill 498, Printer's No. 467 was introduced in the spring of 2023 to require the

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[51] Pennsylvania Department of Human Services, *Monthly Data Report* (August 2023), https://www.dhs.pa.gov/about/Documents/DHS-Data-Report_August-2023.pdf, 15, 17-18. This was the most recent report available on November 27, 2023, when the website was visited.

[52] See Table 1 on page 40 of this report.

[53] ASERT (Autism Services, Education, Resources and Training) is a partnership of medical centers, centers of autism research and services, universities, and other providers involved in the treatment and care of individuals of all ages with autism and their families. ASERT was developed to bring together resources locally, regionally, and statewide. www.paautism.org.

[54] "Pennsylvania Autism and Support Project (PASP)," *PA Department of Human Services*, accessed November 28, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/PASP.aspx.

Department of Human Services to develop an autism screening tool that may be used by child care providers to screen children at ages 18, 24, and 36 months for signs of autism. The bill was referred to the House Human Services Committee on March 17, 2023, where it currently resides.

In November 2023, Senate Resolution 194, Printer's No. 1210, was introduced to direct the Legislative Budget and Finance Committee to conduct a study on workforce shortages among all HCBS programs and the Pennsylvania Lottery-funded OPTIONS program. The resolution was referred to the Senate Health and Human Services Committee on November 9, 2023, where it resides as of this writing.

Eligibility

For purposes of this study, the four waiver programs addressing the needs of persons with intellectual disability, developmental disability, and autism are the focus. Those programs are the Consolidated Waiver, the Community Living Waivers, the Adult Autism Waiver, and the Person/Family Directed Support Waiver (PFDS). While some people with intellectual disability also have physical disability, this report focuses on services for intellectual disability. Physical disability will be addressed to the extent they overlap with intellectual disability needs. The Medicaid income eligibility requirements are beyond the scope of this study, and it will be assumed that a person receiving services meets the income requirements and has received an appropriate diagnosis.

In general, eligibility for Consolidated Waiver, Community Living Waiver, and P/FDS waiver are the same. There is no age limit for intellectual disability or autism. A person under age nine is eligible for services if that child may have a developmental disability with a high probability of the disability resulting in an intellectual disability or autism. Children under age 22 with a developmental disability due to a medically complex condition are also eligible. The person must require an ICF/ID or ICF/ORC level of care (intermediate care facility for intellectual disability or other related condition). The difference between the three waivers is in the variety of services available and the annual budget allocated for the services. The broadest spectrum of services is found in consolidated waiver, which has no budget cap. Community living waiver is capped at $85,000 per year, and PFDS waiver is capped at $41,000, but can be exceeded by $15,000 for advanced supported employment or supported employment services.[55] Persons age 21 or older with autism spectrum disorder, including Autistic Disorder, Childhood Disintegrative Disorder, PDD-NOS (pervasive developmental disorder – not otherwise specified), Asperger Syndrome or Rett Disorder who meet intermediate care facility level of care are eligible for adult autism waiver services.[56]

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[55] These criteria are the result of the latest waiver amendments submitted by DHS and are effective November 1, 2023. Application for 1915(c) HCBS Waiver: PA.0147.R07.02 - Nov 01, 2023 (as of Nov 01, 2023) (Consolidated Waiver); Application for 1915(c) HCBS Waiver: PA.1486.R01.02 - Nov 01, 2023 (as of Nov 01, 2023) (Community Living Waiver); Application for 1915(c) HCBS Waiver: PA.0354.R05.02 - Nov 01, 2023 (as of Nov 01, 2023) (Person/Family Directed Services Waiver).

[56] Application for 1915(c) HCBS Waiver: PA.0593.R03.05 - Nov 01, 2023 (as of Nov 01, 2023).

While Consolidated Waivers and Community Living Waivers resemble each other most closely, P/FDS has a number of significant differences, which are discussed below.

House Bill 421 (Printer's No. 388) was referred to the House Human Services Committee on March 15, 2023. The bill would strengthen cross checks to verify eligibility for medical assistance.

Person/Family Directed Support Waiver

The Person/Family Directed Support (P/FDS) waiver was specifically developed "…to emphasize deinstitutionalization, prevent or minimize institutionalization and provide an array of services and supports in community-integrated settings."[57] Moreover, the waiver is intended to assist individuals with disability to live independently in their homes and communities.[58] The P/FDS waiver was designed not to replace but rather to supplement the available supports to individuals and their families through other sources. Like other waivers, the P/FDS waiver is administered through the Pennsylvania Department of Human Services (DHS), Office of Developmental Programs (ODP). These offices also work in collaboration with each county's respective programs. The waiver operates with 52 percent of its funding coming from the federal government and 48 percent of its funding coming from state coffers.[59]

The waiver encourages the use of a self-directed model, an alternative to the more traditional managed system of services, such as an agency delivery model.[60] The self-directed model, commonly referred to as Participant-Directed Model (PDM or PDS) expands the level of choice and the degree of control of program participants and their families in receiving home and community-based services. In addition to its expansion of choice and control, individuals receiving services also favor the PDS because it helps them access supports that best match their needs and preferences. The PDS also enhances self-advocacy and offers a sense of responsibility for the services individuals receive.[61] The PDS model is also available in community living waivers, and for some services under consolidated waivers.

Through the PDS, participants, or their representatives, exercise decision-making authority over certain services they receive. Participants typically have direct responsibility to manage their services with the assistance of a system of supports.[62] Participating individuals can decide who

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[57] Application for 1915(c) HCBS Waiver: PA.0354.R05.02 – Nov 01, 2023, p. 6.

[58] *Ibid*.

[59] Katie Wilkinson, "PA Person/Family Directed Support Waiver Explained," *Givers*, accessed November 26, 2023, https://www.joingivers.com/programs/pa-person-family-directed-support.

[60] "Person/Family Directed Support Waiver," *Department of Human Services*, accessed November 25, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/PFDS-Waiver.aspx#:~:text=The%20Pennsylvania%20Person%2FFamily%20Directed,including%20self%2Ddirected%20service%20models.

[61] "Participant Directed Services in Pennsylvania: Leading a Self-Determined Community Life," *Temple University College of Education and Human Development, Institute on Disabilities*, accessed November 28, 2023, https://disabilities.temple.edu/sites/disabilities/files/info-sheet-pds-2022-12-16.pdf.

[62] "Self-Directed Services," *Medicaid.gov*, accessed November 25, 2023, https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html.

provides the services and how services are provided. Identified as "employer authority" by Centers for Medicare & Medicaid Services (CMS), individual consumers can recruit, hire, train, and supervise the individuals who furnish their services. They can hire family caregivers to provide them with personal assistance, respite, companion, in-home and community support, or other services. Participants may also have authority over how the Medicaid funds in a budget are spent, referred to as "budget authority."[63] To assist them in directing their own care, people with disability and their families can hire individuals known as supports brokers. These professionals typically work in collaboration with the individual, family, supports coordinator, and service team to help with recruiting, hiring, and supervising support professionals and caregivers. They also assist in completing paperwork, facilitating a circle of support, developing, and maintaining back-up plans, and ensuring compliance with waiver standards, regulations, and policies.[64]

Over the past decade, there has been a steady move toward participant-directed care across the country. As noted in a Legislative Budget and Finance Committee report entitled *Family Caregivers in Pennsylvania's Home and Community-Based Waiver Programs*, participant-directed care, was available, to some extent, in every state and the District of Columbia going back almost ten years to 2014. In that year, Pennsylvania had more than 10,000 individuals enrolled in all participant-directed programs.[65] As of August of 2023, Pennsylvania has 11,797 individuals enrolled in the P/FDS waiver, alone.[66]

Individual Cost Limit

The P/FDS Waiver has a $41,000 cost limit per eligible individual per fiscal year. However, this cap excludes the costs associated with supports coordination and Supports Brokers services. In addition, the limit can be exceeded by $15,000 for advanced supported employment or supported employment services.[67] Advanced supported employment is an employment skills development service designed to help qualifying individuals with little or no job experience to find and maintain competitive, integrated employment. Other supported employment services include job coaching, small group employment, and career assessments.

Selecting Caregivers

As mentioned previously, under the P/FDS waiver, participating individuals receiving services can recruit, hire, train, and supervise the individuals who furnish their services. These service providers can be outside direct service professionals or family members and relatives. While many individuals across the Commonwealth utilize family members as paid caregivers, it is hard to track specific data on these individuals. Hiring family members as paid caregivers under the P/FDS waiver can be a cost-effective way for an individual with disability to remain in the family home, as out-of-home placements are typically associated with higher costs. However, some states in the past have reported that paying family members to take care of individuals may

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[63] *Ibid*.

[64] *Supra*, n. 61.

[65] Legislative Budget and Finance Committee, *Family Caregivers in Pennsylvania's Home and Community-Based Waiver Programs*, (2014), 26.

[66] Pennsylvania Department of Human Services, *Monthly Data Report* (Aug. 2023), 18.

[67] *Supra*, n. 59.

have added to the states' cost of care since many more families, who were previously uncompensated for care they provided, are starting to seek payment for continued caregiving.[68]

Other issues that can be associated with choosing a family member to provide services are the long wait for background checks and the potential for fraud and abuse. An individual can hire a family member who may be ill-suited for the role, which can invite financial abuse. There have been reports that some family members take advantage of the individual by reporting hours worked that they are not actually working, which is not only fraud, but harmful to the person in need of care. Supports coordinators are typically trained to recognize signs of abuse or fraud. Hiring family members as paid caregivers can also raise concerns over quality and performance of care. Just because the caregiver is related to the individual care recipient does not necessarily mean the caregiver is qualified to provide said care. Sometimes, individuals overlook the lack of qualifications because they are a family member.[69]

Financial Management Services

After electing to utilize participant directed services in the P/FDS waiver, an individual will need the assistance of a Financial Management Services (FMS) Organization. The FMS assists the individual with some of the "employer-related work that is associated with self-directing services, such as processing payments and maintaining tax records."[70] In Pennsylvania, the Office of Developmental Programs (ODP) offers two different FMS options: Agency with Choice (AWC) and Vendor Fiscal/Employer Agent (VF/EA).

Financial Management Services Models

Participant Directed Services (PDS)

Vendor Fiscal/Employer Agent (VF/EA)	Agency with Choice (AWC)

There are differences between the two models, specifically regarding the individual or surrogate's level of control and responsibility. The individual chooses the model that best meets his or her needs. Within the PDS model, direct support professionals are referred to as support service professionals (SSPs).

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[68] *Supra*, n. 65, 29.
[69] *Ibid*, 30.
[70] "Participant Direction: PDS-FMS," *Pennsylvania Department of Human Services*, accessed November 28, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Participant%20Direction%20Services.aspx#:~:text=There%20are%20two%20types%20of,levels%20of%20control%20and%20responsibility.

VF/EA. Under this model, the individual with disability who receives services, or their surrogate, is what is known as the Common Law Employer (CLE). The CLE recruits, interviews, hires, and fires the support professionals and caregivers to ensure they meet provider criteria and pass a background check and other qualification checks. In addition, the CLE approves, signs, and submits timesheets to the FMS, develops employee job descriptions, and provides training to the employees. The FMS completes the employee paychecks and handles taxes and insurance-related matters. Overall, this model allows the individual to have more control over the employee and their services.[71]

AWC. Under the AWC model, the individual receiving services, or their surrogate serves as the Managing Employer (ME), while the FMS is the legal employer to administer human resources and payroll. The individual and the FMS act as joint employers. The FMS ensures that the prospective employee is qualified and verifies and processes employee timesheets and invoices the ME submits. The FMS develops FMS-related employee duties, and the ME develops participant-specific job duties. The ME and the FMS jointly provide training as agreed by the ME and the AWC. FMS is responsible for issuing employee paychecks, taxes, and insurance-related matters. Overall, this model provides more joint control between the individual and the FMS over the employee and services provided.[72]

OBRA Waivers

Persons with developmental physical disability generally do not receive services through ODP, but rather through the Office of Long-Term Living (OLTL), another DHS office. OLTL administers OBRA Waivers for adults with developmental physical disability that result in at least three substantial functional limitations that are expected to endure indefinitely. As of August 2023, 593 individuals were receiving OBRA waiver services in Pennsylvania.[73] OBRA waivers are part of the Home and Community Based Services (HCBS) waiver bundle under Medicaid. These are not discussed at length in this report because the focus has been on HCBS programs administered by ODP. However, it was brought to the Task Force and Advisory Committee’s attention that under OBRA waivers, spouses are not currently permitted to provide personal care services. Federal regulations generally prohibit “legally responsible relatives,” such as parents of minor children and spouses from being paid caregivers. This “marriage penalty” is of particular concern for couples who both have disability or who have a limited income. While a significant other can live with and provide services to an individual with disability, the moment a marriage license is signed, the person is no longer eligible. This loss of income to the support providing spouse can be financially devastating and effectively deny individuals the right to marry.[74]

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[71] *Supra*, n. 61.

[72] *Ibid*.

[73] Pennsylvania Department of Human Services, *Monthly Data Report*, (August 2023), https://www.dhs.pa.gov/about/Documents/DHS-Data-Report_August-2023.pdf, 15, 17-18.

[74] Testimony presented at the Disability Summit and Policy Hearing on September 14, 2023, at Temple University in Philadelphia.

Specifically, federal law provides that unless a state agency defines them differently for purposes of a Medical Assistance (MA) waiver… personal care services can be "…[p]rovided by an individual who is qualified to provide such services and who is not a member of the individual's family…*family member means a legally responsible relative*."[75] Simply put, parents cannot be paid caregivers to their children under MA waiver programs, nor can spouses or other family members who have any preexisting legal obligation to take care of the participating individual receiving services. That is, unless the state obtains a waiver from this requirement or statutorily defines personal care services to permit legally obligated family members to be paid through its waiver program. Some states have expanded the definition under their waiver programs to allow legally obligated family members like spouses and parents to become paid caregivers. If states are to allow obligated family members to serve as paid caregivers, they need to establish programs that mandate certain procedures to ensure integrity of the care.

Currently, Pennsylvania does not have a program permitting legally obligated family members to be paid personal care providers under OBRA waivers. However, in May of 2023, legislation (House Bill 1218) was proposed to require DHS to seek a waiver from the CMS to establish a program for personal care services provided by the spouse of an MA recipient.[76] The bill passed the House on July 7, 2023, and was last referred to the Senate Health and Human Services Committee on July 17, 2023.[77]

Funding

In federal fiscal year 2018, 65 percent of federal grants to states were for Medicaid. Pennsylvania ranks 12th among the 50 states in terms of how much federal money received is dedicated to Medicaid alone, at between 65 and 70 percent, consistent with the national average.[78] In 2022, $1.2 trillion in funding was granted to the states, with nearly 51 percent designated for Medicaid and CHIP, with the remaining funds spread among transportation, general purpose fiscal assistance, education, housing assistance, disaster relief, and all other programs. In terms of overall aid, Pennsylvania ranked fifth highest in terms of funding received, at $41 billion. This is consistent with Pennsylvania's ranking as the fifth most populous state in the country.[79] Some private grant programs exist to assist people with disability, but then tend to be focused on physical disability. Some charitable organizations and schools offer private pay living arrangements and services, and autism services are a mandated benefit under Pennsylvania's insurance law. However, the bulk of services are funded by federal Medicaid waiver dollars.

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[75] 42 C.F.R. § 440.167(a)(2), (b) *(Emphasis added)*.

[76] Pennsylvania House Bill 1218, (PN 1766), (Sess. of 2023).

[77] Pennsylvania House Bill 1218, Co-Sponsorship Memo, "Bill Information – History," *Pennsylvania General Assembly*, accessed on November 28, 2023, https://www.legis.state.pa.us/cfdocs/billinfo/bill_history.cfm?syear=2023&sind=0&body=H&type=B&bn=1218.

[78] The Pew Charitable Trusts, "Medicaid Makes Up Most Federal Grants to States: Funding Mix Varies Significantly by State," Fact Sheet, March 2019.

[79] "Which States Rely the Most on Federal Aid?" *USA Facts*, last modified September 1, 2023, https://usafacts.org/articles/which-states-rely-the-most-on-federal-aid/.

The state/county component of services for individuals with disability is found in each county mental health/intellectual disability program. Funding is provided on a 90 percent state/10 percent county funding match.[80] These are known as Base-Funded Services or Family Support Services (FSS)/Individual Payment option and provide an indirect service to assist individuals in employment and management of providers for non-waiver services.[81] In the Pennsylvania Code, they are categorized as "Family Resource Services" and can include respite care, family aid, homemaker services, in-home therapy, family education/training, recreation/leisure-time activities, and special innovative services, all outside of waiver services. [82]

Senate Bill 511 (Printer's No. 480) was referred to the Senate Health and Human Services Committee on March 15, 2023 and House Bill 183 (Printer's No. 141) was referred to the House Human Services Committee on March 8, 2023. Both bills mandate health insurance coverage (including medical assistance and CHIP as well as private insurers) to provide coverage for complex wheelchair maintenance and well-visits.

Role of Counties

Under the Mental Health and Intellectual Disability Act of 1966, counties have the primary responsibility to identify and provide intake for individuals with intellectual disability, developmental disability, and autism into the mental health/intellectual disability system. A person can present themselves for evaluation for services, or referrals may come from families, health care providers, mental and behavioral health providers, and schools.

The county administrator is responsible for establishing an organizational unit consisting of multidisciplinary professional and nonprofessional staff capable of planning, directing, and coordinating appropriate services for individuals with an intellectual disability and in need of service from the county program. This base service unit, and the county administrator have the authority to direct, control and monitor the activities of the base service unit.[83] Eligibility for intellectual disability services through ODP requires a diagnosis of an intellectual disability based on the results of objective standardized testing. An intellectual disability is 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 an intellectual disability requires that both a person's general intelligence and ability to function in daily life are significantly below average.[84] The MH/ID defines intellectual ability further, as "significantly subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social and interpersonal skills, use of community

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[80] 55 Pa.Code § 6350.11.

[81] "Information on Services and Supports," *Services and Supports Directory*, accessed February 14, 2024, https://www.hcsis.state.pa.us/hcsis-ssd/ServicesSupportDirectory/Services.

[82] 55 Pa.Code Ch. 6350.

[83] 55 Pa.Code § 6201.12.

[84] "Eligibility and Contact Information," *Department of Human Services*, accessed February 14, 2024, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Eligibility-Intellectual-Disabilities.aspx#:~:text=The%20local%20county%20mental%20health%2Fintellectual%20disabilities%20%28MH%2FID%29%20programs%27,based%20on%20the%20results%20of%20objective%20standardized%20testing.

resources, self-direction, functional academic skills, work, health and safety."[85] Intake and referrals must be conducted by the county administrator. Other services may be provided by the county directly through its employees or through contracted providers. [86]

Once the county has determined that the person is eligible for services, a supports coordinator will be assigned to the individual. The supports coordinator may be an employee of the county or an individual may choose to use a supports coordination organization. The supports coordinator is responsible for assisting the individual in developing an individualized support plan (ISP). However, creating an ISP requires identification of the needs of the individual, prioritizing those needs and finding providers available to meet those needs.

DHS' County Assistance Offices are responsible for determining the financial eligibility for Medicaid from an income and asset perspective.

Waiting Lists and PUNS

Pennsylvania's struggle to address the service needs of individuals with intellectual disability and/or autism has been occurring for quite some time. When the first state institutions were opened in the late 19th century, there were already too many people seeking services than there were slots allotted. The 1913 Commission Report calling for segregation of the mentally disabled identified 966 individuals on the waiting lists of three then extant state institutions.[87] According to the Commission's 2008 report entitled *The Advisory Committee Report on the Waiting List for Community-Based Mental Retardation Services*, Pennsylvania had had a significant waiting list for services for the previous 40 years. Hoping to reduce the list, the Commonwealth began a series of initiatives in the mid-1980s. One such initiative was to increase state funding. Pennsylvania governors ushering in new administrations requested funding increases and coinciding General Assemblies appropriated them to bolster the agencies and programs providing individuals with disability with services. Despite the increased funding, the waiting list continued to expand. Many families waited for decades without receiving the services they needed, signaling the reality that funding increases alone could not adequately address the full scope of the problem. The Commonwealth's next initiative was to find the source of the systems' problems and the extent of their impact.[88] Many recognized that a failure to adequately capture the full magnitude of the service shortfalls would stymie the ability to resolve them. Simply pinpointing the extent of the system's inadequacies, however, proved to be challenging.

Historically, counties had no real uniform procedure to gather data in support of annual county plans, and individual counties varied widely in their reporting. Some counties' waiting lists were little more than a list of names handwritten on a tablet. There was no clear definition of exactly what a waiting list should comprise. The recordkeeping was so primitive and inconsistent,

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[85] MH/ID Act of 1966, § 102.
[86] *Ibid*. § 301(d)(9) and (f).
[87] *Supra*, n. 9.
[88] Joint State Government Commission, *The Advisory Committee Report on the Waiting List for Community-Based Mental Retardation Services*, (June 2008), 11.

it was hard to determine how many individuals were left unserved. Consequently, and as noted in the Commission's 2008 report, during Fiscal Year 1996-97, Pennsylvania's Department of Public Welfare[89] Office of Developmental Programs (ODP) (formerly Office of Mental Retardation) commissioned Temple University's Institute on Disabilities, Pennsylvania's University Center for Excellence in Developmental Disabilities, to conduct a standardized survey of the people who were waiting for services and supports across the Commonwealth. The PUNS system was developed from this effort.[90]

Development and Implementation

To further address these inconsistent and underdeveloped reporting practices, ODP, in collaboration with system stakeholders, developed definitions and data collection methods for determining the size of the waiting list and the characteristics of persons on the waiting list. The final product of this collaboration was the creation of a system known as the Prioritization of Urgency of Need for Services (PUNS).[91] The PUNS system, first implemented in 1998, is a data collection tool that identifies the different types of services and supports an individual currently receives, as well as the services the individual is still in need of. Services and supports received within the PUNS data include intellectual disability and/or autism services and supports that are available to anyone in each community.[92]

Following its implementation, the PUNS was revised in 2006 and a PUNS manual was published by the Department of Human Services (DHS) the same year. The PUNS manual was updated in 2019 based on input from professionals and stakeholders, including members of the PA Waiting List Campaign[93], advocates, family members, and administrative entities.[94] Likewise, the manual is designed to serve as a resource for much of these same individuals who provide input on its updates – individuals and families, County Mental Health/Intellectual Disability Programs, administrative entities, supports coordination organizations, and other officials within ODP. ODP has adopted the PUNS system as a formal requirement for annual county plans and for use in program budgeting. The county plan and budget process occur annually and are critical for determining the resources required to address the needs of individuals a with disability.[95]

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[89] In 2014, the Department of Public Welfare was redesignated the Department of Human Services pursuant to the Act of September 24, 2014 (P.L.2458, No. 132), § 2; 62 P.S. § 103(a).

[90] *Supra*, n. 88.

[91] *Ibid*.

[92] "Prioritization of Urgency of Need for Services (PUNS), Department of Human Services, accessed May 3, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/PUNS.aspx.

[93] In response to the growing dearth of available services for individuals with intellectual and developmental disabilities and the public outcry that attached to it, the Pennsylvania Waiting List Campaign was established in 1997. The advocacy group sought a "vision of equality" to address the systemic problem of long waiting lists for services. The Waiting List Campaign educates families, government officials, the public, and legislators about the full impact of waiting lists on the health, safety, and welfare of people with intellectual disabilities - "About", *The Pennsylvania Waiting List Campaign*, accessed June 22, 2023, https://pawaitinglistcampaign.org/about/.

[94] PA Department of Human Services, *Office of Developmental Programs Bulletin*, (July 23, 2019).

[95] PA Department of Human Services, *Prioritization of Urgency of Need for Services (PUNS) Manual for Individuals with Intellectual Disabilities and/or Autism* (2019), 5.

Categories of Urgency

A prominent aspect of the PUNS system is its categorization of urgency for individuals' needs. The system allows for the kind of information gathering necessary to categorize the urgency of the needs of individuals who have requested services from the County Program or administrative entity. Once information is extracted and collected through the PUNS intake process (to be discussed in further detail below), the system identifies these individuals as falling into one of the following three categories of needs:

- <u>Emergency Need</u> – The individual needs a service within the next six months.
    - Example: Death, family crisis, serious illness of a caregiver, or caregiver is no longer available to provide care and no other caregivers are available.

- <u>Critical Need</u> – The individual's service need is anticipated to occur after six months but within two years.
    - Example: Person who has a caregiver who is 60+ years old and needs supports within the next two years.

- <u>Planning for Need</u> – The individual's service need is anticipated to occur more than two years away but less than five years away.
    - Example: Person is losing eligibility for Children & Youth supports within the next two to five years.[96]

Since the needs of individuals with a disability vary significantly, the system's categorization helps to ensure those facing emergent services needs are prioritized, while still ensuring those with critical and planning needs receive services when their needs arrive or become emergent. Though the PUNS system has helped mitigate Pennsylvania's ongoing disability services shortage, many individuals are still waiting for services. According to the PA Waiting List Campaign, there were 12,575 individuals in Pennsylvania waiting for needed services as of March 31, 2023. See Table 1 for a breakdown of waiting list needs based on the three needs categories.

Table 2
Individuals With Intellectual Disability in Need of Services
(as of March 31, 2023)

Emergency Needs Category	Critical Needs Category	Planning Needs Category	Total People Waiting
5,569	**4,610**	**2,396**	**12,575**

Source: The Pennsylvania Waiting List Campaign, https://pawaitinglistcampaign.org/, last accessed June 22, 2023.

It is worth noting that those individuals needing services is likely to increase in the next five to ten years, as the number of individuals with autism spectrum disorder (ASD) requiring

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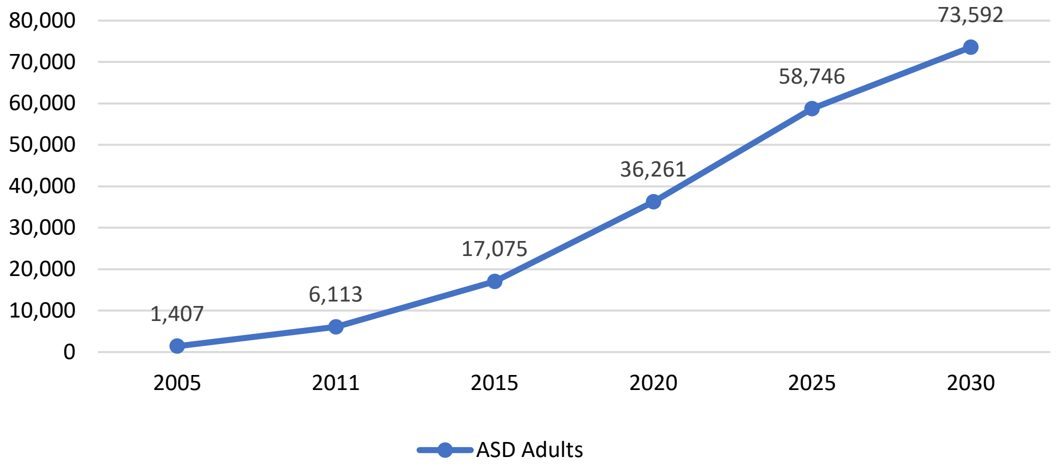
[96] *Ibid*.

services has been on the rise in Pennsylvania for the past 20 years. According to a 2021 ODP - Pennsylvania Bureau of Autism Services report, over 36,260 adults with ASD were receiving services in Pennsylvania in 2021. This number is projected to increase to over 73,500 adults by the year 2030. See Chart 1 below.

Chart 1

Actual & Projected Number of Adults with ASD Receiving Services in Pennsylvania



Source: ODP – Pennsylvania Bureau of Autism Services 2021 Report cited by the Pennsylvania Waiting List Campaign.

The number of individuals receiving home and community-based services through the Consolidated, Community Living, Person/Family Directed, and Adult Autism waivers is determined by the annual approved capacity in each waiver. The approved capacity of the waivers is determined annually by the state budget. Since 2006, the waiting list has been reduced by nearly half, and since 2015, the median wait time on the waiting list has decreased from 4.1 years to 2.6 years.[97]

Utility

The PUNS system is useful for many different reasons. One useful aspect is that the individual and his or her family can utilize PUNS to understand and identify the services he or she needs. PUNS can then assist in categorizing the urgency of their service need. Individual support planning (ISP) teams also use the PUNS system during the annual team planning process. The role PUNS plays in the annual team planning process allows supports coordinators to have useful discussions with affected individuals and their families regarding their needs. In these planning sessions, a PUNS form is completed through a face-to-face conversation between the support

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[97] *Annual Waiting List Report* (DHS, ODP, 2022), https://palms-awss3-repository.s3.us-west-2.amazonaws.com/MyODP_Content/Everyday+Lives/ODP+Annual+Waiting+List+Report+2022.pdf, 3.

coordinator, the individual, and the family. These conversations can play a pivotal role in identifying and planning for needs not just on an individual level, but also at a systems level for county programs and DHS. For instance, county intellectual disability programs can collect a standard set of data on individuals based on information provided in PUNS information who are waiting for intellectual disability services and support. As noted above, ODP can then use aggregate PUNS data to assist in statewide planning and budgeting. Advocacy groups also use PUNS data when representing their affected members and communities to legislators. The data can be used by advocacy groups to effectively inform legislators about the growing needs of individuals on waiting lists for supports and services.[98]

Process

Individuals with a disability within a county program or administrative entity who have a current or anticipated service need within the next five years should complete a PUNS form; however, before discussing the initial PUNS form, several activities should occur. First, the initial intake process must be completed. Information is gathered in the intake process to determine the needs of the individual and their eligibility for intermediate care facilities. The individual then must be registered for disability or autism services and assigned a support coordinator.[99]

After the above steps occur, there is a face-to-face conversation initiated between the assigned support coordinator and the individual and his or her family. In this conversation, the parties work to complete the PUNS form. Oftentimes, the individual and their family comes prepared to the meetings, as the PUNS form is sent out in advance. However, the form can only be formally completed in-person with the consultation of the supports coordinator. Information extracted in the intake form process includes the date of the meeting, the first and last name of the individual, the individual's gender, the individual's birthdate, and the county or administrative entity the individual is requesting supports through. Eventually when the form is completed, a formal electronic PUNS form will be entered into the Home and Community Services Information System (HCSIS) and the individual will receive a Master Client Index (MCI). The MCI is a unique identifying number utilized by DHS and assigned to the individual when they are registered for services through Medical Assistance.[100]

The form also has a collection of questions regarding the specific situation of the applying individual. Individuals reviewing the form must select yes or no to the question options that apply to them. The answers to these questions help inform the PUNS system as to whether the individual has one of the three identified need levels. The PUNS form also requires the completion of a section concerning the specific services and support needed by the individual. For example, individuals will have to identify whether they are currently receiving supports such as, occupational therapy, physical therapy, communication therapy, respite supports, educational support, assistive technology, and transportation assistance, to name a few. These services will be enumerated in a list and the individual will simply select each of the services they are receiving. It is important to note that all listed existing services, whether ODP-provided or non-ODP-provided, must be selected. When describing the services still needed by the individual, the individual and

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[98] *Supra*, n. 95, p. 5, 7.

[99] *Ibid*., 7.

[100] *Ibid*.,7, 13.

their family should only identify services that can be funded through the ODP service system. If an individual falls into the category of highest urgency for a need (emergency need), this will be indicated when the PUNS form is completed in the HCSIS.[101]

When the questions are completed, the form must be executed by the individuals who are present at the meeting. The execution of the form does not signify an agreement for services and need. Instead, it indicates that the following parties participated in the meeting and form completion. Individuals and family members can refuse to sign the form, but the support coordinator must document the reason for the refusal if the information from the form is to be entered into the HCSIS and finalized. Said finalization of the PUNS form must occur within 10 working days of the meeting and a copy of the finalized form must be sent to the individual and family within five working days of finalization of the HCSIS PUNS form.[102]

After finalization of the form, the ISP team reviews and updates the active PUNS, per the requirement of ODP. All active PUNS applications are required to be reviewed and updated in HCSIS within 365 days from the date of the last PUNS. It should be noted that if an individual's needs change within the plan year, the PUNS must be updated to reflect this change within 30 days. If an individual's needs are fully met with services, the PUNS for that individual should be marked inactive.[103]

When the finalized HCSIS PUNS is sent to the individual and their family, the paperwork comes with a package of documents, which include a Disagreement Form. This form comes complete with a cover letter and instructions of how to complete the Disagreement Form, should there be a disagreement with the finalized PUNS form. Per its instructions, the Disagreement Form must be completed and returned to the individual's supports coordinator within 10 calendar days of the receipt of the finalized HCSIS PUNS form. Further, the supports coordinator organization is required to contact the individual and their family within seven calendar days of receipt of the Disagreement Form to begin a review of the concerns surrounding their individual and family's disagreement with the content on the form. If an agreement cannot be achieved with the supports coordinator organization, the PUNS Disagreement Form is forwarded to the County Program or administrative service entity, who will render a final decision on the disagreement. Once the decision is rendered, it cannot be appealed through Pennsylvania's Bureau of Hearings and Appeals.[104]

Oversight

The PUNS process is maintained and monitored by ODP to ensure the PUNS manual is complied with. In addition, ODP and administrative service entity waiver capacity managers monitor an individual's category of need. These managers also determine whether a PUNS is active in relation to waiver enrollment. Waiver capacity is designed for those individuals who have an emergency status first.

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[101] *Ibid*., 7-8, 23-25.
[102] *Ibid*., 7-8.
[103] *Ibid*., 8.
[104] *Ibid*., 9.

House Bill 808 (Printer's No. 766) was referred to the House Human Services Committee on April 3, 2023. The bill mandates that no later than 90 days after a determination of eligibility for home and community-based waiver services, the eligible individual must be offered those benefits.

Supports Intensity Scale (SIS)

While the PUNS is used to identify level of need coming into the county mental health/intellectual disability program, the Supports Intensity Scale (SIS) process is used to identify needs in support of developing the individual support plan (ISP). ISPs are created upon acceptance into the system and are renewed annually and identify what needs will be covered by direct paid services and how unpaid needs will be met through informal, unpaid or other resources.

The SIS and PA Supplement are a means of measuring the supports needed to live an everyday life. They are used in consolidated, community living, and person/family directed waiver services. It is a standardized needs assessment and is typically done before the initial ISP and then every five years. The individual and at least two persons chosen by the individual who know the individual well participate in the interview. ODP has recently announced that it is adopting the second edition of the SIS. Recent announcements have also indicated that while the supports coordinator should be present at all initial interviews, they are no longer required to attend five-year renewals generally. Whenever a significant life change assessment is needed, the supports coordinator is still required to attend. Additionally, the ability to conduct virtual interviews has been expanded.[105]

Concerns have been raised that families do not always understand the importance of this survey, the need to be present at the evaluation, and how it could potentially impact funding for services. Additionally, some families have questioned the applicability of the SIS for individuals with significant support needs.

Rate Setting

The DHS ODP's rate setting rules are found in 55 Pa. Code Chapter 6100. Different approaches are used based upon the type of service and include fee schedule rates, cost-based rates, payment for vendor goods and services, and participant-directed service rates. For medical assistance/Medicaid fee schedules, there is a list of nine factors, plus a catchall factor that adds in "other factors that impact cost." The regulatory language is set forth below:

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[105] DHS, ODP, The Gold Book: Understanding the Office of Developmental Programs (PA DHS, July 2023), 57-59; ODP Announcement 23-014 "Supports Intensity Scale – Adults (SIS-A) and Pennsylvania (PA) Supplement Assessments – Supports Coordination (SC) Participation and Scheduling Guidance," February 8, 2023; and ODP Announcement 23-059 "Supports Intensity Scale – Adult 2nd Edition (SIS-A) & Kepro Name Change/Rebrand," July 5, 2023.

§ 6100.571. Fee schedule rates.

(a) The Department will establish fee schedule rates, based on the factors in subsection (b), using a market-based approach so that payments are consistent with efficiency, economy and quality of care and sufficient to enlist enough providers so that services are available to at least the extent that such services are available to the general population in the geographic area.

(b) In establishing the fee schedule rates in subsection (a), the Department will examine and use data relating to the following factors:

(1) The service needs of the individuals.

(2) Staff wages, including education, experience, licensure requirements and certification requirements.

(3) Staff-related expenses, including benefits, training, recruitment and supervision.

(4) *Productivity*. Productivity is the amount of service delivered relative to the level of staffing provided.

(5) *Occupancy*. Occupancy is the cost related to occupying a space, including rent, taxes, insurance, depreciation and amortization expenses.

(6) Direct and indirect program and administration-related expenses.

(7) Geographic costs based on the location where the HCBS is provided.

(8) Federally-approved HCBS definitions in the waiver and determinations made about cost components that reflect reasonable and necessary costs related to the delivery of each HCBS.

(9) The cost of implementing applicable Federal and State statutes and regulations and local ordinances.

(10) Other factors that impact costs.

(c) The Department will update the data used in subsection (b) at least every 3 years.

(d) The Department will publish a description of its rate setting methodology used in subsection (a) as a notice in the *Pennsylvania Bulletin* for public review and comment. The description will include a discussion of the use of the factors in subsection (b) to establish the fee schedule rates; a discussion of the data and data sources used; and the fee schedule rates.

(e) The Department will make available to the public a summary of the public comments received in response to the notice in subsection (d) and the Department's response to the public comments.

With regard to cost-based rates, ODP has indicated that transportation is the only service that uses cost-based methodology. For vendor goods and services, the reimbursement rate is based on the cost charged to the general public for the good or service. Services reimbursed under this methodology are home and vehicle accessibility adaptations, assistive technology, specialized supplies, remote supports, education support, public transportation, participant directed goods and services, family/caregiver training and support (registration and fees) and respite camp. Vendor goods and services must be the most cost-effective means to meet the participant's needs. Participant-directed service rates are established through the development of standard wage ranges. Supports included are: Homemaker/Chore, Supports Broker, Companion, Supported

Employment, In-Home and Community Support, and Unlicensed Respite.[106] Current rates and the assumption logs used to help calculate those rates can be found on the DHS website.[107]

One of the latest rounds of rate setting by ODP triggered a lawsuit which is ongoing.[108] In September 2023, in response to concerns about the direct support profession workforce shortage, Governor Josh Shapiro ordered DHS to begin updating the data used to set rates for home and community-based services in anticipation of the 2024-2025 budget process.[109]

One of the concerns is that rate-setting appears to be used as a means of promoting one form of program over another. This issue was discussed by the Advisory Committee in the context of the community participation support reimbursements. Community participation support can be limited to a maximum of three to six participants, depending on the location of the community activity. Community participation at locations that do not meet those rules are reimbursed at a lower rate, with the stated intent of community participation supports to

> . . . involve participation in integrated community settings, in activities that involve persons without disability who are not paid or unpaid caregivers. This service is expected to result in the participant developing & sustaining a range of valued social roles & relationships; building natural supports; increasing independence; increasing potential for employment; & experiencing meaningful community participation & inclusion.[110]

Under these rules, an individual could attend a community activity in a small group, and if there is another small group of individuals with disability in attendance, and if the size of the two groups combined exceeds six, both groups would be in violation of the maximum participant rule. Reimbursement for community participant support in the community settings is at a higher per person reimbursement rate than for community participation support in facility settings. Additionally, the community CPS reimbursement rates are limited to 1:1, 2:1, 1:2, 1:3 and 2:3 staff to client ratios.[111] For community participation supports in facilities, the per person reimbursement rate drops as the number of people attending an activity increase (to a maximum ratio of 1:15). Many providers have expressed concern that setting the rates in this manner will drive some providers out of the market because it is not a sustainable reimbursement level and will indirectly

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[106] Application for 1915(c) HCBS Waiver: PA.0147.R07.00 - Jan 01, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Documents/Developmental%20Programs/Consolidated%20Waiver%20Renewal%20Jan%202023.PDF, 433-435.

[107] "ODP Rates," *Department of Human Services*, accessed February 14, 2024, https://www.dhs.pa.gov/providers/Providers/Pages/ODP-Rates.aspx.

[108] *Supra* n. 26.

[109] Commonwealth of Pennsylvania, Pennsylvania Pressroom, "Governor Shapiro Orders Immediate Review of Fee Schedule Rates For Providers of Services For Individuals With Intellectual Disabilities, Autism," September 11, 2023, https://www.media.pa.gov/Pages/DHS_details.aspx?newsid=949#:~:text=The%20rate-setting%20process%20and%20methodology%20for%20ODP%E2%80%99s%20HCBS,rate%20setting%20process%20at%20least%20every%20three%20years.

[110] *Supra* n. 79 at p. 67.

[111] "Fee Schedule Rates for Community-Based Services Effective November 11, 2023," accessed February 14, 2024, *Department of Human Services*, https://www.dhs.pa.gov/providers/Providers/Documents/ODP/Community-Based%20Fee%20Schedule%20rates-chart-UPDATED-2023.pdf.

affect the ability of individuals with disability to have a full array of choices for community participation.

House Bill 661 (Printer's No. 600) was referred to the House Human Services Committee on March 21, 2023 and Senate Bill 684 (Printer's No. 753, was referred to the House Health and Human Services Committee on May 15, 2023. Both bills would require DHS to use a nationally recognized market index to establish fess schedule rates that affect direct support professionals effective July 1 of each year. Further, direct support personal in providing services to persons with intellectual disability or autism are to receive a cost-of-living adjustment based on the federal rate.

House Bill 687 (Printer's No. 630) was referred to the House Human Services Committee on March 23, 2023. The bill would prohibit the use of "prudent pay" rules by ODP. Under those rules, claims submitted by providers are held for 21 days before processing. This practice is not currently occurring but was suspended during the Covid pandemic and not reintroduced. This bill would prevent its reinstatement.

Performance Based (Selective) Contracting

Some advocates say that rate setting should be outcome based and quality emphasized over quantity. Performance based contracting is one model that has the potential to achieve that goal. Performance based contracting is a Medicaid reimbursement methodology that states can adopt in lieu of fee-for-service (FFS) models. In 2023, DHS announced that it was considering adopting selective contracting for residential habilitation, supported living, and life-sharing in the consolidated and community living waivers; supports coordination in the consolidated, community living and person/family directed support waivers; and targeted support management in the Medicaid State Plan.

This move would accomplish three objectives:

- Eliminate contracting with any willing provider (the Medicaid rule for FFS) to requiring providers to meet specific criteria set by ODP.
- Develop a class of "preferred providers" using performance standards that align with Everyday Lives.
- Align payment with outcomes.

One of the concerns prompting this move is an increase in regulatory and procedural compliance issues in residential community homes. Approximately 200 licensed homes were operating under provisional or revocation pending appeal status in January 2023. Violations found in subsequent unannounced monitoring inspections revealed additional violations involving abuse, improper medication administration, and failure to arrange or provide health services. Similar issues have been found with supports coordination services. One of the goals of the plan is to use an alternative payment model that gives added incentive payments to provide high-quality and cost-efficient care similar to a managed care arrangement. By creating multiple tiers of providers whose payments are tied to meeting performance criteria established by ODP, DHS hopes to improve the quality of services and bring them into closer alignment with the Everyday Lives values of integration and inclusion. [112] In a January 2024 meeting of the Medical Assistance Advisory Committee (MAAC) in DHS, ODP provided an update on the status of performance based contracting and noted that among other preparatory actions, draft waiver amendments had were being prepared and a public comment period was anticipated for April 2024.[113]

Concerns of providers and family members is that this transition has the potential to cause some providers to go out of business, thus lessening the choices available to individuals, especially in the area of residential community homes/group homes. Not only could there be fewer choices among residential providers, but the overall number of residential settings could be seriously diminished. While that outcome appears to be in line with the stated goal of moving people back to their homes or individual community settings, it could also have the effect of forcing individuals who are perfectly happy in their current residential setting to move out. Further, by tying payments to specific criteria, for example, how often participants engage in community participation supports, could identify some providers as “less preferred” even though their failure to meet criteria may be due to a disinterest and lack of desire on the part of individuals being served by the program to participate in some integrated activities. However, there are providers and families who support performance-based contracting as a necessary step to improve quality of services for those individuals who depend on providers and supports coordinators for their health, well-being, and safety.

Pandemic-Related Closures

Though the intellectual disability and/or autism service system has had a tumultuous history, progress has been made to improve the care and daily lives of individuals with a disability through persistent advocacy, litigation to secure individual rights, deinstitutionalization, federal legislation, transparency, and the crafting of research and evidence-based practices. However, problems within the system still exist. One notable problem is taking place within the workforce. Staffing shortages and high turnover rates are plaguing employers and agencies within the intellectual disability and/or autism service system, the absence of qualified workers has led to the closing of intellectual disability and/or autism community programs across the country. Moreover, many individuals residing in smaller residences have had to relocate to larger congregate facilities or even back home with their aging parents. Waiting lists remain pervasive and many providers are seeking to increase the size of their existing programs or to consolidate them.[114]

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[112] Pennsylvania Department of Human Services, Office of Developmental Programs, *Selective Contracting: Residential and Supports Coordination Services Concept Paper* (May 24, 2023), https://provideralliance.org/wp-content/uploads/2023/05/Selective-Contracting-Program-Concept-Document-May-2023.pdf.

[113] *ODP Updates* (MAAC, January 2024), https://www.dhs.pa.gov/about/DHS-Information/Documents/InformationforAdvocatesandStakeholders/MAAC/ODP_MAAC%20January%202024%20presentation.pdf.

[114] Julie Bershadsky, PhD, Amy Hewitt, PhD, Valerie Bradley, MA, *et al*., “Community Supports in Crisis: No Staff, No Services,” *National Association of State Directors of Developmental Disabilities Services, Human Services Institute*, and *Institute of Community Integration, University of Minnesota*, (June 2022): 1.

In the spring of 2020, this growing workforce crisis was exacerbated by the COVID-19 pandemic. The arrival of the COVID-19 pandemic in the U.S. caused colossal disruptions in the American workforce. Families forewent holiday gatherings, dining out in restaurants, and participating in public activities, hunkering down instead within their homes. Schools shut down and, in some areas, attempted to employe remote learning for children. Private businesses closed, and many workers either quit their current jobs or began working remotely from home if the option existed. Providers of essential healthcare services, including provider services, largely remained open. However, most day programs were forced to close or substantially reduce their number of offered services.[115]

A 2021 survey reported that approximately 50 percent of community-based intellectual disability and/or autism providers within the Commonwealth reduced their services. Turnover of direct support professionals caring for individuals with a disability increased during the pandemic from 32 percent in 2019 to 55.5 percent in 2021 (prorated from a three-month window), while their vacancies increased from 19 percent in 2019 to 23 percent in 2021. Alternatively, it was reported that 68 percent of surveyed DSPs stated that they were working more hours during the pandemic, with 50 percent of respondents indicating their programs were understaffed. The understaffing was so pervasive, many provider agencies within Pennsylvania were requiring their senior management officials to work as DSPs during the height of the pandemic; 77 percent of provider agencies within the Commonwealth according to a 2021 survey.[116] Today, agencies providing intellectual disability and/or autism services within Pennsylvania are still struggling with recruitment and retainment as evidenced by high levels of turnover and vacancies among its employees and positions.

In 2023, RCPA (Rehabilitation and Community Providers Association), in collaboration with PAR (Pennsylvania Advocacy and Resources for Autism and Intellectual Disability) and TPA (The Provider Alliance) surveyed over 130 providers representing over 30,000 individuals receiving services to study the impact of the Covid-19 pandemic on the closure of providers. The study found that over 4,000 individuals lost service between March 2020 and February 2023. Thirty-four percent of providers reported permanently closing programs. Another 62 percent had experienced reductions in the number of persons served, and 27 percent were considering closing additional services. The bulk of the closures (88 percent) was found to be due to staffing shortages, although inadequate reimbursement rates and complex behavioral and medical needs of individuals served were contributing factors as well. Closures in community participation services, both facility- based and in the community, were most common in approximately 92 percent of the closures. It should be noted that this was a survey of providers by a providers organization and did not include input from individuals and families who use person/family directed waiver funding.

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[115] Provider Consortium, "2022 Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study," *Pennsylvania Center for Disability Information*, (2022), https://paroncloud.egnyte.com/dl/IfZZmtRPrO.

[116] *Ibid*.

TYPES OF SERVICES

As is evidenced by the table below, services for persons with intellectual and developmental disability across the consolidated, community living, and person family/directed services waivers are almost identical. There are two salient differences of note: The amount of money available to the individual with disability under each waiver and the nature of the living arrangements of the individual. With regards to the adult autism waiver, there appears to be an emphasis and focus on employment opportunities and access to them. While this may be sufficient support for most individuals with autism, it does not appear to significantly address the needs of persons with extremely limiting forms of autism. This chapter will define some of the major types of services available and potential living arrangements for waiver service recipients. See Table 3.

Table 3

Types of Services by Waiver
Pennsylvania 2023

Type of Service	Consolidated	Community Living	Person/Family Directed	Adult Autism
Advanced Supported Employment	x	x	x	
Assistive Technology	x	x	x	x
Behavioral Support	x	x	x	--
Benefits Counseling	x	x	x	--
Career Planning: Job Finding; Vocational Assessment	--	--	--	x
Communication Specialist	x	x	x	--
Community Participation Support	x	x	x	--
Community Transition Services	--	--	--	x
Companion	x	x	x	
Consultative Nutritional Services		x	x	x
Day Habilitation	--	--	--	x
Education Support	x	x	x	--
Family/Caregiver Training and Support	x	x	x	--
Family Medical Support Assistant	x	x	x	--
Family Support	--	--	--	x
Home Accessibility Adaptations	x	x	x	
Home Modifications	--	--	--	x
Homemaker/Chore	x	x	x	--

Table 3

Types of Services by Waiver
Pennsylvania 2023

Type of Service	Consolidated	Community Living	Person/Family Directed	Adult Autism
Housing Transition and Tenancy Sustaining Services	x	x	x	--
In-Home and Community Support	x	x	x	--
(Licensed and Unlicensed) Life Sharing	x	x	--	--
Music, Art, and Equine Assisted Therapy	x	x	x	--
Participant-Directed Goods and Services	--	x	x	
(Licensed and Unlicensed) Residential Habilitation	x	--	--	x
Remote Supports	x	x	x	x
Respite	x	x	x	
Shift Nursing	x	x	x	
Small Group Employment	x	x	x	x
Specialized Skill Development: Behavioral Specialist Services, Systemic Skill Building, Community Support	--	--	--	x
Specialized Supplies	x	x	x	--
Specialty Telehealth and Assessment Team	x	x	x	--
Supported Employment	x	x	x	--
Supported Employment: Extended Employment Supports; Intensive Job Coaching	--	--	--	x
Supported Living	x	**needs groups 1 & 2**	--	--
Supports Broker	x	x	x	
Supports Coordination	x	x	x	
Temporary Supplemental Services	--	--	--	x
Therapy: Physical; Speech/Language; Occupational; Orientation, Mobility and Vision	x	x	x	--
Therapies: Occupational; Speech and Language Counseling	--	--	--	--
Transportation	x	x	x	x
Vehicle Accessibility Adaptations	x	x	x	x

Source: "Disabilities & Aging," *Department of Human Services*, accessed November 2, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/default.aspx.

Living Arrangements

The type of waiver funding an individual receives affects the living arrangements that can be utilized. The following section describes the different types of residential settings available to individuals with disability. Of the 38,073 individuals receiving waiver funding, in August 2023, 14,913 (or 39 percent) received licensed and unlicensed residential services.[117] The remainder live in their own homes, with family, or with friends.

State Centers

Selinsgrove and Ebensburg Centers are the only remaining state centers and they function as intermediate care facilities. Selinsgrove and Ebensburg have approximately 200 residents each. Individuals living in state centers are not eligible for waiver funding, although the level of care and financial eligibility requirements under Medicaid are the same as HCBS waivers except the individual must need active treatment (see below).

Intermediate Care Facilities (ICF)

Intermediate care facilities are governed by the regulations found in 55 Pa.Code Chapters 6210 and 6600.. ICFs are defined as:

> ICF/ID—Intermediate care facility for individuals with an intellectual disability (facility)—A State operated or non-State operated facility, licensed by the Department in accordance with Chapter 6600 (relating to intermediate care facilities for individuals with an intellectual disability), to provide a level of care specially designed to meet the needs of persons who have an intellectual disability, or persons with related conditions, who require specialized health and rehabilitative services; that is, active treatment.
>
> ICF/ORC—Intermediate care facility for persons with other related conditions (facility)—A non-State operated facility, licensed by the Department in accordance with Chapter 6600, to provide a level of care specially designed to meet the needs of persons with other related conditions who require specialized health and rehabilitative services; that is, active treatment. Persons with other related conditions are persons with severe physical disability, such as cerebral palsy, spina bifida, epilepsy or other similar conditions which are diagnosed prior to age 22 and result in at least three substantial limitations to activities of daily living.[118]

In order to qualify for ICF/ID care an individual must:

- Require active treatment.
- Have a diagnosis of an intellectual disability.

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[117] *Supra* note 47 and DHS ODP "Annual Data Report FY 21-22," 11.

[118] 55 Pa.Code § 6210.3.

- Have been recommended for an ICF/ID level of care based on a medical evaluation.[119]

ODP reports that 2,300 individuals are served by 172 certified ICF/ID, which presumably includes the state centers.[120] ICFs are funded by Medicaid, but not through any of the waivers.

Community Homes

Community homes, also known as community living homes and group homes, are governed by the provisions of 55 Pa.Code Chapter 6400. They are funded under the consolidated waiver and adult autism waiver. They are defined as follows:

> Community home for individuals with an intellectual disability or autism (home)—A building or separate dwelling unit in which residential care is provided to one or more individuals with an intellectual disability or autism, except as provided in §6400.3(f) (relating to applicability). Each apartment unit within an apartment building is considered a separate home. Each part of a duplex, if there is physical separation between the living areas, is considered a separate home.[121]

Over 4,000 community homes have been granted licenses across the Commonwealth according to the DHS' Human Services Provider Directory, and are divided into two groups, those with eight or fewer beds and those with nine or more beds. Additional regulations apply to the larger group homes.[122]

Life Sharing Home

Life sharing living arrangements can be funded under consolidated waiver and community living waiver and are governed by 55 Pa.Code Chapter 6500. According to the DHS Human Services Directory, 712 life sharing homes have been granted licenses. Life sharing homes are defined as:

- The private home of an individual or a family in which residential care is provided to one or two individuals with an intellectual disability or autism, except as provided in § 6500.3(f) (relating to applicability).
- The term does not include a home if there are more than two individuals, including respite care individuals, living in the home at any one time who are not family members or relatives of the family members.
- If relatives of the individual live in the home, the total number of people living in the home at any one time who are not family members or relatives of the family members may not exceed four.

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[119] 55 Pa. Code § 6210.62.

[120] "Intermediate Care Facilities," *Department of Human Services*, accessed February 14, 2024, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Intermediate%20Care%20Facilities.aspx.

[121] 55 Pa.Code § 6400.4.

[122] 55 Pa.Code §§ 6400.231-6400.245.

Life sharing homes are intended for persons who require less support than in a community home, but more than can be supported in an independent living arrangement. Specifically, life sharing is not applicable to "[A] home providing room and board for one or two people with an intellectual disability or autism who are 18 years of age or older and who need a yearly average of 30 hours or less direct training and assistance per week per home, from the agency, the county intellectual disability program or the family."[123]

Farmhouse and Campus Settings

DHS prohibits individuals with disability living in campus settings from using waiver funding to pay for residential services they receive in those settings. This applies to residential habilitation, life sharing, and housing transition (when an individual is looking for their own home).[124] This is a choice that has been made at the State level. Farmsteads, intentional communities, and campus settings are not explicitly prohibited under Medicaid.[125] Pennsylvania could apply for and receive approval for such residential settings on a case-by-case basis. Further, there are non-profit, privately funded settings in Pennsylvania, such as the intentional community of Camphill Village Kimberton Hills in Chester County.[126]

The HCBS Final Rule issued in 2014 requires all home and community-based settings meet specific criteria:

- The setting is integrated in and supports full access to the greater community;
- Is selected by the individual from among setting options;
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizes autonomy and independence in making life choices; and
- Facilitates choice regarding services and who provides them.

The final rule also includes additional requirements for provider-owned or controlled home and community-based residential settings. These requirements include:

- The individual has a lease or other legally enforceable agreement providing similar protections;
- The individual has privacy in their unit including lockable doors, choice of roommates and freedom to furnish or decorate the unit;

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[123] 55 Pa.Code 6500.3(f)(5).

[124] Application for 1915(c) HCBS Waiver: PA.0354.R05.02 – Nov 01, 2023, pp. 109, 141, 242, 251.

[125] Letter from Anne Marie Costello, Acting Deputy Administrator and Director, Centers for Medicare and Medicaid Services to The Honorable Brian K. Fitzpatrick, U.S. House of Representatives, dated June 11, 2021.

[126] A life-sharing model, the Camphill Village organization was established in 1961, with about 100 communities worldwide. "A Company Cultivates Seeds, and People," *The New York Times*, December 3, 2023.

- The individual controls his/her own schedule including access to food at any time;
- The individual can have visitors at any time; and
- The setting is physically accessible.

The final rule excludes certain settings as permissible settings for the provision of Medicaid home and community-based services. These excluded settings include nursing facilities, institutions for mental disease, intermediate care facilities for individuals with intellectual disability, and hospitals. Other Medicaid funding authorities support services provided in these institutional settings. The final rule identifies other settings that are presumed to have institutional qualities and do not meet the threshold for Medicaid HCBS. These settings include those in a publicly or privately owned facility that provides inpatient treatment; on the grounds of, or immediately adjacent to, a public institution; or that have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS.

If states seek to include such settings in Medicaid HCBS programs, a determination will be made through heightened scrutiny, based on information presented by the state demonstrating that the setting is home and community-based and does not have the qualities of an institution. This process is intended to be transparent and includes input and information from the public.[127]

Some examples of campus communities around the country include Bittersweet Farms in Whitehouse, Ohio, Arc Village in Jacksonville, Florida, Annandale Village in Swanee, Georgia, 29 Acres in Cross Roads, Texas and First Place in Phoenix, Arizona. Others are in development. Concerns have been raised that some of these communities are intermediate care facilities or are not waiver funded. There are also individuals who are opposed to campus settings in any form.

Community Participation Support

Community Participation Support (CPS) was first introduced in Pennsylvania as a waiver service in 2017. CPS is intended to provide opportunities and support for community inclusion, and building interest in, and developing skills and potential for competitive integrated employment. CPS activities should build on the participant's interests, preferences, gifts and strength and are meant to be secondary to employment. Activities should occur in integrated settings "in activities that involve persons without disability who are not paid or unpaid caregivers."

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[127] U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, "Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F)," January 10, 2014. This final rule establishes requirements for the qualities of settings that are eligible for reimbursement for the Medicaid home and community-based services (HCBS) provided under sections 1915(c), 1915(i) and 1915(k) of the Medicaid statute.

Authorized activities include supports for:

- Developing skills and competencies necessary to pursue competitive integrated employment;
- Participating in community activities, organizations, groups, or clubs to develop social networks;
- Identifying & participating in activities that provide purpose and responsibility;
- Fine and gross motor development and mobility;
- Participating in community opportunities related to the development of hobbies or leisure/cultural interests or to promote personal health and wellness such as a yoga class or a hiking group;
- Participating in volunteer opportunities or community adult learning opportunities;
- Opportunities focused on training and education for self-determination and self-advocacy;
- Learning to navigate the local community, including learning to use public/private transportation and other transportation options available in the local area;
- Developing and/or maintaining social networks and reciprocal relationships with members of the broader community (neighbors, coworkers, and other community members who do not have disability and who are not paid or unpaid caregivers) through natural opportunities and invitations that may occur;
- Assisting participants, caregivers, and providers with identifying and utilizing supports not funded through the waiver that are available from community service organizations, such as churches, schools, colleges/universities and other post-secondary institutions, libraries, neighborhood associations, clubs, recreational entities, businesses and community organizations focused on exchange of services (e.g time banks); and
- Assisting participants and caregivers with providing mutual support to one another (through service/support exchange) and contributing to others in the community.

Specific rules apply to approved settings. Community locations must be non-disability specific and meet all federal standards for home and community-based settings. The service cannot take place in licensed facilities, or any type of facility owned, leased or operated by a provider of other ODP services. A maximum of three participants can be served simultaneously by any one provider at a community location at any one time.

Community hubs primarily serve as a gathering place prior to and after community activities. Participants' time will be largely spent outside of the community hub, engaged in community activities. Community hubs should be non-disability specific, accessible, provide shelter in inclement weather, and be locations used by the general public. The use of a community hub must be driven by the interest of the participant(s) served. A maximum of six participants can be served by any one provider at any one point in time in a community hub.[128]

The participation rules have caused some confusion over how the attendance maximums are to be calculated, among other concerns, and ODP presented a webinar to provide further clarification in 2023.[129]

One concern raised with CPS is its focus on employment as a primary goal; some family members have expressed concern that this ignores the need for community participation opportunities for individuals with disability who either choose or are unable to be employed. The effect of some of these rules governing approved services is to unintentionally prevent persons with disability from spending time with people like themselves, a desire which has been expressed to some of the providers on the Advisory Committee. While not an outright prohibition, the number-of-participant rules are seen as having a chilling effect on providers' willingness to engage in some community participation activities for fear that they will exceed approved numbers and be reimbursed at a lower rate because of it.

Community Participation Support may be used to provide prevocational services in Vocational Facilities. Facilities must meet all federal standards for home and community-based settings. Facility-based prevocational services focus on the development of competitive worker traits through work as the primary training method. The service may be provided as:

- Occupational training used to teach skills for a specific occupation in the competitive labor market and includes personal and work adjustment training designed to develop appropriate worker traits and teach understanding work environment expectations.

- Work related evaluation involving use of planned activities, systematic observation, and testing to formally assess the participant, including identification of service needs, potential for employment, and employment objectives.

This service may be used to provide prevocational services in facilities and community locations. All participants receiving prevocational services must have a competitive integrated employment outcome included in their ISP. There must be documentation in the ISP regarding how and when the provision of prevocational services is expected to lead to competitive integrated employment. Prevocational services in community locations or community hubs assist participants in vocational skill development, which means developing basic skills and competencies necessary for a participant to pursue competitive integrated employment. This includes the development and implementation of a preliminary plan for employment that identifies and addresses the participant's basic work interests, as well as skills and gaps in skills for their work interests. It may include situational assessments, which means spending time at an employer's place to explore vocational

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[128] Application for 1915(c) HCBS Waiver: PA.0354.R05.02 – Nov 01, 2023, pp. 65-70.

[129] "Now Available: The Clarifications and Guidance for the Community Participation Support (CPS) Service in the Intellectual Disability/Autism Waivers," PA DHS, ODP, https://palms-awss3-repository.s3.us-west-2.amazonaws.com/Communications/ODP/2022/ODPANN+23-069+Now+Available+The+Clarifications+and+Guidance+for+the+CPS+Service+in+the+Intellectual+DisabilityAutism+(IDA)+Waivers+Webinar+Recording.pdf.

interests and develop vocational skills. Vocational skill development also includes identifying available transportation to help the participant get to and from work and teaching the participant and their family (as appropriate) about basic financial opportunities and benefits information for a move into competitive integrated employment.[130] According to the 2023 Employment First Oversight Commission Report, 3,184 individuals were receiving prevocational services in the community participation support service in 2021.[131]

Day Habilitation

Day habilitation services are provided under the adult autism waiver. Day Habilitation provides individualized assistance with acquiring, retaining, and improving communication, socialization, self-direction, self-help, and adaptive skills necessary to reside in the community. In many ways, these services have goals similar to community participation support. The service includes:

- activities to improve the participant's capacity to perform activities of daily living (i.e., bathing, dressing, eating, mobility, and using the toilet) and instrumental activities of daily living (i.e., communication, survival skills, cooking, housework, shopping, money management, time management, and use of transportation),
- assisting participants with contacting relevant agencies and obtaining documents needed to access employment supports and services that educate participants on the impact of employment on current benefits,
- on-site modeling of behavior, behavior support, intensive behavior episode intervention, training, cueing, and/or supervision,
- planning and coordinating a participant's daily/weekly schedule for day habilitation services,
- personal assistance in completing activities of daily living and instrumental activities of daily living, and
- assistance with medication administration and the performance of health-related tasks to the extent state law permits.[132]

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[130] *ISP Manual for Individuals Receiving Targeted Support Management, Base-Funded Services, Consolidated, Community Living or P/FDS Waiver Services or Who Reside in an ICF/ID* (Commonwealth of Pennsylvania Department of Human Services Office of Human Developmental Programs, 2023), 72-74.

[131] Pennsylvania Employment First Oversight Commission, *2023 Report to Governor Shapiro and the General Assembly* (October 1, 2023), https://www.dli.pa.gov/Individuals/Disability-Services/employment-first/Documents/2023-EFOC-Annual-Report.pdf, 68-70.

[132] "Adult Autism Waiver Amendment, Effective Date: November 1, 2023" *DHS ODP*, https://www.dhs.pa.gov/Services/Disabilities-Aging/Documents/Proposed%20Waiver%20Amendments/AAW%20Record%20of%20Change%2011.1.23.pdf.

Employment Support

Employment support under the consolidated, community living, and person/family directed waiver programs can include several types of support. These include advanced supported employment, small group employment, and supported employment. Within the adult autism waiver program, additional, more intensive support is available including career planning, job finding, extended employment support, and intensive job coaching. Employment support must also be integrated into services provided by the Office of Vocational Rehabilitation, the rules of the U.S. Department of Education's Office of Special Education and Rehabilitation Services, Rehabilitation Services Administration, and the U.S. Department of Labor Employment and Training Administration requirements under the Federal Workforce Innovation and Opportunity Act relating to transitioning students.

In 2016, Governor Tom Wolf issued an executive order adopting an "employment first" policy for Pennsylvania and advocating for increased competitive-integrated employment of Pennsylvanians with a disability.[133] Subsequently, the Employment First Act was enacted in 2018 and provided for competitive integrated employment in state and county agencies and any entity providing publicly funded education, training, employment and related services, and long-term services and supports for working-age Pennsylvanians with a disability; establishing Employment First, the Governor's Cabinet for People with Disabilities, and the Employment First Oversight Commission.[134] A goal was set for state agencies to make an effort to employ individuals with a disability in no less than seven percent of the overall State work force.[135] The oversight commission issued its annual report in 2023. It noted that progress had been made, albeit slowly, and that was believed because many departments do not fully comprehend their role in meeting employment first goals, especially if their agency does not directly work with individuals with disability.[136] The report has a significant amount of data for competitive employment, including breakdowns in different demographic areas. For purposes of this report, it should be noted that the total number of enrollees at ODP in 2022 was reported to be 43,102, and that 16.3 percent, or 7,333 individuals were engaged in competitive integrated employment that year.[137] This is more than double the original goal of seven percent.

In order to further support the Employment First Oversight Commission, legislation has been introduced in the House of Representatives to provide for the appointment of an executive director of the commission. House Bill 1834, Printer's No. 2270, was introduced and referred to the House Labor and Industry Committee on November 8, 2023. It received first consideration in the House and was laid on the table on December 12, 2023.

"Competitive integrated employment refers to full or part-time work at minimum wage or higher, with wages and benefits similar to workers without disabilities performing the same work,

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[133] Commonwealth of Pennsylvania, Employment First Executive Order Summary, March 2017.

[134] Act of Jun. 19, 2018, P.L. 229, No. 36, known as the Employment First Act.

[135] *Ibid*, § 4(h)(1).

[136] *Pennsylvania Employment First Oversight Commission* (2023), https://www.dli.pa.gov/Individuals/Disability-Services/employment-first/Documents/2023-EFOC-Annual-Report.pdf.

[137] *Ibid*., 63-67.

and fully integrated with coworkers without disabilities." Employment supports provided by ODP are expected to lead to an employment outcome. [138] In general, an individual with disability seeking employment should be referred to the Office of Vocational Rehabilitation (OVR) in the Department of Labor and Industry to ensure that the individual has explored options available through OVR. If OVR is unable to provide services to the individual, then waiver services such as supported employment, advance supported employment, or small group employment may be used to assist the individual in reaching an employment outcome.

It should be noted that OVR operates under a broader definition of disability based on the Americans with Disabilities Act than the definition of disability found in the waiver programs. OVR disabilities include physical, mental, and emotional impairments. Additionally, employers are subject to wider definitions of disability when it comes to providing a "reasonable accommodation" in the workplace for an individual with disability.

Two bills introduced in the General Assembly in 2023 would support and encourage Commonwealth agencies to employ persons with disability. House Bill 348 (Printer's No. 311) was referred to the House Labor and Industry Committee on March 13, 2023. The bill provides for noncompetitive appointments and hiring of persons with disability by Commonwealth agencies. Senate Bill 451 (Printer's No. 433) was referred to the Senate State Government Committee on March 14, 2023. The bill provides for a disability preference with regard to grading civil service examinations. Individuals submitting proof of a handicap or disability as defined under the Human Relations Act would receive an additional five points added to their exam score.

Supported Employment

Supported employment can include multiple services. Career assessment is used to identify potential career options, including self-employment, based on the interest and strengths of the individual. These are usually authorized for up to six months and can take place in most locations. Job finding or development includes employer outreach, job searching, resume preparation and interview assistance. Job coaching and support includes training the individual on job assignments, periodic follow-up, or ongoing support with individuals and their employers. The direct portion of job finding as well as job coaching and support may not occur in a vocational facility or adult training facility. In general, these settings are not considered competitive employment settings.

Supported employment hours per week are limited to 40 if the individual is not provided with any other employment service. In total, an individual cannot receive more than 50 hours a week of supported employment, community participation support, and small group employment.[139]

Advanced Supported Employment

Advanced supported employment, as the name suggests, is more intensive supported employment services. They include discovery, job acquisition, and job retention (including

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[138] *ISP Manual*, 93.

[139] *ISP Manual*, 103-110.

extensive job coaching). These services are paid on an outcome basis in three stages: creation of a discover profile, securing a job (receipt of a job offer that meets the definition of competitive-integrated employment or self-employment), and retention of the job, evidenced by the individual working a minimum of five hours per week for at least four months. The direct provision of job acquisition activities cannot be provided in a vocational or adult training facility.[140]

Small Group Employment

Small group employment is intended to support individuals to transition to competitive-integrated employment who need to develop knowledge, experience, and skills in a integrated industry, business, or community setting. Small group employment cannot be provided in an adult training facility or vocational facility. Individuals must be paid at least minimum wage and compensation must be similar to compensation earned by workers without disability performing the same work. These services are only eligible for reimbursement for the time the person is working and receiving wages and during transportation to a work site from the providers facility. Several options exist under this service. These services have the same number of hour limitations as supported employment. They include:

- Mobile workforce: teams that work under supervision away from an agency or facility, such as lawn care, janitorial services and other similar maintenance type jobs.
- Work Station in Industry: Onsite at a community business or industry site, such as a seat on an assembly line.
- Affirmative Industry: A business that sells products or services where at least 51 percent of the employees do not have a disability.
- Enclave: A small group with disability performs specific job functions while working alongside workers without disability.

Small group employment services can be provided with referral to OVR. Small group employment is not considered competitive-integrated employment.

Supported Employment in the Adult Autism Waiver

Supported employment under the adult autism waiver consists of two components: intensive job coaching and extended employment supports. Additionally, an individual who receives specialized skill development services will have their behavioral support plan, crisis intervention plan, and systemic skills building plan implemented as part of their supported employment.

Specialized Skill Development services are used to address challenges individuals may have because of limited social skills, perseverative behaviors, rigid thinking, difficulty interpreting cues in the natural environment, limited communication skills, impaired sensory systems, or other

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[140] *ISP Manual*, 95-99.

reasons. These services use specialized interventions to increase adaptive skills for greater independence, enhance community participation, increase self-sufficiency, and replace or modify challenging behaviors. Three levels of support include: behavioral specialist services, systemic skill building, and community support.[141]

Intensive job coaching under the adult autism waiver includes onsite job training and skills development, assisting the participant with development of natural supports in the workplace, coordinating with employers, coworkers (including developing coworker supports), and customers as necessary, to assist the participant in meeting employment expectations and addressing issues as they arise, such as training the participants in using public transportation to and from the place of employment. Individuals who require on-the-job support for more than 20 percent of their work week at the outset of the service are expected to have the support fade. A fading plan must be developed within six months and the service can be renewed for up to a maximum of 18 consecutive months, unless an exception is made. If ongoing support is needed, extended employment supports may be provided.[142]

Extended Employment Supports may continue indefinitely as needed by the individual for 20 percent or less of their work week. The services may include reminders of effective workplace practices and reinforcement of skills gained prior to employment or during the period of Intensive Job Coaching, coordinating with employers or employees and coworkers (including maintaining coworker supports). At least one visit per month by the provider to the workplace is required.[143]

Subminimum Wage Employment

The Federal Fair Labor Standards Act, enacted in 1938, provides, among other things, the federal minimum wage rate. An exception to the minimum wage mandate is found in Section 14(c), sometimes referred to as "subminimum wage." The statute authorizes an employer to pay less than the minimum wage to selected workers "in order to prevent curtailment of opportunities for employment." A special certificate must be obtained. Workers who may be paid this lower wage are those whose "earning or productive capacity is impaired by age, physical or mental deficiency, or injury." Subminimum wages must be "commensurate with those paid to nonhandicapped workers, employed in the vicinity in which the individuals under the certificates are employed, for essentially the same type, quality, and quantity of work, and related to the individual's productivity." Wages must be reviewed at least once every six months, adjusted annually to "to reflect changes in the prevailing wage paid to experienced nonhandicapped individuals employed in the locality for essentially the same type of work.[144] This minimum wage standard has been incorporated into Pennsylvania's minimum wage statute.[145]

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[141] "Adult Autism Waiver Amendment, Effective Date: November 1, 2023," DHS ODP, https://www.dhs.pa.gov/Services/Disabilities-Aging/Documents/Proposed%20Waiver%20Amendments/AAW%20Record%20of%20Change%2011.1.23.pdf, 143-145.

[142] *Ibid*., 77.

[143] *Ibid*., 78.

[144] Section 14 (c) of the Fair Labor Standards Act, Pub. L. 75-718, 29 U.S.C. 214(c); and United States Department of Labor, Wage and House Division, "Fact Sheet #39: The Employment of Workers with Disabilities at Subminimum Wages. https://www.dol.gov/agencies/whd/fact-sheets/39-14c-subminimum-wage.

[145] Section 4(d) of the act of January 17, 1968, P.L. 11, No. 5, known as the Minimum Wage Act of 1968.

The Department of Labor lists 50 employers in Pennsylvania who employ 3,102 persons with disability at subminimum wage.[146] For comparison, note that Pennsylvania's population in 2022 was estimated to be 12,972,000 individuals,[147] of whom 2,751,000 are identified as having some type of disability (mobility, cognition, independent living, hearing, vision, or self-care).[148] These 3,102 employees equal 8.15 percent of the total number of persons with disability receiving waiver services in August 2023.

The U.S. Department of Labor held a series of stakeholder engagement sessions in October and November 2023 to discuss the merits of repealing Section 14(c). There has been substantial support advanced for the repeal. The U.S. Commission on Civil Rights has recommended that it be repealed with a planned phase-out period to allow providers and individuals with disability to transition other forms of supported employment, prioritizing competitive-integrated employment.[149] The Association of People Supporting Employment First, based in Rockville Maryland, is "the only national organization focused exclusively on Employment First to facilitate the full inclusion of people with disability in the workplace and community" has been extremely active in promoting competitive-integrated settings.[150] Joint State Government Commission staff attended the first DOL engagement session on October 26, 2023. The first speaker was a representative of Microsoft, which has publicly supported abolition of 14(c). The company has employed 500 people nationwide and continues to extend its workforce to include persons with disability. Assistive technology has played a significant role in the ability of some individuals with disability to become gainfully employed. Several self-advocates spoke, with the message that 14(c) is stigmatizing and that all persons should be able to receive wages equivalent to similar persons without disability. Several family members spoke as well, and urged to retention of 14(c), as their family members want to work, but cannot, because of the severity and profundity of their disability, ever be competitively employed. If they do not have access to 14(c) jobs, their families fear they will be relegated to day programs that center-on volunteer activities, arts and crafts, or other activities that hold no interest for them. Additionally, there are family members who fear that their person would lose Medicaid funded health benefits, not receive health benefits from their employers, and not be able to afford to purchase insurance on their own.

The ability of an individual with disability to accept a subminimum wage is already restricted in Pennsylvania and is essentially the employment setting of last resort. This is demonstrated in part by the eligibility requirements for Supported Employment services.

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[146] "Wage and Hour Division, 14(c) Certificate Holders," *U.S. Department of Labor*, last modified November 1, 2023, https://www.dol.gov/agencies/whd/workers-with-disabilities/section-14c/certificate-holders.

[147] "Our Changing Population: Pennsylvania," *USA Facts*, accessed February 14, 2024, https://usafacts.org/data/topics/people-society/population-and-demographics/our-changing-population/state/pennsylvania/.

[148] "Disability & Health U.S. State Profile Data for Pennsylvania (Adults 18+ years of age)," CDC, accessed December 5, 2023, https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/pennsylvania.html.

[149] *Subminimum Wages: Impacts on the Civil Rights of People With Disabilities* (U.S. Commission on Civil Rights, September 2020), https://www.usccr.gov/reports/2020/subminimum-wages-impacts-civil-rights-people-disabilities.

[150] "About APSE," *APSE1*, accessed February 14, 2024, https://apse.org/about-2/.

> Supported employment services may not be rendered under the Waiver until it has been verified that:
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> - The services are not available in the student's (if applicable) complete and approved Individualized Education Program (IEP) developed pursuant to IDEA;
> - OVR has closed the participant's case or has stopped providing services to the participant;
> - It has been determined that OVR services are not available. If OVR has not made an eligibility determination within 120 days of the referral being sent, or a participant has received an offer of competitive integrated employment prior to OVR making an eligibility determination, then OVR services are considered to not be available to the participant; or
> - The participant is determined ineligible for OVR services.
>
> A participant does not need to be referred to OVR if:
>
> - The participant is competitively employed and solely needs extended supports to
> - maintain the participant's current job.
> - The participant is competitively employed and is seeking job assessment or job finding services to find a new job, unless the purpose is job advancement which can be provided by OVR. [151]

With respect to Small Group Employment services, if a person receives below minimum wage, employment services are not appropriate and the person should be directed to community participation support.[152]

Within Community Participation Supports there are restrictions on the provisions of prevocational services.

> Participants who are under the age of 25 are not required to be referred to OVR when they will be working on skill development and/or participating in activities for which they will not receive subminimum wage. It is not allowable, however, for these prevocational activities to occur in a licensed vocational facility unless OVR has closed their case or the participant has been determined ineligible for OVR services. Participants who are under the age of 25 also may not receive prevocational services that pay subminimum wage unless they have been referred to OVR and OVR has determined that the participant is ineligible for OVR services or has closed the OVR case (except if the case was closed for one of the reasons

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[151] *ISP Manual*, 105.

[152] *ISP Manual*, 101.

noted in the current OVR Referral Process bulletin). This includes prevocational services that pay subminimum wage in any setting including:

- A licensed Vocational Facility (55 Pa. Code Chapter 2390).
- A licensed Adult Training Facility (55 Pa. Code Chapter 2380).
- A Community Hub.
- A Community Location.
- Any service location that holds a 14c certificate.[153]

House Bill 1135 (Printer's No. 1193) was referred to the House Labor and Industry Committee on May 10, 2023. This bill abolishes subminimum wages in Pennsylvania.

In-Home and Community Support

In-Home and Community Support cannot be provided to a person who is receiving residential habilitation, life sharing, or supported living, as it is designed to provide similar supports to persons who choose to live more independently. It is similar in many ways to day habilitation in the adult autism waiver program. It is a direct service provided in home and community settings to assist participants in acquiring, maintaining, and improving the skills necessary to live in the community, to live more independently, and to participate meaningfully in community life. To the extent that In-Home and Community Support is provided in community settings, the settings must be inclusive rather than segregated. Services consist of assistance, support and guidance (physical assistance, instruction, prompting, modeling, and positive reinforcement) in the general areas of self-care, health maintenance, decision making, home management, managing personal resources, communication, mobility and transportation, relationship development and socialization, personal adjustment, participating in community functions and activities and use of community resources. The type and amount of assistance, support and guidance are informed by the assessed need for physical, psychological, and emotional assistance established through the assessment and person-centered planning processes. The type and amount of assistance is delivered to enhance the autonomy of the participant, in line with his or her personal preferences and to achieve their desired outcomes.

In-Home and Community Support (aka Home and Community Habilitation) can be paid for under consolidated, community living, or person/family directed waivers. If it is provided under consolidated waiver, it is limited to a maximum of 14 hours per day. Relatives and legal guardians can provide these supports, but any one individual is limited to 40 hours per week of

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[153] *ISP Manual*, 72-74.

authorized support.[154] Variances may be granted beyond those hour limitations if the individual needs more intensive support.[155]

Residential Habilitation

Consolidated waiver is the only waiver that will pay for licensed residential habilitation. Unlicensed residential habilitation can be paid for in the community living waiver.[156] Licensed residential habilitation is defined as direct service and services to meet regulatory requirements and contract conditions provided in licensed community homes to assist individuals in acquiring, retaining, and improving self-help, socialization and adaptive skills. All homes must be integrated and dispersed; homes on campuses are not eligible for waiver. Settings should be located in the community and surrounded by the general public. New settings or changes to existing settings must be approved by ODP or its designee. Settings shall not be located in any development or building where more than 25 percent of the apartments, condominiums, or townhouses have waiver funded Residential Habilitation, Life Sharing, or Supported Living being provided.

Services may be direct or indirect, and are provided in licensed and unlicensed provider owned, rented, or leased residential settings. Services consist of assistance, support, and guidance (physical assistance, instruction, prompting, modeling, and reinforcement) in the general areas of self-care, health maintenance, decision making, home management, managing personal resources, communication, mobility and transportation, relationship development and socialization, personal adjustment, participating in community functions, and activities and use of community resources.[157]

Persons living in residential homes must receive an annual assessment.[158] Services provided by the home include day service, such as competitive community-integrated employment, education, vocational training, volunteering, civic-minded and other meaningful opportunities.[159] Opportunities for recreational and social activities, including volunteering or civic-minded opportunities, and membership in national or local organizations are also provided.[160]

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[154] "Individual Support Plan (ISP) Manual for Individuals Receiving Targeted Support Management, Base-Funded Services, Consolidated, Community Living or P/FDS Waiver Services or Who Reside in an ICF/ID," *Department of Human Services, Office of Developmental Programs*, accessed November 30, 2023, https://www.dhs.pa.gov/providers/Providers/Documents/ISP%20manual%20for%20Individuals%20with%20ID.pdf, 131.

[155] ODP Bulletin 00-18-06, "Instructions for Completing the Consolidated, Person/Family Directed Support and Community Living Waiver Variance Form (DP1086)," last modified December 12, 2019, https://www.dhs.pa.gov/docs/Publications/Documents/FORMS%20AND%20PUBS%20ODP/00-18-06%20B.pdf

[156] *Ibid*., 150.

[157] *Ibid*., 250.

[158] 55 Pa. Code §§ 6400.181 and 6400.182.

[159] 55 Pa. Code § 6400.189.

[160] 55 Pa.C ode § 6400.190.

Supported Living

These are direct and indirect services provided to participants who live in a private home that is owned, leased, or rented by the participant or provided for the participant's use via a Special or Supplemental Needs trust and located in Pennsylvania. Through the provision of this service participants will be supported to live in their own home in the community and to acquire, maintain or improve skills necessary to live more independently and be more productive and participatory in community life. Consolidated and some levels of community living waiver can be used to fund these services.[161]

Transportation

Having adequate transportation is critical to live independently. In many cases, it is necessary to work a job, attend school, visit friends and relatives, attend doctor's visits, shop for groceries, and participate in other everyday life activities within one's community. For all these reasons, adequate access to transportation can improve one's quality of life. One major hurdle that individuals with a disability routinely face is finding access to consistent, reliable, and safe modes of transportation. In fact, transportation is often the most frequently reported challenge for individuals with disability, in general.[162] Virtually every mode of transportation (air, water, road, rail, and even pedestrian transportation) has its own barriers for individuals with a disability.[163] A 2020 *Journal of Transport & Health* report identified that 49 percent of adults with intellectual and/or developmental disability lack access to adequate transportation, leaving many dependent on others to meet their transportation needs.[164] This occurs despite the fact that transportation services are funded under consolidated, community living and person/family directed waivers, as well as new, additional benefits added to the adult autism waiver effective 2023.

Transportation Utilized by Individuals with a Disability

There are several different methods of transportation typically relied upon by individuals with a disability, oftentimes differing based on their living circumstances. For instance, individuals living in a group home may utilize different transportation options than individuals living independently in single homes or apartments or those living at home with family. Those living at home with family sometimes rely on in-home family members for transportation or private transportation services such as taxis, shuttle businesses, or paratransit. If these individuals are

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[161] *Ibid*., 251-252.

[162] Carli Friedman, PhD and Mary C. Rizzolo, PhD, "The State of Transportation for People with Intellectual Disabilities in Medicaid Home and Community-Based Services 1915(c) Waivers," *Journal of Disability Policy Studies* 27, No. 3 (July 24, 2016), DOI: https://doi.org/10.1177/1044207316644413.

[163] "Transportation," *American Association on Intellectual and Developmental Disabilities*, accessed August 7, 2023, https://www.aaidd.org/news-policy/policy/position-statements/transportation#:~:text=People%20with%20IDD%20lack%20sufficient,barriers%20for%20individuals%20with%20IDD.

[164] Beth Pfeiffer, Annalisa Sell, and Katherine B. Bevans, "Initial Evaluation of Public Transportation Training Program for Individuals with Intellectual and Developmental Disabilities: Short Report," *Journal of Transport & Health* 16 (March 2020), DOI: https://doi.org/10.1016/j.jth.2019.100813.

living in an area with public transit, they may opt to use public buses, if they are able to do so and can participate in shared-ride and paratransit programs. Alternatively, individuals living in group homes or intermediate care facilities often use privately hired life-sharing drivers.[165] Pennsylvania's § 1915(c) Home and Community-Based Services Waiver also provides funds for vehicle accessibility adaptation services to individuals with disability who require them.[166]

Some individuals with disability use transportation services like Uber or Lift. However, ride-sharing services such as these have been criticized in the past for being unable to provide needed accommodations for disabled individuals. Consequently, these services have been making efforts to improve their services to be more accessible to all individuals with disability.[167]

State Transportation Programs

Federal law requires that in a public setting, fixed-route or demand responsive transportation, such as bus systems, subways, light rail systems and inter-city rail transportation comply with regulations promulgated pursuant to the Americans with Disabilities Act (ADA).[168] Both public and private transportation services (airports, university transport systems, hotel shuttles, private buses, and taxis) must follow accessibility guidelines that accommodate disabled individuals.[169] Some of these accessibility guidelines include service design, system policies, ride-booking, construction of bus stops, transit facilities, and maintenance of accessibility equipment. The law also requires that complimentary paratransit services be made available in any location where there is a fixed-route transportation service. Said paratransit service must be accessible on the same days and hours as the fixed-route transit. Complimentary paratransit services include door-to-door services and curb-to-curb bus services.[170]

Pennsylvania has established some transportation programs to increase accessibility to individuals with a disability. To assist with the cost of public transit, Pennsylvania's Department of Transportation (PennDOT) provides individuals with disability a Reduced Transit Fare Identification Card to use when riding on a fixed-route public transit service. The card must be presented by the individual to the public transit operator at the time of fare payment and said individual may ride for half-fare. However, the half-fare program is limited to non-peak periods and to certain counties.[171]

PennDOT also offers a rural transportation program for individuals with a disability known as the Persons with Disabilities (PwD) program. The PwD program permits individuals aged 18 through 64 to receive reduced rates on shared-ride, curb-to-curb, and advance reservation transportation services. This reduced rate is available in 66 counties; it is not available in

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[165] Discussion in House Resolution 212 of 2022 Advisory Committee Meeting held on August 24, 2023.

[166] Section 1915(c) Home and Community-Based Services (HCBS), (1486.R01.00).

[167] *Supra*, n. 164.

[168] The Americans with Disabilities Act of 1990, Pub. L. 101-336, 104 Stat. 327; 42 U.S.C. § 12101 *et seq*.

[169] 49 C.F.R. §§ 37.21, 37.25, 37.29, 37.33, 37.35.

[170] 49 C.F.R. §§ 37.121-37.155, Subpart G.

[171] "Persons with Disabilities," *Pennsylvania Department of Transportation*, accessed August 8, 2023, https://www.penndot.pa.gov/TravelInPA/PublicTransitOptions/Pages/Seniors-and-Persons-With-Disabilities.aspx#:~:text=Also%2C%20individuals%20with%20disabilities%2C%20presenting,peak%20periods%20in%20certain%20counties.

Philadelphia County since Philadelphia has fixed-route transit services. Under this program, persons with disability pay a portion of the regular transportation fare and the PwD program pays the remainder of the fare (up to 85 percent) for trips not eligible for any other funding sources.[172]

In 2021 Pennsylvania amended its Adult Autism Waiver within § 1915(c) Home and Community-Based Services (HCBS) Medicaid waiver, designed to provide long-term services for community living for the needs of adults aged 21 or older with autism spectrum disorder (ASD), to provide for transportation services and vehicle accessibility adaptations. The amendment prevents individuals from losing services due to changes in their transportation service by increasing the annual fiscal limits on Transportation-Trip to $10,000 per annual plan year and $7,500 on Transportation-Public per annual plan year. The amendment also increases community participation and requires providers of Day Habilitation services to include in their quality management plans provider performance improvement targets and strategies. The targets and strategies are designed to ensure opportunities for access to the community for service locations where individuals' participation in integrated community activities is low. The amendment also adds additional provider qualification standards for the financial preparedness for residential and supports coordination services.[173]

Lack of Access

Despite the availability of the transportation programs mentioned above, individuals with a disability often have unmet transportation needs. Lack of access is usually one of the biggest reasons individuals with disability are without adequate transportation. Driving a car is typically not an option due to the limitations of their disability. Consequently, many must rely on family, friends, public transportation (if available), or other available transport services. The question is whether an individual can rely on any of these possible options. Many times, individuals with disability cannot, as some individuals do not have family and friends consistently available to provide the level of transportation they need.

Those who cannot rely on family and friends may also not be able to rely on public transportation. Much of Pennsylvania is made up of rural or suburban locations that often do not have viable public transportation options, such as buses, trains, taxis, shuttle systems. While public transportation is available to some extent within each of the Commonwealth's 67 counties, many individuals living in certain parts of certain counties may still not be within proximity to them.[174] Moreover, even if an individual lives in a location with close access to public transit, individuals may not be able to afford the cost of using it. Some of the shared-ride services, paratransit, and discount programs are also only available during non-peak periods of travel, which limit their accessibility to individuals with a disability.

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[172] *Ibid*.

[173] Section 1915(c) Home and Community-Based Services (HCBS), Pennsylvania Adult Autism Waiver (0593.R03.00) (Approval 2021, eff. Nov. 1, 2023); Discussion in the Advisory Committee Meeting, October 27, 2022.

[174] "Public Transit Options," *Pennsylvania Department of Transportation*, accessed August 7, 2023, https://www.penndot.pa.gov/TravelInPA/PublicTransitOptions/Pages/default.aspx#:~:text=Public%20transportation%20is%20available%20in,services%20in%20all%20Pennsylvania%20counties.

Inadequate Accommodation

Public transportation services are sometimes inadequate for the needs of individuals with a disability. It can be challenging for public and private transportation entities to accommodate the broad range intellectual disability and/or autism needs. Some entities lack all relevant assistive or adaptive technology that an individual may require. For instance, public transportation alternatives may not be feasible for individuals with ASD and have sensory disability. Public transit buses and trains can result in too much stimulation for an individual who has complex sensory needs. Other individuals with a disability may suffer from uncontrolled seizures, severe hypertension, or the inability to communicate, each of which can make being a passenger on public transit difficult, and even dangerous.[175] Many individuals with a disability may also be unfamiliar with public transportation modes or may not have the ability to navigate public transportation without assistance. Even adult individuals without intellectual disability and/or autism needs often have trouble navigating the system complexities, transfers, and complicated schedules of public transit.[176] Some individuals with a disability must opt for special private transportation alternatives because they are not provided adequate training to utilize public transit systems. For instance, a 2012 survey found only slightly more than 10 percent of individuals with ASD had any travel training.[177] Finding necessary accommodation for severe medical, physical, and sensory needs can also be difficult through private ride-sharing services, though as mentioned previously, ride-sharing companies like Uber and Lift are attempting to innovate to better accommodate special needs passengers.

Individuals with a disability also struggle with the logistical aspects of utilizing taxicab services. Individuals often need to use cab services for running routine errands, such as a grocery store run or a doctor's appointment. However, cab services generally do not wait for the individual to complete their shopping or appointment after they arrive at the destination. Consequently, a routine errand can morph into a time-consuming all-day affair because once the initial cab leaves to transport other clientele, the individual must work to procure and wait for a new cab to arrive and deliver them home.[178]

Unreliability

Having to rely on transportation services can result in other travel obstacles, such as reliability, which is a commonly cited concern for individuals with a disability and families in Pennsylvania. Individuals who contract with private drivers or shuttle services sometimes end up stranded at home or at work because the driver did not show up for their pickup. This unreliability can result in a domino-effect of problems that can negatively impact an individual's life. Some examples include being able to show up for important matters such as doctor's appointments or one's employment.[179]

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[175] *Ibid.*; "Transit Accessibility for People with Disabilities," *National Aging and Disability Transportation Center*, accessed August 8, 2023, https://www.nadtc.org/news/blog/transit-accessibility-for-people-with-disabilities/.

[176] *Supra*, n. 163

[177] *Supra*, n. 162.

[178] Discussion in the Advisory Committee Meeting, October 27, 2022.

[179] *Ibid.*

If an individual is unable to consistently procure reliable transportation to their place of employment, they may be viewed as unreliable themselves and could lose their job. If a private driver or shuttle service does not show for pick up or has an unexpected conflict, family members and friends often must step in to complete the transportation. However, for some individuals, having available family or friends to drive them may not be a viable alternative, especially if the individual is working atypical work hours. Individuals who rely on transportation services cannot always count on reliability of the transporting vehicles, as they are not always maintained sufficiently.[180]

Inadequate Driver Training

Public transit workers, as well as service drivers, are also not always friendly or patient with individuals with a disability. Some drivers and transit workers lack the necessary familiarity and training to engage with an individual with a disability and are less likely to support them. A 2013 study found that one third of transit bus drivers believed that individuals with disability had increased behavioral challenges and were more likely to be difficult passengers to transport. In addition, the study found that only 36.7 percent of the bus drivers had significant knowledge or understanding about the struggle individuals with a disability regularly deal with.[181]

High Costs and Low Compensation

Though they are included in the consolidated, community living, person/family directed, and adult autism waivers, transportation services are expensive and tend to consume a lot of the budgeted expenses under the waiver for an individual's annual service budget. This is especially true for specialized transportation, which is often needed. As such, many individuals and their families try to avoid utilizing the waiver-covered transportation services to maximize their ability to budget for other needed services for their yearly allocated funding.[182]

Finding reliable transportation services can also be challenging due to the low rate typically offered to drivers. For example, it can be difficult to find drivers for individuals residing in life-sharing arrangements because the rate is so low - many people do not view the compensation as worthy of their time. Transportation expense is not just a problem for transportation of an individual with a disability. Care providers who must travel to the individuals generate a significant expense related to their travel, alone. For example, job coaches and direct support professionals often travel to provide care to individuals or support for those who maintain steady employment. However, in rural areas, job coaches tend to travel greater distances and with the climbing costs of gasoline and car maintenance, providers need to be appropriately compensated with an appropriate rate, driving up care costs and placing strain on an individual's budget.[183]

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[180] *Ibid*.

[181] *Ibid*; *Supra*, n. 163.

[182] *Ibid*.

[183] *Ibid*.

Shortage of Drivers

A shortage of drivers willing to transport individuals with a disability continues to be a problem. One of the primary reasons for this shortage has been linked to the low compensation mentioned above. However, the often-irregular work hours of many individuals with a disability can also negatively impact the availability of drivers for these services.

Considerations

To overcome or mitigate the transportation challenges for individuals with a disability, there must be increased focus on developing more transportation-specific services within the Medicaid HCBS Waivers. The Commonwealth has started to increase this focus by recently amending its Adult Autism Waiver to provide transportation services and vehicle accessibility adaptations. As mentioned previously, Pennsylvania has also increased the annual fiscal limits on transportation allowances. However, many individuals with a disability and families still try to avoid the use of these services due to the high costs in relation to annual budget allocations for their services. Larger annual allocations to help absorb costly transportation services are needed.

In addition, public and private transit service employees are often underpaid and inadequately trained. It may be beneficial to explore the possibility of requiring drivers and public transit employees to be trained in interacting with individuals with a disability and addressing their needs. Drivers must also receive appropriate compensation to incentivize them to work in this industry. In addition, services available to individuals with a disability should include travel training to assist them in navigating complicated public transportation systems (if they are able), so they do not have to rely on other alternative means.

House Bill 1421 (Printer's No. 1602) was referred to the House Transportation Committee on June 15, 2023, and House Bill 1668 (Printer's No. 1972) was referred to the House Transportation Committee on September 12, 2023. The bills both provide that an individual with an autism spectrum disorder may request to have a notation of the diagnosis placed on their driver's license or identification card. HB 1421 also establishes an autism spectrum disorder awareness account that can be donated to at the time a driver applies for or renews a license. The fund is to be used by the Department of Health for education and training of working professionals on autism spectrum disorder.

Senate Bill 932 (Printer's No. 1090) was referred to the Senate Transportation Committee on September 14, 2023. The bill provides that a person who has deafness, a hearing loss, or an autism spectrum disorder may request PennDOT to place a communication impairment designation on the person's vehicle registration, driver's license, or identification card.

Individuals with High Acuity/Complex Needs

One of the directives this HR 212 is to study the Commonwealth's current treatment needs, including network capacity to treat and care for high acuity individuals, individuals with complex medical needs in addition to intellectual disability and individuals who need special care and assistance with intensive behavioral health issues, including, when appropriate, provider referral, admission and discharge practices.

Network Capacity

In July of 2020, the Joint State Government Commission released a report entitled, "Behavioral Health Care System Capacity in Pennsylvania and Its Impact on Hospital Emergency Departments and Patient Health." This report addresses many of the concerns raised in this particular directive, including network capacity, wait times, emergency room boarding, emergency response models, and referrals to other appropriate facilities in a timely manner.[184] The 14 recommendations contained in that report, the product of the deliberations of an advisory committee composed of representatives of state agencies, mental health and substance use disorder provider organizations, county mental health and intellectual disability administrators, consumers of mental health and substance use disorder services, emergency medical service providers, nurses, emergency department physicians, psychiatrists and psychologists, remain current and the research appropriate for review regarding current network capacity to assist individuals with high acuity or complex medical needs.

Pennsylvania has a total of a total of 34,690 licensed beds within the 146 general acute care facilities throughout the commonwealth.[185] While these hospitals are required to adhere to the ADA, the focus of the regulations deals with how to accommodate individuals with mobility issues or individuals who are blind/deaf. The ADA includes intellectual disability, developmental disability and/or autism under the umbrella of what is a categorical disability, but there lack specific regulations on how to ensure that these individuals are receiving equal care. In fact, there is a complete absence of requirements regarding exactly how a hospital can provide equal access to healthcare particularly for individuals with disability.[186] This lack of guidance leaves many acute care facilities in the Commonwealth without accessible accommodations for individuals with disability.

House Bill 22 (Printer's No. 12) was referred to the House Human Services Committee on March 7, 2023. The bill establishes the Medicaid Care Transition Program to assist in placing individuals in post-acute treatment settings when waiting for transfer from an emergency department, inpatient unit or crisis center.

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[184] *Behavioral Healthcare System Capacity in Pennsylvania and Its Impact on Hospital Emergency Departments and Patient Health*, (Joint State Government Commission, July 2020), http://jsg.legis.state.pa.us/resources/documents/ftp/publications/2020-07-30%20ER-BH%20REPORT%20%20web%207.30.20.pdf.

[185] "Hospital Reports," *Department of Health*, accessed February 14, 2024, https://www.health.pa.gov/topics/HealthStatistics/HealthFacilities/HospitalReports/Pages/hospital-reports.aspx.

[186] "What Is This Topic About?" *AASPIRE Healthcare Toolkit for Patients & Supporters*, accessed February 14, 2024, https://autismandhealth.org/?a=pt&p=detail&t=pt_rts&s=rts_access&theme=lt&.

Accessibility

As the understanding of intellectual disability, developmental disability, and autism progresses both in the medical field and society, it is increasingly clear that accessibility accommodations encompass much more than mobility. So, while the current laws quite literally ensure that patients are able to come through the doors, the conditions inside are relatively the same: florescent lights, beeping monitors, constant commotion in the hallways, noise from overhead loudspeakers. These disturbances are part of the emergency room experience for everyone. However, for an individual with disability, the presence of any one of these stimuli can severely impact their ability to receive the care they require. Something as simple as a fever may trigger seizures in a person with a seizure disorder. Gastrointestinal illness can affect the way an individual's body process medications, something particularly important for individuals who rely on daily medications to assist in control of some of the manifestations of their disability.

Additionally, persons with dual diagnoses present particular challenges to health care providers, especially in the emergency department. An individual can have any combination of intellectual disability, developmental disability, autism, and mental health or behavioral health concerns all of which may present differently under different conditions, including when the individual is sick. Just because a patient with disability does complain of pain does not always mean that pain does not exist; nor does not answering a question mean that the patient is noncompliant. The CDC offers guidance and information for health care providers to provide inclusive care for persons with disability. The Surgeon *General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* asks that all health care providers:

- Give each patient—including people with disabilities—the information needed to live a long and healthy life.

- Listen and respond to the patient's health concerns. Give each patient the information needed to prevent or treat a health concern—even if the patient does not ask for it. As a health expert, you should offer the information.

- Communicate clearly and directly with the patient. If your patient does not understand your questions or instructions, repeat what you have said, use other words, or find another way to provide the information.

- Take the time needed to meet the patient's health care needs. [187]

ASERT (Autism Services, Education, Resources and Training) is a partnership of medical centers, centers of autism research and services, universities, and other providers involved in the treatment and care of individuals of all ages with autism and their families. ASERT has developed a training module and manual to assist emergency department personnel in providing appropriate care and treatment to individuals with autism.[188]

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[187] "Disability and Health Information for Health Care Providers," *CDC*, accessed December 5, 2023, https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html#print.

[188] "Tools to Support Emergency Room Personnel," *ASERT*, accessed February 15, 2024, https://paautism.org/resource/emergency-room-tools/.

HealthChoices

HealthChoices is a mandatory managed care program created and maintained for Medicaid recipients by the Department of Human Services. It is the hub through which all health care services are routed. The commonwealth split up into five coverage areas and the individuals receiving services can choose their insurance plan from the authorized list that is determined based on the county of residence.[189]

This choice is critical for any and all health services that may be required in the future as all health services (behavioral, specialists, community, and routine care) are dependent on the providers' participation with the chosen plan. After a plan is chosen, an information packet is mailed to the individual which includes a list with contact information of the physicians and facilities that participate with the chosen insurance. It is important to note that not all providers take all of the insurance plans that are offered within their region, so it is quite possible that if an individual already has established care with a group of physicians, they may be required to seek a different physician within their plan's coverage.

Behavioral HealthChoices is a program within HealthChoices that provides mental health and drug and alcohol services to all Medicaid recipients. Each HealthChoices consumer is assigned a Behavioral Health Managed Care Organization (BH-MCO) based on his or her county of residence. Members, then, have a choice of behavioral health care providers within the BH-MCO's network. See Table 4.

Table 4
Behavioral Health Managed Care Organizations by County
Pennsylvania
2023

BH-MCO	Counties Served
Community Behavioral Health (CBH)	Philadelphia
Community Care Behavioral Health Organization (CCBHO)	Adams, Allegheny, Bedford, Bradford, Berks, Blair, Cameron, Carbon, Centre, Chester, Clarion, Clearfield, Clinton, Columbia, Delaware, Elk, Erie, Forest, Greene, Huntingdon, Jefferson, Juniata, Lackawanna, Luzerne, Lycoming, McKean, Mifflin, Montour, Monroe, Northumberland, Pike, Potter, Schuylkill, Snyder, Sullivan, Somerset, Susquehanna, Tioga, Union, Warren, Wayne, Wyoming, York
Magellan Behavioral Health of Pennsylvania (MBH)	Bucks, Lehigh, Montgomery, Northampton, Cambria
PerformCare	Cumberland, Dauphin, Franklin, Fulton, Lancaster, Lebanon, Perry
Carelon Health of PA, Inc.	Armstrong, Beaver, Butler, Crawford, Fayette, Indiana, Lawrence, Mercer, Washington, Westmoreland, Venango

Source: "Behavioral HealthChoices," *Department of Human Services*, accessed February 15, 2024, https://www.dhs.pa.gov/HealthChoices/HC-Services/Pages/BehavioralHealth-Main.aspx.

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[189] "Behavioral HealthChoices," Department of Human Services, accessed February 15, 2024, https://www.dhs.pa.gov/HealthChoices/HC-Services/Pages/BehavioralHealth-Main.aspx.

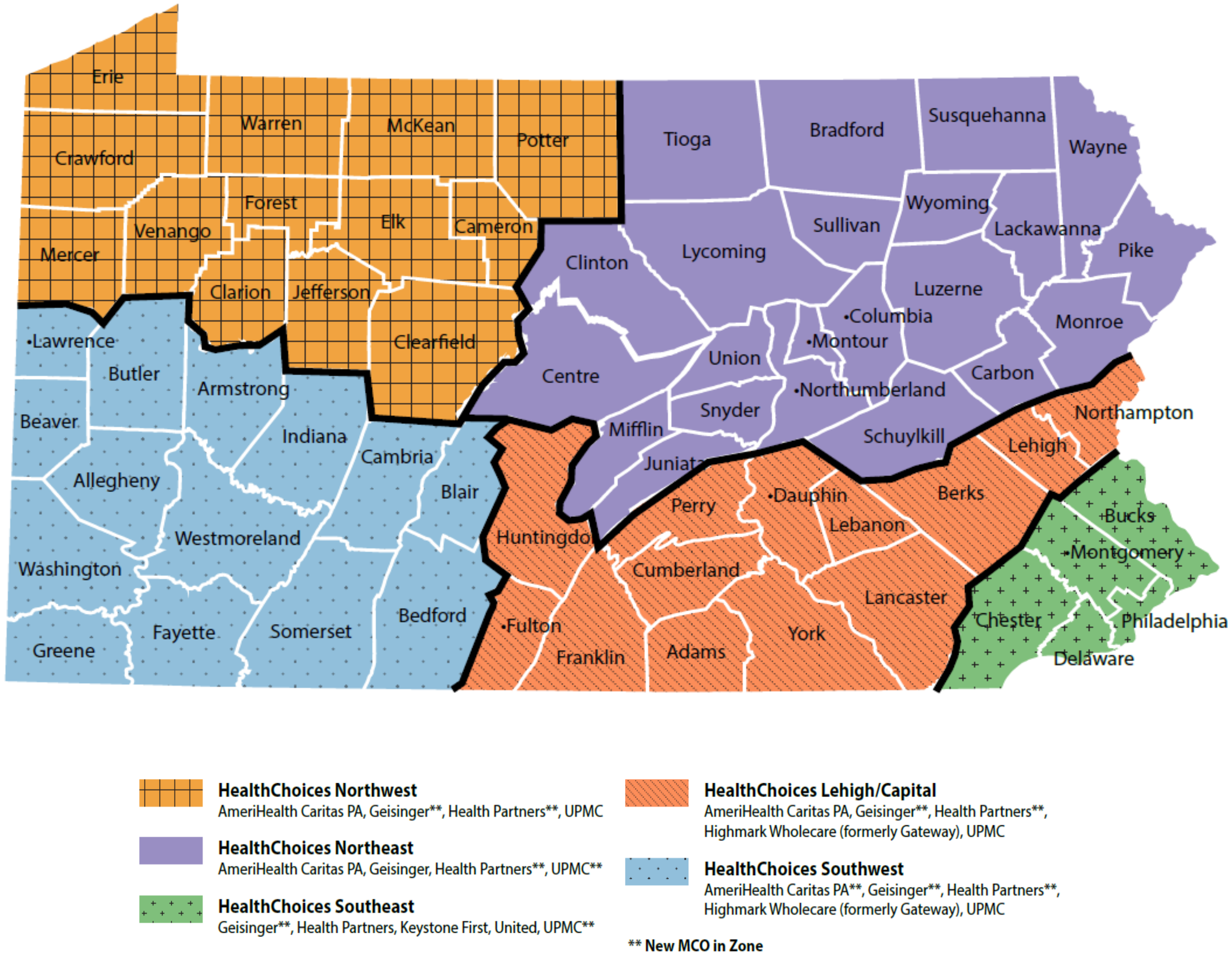
Community HealthChoices is a managed care program for older Pennsylvanians and individuals over the age of 21 who have physical disability. Individuals who are 21 or older and have both Medicare and Medicaid, or receive long-term supports through Medicaid for with everyday personal tasks are covered by Community HealthChoices (CHC).

One of the goals of CHC is to coordinate health care coverage to improve the quality of health care experiences — serving more people in communities rather than in facilities, giving them the opportunity to work, spend more time with their families, and experience an overall better quality of life.[190] The state is divided into the same five zones as established for physical health managed care. See Map 1.

Map 1

Statewide HealthChoices Physical Health Managed Care

Effective September 1, 2022



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[190] "Welcome to Community HealthChoices!" *Department of Human Services*, accessed February 15, 2024, https://www.dhs.pa.gov/HealthChoices/HC-Services/Pages/CHC-Main.aspx.

There are four CHC-MCOS approved in Pennsylvania: AmeriHealth Caritas Pennsylvania, Keystone First, PA Health & Wellness, and UPMC Community HealthChoices.[191]

Specific Waiver Services for Hospitalized Individuals

Persons whose services are funded by PF/D waivers may have in-home and community supports delivered at an acute care hospital if the service is to assist the individual with communication, intensive personal care; or behavioral support/stabilization as enumerated in the behavior support plan.[192] Similar services may be provide in the form of Supplemental Habilitation to temporarily meet the short-term unique behavioral or medical needs of a participant who receives licensed Residential Habilitation, licensed Life Sharing or Supported Living services funded through the Consolidated or Community Living Waiver.[193] Base-funded Respite can be used where waiver services are not provided and the respite can be provided at medical facilities such as a hospital when there is documented medical needs, and the County Administrator approves the Respite service in a medical facility.[194]

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[191] "Community HealthChoices Managed Care Organizations (MCOs)," *Department of Human Service*s, accessed February 15, 2024, https://www.dhs.pa.gov/HealthChoices/HC-Services/Pages/CHC-MCOs.aspx.
[192] *ISP Manual*, 133.
[193] *ISP Manual*, 155-156.
[194] *ISP Manual*, 246.

Transitions can occur for individuals with disability at the beginning and end of their compulsory education careers. This study has focused on adults, not children, and so the transition between early intervention under the Department of Human Services (children under age three) and the Department of Education and the local intermediate unit are not covered in this report. However, the end of the individual's compulsory education requires significant planning. This process is set forth in the following section.

Secondary Transition

One of the biggest hurdles for parents and individuals with children who have intellectual disability and/or autism disability is navigating the complex state system of care for both youth and adult intellectual disability and/or autism services. An especially challenging component of that system is the planning period for an individual with a disability to transition from youth services to adult life after high school. Once a child reaches a certain age, they are no longer entitled to services through the educational system. Consequently, much planning is needed to help the individual successfully transition into adulthood. The planning period leading up to the date of transition is often referred to as "secondary transition," which has been described as "a bridge between school programs and the opportunities of adult life…"[195]

The transition planning process spans through high school where secondary academic instruction and community experiences can help clarify and support a student's goals for life after high school. These goals are primarily related to attending college or career training, gaining employment supported through the appropriate continuum of employment services, and living independently in the community of their choice.[196] These three primary goals "are the driving force behind the IEP written for students in high school."[197]

A six-step process is typically recommended for addressing secondary transition. These six steps include the following:

STEP 1 – Use assessment to identify the student's post-secondary desired goals or vision.

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[195] "What is Secondary Transition," *Pennsylvania Training and Technical Assistance Network (PaTTAN),* accessed August 30, 2023, https://www.pattan.net/Graduation-Post-Secondary-Outcomes/Educational-Initiatives/What-is-Secondary-Transition.

[196] "What is Secondary Transition," *PA Secondary Transition*, accessed August 30, 2023, https://www.pasecondarytransition.com/

[197] Pennsylvania Department of Health, *Transition to Adult Living in Pennsylvania*, (Revised 2012), 1.

STEP 2 – Describe the student's present levels of academic achievement and functional performance, embedding assessment data.

STEP 3 – Establish transition team partnerships.

STEP 4 – Design a transition plan that includes courses of study and services and activities.

STEP 5 – Determine measurable annual goals that address skill deficits and lead to post-secondary goals.

STEP 6 – Monitor progress and adjust instruction based on data.[198]

Federal Requirements

Federal regulations promulgated pursuant to the Individuals with Disabilities Education Act (IDEA)[199] requires that transition planning for students receiving special education services and having an Individualized Education Plan (IEP)[200] must begin by age 16, or younger if determined appropriate by their respective IEP team. However, *some states, such as Pennsylvania require the process to start even earlier.*[201] An IEP is essentially an agreement between the parent and student and the school that is designed for that student. The purpose is to create individualized opportunities for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for children with disability. Pennsylvania defines an IEP as "…a written plan for the provision of appropriate early intervention services to an eligible child, including services to enable the family to enhance the young child's development."[202] The IEP is viewed as "the cornerstone of a quality education for each child with a disability."[203]

Under federal law, a student's IEP must be updated annually and include the following:

- Appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and

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[198] *Supra*, n. 195.

[199] The Individuals with Disabilities Education Act, Pub. L. 101-476, 104 Stat. 1142; 20 U.S.C. § 1400 *et seq.*

[200] An IEP is essentially an agreement between the parent and student and the school that is designed for that student. The purpose is to create individualized opportunities for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for children with disabilities. The IEP is viewed as "the cornerstone of a quality education for each child with a disability." "A Guide to the Individualized Education Program," *U.S. Department of Education*, accessed August 30, 2023, https://www2.ed.gov/parents/needs/speced/iepguide/index.html#introduction.

[201] 34 C.F.R. § 300.320(b).

[202] 22 Pa. Code § 14.154(a).

[203] "A Guide to the Individualized Education Program," *U.S. Department of Education*, accessed August 30, 2023, https://www2.ed.gov/parents/needs/speced/iepguide/index.html#introduction.

- The transition services (including course of study) needed to assist the child in reaching those goals.[204]

Federal law defines "transition services" as a coordinated set of activities for a child with a disability that –

- Is designed to be within a results-oriented process, focused on improving academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and/or community participation.

- Is based on the individual child's needs, considering the child's strengths, preferences, and interests; and includes –

    1. Instruction;
    2. Related services;
    3. Community experiences;
    4. The development of employment and other post-school adult living objectives; and
    5. If appropriate, acquisition of daily living skills and functional vocational evaluation.[205]

Federal regulations place several mandates on state special education systems related to notice of transfer of rights when the child reaches the age of majority, IEP team composition, and other broad requirements for the secondary transition process. Federal law also requires an IEP team to be involved in the transition services of the child.[206]

State Requirements

States are permitted to enact their own requirements related to secondary transition, so long as they do not conflict with existing federal regulations. In Pennsylvania, the official age of transition for an individual with a disability is 22. While federal law requires planning to start no later than the child reaching 16 years of age, Pennsylvania requires planning to start when the child is 14. Planning can also start when the child is younger than 14, if determined appropriately by the child's IEP team.[207] Pennsylvania law also requires that in addition to all the federal requirements under 34 C.F.R. §§ 300.320 – 200.324, a student's IEP must include "[a] description of the type or types of support … that the student will receive, [and] the determination of which may not be based on the categories of the child's disability alone."[208]

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[204] 34 C.F.R. § 300.320(b)(1)-(2).
[205] 34 C.F.R. § 300.43(a)(1)-(2).
[206] 34 C.F.R. § 300.321(b)(1).
[207] 22 Pa. Code § 14.131(a)(5).
[208] 22 Pa. Code § 14.131(a)(1).

Students with a disability may receive more than one type of support as appropriate and as outlined in their IEP. For the student's educational placement, the IEP team must first consider the regular classroom with the provision of supplementary aids and services before considering the provision of services in other settings.[209] Support services may include autistic support, blind-visually impaired support, deaf and hard of hearing support, emotional support, learning support, life skills support, multiple disability support, physical support, and speech and language support.[210] Pennsylvania also requires that IEPs include all necessary supplementary aides and services, a description of the type or types of support, the location where the student attends school and whether this is the school the student would attend if the student did not have an IEP, and the secondary transition plan once the student turns 14.[211]

State Agencies and Departments

The Pennsylvania Department of Education is responsible for developing and overseeing Pennsylvania's special education system and the local agencies who directly provide services under it. The Department must ensure that each child with a disability receives a free appropriate public education (FAPE).[212] There are a collection of state offices and bureaus under the Department of Education and the Department of Human Services that collaborate to facilitate and support the secondary transition process. Since their duties related to intellectual disability and/or autism services often overlap, the Pennsylvania Office of Vocational Rehabilitation (OVR), along with the Department of Education's Bureau of Special Education (BSE), and the Office of Developmental Programs (ODP) work closely together and communicate weekly. Prior to the pandemic, the OVR and BSE worked on finalizing a new Memorandum of Understanding (MOU) outlining their partnership, with the possibility of a three-pronged MOU being discussed to include ODP. It is important for these offices to work together for the successful transition of kids out of school, as they each play a role in the process.[213]

Office of Vocational Rehabilitation (OVR). The support provided by OVR regarding setting and obtaining vocational goals is important when a disabled individual is transitioning to adult living. OVR provides vocational rehabilitation services for disabled individuals to help them prepare or obtain or maintain stable employment. OVR also provides services to eligible individuals, both directly and through a network of state-approved vendors. OVR counselors conduct face-to-face interviews, assist disabled individuals in pinpointing their vocational goals, services, and service providers.[214] OVR also advises school districts on the need to update assessment forms, provides intermediate units and school districts with current OVR eligibility criteria, participates in teacher orientation, provides information on work incentives, such as Ticket to Work, Assistance and Outreach, and PA Career Link.[215]

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[209] *Ibid*.

[210] 22 Pa. Code § 14.131(a)(1)(i)-(ix).

[211] 22 Pa. Code § 14.131(a)(2)-(5).

[212] 22 Pa. Code § 14.102(a)(4); 22 Pa. Code § 711.4(a).

[213] *Ibid*; Carole Clancy, Bureau of Special Education, Director.

[214] "Vocational Rehabilitation Services," *Pennsylvania Department of Labor and Industry*, accessed August 30, 2023, https://www.dli.pa.gov/Individuals/Disability-Services/ovr/Pages/default.aspx.

[215] "Transition Planning in Your IEP: Check List for Yearly Best Practices in Transition Services," *Pennsylvania Education for All Coalition*, accessed February 15, 2024, http://www.paedforall.org/wp-content/uploads/2016/12/Transition_-_Yearly_Checklist_of_Best_Practices.pdf.

Office of Developmental Programs (ODP). ODP is one of seven program offices within the Pennsylvania Department of Human Services. The mission of ODP is to improve the quality of life for individuals with developmental disability and their families within the Commonwealth. ODP also works to promote opportunities for independent living for said individuals, through service and supports.[216]

Bureau of Special Education (BSE). The BSE operates within the Pennsylvania Department of Education and collaborates with educators, schools, agencies, and other stakeholders across the Commonwealth to make sure all students have access to quality and meaningful education through supports, services, and opportunities. The BSE also develops and supervises Pennsylvania's special education system to ensure that every child with a disability receives a FAPE. Like the ODP and OVR, the BSE plays a role in the secondary transition process. BSE develops information resources on transition and performs special education planning, compliance monitoring, data gathering, and regulation and policy review and drafting.[217]

Local Education Agencies

While the Pennsylvania Department of Education is responsible for developing and supervising the Commonwealth's special education system, local education agencies (LEAs) and mutually agreed upon written arrangement (MAWA) holders have the primary and direct responsibility for providing FAPE. LEAs are defined under Pennsylvania law as "[a] Pennsylvania institution certified by the Department of Education, which may include any of the following:

1. Area vocational-technical schools.
2. Community, technical and junior colleges.
3. Intermediate units.
4. Licensed private/proprietary business and trade schools.
5. Public school districts.
6. State or private colleges.[218]

Charter schools and cyber charter schools are also considered LEAs.[219] Some examples of LEAs involved in the secondary transition process are school districts and Intermediate units.

School Districts. School districts throughout the Commonwealth provide special education staff and coordinators, facilities, and other resources to students with disability. They also partner with other agencies (both state and local), as well as other organizations to facilitate the secondary transition process for families. They are typically responsible for passing along information to parents provided by state agencies regarding the secondary transition process.

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[216] "Developmental Programs," *Pennsylvania Department of Human Services*, accessed August 30, 2023, https://www.dhs.pa.gov/providers/Providers/Pages/Developmental-Programs.aspx.

[217] "Special Education," *Pennsylvania Department of Education*, accessed August 30, 2023, https://www.education.pa.gov/K-12/Special%20Education/Pages/default.aspx.

[218] Act of December 18, 2001 (P.L. 949, No. 114), § 702-A; 24 P.S. § 6250.702-A.

[219] 22 Pa. Code § 711.4(a).

IEP Team. A child's IEP team also plays an integral role in the secondary transition process. An IEP team is intended to help achieve all the goals outlined in a child's IEP. Pursuant federal regulations, an IEP team for each child with a disability must include the following:

- The parents of the child;
- Not less than one regular education teacher of the child, or where appropriate, not less than one special education provider of the child;
- A representative of the public agency who:
    - Is qualified to provide, or supervise specifically designed instruction to meet the needs of children with disability;
    - Is knowledgeable about the general education curriculum; and
    - Is knowledgeable about the availability of public agency resources.[220]

In addition to the federal requirements, Pennsylvania regulations require the IEP team to have at least one special education teacher or provider, an agency familiar with the availability of resources of the early intervention agency and an agency representative qualified to provide or supervise the provision of specially designed instruction to meet the needs of children with disability. The agency representative can include a preschool supervisor or service coordinator or designee of the early intervention agency.[221]

School districts (or other LEAs involved) must include a child with a disability in the IEP team meeting to discuss postsecondary goals for the child and the transition services needed to assist the child in reaching those goals.[222]

Intermediate Units. Intermediate units are educational service agencies that are considered a part of the Pennsylvania public school system. Intermediate units deliver services to school districts and communities across Pennsylvania. They were established by state statute in 1970 and became operational in 1971.[223] Intermediate units typically coordinate and perform instructional assessment, instructional enhancement and development, professional development, and technical and administrative functions.[224] The Pennsylvania Public School Code (PSC) specifically authorizes intermediate units to adopt programs and services under seven general categories which include curriculum development and instructional improvement services, educational planning services, instructional materials services, continuing professional education services, pupil personnel services, state and federal agency liaison services, and management services.

Each school district within the Commonwealth is assigned to an intermediate unit and as such, are entitled to intermediate unit services in accordance with a program of services adopted by the Intermediate Unit Board of Directors.[225] The PSC also requires that the arrangement of the

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[220] 34 C.F.R. § 300.321(b)(1).

[221] 22 Pa. Code § 14.154(b)(1)-(2).

[222] *Ibid.*

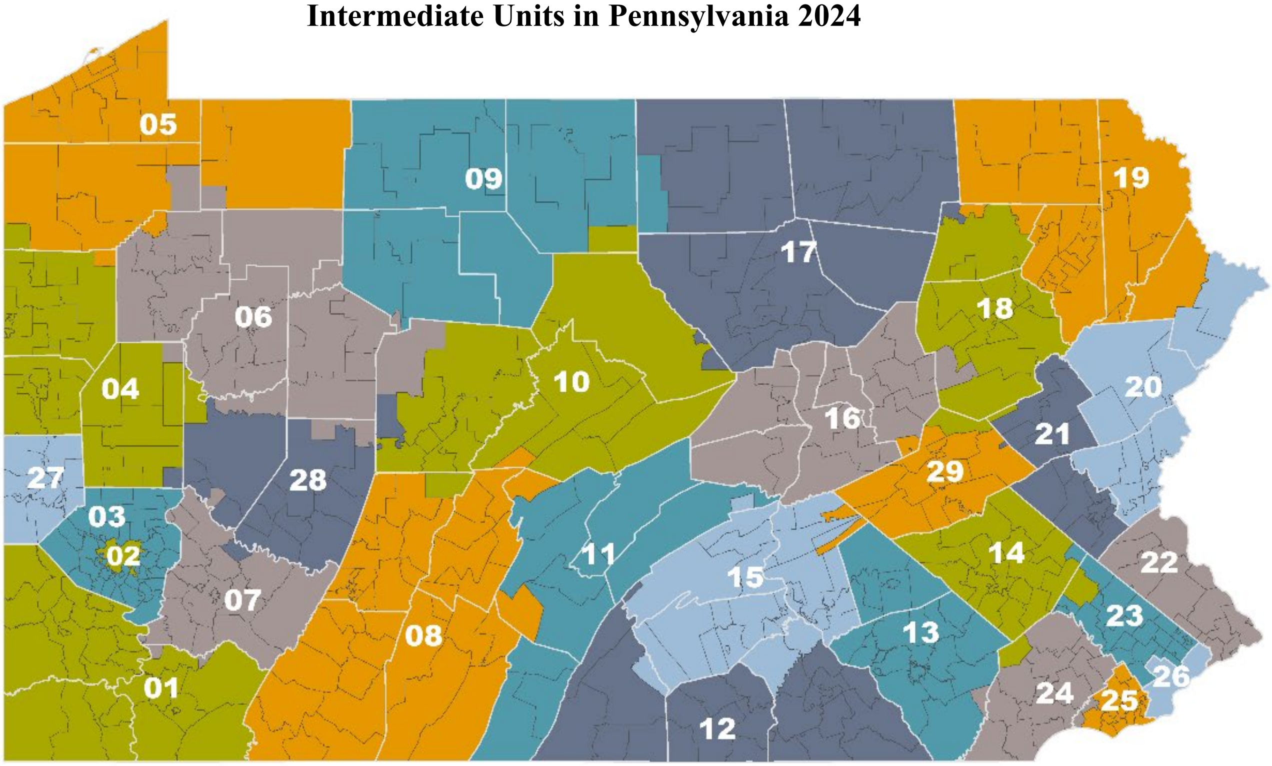
[223] Public School Code of 1949 (PSC), Act of March 10, 1949 (P.L. 30, No. 14), art. IX-A, § 901-A, added by Act of May 4, 1970 (P.L. 311, No. 102), § 1; 24 P.S. § 9-901-A.

[224] "About Pennsylvania's IUs," *Central Susquehanna Intermediate Unit*, accessed September 6, 2023, https://www.csiu.org/site/Default.aspx?PageID=105#:~:text=Pennsylvania's%20intermediate%20units%20(IUs)%20are,operational%20on%20July%201%2C%201971.

[225] *Ibid.*

school districts into intermediate units reflect consideration of the number of public-school children enrolled in kindergarten through grade twelve, ease of travel within each intermediate unit, and the opportunity to provide adequate basic services.[226] Some Intermediate units provide services to only a single county, while others provide services to multiple counties. For example, Bucks County receives services from one unit designated singularly for its students. In the south-central portion of the state, the Lancaster-Lebanon Intermediate Unit-13 (IU-13) provides services to public school districts in both Lancaster and Lebanon counties. There are a total of 29 intermediate units across Pennsylvania and they are identified by their designated number. See Map 2 below:

Map 2
Intermediate Units in Pennsylvania 2024



Intermediate Unit	#
Allegheny Intermediate Unit	3
Appalachia Intermediate Unit	8
ARIN Intermediate Unit	28
Beaver Valley Intermediate Unit	27
Berks County Intermediate Unit	14
BLaST Intermediate Unit	17
Bucks County Intermediate Unit	22
Capital Area Intermediate Unit	15
Carbon-Lehigh Intermediate Unit	21

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[226] PSC § 901-A; 24 P.S. § 9-901-A.

Intermediate Unit	#
Central Intermediate Unit	10
Central Susquehanna Intermediate Unit	16
Chester County Intermediate Unit	24
Colonial Intermediate Unit	20
Delaware County Intermediate Unit	25
Intermediate Unit	1
Lancaster-Lebanon Intermediate Unit	13
Lincoln Intermediate Unit	12
Luzerne Intermediate Unit	18
Midwestern Intermediate Unit	4
Montgomery County Intermediate Unit	23
Northeastern Educational Intermediate Unit	19
Northwest Tri-County Intermediate Unit	5
Pittsburgh-Mt. Oliver Intermediate Unit	2
Riverview Intermediate Unit	6
School District of the City of Philadelphia	26
Schuylkill Intermediate Unit	29
Seneca Highlands Intermediate Unit	9
Tuscarora Intermediate Unit	11
Westmoreland Intermediate Unit	7

Source: Compiled by the Commission from the Pennsylvania Association of Intermediate Units, accessed September 6, 2023, https://www.paiu.org/Find-an-IU.

Intermediate units have the legal authority to hire staff, which include an executive director and such assistant executive directors, program specialists, and other personnel as the intermediate unit board of directors deems necessary to employ.[227]

Intermediate units provide school districts with information related to secondary transition needs of students as they progress in age toward adulthood. They also build capacity in school districts to meet the federal requirements under the IDEA.[228]. According to Pennsylvania's Education for All Coalition Transition Planning Check List for Yearly Best Practices, intermediate units and school districts should execute the following best transition planning practices:

- Link student with adult developmental delay (DD) Service System.
- Invite student to participate in IEP meeting.
- Determine if student is eligible for DD services, check if student is registered with Mental Health (MH)/DD, if not, refer family to a program to register for services.
- Identify initial set of desired post school outcomes.

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[227] PSC § 913-A; 24 P.S. § 9-913-A(a).

[228] "Transition Supports and Resources," *IU-13*, accessed September 6, 2023, https://www.iu13.org/students-families/special-ed/support-services/transition/.

- At least one month prior, invite county DD program to attend IEP meeting.
- Invite others who may be significant to student achievement to attend IEP meeting.
- Organize teacher orientation focusing on adult agency services, practices, and eligibility.
- Forward student assessment forms to county DD program, OVR, and other adult service agencies at the beginning of the school year to consider changes and promote efficient record sharing.[229]

Other County Mental Health/Developmental Delay Programs

Counties often have other mental health or developmental delay programs that indirectly assist in the transition process. These programs and offices can provide intermediate units or school districts with information on services, supports, eligibility, and family peer support and contacts for families at IEP meetings. They can also advise school districts on assessment form updates, and they sometimes participate in the orientation for teachers and discussions on the transition roles and responsibilities.[230]

Challenges

The secondary transition planning process is not an easy one. Most parents with children with a disability are busy with the day-to-day struggles of parenting and addressing the immediate special needs of their child. Consequently, many parents are understandably overwhelmed and cannot utilize time to plan for something that is several years into the future. Instead, they are simply trying to get through the present, that is, until the child finishes high school and transition becomes a stark reality. In addition, it is difficult to predict the opportunities that will be available for one’s child after high school graduation when it is so far away. This is especially true for parents of children with severe developmental and intellectual disability, whose developmental and medical situations could change significantly.[231]

Nonetheless, parents need to start planning early the best they can; waiting until the child reaches the end of high school is typically too late. Beginning secondary transition planning as early as possible allows the IEP team to work with the student and his or her family to plan. This important planning includes selecting classes, activities, and services that will be meaningful and motivating to the child and help develop his or her postsecondary goals.[232] Unfortunately, many parents find themselves unprepared for transition when their child graduates.[233]

Compounding these challenges is the fact that many schools are not always reliable for informing and educating parents on what is available after transitioning out of high school. There are state resources and informational tools available to help educate families on how to best

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[229] *Supra*, n. 215.
[230] *Ibid*.
[231] Discussions in the House Resolution 212 Advisory Committee Meeting held on August 24, 2023.
[232] *Supra,* n. 197
[233] *Ibid*.

navigate secondary transition; however, many families are unaware these resources and tools exist. The information surrounding them is simply not making its way to the people who need it most. State agencies like the Pennsylvania Department of Human Services (DHS), the ODP and the BSE are aware that despite significant outreach, many state-provided materials and information are not being received by families. Agencies like the BSE work with advocacy groups and county programs to distribute useful information on the planning process. The agency floods email systems with related information; however, many emails are already besieged with information and messages, especially for parents with disabled children, leading to them go unread or noticed. Agencies like the BSE are working to improve the messaging system so parents and providers do have adequate access to all the information they need. Getting the information into the rights hands is key because there are several helpful resources out there for families looking to start the secondary transition planning process.[234]

Resources and Initiatives

State agencies are trying to actively address some of the challenges that families face during and leading up to transition planning by providing new resources and initiatives to educate families and make the transition planning process more seamless.

<u>PA Secondary Transition</u>. PA Secondary Transition is a comprehensive website that serves as an informational hub on secondary transition. The site is maintained and operated by the Pennsylvania Secondary Transition Leadership Team comprised of representatives from various state departments and agencies such as the BSE, PaTTAN, ODP, the Office of Long-Term Living, OVR, the Parent Education and Advocacy Center (PEAL), and the Pennsylvania Youth Leadership Network (PYLN). The team also partners with these agencies, as well as the Office of Mental Health and Substance Abuse Services (OHMSAS), Transition Discoveries, the Autism Services, Education, Resources, and Training Collaborative (ASERT), HUNE (not for profit organization), and the Pennsylvania Inclusive Higher Education Consortium (PIHEC), which is funded by the U.S. Department of Education through the acquisition of a Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) grant.[235]

The PA Secondary Transition website has been in operation for approximately three years and contains transition resources such as best practices and commentary explaining what transition involves. The website also provides informational webinars on understanding the MOU between the contributing state agencies, engaging stakeholders, and strategies for aligning efforts related to transition. The site also provides "Transition Discoveries," a clickable option that looks at opportunities at a local level for transition assistance. The site also offers use of the "Transition Tid-Bits" option which provides updates on transition practices and requirements. The online resource also helps families stay connected for employment opportunities. The site helps provide useful information to local entities to address the lack of consistency and practice at the local level. PA Secondary Transition also provides a "What's Happening" link that details related events and announcements.[236]

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[234] *Ibid*.

[235] "About Us," *PA Secondary Transition*, accessed August 30, 2023, https://pasecondarytransition.com/leadership.

[236] "PA Secondary Transition," *PA Secondary Transition*, accessed August 30, 2023, https://pasecondarytransition.com/.

Partnership Conferences. In July 2022, ODP, OVR, BSE, and the Intermediate Units (IU) attended a joint transition conference. All agencies essentially sat at a table and discussed their partnership and how to improve their communication. There were training videos available for educators, agency employees, and other stakeholders. The specific focus of the conference was to help the agencies and their employees and administrative officials better understand each other's objectives and duties in relation to one another. The departments and agencies met together again in 2023. In addition, the agencies have jointly applied for and received a federal grant of 9.9 million dollars to address their statewide transition plan and the transportation barriers facing individuals with a disability.[237]

PA Youth Leadership Network. There has also been a new focus at the state-level on putting increased attention on engaging youth through the creation of the PA Youth Leadership Network (PYLN). The PYLN is a group of young adults with disability working to help youth throughout the Commonwealth. The group's mission is to "develop self-determination, empowerment, and leadership of youth that promotes successful post school outcomes in the areas of education, employment, independent living, and health and wellness among youth and young adults."[238] The PYLN has its own sessions at the transition conference and works regularly to support the mentoring of young adults through creating student ambassadors.[239]

PaTTAN. The BSE works with the Pennsylvania Training and Technical Assistance Network (PaTTAN) to provide professional development and technical assistance targeted for improving student results. Professional development and technical assistance provided by PaTTAN occur through week-long summer institutes, ongoing professional development series, webinars, on-site assistance, and individual student or teacher supports.[240] PaTTAN's website offers helpful information on compliant secondary transition practices and is also going to be offering resources on the "Effective Practices for Transition Planning" in the future. PaTTAN also provides the Secondary Transition Crosswalk document that contains examples of pre-employment transition services and school-level transition services regarding Pennsylvania's career education and work standards, career awareness and preparation, career acquisition, career retention and advancement, and entrepreneurship.[241]

Pennsylvania Community on Transition. The Pennsylvania Community on Transition is a group of various stakeholders from across Pennsylvania working together to help bring about appropriate transition outcomes for Pennsylvania youth and young adults with disability. The team consists of a diverse group of representatives from the State Departments of Education, Health, Labor and Industry, and Human Services; various youth-serving agencies; young adults; parent organizations; advocates; higher education; and employers.[242]

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[237] U.S. Department of Education, Rehabilitation Services Administration, Grantees | Rehabilitation Services Administration (ed.gov).

[238] "Pennsylvania Youth Leadership Network (PYLN)," *Pennsylvania Training and Technical Assistance Network*, accessed August 30, 2023, https://www.pattan.net/Graduation-Post-Secondary-Outcomes/Educational-Initiatives/Pennsylvania-Community-of-Practice/Pennsylvania-Youth-Leadership-Network-PYLN.

[239] *Ibid*.

[240] "About PaTTAN," Pennsylvania Training and Technical Assistance Network, accessed August 30, 2023, https://www.pattan.net/.

[241] PaTTAN, *IDEA-WIOA: Secondary Transition Crosswalk* (March 2021).

[242] *Ibid*.

Transition Coordinating Council (TCC). TCC is a network of parents, consumers, educators, and community service providers helping students with special needs to successfully transition from school to adult life. The mission of the TCC is to “promote effective transition planning for students with disability…” TCCs are usually facilitated by the special education services of intermediate units.[243]

Transition to Adult Living in Pennsylvania Guide. The Pennsylvania Department of Health publishes a *Transition to Adult Living in Pennsylvania* guide that provides information to families and stakeholders on planning for post-high school living. Specifically, the goal of the guide is to provide a checklist, resources, and steps to assist youth and families to make a successful transition to adult living that includes a focus on health and healthcare. The guide appears to have been last revised in 2012.[244] A gap in health services for students with special health care needs identified by the department prompted the publishing of the guide and checklist to fill those gaps.[245]

RENEW. The Rehabilitation for Empowerment, Natural Supports, Education, and Work (RENEW) is another resource available to youth with disability and their families. RENEW was developed in 1996 by staff at the Institute on Disability (IOD), while the program has been adopted in Pennsylvania since 2012. The program offers school-to-career transition planning and an individualized process for youth with emotional and behavioral challenges. The program is provided by schools, community mental health centers, community-based providers, and IOD staff members. The program uses a model focused on assisting young adults to pursue a plan for secondary transition.[246]

House Bill 1587 (Printer’s No. 1667) was referred to the House Education Committee on July 25, 2023. The bill requires each school district to hire at least one full-time dedicated and highly qualified or credentialed transition coordinator for each senior high school of the district. The coordinator’s primary responsibility will be to help implement the Employment First Act.

House Bill 342 (Printer’s No. 305) was referred to the House Committee on Education on March 13, 2023. The bill is designed to improve the transition to college for students with disability, including reducing duplicate documentation requirements, policies that are transparent and easily accessible, and requiring transition planning no later than entry into 12th grade relating to potential post-secondary educational institution attendance.

House 1214 (Printer’s No. 1290) was referred to the House Education Committee on May 23, 2023. The bill would require school entities to complete and present an initial evaluation of a child no later than 60 days after parental consent for the evaluation has been received.

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[243] *Ibid*.

[244] *Supra*, n. 197.

“Transition,” *Pennsylvania Department of Health*, accessed August 31, 2023, https://www.health.pa.gov/topics/school/Pages/Transition.aspx.

[246] *Ibid*.

Transitions Within the Waiver Programs

Whenever there is a significant change in a individual's needs, transitions can occur with waiver programs. Persons can transition between various levels of support within the same provider, usually based on a change in personal care needs. If the supports system that an individual has been using has changed and a different level of waiver is called for, transition can occur between waivers as well. For example, an individual living at home with an elderly parent and receiving person/family directed services may be adequately supported until the parent suddenly dies. The individual may not be able to live independently and may need and qualify for community living or consolidated waiver services to fund a supported living environment. Changes in circumstances should trigger a re-evaluation or significant life change assessment through the SIS and the creation of a new individualized service plan.

An individual may wish to transition to a new provider, for whatever reasons. A provider may not be willing or able to supply a service and initiate a transition as well. Minimal disruption of services can occur, all parties to the transition are to cooperate with DHS, and the individual's choice of the timing of the transition should be respected to the extent possible and in accordance with regulations.[247]

Permanency Planning

In Pennsylvania, the concept of "permanency planning" is generally the idea that courts and county agencies should make dedicated efforts to rehabilitate and reunite a child with their family in a reasonable time, instead of forcing them into the limbo of spending their childhood in foster homes, and adoption.[248] Permanency was first introduced within the child welfare system during the 1970s. Permanency planning subsequently became federally mandated within state systems in 1980 pursuant to the federal Adoption Assistance and Child Welfare Act (AACWA), signed into law by President Jimmy Carter.[249] Currently, the AACWA requires that state child welfare agencies receiving federal funding create and enforce a set of permanency planning procedures for children in foster care or institutions.

The idea of "permanency" has also applied specifically to situations involving children with disability. Permanency as used by the intellectual disability and/or autism services systems "describes both a philosophy and a process to address a child's developmental need for an enduring nurturing parental figure for healthy development."[250] Permanency is based on the following concepts:

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[247] 55 Pa.Code § 6100.301 *et seq.*

[248] *In re M.B.*, 674 A.2d 702, 704 (Pa. Super. 1996) (*quoting in re Quick*, 559 A.2d 42 (Pa. 1989)).

[249] Imagine Different Coalition, *Permanency Planning for Children with Disabilities Living in or at Risk of Admission to Facilities Executive Summary* (May 2023), 5; The Adoption Assistance and Child Welfare Act of 1980, Pub. L. 96-272.

[250] *Ibid.*, 5.

- A child's need for emotional security and continuity of parental relationship in daily life.

- A child's need for physical security and continuity of a stable, safe living arrangement.[251]

By and large, it is expected that children will grow up in a family. This is simply not the case for all children. In fact, many children with disability grow up in facilities with no real planning or anticipation of returning to their family. Oftentimes living out-of-home is viewed as the only service option, while the child's loss of family life is overlooked.[252] The toll of this loss is not always easy to quantify, but in many cases, in can be devastating to the child. Family can provide a sense of love, security, continuity, stability, values, and trust. Moreover, growing up with a family, especially in one's early years, can lay the groundwork for further social, emotional, and cognitive development.[253] A child living in a facility will lose out on much of these benefits, as well as the day-to-day experience of a nurturing parent-child relationship, which is typically "at the heart of family life" and from a developmental perspective, serves as "the 'active ingredient' in optimal development."[254]

Recognizing the impacts of removing a child with disability from their family and community, Pennsylvania has pursued a deinstitutionalization movement while embracing home and community living arrangements. However, human service systems across the Commonwealth have inconsistently prioritized family living and the permanency planning that makes it possible. Child welfare agencies and offices within the Commonwealth have published guidance and policy bulletins acknowledging the importance of permanency; however, no comprehensive planning policy or strategies appear to exist for most of the service agencies and offices serving children with a disability.

The Pennsylvania Department of Human Services (DHS) does not appear to have an express cross-agency permanency policy covering the Office of Developmental Programs, the Office of Medical Assistance Programs (OMAP), the Office of Mental Health and Substance Abuse Services (OMHSAS), and the Office of Children, Youth, and Families (OCYF). DHS has expressed a focus on permanency in some of its past policies. One example is the DHS *Complex Case Planning for Children and Youth Under Age 21 Bulletin*, published in 2021. In this bulletin, DHS stated that it seeks to provide "…a comprehensive approach to serving children and youth, birth to 21 years of age, through programs that focus on … services that support family stability, safety, community protection, and the child/youth's healthy development and permanent connections."[255] In addition, the bulletin advised that use of congregate care facilities should be limited only when deemed necessary. DHS policy also requires that prior to use of congregate settings, less restrictive settings must be tried first and there must be no family-based setting able to meet the child or youth's needs.[256] It is also worth mentioning that in 2006, the Center for

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[251] *Ibid*., 4.

[252] *Ibid*.

[253] "Parents and Caregivers are Essential to Children's Healthy Development," *American Psychological Association*, accessed November 1, 2023, https://www.apa.org/topics/families/parents-caregivers-kids-healthy-development.

[254] *Supra*, n. 249.

[255] *Supra*, n. 249, 10.

[256] *Ibid*., 10-11.

Medicare and Medicaid Services (CMS) approved one of Pennsylvania's Consolidated Waivers which offered permanency planning as an eligible service for children with a disability. However, the waiver was later amended and the permanency planning services for children was removed.[257]

Policy direction related to permanency planning can be found in Physical Health-Managed Care Organization (PH-MCO) contracts overseen by OMAP. In fact, permanency planning for children with disability living in facilities is required by the contracts. Specifically, an exhibit within 2022 PH-MCO expressly states that discharge planning from a residential facility or extended inpatient hospital stay for each child must begin upon admission and have the primary goal of going home to family or a family model alternative. Despite these permanency planning requirements in the PH-MCO contracts, many children are still placed within institutional settings and expectations for meeting permanency planning requirements are not fully laid out.[258]

Behavioral Health Managed Care Organization (BH-MCO) agreements for Medicaid recipients falling under OMHSAS imply a preference for children served by the BH-MCO, living with families. While the implication is there, there is no formal language prioritizing the idea.[259] Conversely, OCYF does have explicit requirements for permanency planning in compliance with AACWA requirements for child welfare systems.[260]

The lack of a comprehensive policy requiring permanency planning across all agencies serving children with a disability leads to inconsistency among the agencies. The policies that are in place in each of the agencies lack specificity. Consequently, many believe the policies are not ensuring that children with a disability have adequate opportunities to live with families. Given that studies have shown, and the Commonwealth has acknowledged that family life is critically important for children and their quality of life and development, practices should be bolstered with specificity and express requirements to ensure permanency planning is utilized as a priority service for disabled children.

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[257] *Ibid*., 12-13.

[258] *Ibid*., 14-15.

[259] *Ibid*., 15; *HealthChoices Behavioral Health Program Standards and Requirements* (Jan. 1, 2022), App. T (Part B.1), 3.

[260] Pennsylvania's Child Welfare Practice Model, Family Service Plan/Child Permanency Plan Summary, Child Welfare Resource Cetner, University of Pittsburgh, https://www.pacwrc.pitt.edu/Curriculum/209_CncrrntPlnnng1/TrnrRsrcs/TR04_FSP-CPPSmmry.pdf.

WORKFORCE DEVELOPMENT

The workforce composition of those involved in caring for and assisting individuals with intellectual and developmental disability and autism often varies based on the disability and age of an individual. However, Direct Support Professionals (DSPs), frontline supervisors, residential program managers, program directors, and care coordinators are the most common professionals within the intellectual disability and/or autism service system in Pennsylvania. Job coaches, business support professionals and quality, performance, and regulatory compliance officials are also common jobs within the system, though DSP roles have expanded to assume some of the traditional tasks of job coaches. DSPs and other professionals caring for individuals with a disability can work in a variety of different settings, such as a person's home, in day programs, schools or elsewhere within the community.[261] Support Service Professionals (SSPs) serve the same functions as DSPs in the person/family directed service model.

Demographics

Much of the workforce is composed of women. This is especially true for DSPs, who are primarily low-income women, and people of color, many of whom face obstacles to education and careers in other settings. According to a 2020 report on the direct care workforce, as of 2017, 86 percent of DSPs were female, with 92 percent of nursing assistants in nursing homes being female, and 87 percent of home care workers being female. The report also found that around 84 percent of residential care aides were female.[262] A 2022 report found that approximately 70 percent of DSPs in the overall workforce were female.[263]

When broken down by age, the same report found that DSPs' median age was 41 in 2017. For in-home care providers, the median age was 46, whereas the median age for nursing assistants in nursing homes was 37. As previously noted, the DSP portion of the workforce is very racially

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[261] Kezia Scales, PhD, "It's Time to Care: A Detailed Profile of America's Direct Care Workforce," PHI National, (2020), 7; Provider Consortium, "2022 Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study," *Pennsylvania Center for Disability Information*, (2022). Some literature also discusses the roles of Direct Care Workers (DCWs). These are comprised of three primary occupations: personal care aides, home health aides, and nursing assistants. According to the Bureau of Labor Statistic's Standard Occupational Classification (SOC) system, personal care aides assist individuals with daily living activities and provide support with instrumental activities of daily living and community activities. Home health aides and nursing assistants' duties are like those of personal care aides. However, home health aides and nursing assistants are also responsible for performing clinical tasks such as monitoring vitals, performing range of motion tests, or administering medication. These tasks often must be supervised by licensed professionals. This report focuses more on DSPs.

[262] *Ibid*.

[263] Julie Bershadsky, PhD, Amy Hewitt, PhD, Valerie Bradley, MA, *et al*., *Community Supports in Crisis: No Staff, No Services* (National Association of State Directors of Developmental Disabilities Services, Human Services Institute, and Institute of Community Integration, University of Minnesota, June 2022): 1.

and ethnically diverse – 59 percent of DSPs are people of color, including 30 percent who are African American, 18 percent who are Hispanic, seven percent who are Asian or Pacific-Islanders, and four percent identifying as other races or ethnicities. Many DSPs are immigrant workers; approximately one in four DSPs were born outside the U.S. in 2020.[264]

According to the 2021 *National Core Indicators Intellectual and Developmental Disabilities State of the Workforce Survey Report* (2021 NCI Report) of the DSPs working within the services system, 40.1 percent were black or African American, 38.6 percent were white, 5.4 percent were Hispanic, and 1.5 percent were Asian. The study also found that across participating states, agencies reported that 71.2 percent of DSPs were female, 24.1 percent were male, 4.4 percent were of unidentified genders, and 0.3 percent were of non-conforming or other genders.[265]

Job Categories

The following is a detailed breakdown of the most common job categories making up the services workforce in Pennsylvania. Within each category is the commonly known job title, a job description, average annual salary or hourly wage, and list of offered benefits to employees within each category.

Direct Support Professionals (DSPs)
Job Description/Roles
DSPs are the largest portion of the workforce in Pennsylvania and have primarily served as the chief caregivers for the individuals with disability they support. The primary role of DSPs has begun to shift in the past few decades as the needs of those they serve began to change. Expanding beyond everyday caregiving, DSPs roles now often include supporting individuals to participate fully in their communities and often live in integrated settings. DSPs have also assumed the role of assisting individuals in obtaining competitive integrated employment.[266]
Other roles of DSPs include assisting individuals to become more independent, providing caregiving and support with daily living activities (which sometimes include medication

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[264] *Supra*, n. 261 at pp. 10-11.

[265] 2021 National Core Indicators Intellectual and Developmental Disabilities: State of the Workforce Survey Report, executive summary. Each year the National Core Indicators Intellectual and Developmental Disabilities (NCI – IDD), a collaboration between the National Association of State Directors of Developmental Disabilities Services, the Human Services Research Institute, and participating state developmental disability agencies with member states to implement the State Stability Workforce Survey. In 2021, 29 states including Pennsylvania and the District of Columbia participated. All data obtained from the survey is based on the 29 participating states and their responding agencies.

[266] "Direct Support Professionals: The Importance of DSPs," *U.S. Department of Labor, Office of Disability Employment*, accessed June 27, 2023, https://www.dol.gov/agencies/odep/program-areas/individuals/DSP.

Direct Support Professionals (DSPs)

administration, mobility assistance, wound care, and accessing food), advocating for an individual's rights to services and accommodations, and providing emotional support.[267]

In residential settings, DSPs work a variety of shifts and provide a host of services. In either community residences or day programs, they assist individuals with tasks such as meal preparation, instruction on hygiene or academic skills. They often accompany individuals to doctor visits, to the bank, or on recreational activities. In some circumstances, their most basic function is to serve as a companion.[268] It is estimated that as of 2022, there were approximately 55,000 DSPs employed within Pennsylvania's intellectual disability and/or autism system.[269] Additionally, there were approximately 15,940 SSPs serving individuals in the person/family directed waiver system.[270]

Hourly Wage

Within Pennsylvania, full-time DSPs were paid an average hourly wage of $16.79, whereas part-time DSPs on average received an hourly wage of $16.99. The overall hourly pay rate for DSPs working within the Commonwealth was determined to be $16.83 as of October 2022. This $16.83 per hour wage is approximately 52 percent of a living wage for a single person with one child in the Philadelphia region of the state.[271] Pennsylvania's average hourly wage for DSPs is higher than the 2021 national average (based on a 29-state participant survey) of $14.41 per hour.[272]

Benefits Offered

DSPs within Pennsylvania have generally received benefit packages provided by their employers. According to 2022 survey data, DSP employers consistently provided employee benefits such as health care, 403(b) retirement plans, paid time off (PTO), and holidays. Some of these benefits and the percentage of agencies reporting to offer them include:

- No cost healthcare – 11.2%
- Shared cost healthcare – 89.9%
- Family healthcare – 73.0%
- Pension – 21.3%
- 403(b) or similar plans – 74.2%
- 15-plus days of PTO – 79.8%
- 7-plus days of holidays – 86.5%[273]

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[267] *Ibid*.

[268] *Supra,* n. 261.

[269] Provider Consortium, "2022 Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study," *Pennsylvania Center for Disability Information*, (2022), 13.

[270] Email from Pamela Zotynia, advisory committee member, to Commission staff, dated January 26, 2024.

[271] *Supra,* n. 269.

[272] *Supra*, n. 265 at p. 44.

[273] *Ibid*.

Residential Program Managers

Job Description/Roles

Residential program managers are responsible for the operation of large group homes or several smaller group homes for residing individuals with a disability. These managers direct front line supervisors and DSPs as they carry out their job responsibilities. According to the 2022 *Provider Consortium, Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study* (2022 Provider Consortium Study), 61 agencies within the Commonwealth reported employing a total of 767 residential program managers, with the number of managers varying by agency from 1 to 107. The study noted that this significant variation in number could suggest that agencies may be defining the position differently.[274]

Annual Salary

Residential program managers employed within Pennsylvania received an average annual salary of $52,597, as of October 2022. However, this reported average salary is unweighted, meaning that the amount decreased when the values were weighted for agency size.[275]

Benefits Offered

As is the case for DSPs, residential program managers by and large receive tangible employee benefits provided by their employing agencies. Some of these benefits and the percentage of agencies reporting to offer them include:

- No cost healthcare – 16.4%
- Shared cost healthcare – 88.5%
- Family healthcare – 75.4%
- Pension – 23.0%
- 403(b) or similar plans – 80.3%
- 15-plus days of PTO – 90.2%
- 7-plus days of holidays – 90.2%[276]

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[274] *Supra*, n. 269 at p. 17.

[275] *Ibid*.

[276] *Ibid*.

Program Directors	
Job Description/Roles	
Program directors are responsible for overseeing the overall operation of the intellectual disability and/or services program. Program directors also supervise managers. This position includes individuals who serve as residential directors and day program directors. However, this position does not include directors serving in clinical or educational areas within the system.[277]	
Annual Salary	
The average reported annual salary for program directors in Pennsylvania was $82,199, as of October 2022.[278]	
Benefits Offered	
The benefits and the percentage of agencies reporting to offer said benefits to program directors throughout the Commonwealth include:	- No cost healthcare – 14.3% - Shared cost healthcare – 90.5% - Family healthcare – 78.6% - Pension – 22.6% - 403(b) or similar plans – 75.0% - 15-plus days of PTO – 92.9% - 7-plus days of holidays – 90.5%[279]

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[277] *Ibid*., 17-18.
[278] *Ibid*., 18.
[279] *Ibid*.

Front Line Supervisors

Job Description/Roles

Front line supervisors are often described as being the individuals that monitor and oversee the daily operation of a program providing direct services and supports to individuals with a disability. These supervisors will usually have direct supervision over DSPs. The front line supervisor is also typically responsible for at least one home or program area. Seventy-seven agencies who responded to the 2022 Provider Consortium Study reported employing a total of 2,018 frontline supervisors in Pennsylvania.[280]

Hourly Wage

The average hourly wage for front line supervisors was calculated to be higher than that of DSPs at $21.25. The 2022 Provider Consortium Study indicated that this figure is roughly 66 percent of the $32.41 living hourly wage for a single adult with one child living in Philadelphia.[281]

Benefits Offered

Agencies in Pennsylvania generally offer benefits packages to their frontline supervisors. The 2022 *Provider Consortium Study* reported that these benefits and the percentage of agencies reporting to offer them to their front line supervisors include:

- No cost healthcare – 13.0%
- Shared cost healthcare – 92.2%
- Family healthcare – 80.5%
- Pension – 22.1%
- 403(b) or similar plans – 85.7%
- 15-plus days of PTO – 92.2%
- 7-plus days of holidays – 90.9%[282]

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[280] *Ibid*., 16.
[281] *Ibid*., 16.
[282] *Ibid*.

Care Coordinators	
Job Description/Roles	
Professionals who serve as care coordinators are responsible for coordinating the provision of supports and services for individuals with a disability. Sometimes, these personnel are referred to as program specialists, case managers, supports coordinators, or social workers. The 2022 Provider Consortium Study reported that 59 agencies within Pennsylvania indicated that they employe a total of 818 care coordinators.[283]	
Average Salary	
As of 2022, the average annual salary for a care coordinator in Pennsylvania was reported to be $44,641.[284]	
Benefits Offered	
Like other professionals mentioned, care coordinators in Pennsylvania generally receive employer-provided benefits packages. It was reported that these benefits and the percentage of agencies reporting to offer them to these coordinators in 2022 include:	- No cost healthcare – 8.5% - Shared cost healthcare – 91.5% - Family healthcare – 78.0%Pension – 20.3% - 403(b) or similar plans – 78.0% - 15-plus days of PTO – 91.5% - 7-plus days of holidays – 91.5%[285]

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[283] *Ibid*., 18.
[284] *Ibid*.
[285] *Ibid*., 19.

Professional Staff

Roles/Positions

Professional staff who provide care and assistance to children with intellectual disability, such as down syndrome or autism spectrum disorder (ASD), can encompass several specific professional positions. For example, common provider types commonly involved in providing care to children with ASD include child psychiatrists, pediatricians and primary care providers, child psychologists, social workers, behavioral analysis therapists, speech therapists, occupational therapists, physical therapists, and mental health counselors.[286] These professionals are typically individuals who hold professional licenses.[287]

Average Salary

Since the positions of professional staff vary, so do the average annual salaries for these positions. The 2022 Provider Consortium Study reported that the average annual salaries for professional staff personnel in Pennsylvania, as of 2022 are as follows:

Professional	*Average Salary*
Psychiatrist	$281,483
Nurse Practitioner	125,840
Psychologist	98,276
Nurse RN	81,408
Physical Therapist	78,121
Occupational Therapist	71,076
Speech Therapist	70,409
Board Certified Behavioral Analyst	67,212
Teacher	54,743
Nurse LPN	54,320
CAN or Medical Staff	35,695

Source: Provider Consortium, "2022 Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study," *Pennsylvania Center for Disability Information*, (2022), p. 19.

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[286] Ryan McBain, PhD, MPH; Vishnupriya Kareddy, BS; Jonathan H. Cantor, PhD; *et al.*, "Systematic Review: United States Workforce for Autism-Related Child Healthcare Services RH = US Health Workforce for Autism Care: A Review," *Journal of American Academy of Child Adolescence Psychiatry* 59, No. 1 (Jan. 2020): 113-139, DOI: 10.1016/j.jaac.2019.04.027.

[287] *Supra*, n. 269, p. 19.

Other Personnel
Job Description/Roles
Job coaches also work within the intellectual disability and/or autism workforce. They help individuals with a disability find employment and prepare for their jobs. These professionals also provide on-site support to help individuals adjust at work. Job coaches may also work for the employers as their on-site agents. Job coaches typically earn more than DSPs and usually have a bachelor's or associate degree. It should be noted that DSP roles have expanded in recent years to include assisting individuals with a disability in finding gainful employment.[288] There are also many other personnel within the workforce, many of which hold a variety of business support positions. These positions include human resources workers, billing staff, food service workers, and facility maintenance workers.
Average Salaries
According to the 2022 Provider Consortium Study, the average annual salary for these positions varies significantly in Pennsylvania, with food service staff earning on average, $36,200 per year and human resources and employee relations staff earning on average, $62,710 per year. The workforce also includes professionals who work in quality, performance, and regulatory compliance positions. These professionals are less numerous within provider agencies; the 2022 study suggested that there is an average of two or three of these professionals per provider or agency. The study also reported that the model salary range for these positions was between $50,000 and $75,000.[289]

Challenges

Though the service system has had a tumultuous history, progress has been made to improve the quality of care and daily lives of individuals with disability. This progress has been the product of persistent advocacy, litigation to secure individual rights, deinstitutionalization, federal legislation, transparency, and the crafting of research and evidence-based practices. However, problems within the system persist. One notable problem is staffing shortages and high turnover rates plaguing employers and agencies within the service system. The absence of qualified workers has led to the closing of community programs across the country. Moreover, many individuals residing in smaller residences have had to relocate to larger congregate facilities or even back home with their aging parents. Waiting lists remain pervasive and many providers are seeking to increase the size of their existing programs or to consolidate them.[290]

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[288] *Ibid*.
[289] *Ibid*., 21.
[290] *Supra*, n. 263 at p. 2.

This growing workforce crisis was exacerbated in the spring of 2020 by the COVID-19 pandemic. The arrival of the pandemic in the U.S. caused colossal disruptions in the American workforce. Families forewent holiday gatherings, dining out in restaurants, and participating in public activities, instead, opting to hunker down within their homes. Schools shut down and, in some areas, attempted to employ remote learning for children. Private businesses closed, and many workers either quit their jobs or began working remotely from home if the option existed. Providers of essential healthcare services, including provider services, largely remained open. However, most day programs were forced to close or substantially reduce their number of offered services.[291]

A 2021 survey reported that approximately 50 percent of community-based providers within the Commonwealth reduced their services. Turnover of DSPs caring for individuals with a disability increased during the pandemic from 32 percent in 2019 to 55.5 percent in 2021 (prorated from a three-month window), while their vacancies increased from 19 percent in 2019 to 23 percent in 2021. Alternatively, it was reported that 68 percent of surveyed DSPs stated that they were working more hours during the pandemic, with 50 percent of respondents indicating their programs were understaffed. The understaffing was so pervasive, 77 percent of provider agencies within Pennsylvania were requiring their senior management officials to work as DSPs during the height of the pandemic.[292] Today, agencies providing services within Pennsylvania are still struggling with recruitment and retention as evidenced by high levels of turnover and vacancies among its employees and positions.

High turnover, short tenure, and soaring vacancies have been reoccurring issues within the workforce year after year. Each of these can exact a negative impact on the provider workforce for individuals with a disability. They disrupt organization operations, aggravate already long waiting lists for those who desperately need care, and generate higher costs to organizations constantly stuck in a reoccurring recruitment, screening, and training cycles. They can also adversely impact the quality of care provided to individuals with disability, especially children who need structure and consistency. High turnover, short tenure, and abundant vacancies are occurring among all the different service positions to varying degrees and compound the growth of wait lists for services.

Direct Support Professionals

<u>Turnover</u>. A common metric used to illustrate the increasingly anemic intellectual, developmental disability, and autism workforce is DSP turnover. DSPs are viewed as "the backbone of the field" and "represent the core and vast majority of the workforce."[293] As such, there is generally more data on their work patterns. For instance, the Commission was able to obtain data on the average tenure of a DSPs in Pennsylvania but was unable to find similar tenure data for other job categories within the Commonwealth's system. Across the country, pre-pandemic turnover rates among DSPs were over 40 percent between 2014 and 2020. See Chart 1.

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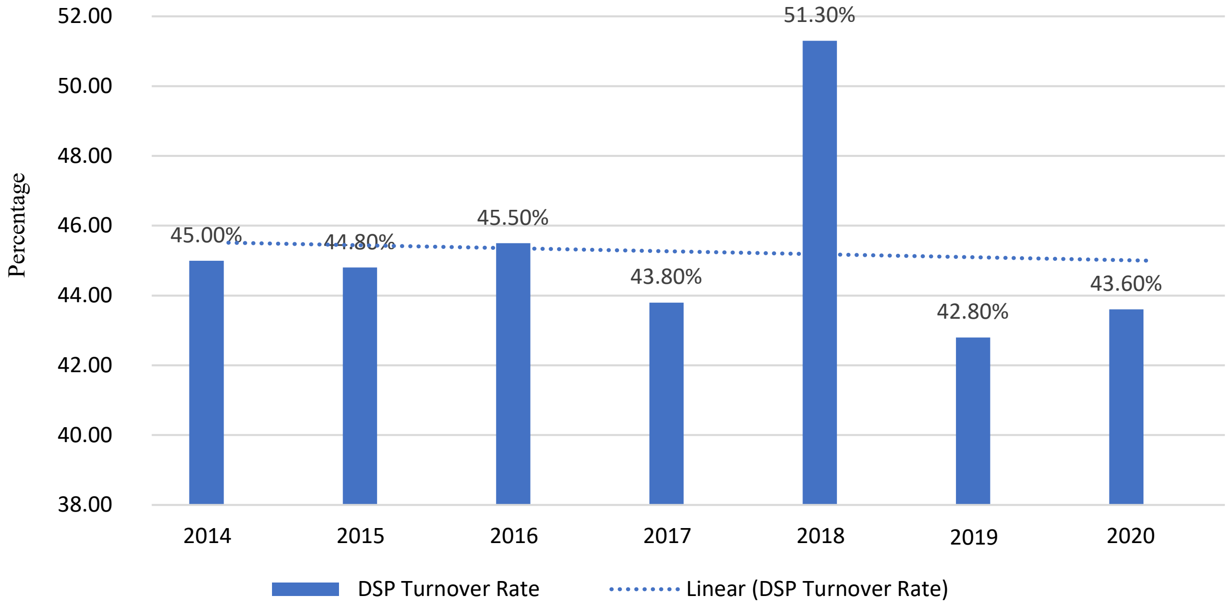
[291] *Supra*, n. 263.

[292] *Supra*, n. 269, p. 3.

[293] "Provider Workforce Challenges to Serving Individuals with Developmental Disabilities," *National Association of County Behavioral Health & Developmental Disability Directors*, accessed August 26, 2022, https://www.autism-society.org/wp-content/uploads/2018/04/IDD-BRIEFING-Workforce-challenges-Final-2.22.18.pdf.

Chart 2

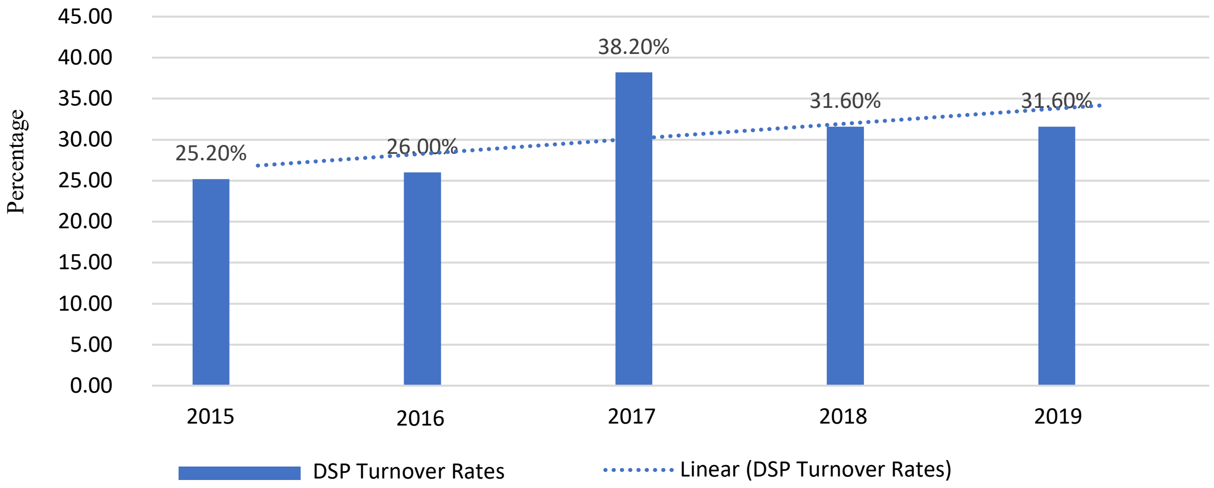
DSP Turnover
U.S.
2014-2020



Source: Provider Consortium, "2022 Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study," *Pennsylvania Center for Disability Information*, (2022).

Chart 3

Annual DSP Turnover
Pennsylvania
2015-2019



Source: Provider Consortium, "2022 Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study," *Pennsylvania Center for Disability Information*, (2022).

When compared to 29 other states surveyed in the 2021 NCI Report Pennsylvania's DSP turnover rate of 40.7 percent (during the pandemic) was just slightly below the 29-state average of 43.3 percent as shown below in Table 1.

Table 5

STATE DSP TURNOVER RATES
2021

1. Wyoming	59.0%
2. North Dakota	54.7
3. Delaware	53.7
4. Connecticut	52.8
5. Tennessee	52.0
6. Alabama	52.0
7. Missouri	51.8
8. Utah	51.2
9. South Dakota	50.7
10. Indiana	50.6
11. Nebraska	50.2
12. Colorado	49.9
13. Wisconsin	49.9
14. Oregon	47.4
15. South Carolina	44.8
16. Illinois	44.8
17. Georgia	44.3
18. Kentucky	44.2
19. Arizona	42.3
20. Alaska	41.5
21. Louisiana	41.4
22. Pennsylvania	**40.7**
23. New York	38.3
24. New Jersey	37.9
25. Florida	36.9
26. Maryland	34.6
27. North Carolina	32.8
28. Massachusetts	31.4
29. District of Columbia	28.5
Average	**43.3**

Source: *2021 National Core Indicators Intellectual and Developmental Disabilities: State of the Workforce Survey Report* (NCI IDD, 2021), 29.

The 2022 Provider Consortium Study reported that based on 101 survey-responding agencies within Pennsylvania, 5,368 full-time DSPs and 1,660 part-time DSPs left their employment. According to the study, these figures would translate to an overall DSP turnover rate of 35.7 percent (33.8 percent and 43.9 percent for full-time and part-time DSPs, respectively) throughout the Commonwealth.[294]

Tenure. Another metric that can be used to illustrate the severity of the staffing shortages in the workforce is the average tenure or length of employment of DSPs. In other words, the short duration of employment for DSPs has been used to highlight the inability of service providers and programs to retain members of their workforce after hire. According to the 2021 NCI Report, only slightly more than 50 percent of the DSPs within the 29 states surveyed remained a DSP for their provider or agency for more than two years after hire. The survey broke down the tenure of DSPs in six separate durational increments as illustrated below in TABLE 2 and TABLE 3 which show the 29-state average tenure and Pennsylvania average tenure, respectively. As shown in the tables, the Commonwealth's tenure among DSPs percentages is comparable to the 29-state survey average.

Table 6

Tenure Among DSPs Employed as of December 31, 2021
(29-State Survey Average)

Duration	Less than 6 months	6-12 months	12-24 months	24-36 months	More than 36 months
Percentage	18.0%	15.4%	15.5%	11.7%	39.4%

Source: *2021 National Core Indicators Intellectual and Developmental Disabilities: State of the Workforce Survey Report* (NCI IDD, 2021), 32.

Table 7

Tenure Among DSPs Employed in Pennsylvania as of December 31, 2021

Duration	Less than 6 months	6-12 months	12-24 months	24-36 months	More than 36 months
Percentage	16.5%	14.9%	15.7%	11.6%	41.3%

Source: *2021 National Core Indicators Intellectual and Developmental Disabilities: State of the Workforce Survey Report* (NCI IDD, 2021), 32.

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[294] *Supra*, n. 269 at p. 13.

Vacancies. According to the 2021 NCI Report, the vacancy rate for full-time and part-time DSPs in Pennsylvania was 15.6 percent and 23.5 percent, respectively. The national vacancy rate averages among the 29 states surveyed in the report was 16.5 percent for full-time DSPs and 20.3 percent for part-time DSPs.[295] The 2022 Provider Consortium Study reported higher vacancy rates for 2022. The study's survey found that Pennsylvania had 19 percent and 44 percent vacancy rates for full-time and part-time DSPs, respectively.[296]

Residential Program Managers

Turnover. According to the 2022 Provider Consortium Study who received responses from 61 agencies throughout Pennsylvania, 145 residential program managers departed from their agencies during the 2021 fiscal year, representing an annual turnover rate of approximately 19 percent.[297]

Vacancies. These same agencies cited in the study also reported 71 residential program manager vacancies which amount to an eight percent vacancy rate as of October 2022.[298]

Program Directors

Turnover. The turnover rate of program directors in Pennsylvania agencies is lower than that of DSPs and residential program managers. For the 2021 fiscal year, approximately 14 percent of program directors separated from their employer agency.[299]

Vacancies. As of October 2022, it was reported that there was an eight percent vacancy rate for program director positions.[300]

Front Line Supervisors

Turnover. According to respondent 77 service agencies who employ front line supervisors, 436 front line supervisors left their employment within the 2021 fiscal year. This figure of 436 would amount to a 22 percent turnover rate for front line supervisors working within Pennsylvania.[301]

Vacancies. According to the same responding agencies, there were a total of 198 vacant positions within these agencies collectively at the time of the 2022 survey. This figure translates to a nine percent vacancy rate.[302]

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[295] *Supra*, n. 265at p. 41.
[296] *Supra*, n. 269 at p. 13.
[297] *Ibid*., 17.
[298] *Ibid*.
[299] *Ibid*., 18.
[300] *Ibid*.
[301] *Ibid*., 16.
[302] *Ibid*.

Care Coordinators

Turnover. Of 189 responding service agencies within Pennsylvania, it was reported that 189 care coordinators left their employment during the 2021 fiscal year, which amounted to an annual turnover rate of 23 percent.[303]

Vacancies. As of October 2022, 66 care coordinator positions remained vacant, translating to a seven percent vacancy rate for the position within Pennsylvania.[304]

See Table 8 for a comparison of the turnover and vacancy rates by position based on the 2022 Provider Consortium Study.

Table 8
Turnover and Vacancy Rate Comparison by Job Category
(2021 and 2022, respectively)

Job Category	Turnover	Vacancy
Direct Support Professionals	35.7%	31.5%
Care Coordinators	23	7
Front Line Supervisors	22	9
Residential Program Managers	19	8
Program Directors	14	8
PA State Average	2.1 (as of Aug. 2021)	6.7 (as of Dec. 2022)

Source: Compiled by the Commission from data found in the Provider Consortium, "2022 Pennsylvania Direct Support Professional & Frontline Supervisor Compensation Study," *Pennsylvania Center for Disability Information*, (2022), pp. 13-18; Aimee Picchi, "3 States Lead the U.S. in the Rate of Workers Quitting Their Jobs," *CBS News*, (Oct. 25, 2021), https://www.cbsnews.com/news/quitting-job-great-resignation-georgia-kentucky-idaho/, last accessed July 5, 2023; U.S. Bureau of Labor and Statistics, "Pennsylvania Job Openings and Labor Turnover – December 2022, https://www.bls.gov/regions/mid-atlantic/news-release/Jobopeningslaborturnover_pennsylvania.htm, last accessed July 5, 2023.

NOTE: The DSP percentages are averages of the full-time and part-time turnover and vacancy percentages.

As Table 4 above illustrates, the numbers of turnover and job vacancies for service workers are higher than the state average. Turnover rates are significantly higher, especially among DSPs, which comprise the largest portion of the workforce. Though vacancy rates for positions (excluding DSPs) are higher than the state average, they are closer in size. However, it is worth noting that these positions account for smaller portions of the workforce.

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[303] *Ibid.*, 18.
[304] *Ibid.*

Worker Supply and Demand

One contributing factor aggravating the intellectual, developmental disability, and autism workforce shortages is the demographic shifts occurring not just in Pennsylvania, but across the country. For instance, there is an inadequate number of individuals entering the workforce to keep pace with the increasing demand for services. While the supply of DSPs in the workforce has increased, the increase has fallen short of the needed demand. Some of this is attributable to a decline in population growth and increase in the number of Americans entering retirement age (some individuals of which require support services). According to the U.S. Census Bureau's 2020 Census, one in six people in the U.S. were aged 65 years or older.[305] As of 2022, one in seven people in the U.S. were over 65.[306] The number of senior individuals participating in the workforce was expected to grow in the U.S.[307] In 2021 Bureau of Labor and Statistics (BLS) projected the number of individuals aged 75 years and older in the workforce was expected to grow 96.5 percent by 2030. However, the number of individuals from younger age groups participating in the workforce was expected to either drop or remain stagnant.[308]

To illustrate, the BLS is projecting the labor force participation rate for people aged 16 and older to decline, from 61.7 percent in 2020 to 60.4 percent in 2030. According to the BLS, the labor force participation rate for individuals between the ages of 16 and 24 is projected to drop from 53.9 percent in 2020 to 49.6 percent in 2030. Moreover, the rate for people between the ages of 25 and 54 is projected to remain steady. The rate for people ages 55 to 74 is projected to decrease marginally. The only age group with a labor force participation rate projected to rise are people 75 and older, from 8.9 percent in 2020 to 11.7 percent by 2030.[309] See Chart 3.

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[305] Zoe Caplan, "2020 Census: 1 in 6 People in the United States were 65 and Over, (March 25, 2023)," *United States Census Bureau*, accessed July 10, 2023, https://www.census.gov/library/stories/2023/05/2020-census-united-states-older-population-grew.html.

[306] *Supra*, n. 263 at p. 6.

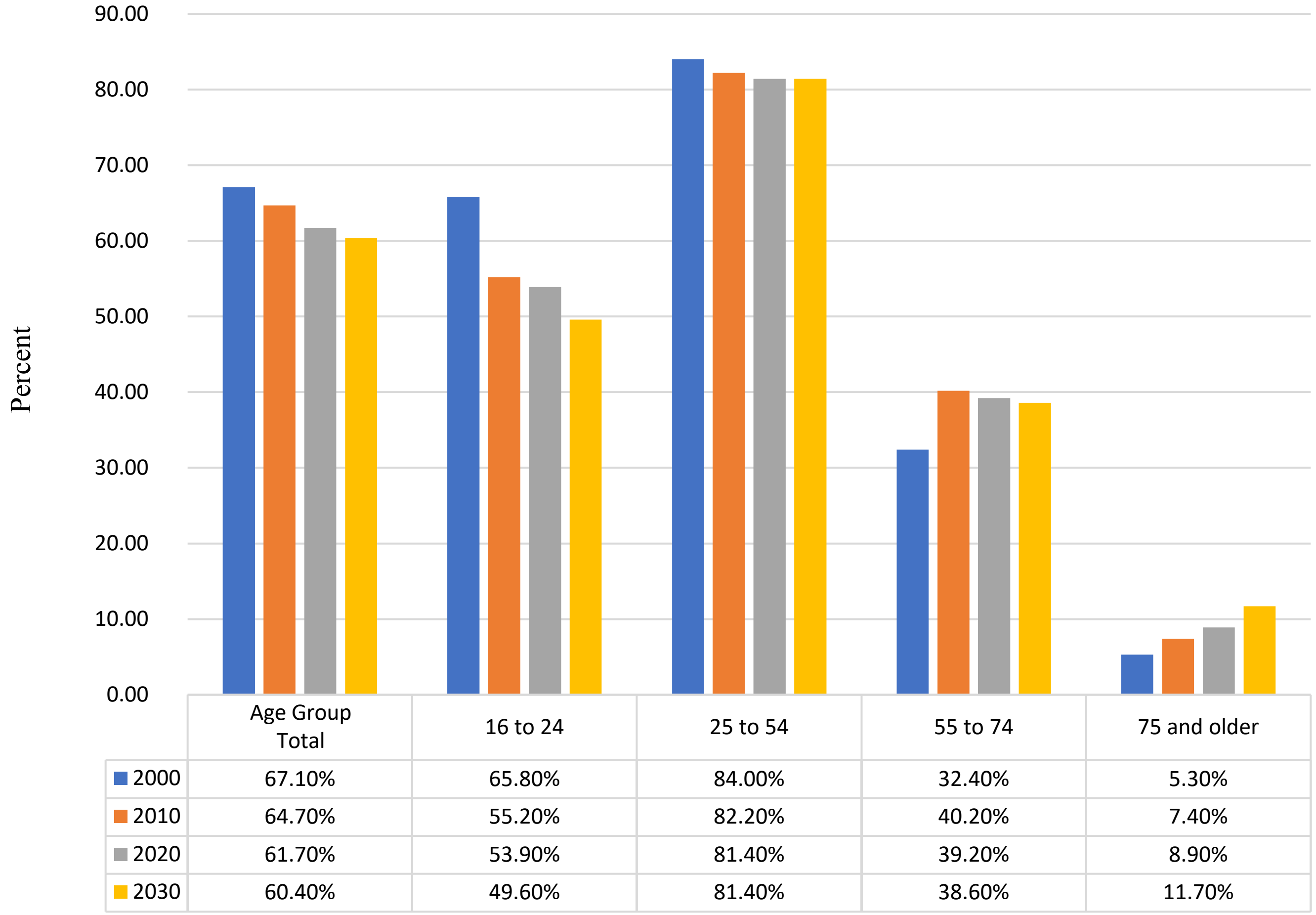
[307] *Supra*, n. 305.

[308] "Number of People 75 and Older in the Labor Force is Expected to Grow 96.5 Percent by 2030," *U.S. Bureau of Labor and Statistics*, accessed July 10, 2023, https://www.bls.gov/opub/ted/2021/number-of-people-75-and-older-in-the-labor-force-is-expected-to-grow-96-5-percent-by-2030.htm.

[309] *Ibid*.

Chart 4

Percent Civilian Labor Foce Participation Rates
by Age
U.S.
2010, 2020, and Projected 2030



	Age Group Total	16 to 24	25 to 54	55 to 74	75 and older
🟦 2000	67.10%	65.80%	84.00%	32.40%	5.30%
🟧 2010	64.70%	55.20%	82.20%	40.20%	7.40%
⬜ 2020	61.70%	53.90%	81.40%	39.20%	8.90%
🟨 2030	60.40%	49.60%	81.40%	38.60%	11.70%

Source: Number of People 75 and Older in the Labor Force is Expected to Grow 96.5 Percent by 2030," *U.S. Bureau of Labor and Statistics*, accessed July 10, 2023, https://www.bls.gov/opub/ted/2021/number-of-people-75-and-older-in-the-labor-force-is-expected-to-grow-96-5-percent-by-2030.htm.

Smaller numbers of younger individuals entering the workforce (and the workforce more specifically) will aggravate the inability to keep up with the increasing need for services, which is occurring in large part, because individuals with disability are living longer and thus need supports for longer periods of time. These younger age groups are needed to match the physical and mental demands of working in the service system. However, the staffing needs are going unmet. It was estimated that another 117,000 full-time equivalent DSPs are needed to fill known vacancies nationally.[310]

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[310] *Supra*, n. 269 at p. 7.

The fact remains, slower growth in the number of new and younger workers entering the labor force will continue to have a negative effect on the supply of workers, especially with home- and community-based services for individuals with a disability.

Skills-Gap

As is evidenced by the data, the system workforce is shrinking mainly due to the shifting demographics mentioned above. However, the issue is more than just a lack of workers. There is also an incongruity between the skills of workers willing to enter the workforce and the requirements of the job. In other words, there is a noticeable skills-gap necessary for the job, among individuals who may be willing to work. Employers hiring for entry-level positions find it increasingly difficult to recruit workers with some of the most basic work-readiness skills, such as understanding the importance of reliability, self-direction, being prompt, dressing appropriately, workplace etiquette, and use of appropriate language. As society has evolved to rely more heavily on technology, many workers no longer have direct supervision by professionals, which has led to a lack of some of these basic skills. Today, individuals often work with minimal supervision and peer supports, and need greater technical and problem-solving skills and initiative.[311]

It has also been suggested that there are inadequate and inconsistent training and competency requirements for DSPs, not only in Pennsylvania, but nationwide. Personal care assistants and nursing assistants have defined federal training and competency requirements. For instance, nursing assistants must undergo a 75-hour pre-service education requirement. Alternatively, DSPs have no federal training requirements, though they often need to be versed in similar skills. Without any federal requirements, DSP training requirements vary by state, with states typically requiring around 40 hours of post-hire training.[312]

Low Compensation

The issue of high turnover among workers has also been linked to low compensation. As mentioned previously, DSPs account for the largest number of workers within the intellectual, developmental disability, autism workforce. Currently in Pennsylvania, their average hourly pay rate is just above $16 per hour. In certain parts of the Commonwealth like the Philadelphia region, this amounts to a little over half of a living wage, especially if the worker is single and has children or dependents. This average hourly pay rate is lower than both the state and federal averages. By way of comparison, the median wage in Pennsylvania was $18.16 per hour in 2022. Nationally, it was $18.00 per hour.[313]

Many individuals who begin employment as a DSP and see the challenges and intensity that comes part and parcel with caring for individuals with a disability begin to recognize they can find more financially lucrative employment and less intense working environments with other

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[311] Diane Winiarski, "Employers Stuck with a Skills Gap? It's Time to Reimagine Workplace Learning," *Forbes*, last modified April 18, 2023, https://www.forbes.com/sites/dianewiniarski/2023/04/18/employers-stuck-with-a-skills-gap-its-time-to-reimagine-workplace-learning/?sh=2fe635333e39.

[312] *Supra*, n. 263 at p. 3.

[313] Pennsylvania Department of Labor, *Analysis of the Pennsylvania Minimum Wage* (Center for Workforce Information and Analysis, March 2022), 3.

employers and in other fields. It is also worth noting that the roles and responsibilities of DSPs are expanding, making the job more challenging and requiring a bigger skill portfolio in large part due to the shift from congregate care to home- and family-based services. Increasing work requirements compensated for an hourly wage lower than both the state and federal averages cause many DSPs to rethink their line of work.[314]

DSPs also consistently receive lower average wages than other direct care professionals, some of whom work outside the service system. For example, nurses and nursing assistants generally have higher pay levels than DSPs. This disparity can lead many DSPs to leave their positions to pursue education to eventually move into nursing positions. These job shifts are especially likely with recent high inflation, which as of April 2022 had reached 8.2 percent. Inflation of this size makes it even harder for DSPs and other care workers earning already-low hourly wages to afford essential living expenses. Consequently, agencies have been unable to increase DSP wages enough to counter inflation without increased service rates set by state and federal governments.[315] Support Services Professionals (SSPs) generally are employed by individuals with community living or P/FDS waiver funding, which have annual caps. Additionally, they may be only one of a handful of employees of a particular individual with disability. The caps and the limited number of employees employed by any one individual with disability make it more difficult for these employees to be offered or receive benefits such as health insurance.

House Bill 1135 (Printer's No. 1193) was referred to the House Labor and Industry Committee on May 10, 2023. The bill increased the state minimum wage over time. To the extent increased wages have the effect of assisting individuals to no longer need public welfare programs, the savings realized by the Department of Human Services are to be used to provide increases to childcare providers, direct care workers, and for home and community-based services.

Increase in Behavioral Challenges

There has been a documented increase in behavioral challenges among individuals with a disability in need of services. The number of people with complex disability living and working in their choice of communities and neighborhoods cared for by DSPs has increased as fewer individuals choose to live in large congregate settings. More specifically, the proportion of individuals with behavioral challenges in these groups has more than doubled from 15 percent in 2012 to 31 percent in 2019. In addition, the proportion of these same individuals afflicted with anxiety disorders receiving care from DSPs in the community grew from 14 percent to 29 percent within the same period, and the proportion afflicted with mood disorder increased from 23 percent to 31 percent. Furthermore, NCI data found that, based on a national sample of respondents, 67 percent of the individuals with a disability cared for by DSPs within the community require 24-hour supervision and support or at least daily support.[316]

To illustrate the wide array of health and behavioral issues many of these individuals and the needs and supports they require, see Chart 4.

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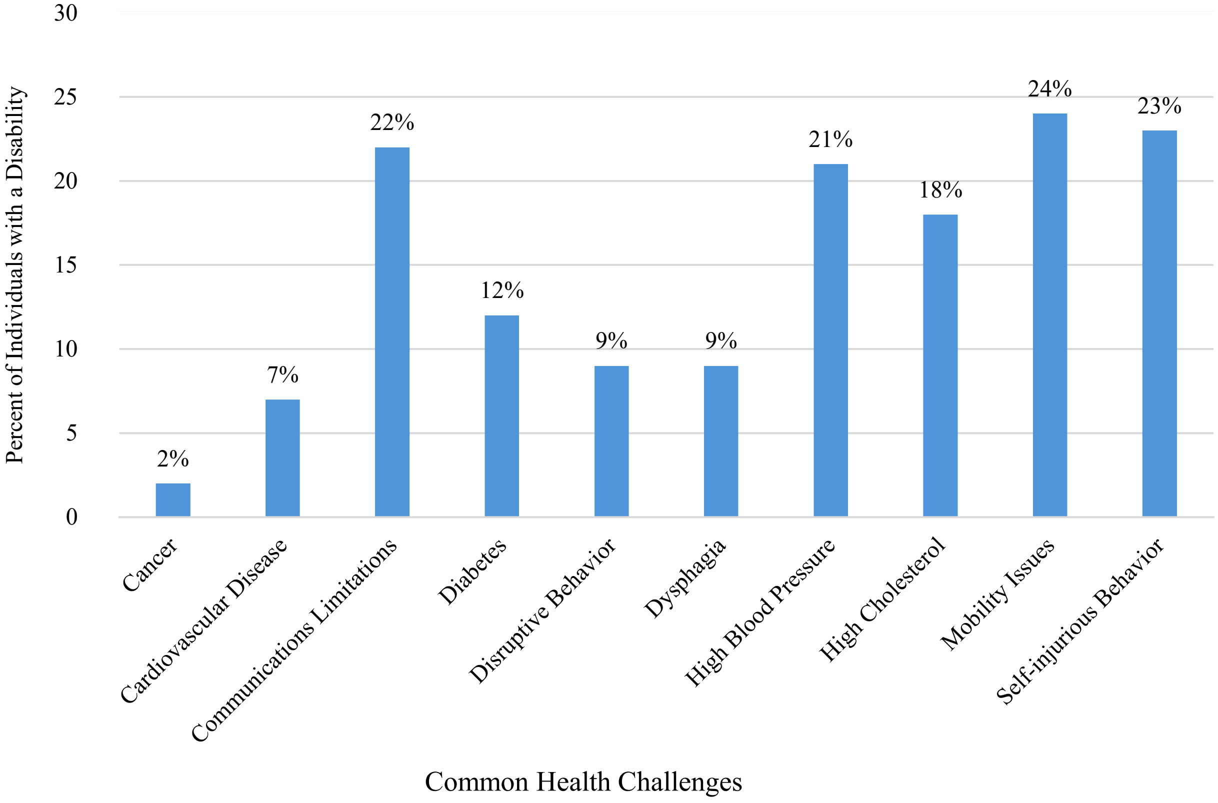
[314] *Supra*, n. 263 at p. 3.
[315] *Ibid*., 7.
[316] *Ibid*., 4.

Chart 5

Individuals with a Disability
Common Health Challenges
US
2021



Source: Julie Bershadsky, PhD, Amy Hewitt, PhD, Valerie Bradley, MA, *et al.*, "Community Supports in Crisis: No Staff, No Services," *National Association of State Directors of Developmental Disabilities Services, Human Services Institute*, and *Institute of Community Integration, University of Minnesota*, (June 2022), 1. Note: *Dysphagia* is the inability to swallow.

This broad range of health challenges facing individuals with a disability requires DSPs to master a wide range of skills, knowledge on behavioral, medical, and social engagement; relationship building, and quick decision-making. However, they continue to be compensated at low levels, which many believe to be inadequate for all that is expected within their job responsibilities.[317]

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[317] *Ibid*.

Increase in One-to-One Coverage

Structural changes within the service system have also put added stress on its workforce. One key example of this is what is referred to as the Centers for Medicare and Medicaid Services Settings Rule. The Settings Rule "provided additional impetus for the deconstruction of larger residential and services."[318] The rule has ignited a "more individualized and person-centered approach…in keeping with a consensus in the…field about how to enhance quality of life but requires more one-to-one coverage and less group support, which requires more staff."[319]

Burnout

Job burnout, especially among DSPs, is another cause of high turnover and instability within the workforce. The term "burnout" has varied since its inception. The World Health Organization defines "job burnout" as a "syndrome resulting from chronic workplace stress that has not been successfully managed."[320] As mentioned in the Commission's 2020 staff study *Pennsylvania Mental Health Care Workforce Shortage: Challenges and Solutions*, a plurality of researchers have favored the definition initially developed by University of California – Berkeley professor Christina Maslach and Rutgers University professor Susan E. Jackson. According to Maslach and Jackson, the term "burnout" refers to a "psychological syndrome emerging as a prolonged response to chronic interpersonal stressors on the job."[321] Prolonged responses under this definition include overwhelming exhaustion, feelings of cynicism and detachment from the job, a sense of ineffectiveness and lack of accomplishment or any combination thereof.[322]

Job burnout is a contributing factor in turnover of DSPs. The emotionally and sometimes physically taxing and demanding aspects of a DSP's job increases the likelihood of burnout and turnover rates. Many DSPs burnout stems from inadequate job instruction, limited support, and role confusion.

Such phenomenon is not limited to DSPs in the U.S. A 2021 study from the *Scandinavian Journal of Caring Sciences* surveyed over 100 DSPs who cared for adults with autism spectrum disorder and intellectual disability daily. Based on the survey results, the study found that five percent of DSPs were in a state of burnout, while 18 percent showed high average scores of emotional exhaustion. In addition, the study found that six percent had high average scores for depersonalization, and 59 percent demonstrated high scores for loss of a sense of personal accomplishment.[323]

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[318] *Supra*, n. 263 at p. 7.

[319] *Ibid*.

[320] "Burn-Out an 'Occupational Phenomenon': International Classification of Diseases," *World Health Organization*, last modified May 28, 2019, https://www.who.int/news/item/28-05-2019-burn-out-an-occupational-phenomenon-international-classification-of-diseases.

[321] JSGC, *Pennsylvania Mental Health Care Workforce Shortage: Challenges and Solutions*, (2020), 59 *citing* Ian J. Deary, Raymond M. Agius, Andrew Sadler, "Personality and Stress in Consultant Psychiatrists," *International Journal of Social Psychiatry* 42, No. 2 (Jun. 1996), https://doi.org/10.1177/002076409604200205.

[322] *Ibid*; Christina Maslach and Michael P. Leiter, "Understanding the Burnout Experience: Recent Research and its Implications for Psychiatry," *World Psychiatry* 15, No. 2 (Jun. 2016): 103-111.

[323] Sylvie Couderc, PhD, Florence Cousson-Gelie PhD, Eric Pernon PhD, *et al.*, "Burnout Among Direct Support Workers of Adults with Autism Spectrum Disorder and Intellectual Disability," *Scandinavian Journal of Caring Sciences* 37, No. 1 (June 2021): 131-140, https://doi.org/10.1111/scs.13008.

A 2017 Australian study surveyed disability support workers on their job experiences and found that many workers identified rewarding aspects of their jobs, such as watching a client learn and develop new skills and being shown appreciation. However, many of these same survey participants also indicated that such uplifting moments were sharply contrasted by emotionally and physically draining aspects of their work. Some examples of this include challenging client behavior, earning low income, and having limited power to make any decisions. Survey participants also indicated that a lack of job support left many of them to their own devices and strategies as to how to manage their stress on the job. Many participating workers explained that the negative job aspects cumulatively outweighed the positives.[324]

Impact

While much of the impact stemming from the workforce challenges is reflected in the data discussed at length above, there are a few points worth reiterating. Staff shortages continue to lead to home care agencies having to carefully limit who they serve. Oftentimes, they must provide services only to aged adults living alone and lack the ability to provide care to children who live with their family. This results in financial strain for working class families who must consider leaving their jobs to provide adequate support to their struggling children.[325] As noted previously, some agency providers have even closed, permanently. When services become limited or shutdown, individuals with a disability in need of supports and services are relocated. Relocations can negatively impact individuals who thrive with consistency and the familiarity they enjoyed in their previous environment and with their previous care professionals. These care professionals are also familiar with the individuals they have been caring for and all their unique qualities and needs. Shuffling them around due to closures and staffing limitations can severely diminish their quality of life and care and can force them to be relocated further away from their family members and siblings.

If services are not immediately available for an individual, oftentimes parents or family members must work to find them a suitable location that can meet their needs. Sometimes they must take care of the individual themselves. Many times, in these circumstances, older parents facing their own health problems must care for their adult children who have needs. One report found that 67 percent of family members with an adult individual with a disability living at home were over 55 and 12 percent were 75 or older.[326]

To mitigate the staffing shortages within the services workforce, attention must be directed at improving worker salaries, especially among DSPs. There must also be a focus on bridging the skills gap through adequate training requirements and credentialing. Provider agencies must also have the resources to provide effective job support for DSPs and other workers to help counter the soaring rate of burnout among their employees.

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[324] Megan J. Judd BPysch MPsych, Kate P. Dorozenko BPsych(Hons) PhD, Lauren J. Breen BSc(Hons) GadCertEd PhD, "Workplace Stress, Burnout and Coping: a Qualitative Study of the Experiences of Australian Disability Support Workers," *Health and Social Care* 25, No. 3 (November 23, 2016): 1109-1117, https://doi.org/10.1111/hsc.12409.

[325] *Supra*, n. 263, p. 3.

[326] *Ibid.*, 6.

Recruitment and Retention Strategies

Building and maintaining workforce capacity within the service system should be a priority for addressing current workforce challenges. To build workforce capacity, providers within the service system need to find highly qualified and dedicated individuals to work as DSPs, care coordinators, program managers, and other employees. However, they also need to incentivize them to stay once they find them. Increased attention is needed on improving recruitment and retention strategies. Failing to have qualified employees, and employees who are willing to stay for long tenure negatively impacts the quality of services for individuals with a disability.

As mentioned previously, employee turnover, especially among DSPs, can be disruptive to individuals with disability receiving their support. It can impact their quality of life, and many have reported that "…lack of stable, reliable supports negatively impact peoples' sense of safety, health, participation in community life, developing and maintaining friendships and intimate relationships, being treated with fairness and respect, choice in where and with whom to live, choice in services, and others."[327] A lack of stable and consistent supports also can lead to individuals and their families to miss out on opportunities such as work and important doctor's appointments.[328] Lack of consistency can be especially harmful to individuals with Autism Spectrum Disorder, who tend to thrive on consistency and often reject frequent and unanticipated change.

The costs of turnover are not limited to the individual consumer of services. Service organizations bear significant costs of turnover related to recruitment, on-boarding, and the seemingly endless cycle of training of new employees. As of 2021, it was estimated that turnover costs to an organization were at $4,630 per exiting DSP.[329] In 2017, the services field saw turnover rates close to 50 percent annually, for an estimated total cost of $2.3 billion nationally.[330]

Increased Wages

Oftentimes, it is the wage, more than other factors, such as employer incentives, that predict staff retention.[331] If service organizations want to improve the retention and recruitment of qualified staff who will maintain their positions long-term, the wages offered must be higher. However, this is not a simple solution. Many service organizations know that DSPs are essential to their workforce. Many organizations are also aware that the best way to attract DSPs is through salary incentivization. This is why, in many cases, most of the funding directed to service providers goes to DSPs and nurses. Unfortunately, many organizations find that the salary they can afford to

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[327] Sandra L. Pettingell, James Houseworth, Renata Ticha *et al*., "Incentives, Wages, and Retention among Direct Support Professionals: National Core Indicators Staff Stability Survey," *Intellectual and Developmental Disabilities* 60, No. 2 (2022): 113-127, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10288864/.

[328] *Ibid*.

[329] *Ibid*.

[330] President's Committee for People with Intellectual Disabilities, *Report to the President 2017 America's direct support workforce crisis: Effects on people with intellectual disabilities, families, communities, and the U.S. economy*, (The Administration for Community Living, 2017), https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF.

[331] *Ibid*.

offer is grossly under competitive to many other employers in different fields, which often provide easier working environments.[332]

In-House Assistance Funds

If service organizations lack the budget to increase the wages of their care professionals, they can explore other creative ways to assist their employees financially to attract or retain them. They can consider establishing internal grant programs to help struggling employees. One example of this is KenCrest's Rod Hibbard Memorial Fund for Staff Emergencies (RH Fund). KenCrest is an organization that provides educational services and community-based supports to children and adult individuals with developmental or intellectual disability in Philadelphia.[333] The RH Fund was established by the founding director of the organization's Philadelphia Community Living program, Rod Hibbard in 1994.[334]

The purpose of the fund is to assist fellow staff members who face unexpected emergencies including fire, flood, or medical bills. Requests for emergency assistance under the fund can also include financial emergencies related to past due rent/mortgage, utilities at risk of shut-off, and critical equipment failure (e.g., heater, hot water heater, air conditioner, etc.).[335] KenCrest does not have to bear the full cost of supporting the fund through its budget. Instead, the RH Fund receives funding from several sources, including periodic fundraisers held by KenCrest. KenCrest staff can also make contributions through payroll deductions, or by participating in KenCrest. Since its inception, the fund has distributed over $355,000, granted 569 requests for assistance, and over 305 staff employees have donated to the fund since 2020.[336]

To be eligible, applicants must demonstrate a financial need where other financial resources are unavailable. The applicant must also be an employee in good standing (not on probation or administrative leave). The applying employee's supervisor must verify that the employee qualifies for the request and payment for the request is issued through the organization, to then be transmitted to the individual employee. Applications must include documentation to be considered. The RH Fund requires a six-month time frame between requests from the same individual of the same type.[337]

Improved Training and Credentialling

Professionals caring for individuals need to possess the necessary skills to competently do their job. However, in addition to earning low wages, many DSPs feel overwhelmed and undertrained for their expanding roles. When DSPs and other care providers reach this point, the

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[332] Discussions in the HR 212 Advisory Committee Meeting held on October 5, 2023.

[333] "About KenCrest," *KenCrest*, accessed November 13, 2023, https://www.kencrest.org/about-kencrest/.

[334] "Rod Hibbard Staff Emergency Fund," *KenCrest*, accessed November 13, 2023, https://www.kencrest.org/employees/rod-hibbard-staff-emergency-fund/.

[335] *Ibid*.

[336] "Rod Hibbard Memorial Fund for Staff Emergencies Deduction Form (2021)," *KenCrest*, accessed November 13, 2023, https://kencrest.wpenginepowered.com/wp-content/uploads/2021/10/Rod-Hibbard-Deduction-Form.pdf.

[337] "The Rod Hibbard Memorial Fund for Staff Emergencies: Guidelines," *KenCrest*, accessed November 13, 2023, https://kencrest.wpenginepowered.com/wp-content/uploads/2021/10/Rod-Hibbard-Memorial-Fund-Guidelines.Oct2021.pdf.

quality of care for the individual decreases and some DSPs leave to seek easier and higher paying employment elsewhere. Many service organizations provide inadequate training to DSPs, which may, in part, be linked to the fact that investing significant money and time into training an employee who is likely to become a turnover statistic does not make a lot of sense to the employer.

There is also little credentialling required for DSPs and the solution is not as simple as upgrading the qualifications. Significantly increasing the requisite qualifications could have the negative effect of shrinking an already anemic workforce by forcing certain credentialling for low-paying wages that people ultimately decide is not financially worth the trouble. Service organizations also struggle with a lot of inefficiency and retraining of people who must be moved around in different locations and positions.[338]

A focus on improving training and credentialling requirements may help mitigate high turnover by retaining the most qualified and competent individuals for the available jobs and instilling the necessary level of confidence in said individuals to make their job more rewarding. Organizations and providers should invest more in competency-based training for DSPs and other care professionals.[339] One possible resource that service organizations could utilize to improve their level of competency-based training is the Council on Quality and Leadership (CQL).

Founded in 1969, the CQL offers accreditation, training, certification, research, and consultation services to human services organizations. The CQL works to improve the quality of life for people with intellectual, developmental, and psychiatric disability.[340] CQL training allows for an intensive self-evaluation program where the provider must self-evaluate its personnel outcomes and then independent auditors review the self-evaluation to verify its authenticity. The program is very outcome oriented and has proven to be a successful tool to improve the training of provider employees and ultimately the quality of care provided to individuals with a disability.[341]

CQL provides several different types of training options. One option is organization-hosted training, where organizations can work directly with CQL to conduct customized training designed for their employees regarding the organization's unique needs. CQL also provides CQL-hosted training, where disability service professionals can receive individual training virtually or in-person. CQL also offers e-learning courses.[342]

It should be noted that consultation services through the CQL can be a significant expense and can amount to over $30,000 a year for a provider to go through the rigorous accreditation process. Though the program can be a successful tool in training service employees, there is aways risk associated with training employees and having the confidence to allow them to perform the

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[338] Discussions in the HR 212 Advisory Committee Meeting held on August 6, 2023.

[339] "Addressing DSP Workforce Challenges: Strategies for Agencies," *National Direct Support Workforce Resource Center*, accessed November 14, 2023, https://publications.ici.umn.edu/impact/20-2/addressing-dsp-workforce-challenges.

[340] "About Us," *The Council on Quality and Leadership*, accessed November 13, 2023, https://www.c-q-l.org/about-us/#more.

[341] *Ibid.*

[342] "Training," *The Council on Quality and Leadership*, accessed November 13, 2023, https://www.c-q-l.org/training/.

job duties. That necessary risk means that the trained personnel will not always perfect the training.[343]

Mandating CQL certification or accreditation would likely impose a significant financial burden on many already-struggling service organizations. However, the Commonwealth may want to consider incentivizing organizations to seek certification through programs like CQL through grants or other funding-related incentivization programs. The Commonwealth could also consider encouraging financial incentives to organizations who maintain a certain percentage of employees who obtain certification, to pass on to the certified employees.

Additionally, both The National Association for Direct Support Professionals (NADSP) Certification - NADSP and the National Association for the Dully Diagnosed (NADD) DSP Certifications - The NADD offer Direct Support Professional Specific certifications. ODP has proposed using these certifications for both DSPs and front-line supervisors as a means of professionalizing the workforce.[344]

To ensure that employees are properly trained and are performing with the level of confidence they need to be successful on the job, some organizations also perform regular check-ins with employees. These routine check-ins assess how the employee feels about the job and their ability to perform their duties. It also gives the organization an opportunity to audit their own practices as the employer and to take note of any suggestions from the employee on how they can improve their operations. Organizations can also perform employee confidence checks, which is where administrative personnel within the organization conduct planned observations of staff and conduct interviews with them to ensure the staff are confidently providing care.[345]

Peer Mentoring Programs

Another possible retention strategy to reduce turnover is to implement peer mentoring programs for DSPs. A peer mentoring program typically involves seasoned DSPs, regardless of their age or job function, assisting new or less experienced DSPs. Mentors can work and mentor other newer DSPs and help them develop skills competencies, help them socialize and assimilate to the culture of the organization, and help them learn about all major aspects of the job. A peer mentor program of this kind could be especially valuable to DSPs since many DSP employees are immigrants and may struggle with cultural differences.[346]

Newly hired DSPs are more likely to stay longer in their positions if they have more adequate support, direction, and training, all of which can be provided through mentoring. More longevity among DSP employees translates to a reduction in turnover costs to service organizations. Peer mentoring programs comprised of experienced DSPs within a service organization is often viewed as a low-cost option to achieve high quality and meaningful support

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[343] *Ibid.*

[344] Email from G.N. Janes, Advisory Committee member, to Commission staff, December 20, 2023.

[345] *Ibid.*

[346] *Supra*, n. 261.

for new employees, as opposed to hiring an outside consulting agency.[347] Mentoring programs can also improve supervisory skills, work habits, and productivity, as well as increase employee job satisfaction.[348]

The Institute on Community Integration at the University of Minnesota provides information on the Peer Empowerment Program (PEP). The PEP provides guidance for service organizations on how to plan and customize a peer mentoring program internally within an organization. The PEP toolkit also provides details on how to select, train, and sustain mentors and instructions for preparing mentees.[349] Organizations could consider availing themselves to resources like PEP to establish their own peer mentoring program.

Ease Administrative Burdens

Highly competent staff that can confidently care for their patients or clients often cannot perform the quality of care needed because they are spending significant time documenting what they have done and justifying why they did it. This can create a moral dilemma for staff which can lead to unhappiness on the job and can ultimately fuel the employee's desire to leave for different, more satisfying work. Documentation responsibilities for care professionals are important but they need to be more streamlined and efficiently addressed. Most DSPs and care professionals willing to stay long-term do so because they enjoy caring for individuals, not completing oppressive paperwork. Increased attention should be given to ensuring that care professionals can optimize their time to provide quality care to individuals who need it, while upholding the need for transparency and due diligence regarding the documentation of care.[350]

Bridging Connections between Employees

Within service organizations, there is sometimes a disconnect between administrative executives and staff as to resources necessary to adequately meet the needs of individuals. Many DSPs and other professionals tasked with providing actual care to individuals are ignored when it comes to managing the resources for an individual's care. For instance, administrative or management personnel tend to make important decisions on the number of employees needed to support the consumer population being served within the organization. The employees providing direct care to individuals are typically left out of these discussions and sometimes their volunteer input is ignored. Since DSPs directly provide care to individuals, they often have a strong knowledge and understanding of the resources required for the continued provision of high-quality care. Consequently, there needs to be a bridge built between the resources administrative executives think is needed and the input from direct care staff as to what is needed. To do so can send a message to employees that they are respected, and their input appreciated. In addition, accepting direct care staff input can lead to improved care for the individual consumer.[351]

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[347] "Peer Mentoring," *University of Minnesota, Institute of Community Integration*, accessed November 14, 2023, https://tenncare.ici.umn.edu/dsp-workforce-toolkit/retention/peer-mentoring.

[348] "Cultivating Leadership: Mentoring Youth with Disabilities," *U.S. Department of Labor, Office of Disability Employment Policy*, accessed November 14, 2023, https://www.dol.gov/agencies/odep/program-areas/individuals/youth/mentoring-youth-with-disabilities.

[349] *Supra*, n. 347.

[350] *Supra*, n. 344.

[351] *Ibid*.

Miscellaneous Recruiting and Retention Tools

There are several different recruiting and retention tools organizations are utilizing to maintain adequate staffing levels and resources. Some of these tools include the following:

- Badge-cash system for high performance.
- Career ladder system (entry level DSP to lead DSP and program manager).
- No cost health insurance.
- Intensive entry level supervisor training.
- Changed human resource model to include on-boarding specialists to ensure flexibility.
- All new hires offered partial virtual training options.
- Employee assistance program to provide virtual financial assistance advice and wellness consultation.
- Benefits for employees who must work long weekends. For example, a policy that if an employee works 24 hours in a weekend (two 12-hour shifts, they get paid higher hourly rate and receive full benefits).
- Full family leave to visit family in other country (keeps them from leaving the job entirely).
- Increased tuition reimbursement for nurses.
- Employee recognition events.
- Instilling a culture of gratitude – opening meetings while expressing gratitude to the employees.
- Raffles for employees to encourage some fun.
- Training and quizzes to employees on how facilities are funded.
- Performing impact studies on wages to employees and their lives.
- Employee listening sessions for questions.
- Trauma informed and diversity and equity inclusion efforts.[352]

Better Care Better Jobs Act

The issues plaguing the intellectual, developmental disability, and autism workforce have received some recent attention at the federal level in Congress and the Senate. In January of 2023, federal legislation known as the Better Care Better Jobs Act[353] was introduced in both the Senate and the House of Representatives. The acts are intended to expand access to home and community-based services for seniors, people with disability, and injured workers while increasing the compensation and improving benefits for the employees who provide care for these individuals.

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[352] *Ibid.*

[353] S. 100, 118th Congress (2023-2024); H.R. 547, 118th Congress (2023-2024).

The acts would enhance Medicaid funding for home care and would increase payment rates to improve the recruitment and retention of direct care professionals. The Better Care Better Jobs Act also aims to develop and update training opportunities for care professionals.[354] The bill in the House was last referred to the Subcommittee on Health on February 3, 2023, while the last action on the Senate bill was read twice and referred to the Committee on Finance on January 26, 2023.[355]

As mentioned previously, staff shortages and the underpaying of employees can lead to diminished quality of care. Diminished quality of care can even pose dangers to individual consumers. For example, understaffed and underpaid employees frequently must work multiple jobs or double shifts to afford a minimum standard of living. This scenario can lead to medical accidents due to fatigued, overworked employees coming off their second or sometimes third shift. Recruitment and retention problems have existed for a while; however, the problem is aggravating throughout the industry, and many believe it is currently worse than ever. A failure to draw renewed attention to new and innovative recruitment and retention strategies could lead to an unsustainable service system for individuals with a disability.

Legislative Proposals

House Bill 1218 (Printer's No. 1766) passed the House July 7, 2023 (109-94) and was referred to the Senate Health and Human Services Committee on July 17, 2023. The bill directs the Department of Health and Human Services to seek a waiver for CMMS to establish a program to provide, for payment of personal care services rendered to a medical assistance recipient by their spouse.

Senate Bill 874 (Printer's No. 1041) was referred to the Senate Education Committee on August 16, 2023. The bill creates a mental health and intellectual disability staff loan member forgiveness program. A staff member is defined as a caseworker, direct support professional, therapist, program coordinator or director.

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[354] *Ibid*; "Casey, Dingell Introduce Bill to Provide Historic, Permanent Investment in Home Care for Seniors and People with Disabilities," *Bob Casey U.S. Senator for Pennsylvania*, last modified Jan. 26, 2023, https://www.casey.senate.gov/news/releases/casey-dingell-introduce-bill-to-provide-historic-permanent-investment-in-home-care-for-seniors-and-people-with-disabilities.

[355] Congress.Gov, H.R. 547 Better Care Better Jobs Act, "Actions," S. 100 Better Care Better Jobs Act, "Actions."

PROGRAM AND PROVIDER ACCOUNTABILITY

Several tools exist to ensure that county MH/ID programs and providers properly administer the services that have been entrusted to them.

ISP Monitoring Tool

In Pennsylvania, an Individual Support Plan (ISP) is a detailed plan pertaining to an individual with intellectual disability' needs and areas of interests that directs all those supporting the individual to focus on. The ISP is developed through a Person-Centered Planning Process (PCP) and collects information on an individual's preferences, desires, medical history, current medical concerns, and communication preferences.[356] The PCP is a process for selecting and organizing needed services for individuals with a disability to live in the community. The process is directed by the person who receives the support.[357]

The ISP process is a key component in helping people develop strategies to achieve the life they desire to lead. Supports coordinators (SCs) lead the process and help individuals with intellectual disability explore the experiences, opportunities, and resources available to them through family, friends, and their community. To be effective, it is advised the process be conducted in plain language and in a manner accessible to the individual receiving services and their family. SCs must be sensitive to the lived experience of the individual and family including cultural considerations. If an alternate means of communication is needed or if the individual does not speak English, the ISP process should utilize the individual's primary means of communication or someone who can interpret on their behalf. [358]

The Individual Support Plan (ISP) Monitoring Tool is designed to provide guidance to SCs when conducting monitoring visits with individuals, families and/or team members. The tool allows for frequent communication to address current needs and to ensure an individual's health and safety. It also allows SCs to help individuals and families plan for services throughout an individual's lifetime. Utilizing the ISP tool, SCs can "…verify that the individual is receiving the appropriate type, amount, scope, duration, and frequency of services to address their assessed

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[356] "Individual Support Plan," *Department of Human Services*, accessed December 4, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Individual%20Support%20Plan.aspx#:~:text=%E2%80%8BIndividual%20Support%20Plan&text=Developed%20through%20a%20Person%20Centered,Individual%20Support%20Plan.

[357] "Person Centered Planning," Administration for Community Living, accessed December 4, 2023, https://acl.gov/programs/consumer-control/person-centered-planning.

[358] DHS Bulletin 00-22-05, ISP Process, (Updated 6-16-2023), accessed December 4, 2023, https://www.dhs.pa.gov/providers/Providers/Documents/ISP%20manual%20for%20Individuals%20with%20ID.pdf.

needs and desired outcome[s]…" per their approved and authorized ISP.[359] The monitoring tool also offers participants access to services.[360]

The monitoring tool requires SCs to document all issues identified during the monitoring and follow their SCO protocol regarding notification of monitoring issues for it to be addressed. Documenting all issues during monitoring, as well as the follow-up actions should be documented in service notes and upcoming monitoring's to ensure that the issue was resolved helps promote accountability of service coordinators and providers.[361]

Independent Monitoring for Quality Surveys

The Independent Monitoring for Quality (IM4Q) is an information-gathering tool utilized by ODP to measure and monitor the quality of services provided to individuals with disability and their outcomes statewide. The IM4Q program was established in a 1997 recommendation from ODP's Planning Advisory Committee "…to develop a mechanism to monitor the quality of life of individuals receiving services under the auspices of the ODP."[362] The IM4Q program was subsequently piloted shortly thereafter in 2002.[363] One major component of the IM4Q method is the conducting of surveys. The IM4Q team performs an annual survey designed to collect data on individuals with intellectual and developmental disability receiving services from ODP.[364] Each year, about 5,500 people with intellectual and developmental disability participate.[365]

The survey process starts with IM4Q team members formally requesting interviews from individuals receiving services; participation is optional. Interviews take place at the convenience and comfort of the individual. For example, if home or a day program is the most comfortable location for the individual, the interviews can take place in either. The interview team is fully independent from ODP, the county or the individual's provider. They are typically composed of two or three people, with at least one member who is either an individual with a disability or a family member of an individual with a disability.[366]

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[359] DHS Bulletin 00-22-05, ISP Process, (Updated 6-16-2023), accessed December 4, 2023, https://www.dhs.pa.gov/providers/Providers/Documents/ISP%20manual%20for%20Individuals%20with%20ID.pdf.

[360] *Ibid*.

[361] "Individual Support Plan Monitoring Tool Supports Coordination Guidance Document," *Office of Developmental Programs*, Version Date 12/07/2019, accessed December 4, 2023, https://www.dhs.pa.gov/docs/HHSDC/Documents/3_4_ODP%20NEW%20IMT%20Guidance.pdf.

[362] "Outcome Measurement Program Case Studies: About IM4Q," *University of Minnesota*, *Institute on Community Integration*, accessed December 4, 2023, https://publications.ici.umn.edu/rtcom/case-studies/IMQ4/about-im4q.

[363] *Ibid*.

[364] "Independent Monitoring for Quality," *Department of Human Services*, accessed December 3, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Independent%20Monitoring%20for%20Quality.aspx.

[365] "IM4Q Data: Examples," *Temple University, College of Education and Human Development, Institute on Disabilities*, accessed December 3, 2023, https://disabilities.temple.edu/programs-services/advocacy/independent-monitoring-quality/im4q-data-examples#:~:text=The%20IM4Q%20team%20conducts%20an,Programs%20in%20Pennsylvania%20(ODP).

[366] *Supra*, n. 364.

The survey questions concern the participants' thoughts and perceptions of their quality of life, measured through areas, such as satisfaction; dignity, respect, and rights; choice and control; inclusion; emergency preparation; employment; and relationships. In certain circumstances, the participants being interviewed allow their family members to also be interviewed.

Satisfaction – How much the participant likes or dislikes their place of work, where they live, and the people they spend time with.

Dignity, Respect, and Rights – How the participant is treated and whether they can engage in activities other individuals typically do, such as carrying ID, having a key to their home, and voting.

Choice and Control – How much control the participant has in their lives regarding their own schedules, budgets, their employment, and their home.

Inclusion – How much the participant can go out into the community and eat at restaurants, shop at stores, go on vacation, seek entertainment, and visit friends and family.

Emergency Preparation – How prepared the participant is in an emergency involving themselves or their service providers.

Relationships – How beneficial are the participants' relationships with family, friends, and service staff.[367]

After the conclusion of the interview, the team shares the participant's survey answers with the county Mental Health/Intellectual Development program for appropriate action. The interview team must first obtain consent of all those interviewed before sharing the answers. Combined anonymous data reports based on the information obtained by the surveys are then shared with ODP and its stakeholders for efforts to improve quality going forward by ODP, Administrative Entities, and provider quality groups. In addition, the data reports are used by the IM4Q Steering Committee (composed of ODP stakeholders) to identify system improvement recommendations for action. The committee then submits them to ODP's Information Sharing and Advisory Committee (ISAC), which serves as ODP's stakeholder quality council. The ISAC Quality Council, a 36-member council with members appointed by DHS. The council members are primarily organizational. For example, members include provider organizations, county administrator organizations, self-advocacy organizations, and other major stakeholder organizations. In 2015, ISAC members developed a new strategic plan for ODP. The council also adopted 13 different recommendations for improving the waiver system. Some of those recommendations were related to employment, access to community living, community participation, and improvements in agency communication. ISAC also develops strategies to

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[367] "Independent Monitoring for Quality," *Department of Human Services*, accessed December 3, 2023, https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Independent%20Monitoring%20for%20Quality.aspx; "IM4Q Data: Examples," *Temple University, College of Education and Human Development, Institute on Disabilities*, accessed December 3, 2023, https://disabilities.temple.edu/programs-services/advocacy/independent-monitoring-quality/im4q-data-examples#:~:text=The%20IM4Q%20team%20conducts%20an,Programs%20in%20Pennsylvania%20(ODP).

achieve all stated goals.[368] ODP and ISAC then prioritize opportunities for system improvements for implementation in the field.[369]

The IM4Q system has several notable strengths in its method to improve the quality of life and services for individuals with disability. IM4Q allows the actual individuals receiving services and their families to participate in the interview process that directly relates to the policy at a system level. In addition, there is a level of independence in the survey process that allows data to be collected by organizations that do not have a conflict of interest in the service delivery system. The process provides a longitudinal component that makes it possible to monitor the effects of policy changes over time and allows for data-driven policy and programming decisions.[370]

Some individuals with disability and their families have concerns about the way in which the IM4Q surveys are conducted, and the information is gathered. Some of the survey questions tend to lack a varied understanding of people with intellectual disability and autism, and how they understand and respond to questions. For example, surveys often contain leading questions. Some people with intellectual disability or autism often answer "yes" to everything or "no" to everything. Some individuals also may pick the last choice given in a question. This can be problematic because if the purpose of the survey is to extract data from the participant's real perspective, the questions asked may not be capturing accurate data from the responses.

It has also been reported that there is a lack of centralized training for interview team staff. Moreover, coordinators and interviewers have highlighted many challenges to recruiting and retaining participants due to "participant fatigue" and growing difficulty in reaching participants as more people live in their own homes or family homes.[371]

Licensure Reviews and Inspections

All facilities and agencies providing services under the supervision of the Department are subject to licensure via certification of compliance with program regulations. A certificate of compliance permits a legal entity (which includes a person) to operate a specific type of facility or agency at a given location for a specified period of time according to appropriate program licensure or approval regulations. All facilities and agencies receive a scheduled on-site inspection at least once every 12 months. Additional unannounced on-site inspections can occur randomly or if the facility or agency is subject to compliant inspections.[372]

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[368] Discussion of the Advisory Committee Meeting held on July 14, 2023.
[369] *Supra*, n. 364.
[370] *Supra*, n. 362.
[371] *Supra*, n. 362.
[372] 55 Pa.Code Chapter 20.

Residential Settings

Community homes (group homes) and life-sharing homes are subject to additional regulations. The regulations regarding community homes and life sharing homes are identical in many instances. However, many of those regulations provide for the facility or agency to police itself.[373]

Self-Assessment

Both types of homes are required to complete a self-assessment within three to six months prior to the expiration of the certificate of compliance. Both types of homes are required to use DHS's licensing inspection instruments and maintain a copy of the self-assessment results and a written summary of corrections for at least one year.[374]

Incident Reports and Investigations

A variety of incidents must be report through DHS' information management system or on a form specified by the department within various time frames, depending on the severity of the incident.

The following incidents (actual, alleged, or suspected) must be reported with 24 hours of discovery by a staff person:

- Death.
- A physical act by an individual in an attempt to complete suicide.
- Inpatient admission to a hospital.
- Abuse, including abuse to an individual by another individual.
- Neglect.
- Exploitation.
- An individual who is missing for more than 24 hours or who could be in jeopardy if missing at all.
- Law enforcement activity that occurs during the provision of a service or for which an individual is the subject of a law enforcement investigation that may lead to criminal charges against the individual.
- Injury requiring treatment beyond first aid.
- Fire requiring the services of the fire department. This provision does not include false alarms.

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[373] Community homes: 55 Pa.Code Chapter 6400; share living homes: 55 Pa.Code Chapter 6500.

[374] 55 Pa.Code §§ 6400.15 and 6500.17. There are links to the assessment tools for both types of homes at https://www.dhs.pa.gov/providers/Clearances-and-Licensing/Pages/Developmental-Programs-Licensing.aspx.

- Emergency closure.
- Theft or misuse of individual funds.
- A violation of individual rights.[375]

The following incidents (actual, alleged, or suspected) must be reported with 72 hours of discovery by a staff person:

- Use of a restraint.
- A medication error as specified in § 6400.167 (relating to medication errors), if the medication was ordered by a health care practitioner.[376]

The home is required to take immediate action upon initial knowledge or notice of the incident to protect the health, safety, and well-being of the individual, and to initiate an investigation withing 24 hours of the discovery.[377] Investigations remain in-house, except in certain incidents where a department-certified incident investigator must conduct the investigation of the following incidents:

- Death that occurs during the provision of service.
- Inpatient admission to a hospital as a result of an accidental or unexplained injury or an injury caused by a staff person, another individual or during the use of a restraint.
- Abuse, including abuse to an individual by another individual.
- Neglect.
- Exploitation.
- Injury requiring treatment beyond first aid as a result of an accidental or unexplained injury or an injury caused by a staff person, another individual or during the use of a restraint.
- Theft or misuse of individual funds.
- A violation of individual rights.[378]

All incidents are reported to the individual and their designated person within 24 hours of discovery. The incident report, or a summary of the incident, the findings and the actions taken, are not automatically provided to the individual or their designee unless requested. shall be available to the individual, and persons designated by the individual, upon request.[379]

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[375] 55 Pa.Code §§ 6400.18(a) and 6500.20(a).
[376] 55 Pa.Code §§ 6400.18(b) and 6500.20(b).
[377] 55 Pa. Code §§6400.18(f) and (g); 6500.20(f) and (g).
[378] 55 Pa.Code §§ 6400.18(h) and 6500.20(h).
[379] 55 Pa.Code §§ 6400.18 (c) and (e); 6500.20(c) and (e).

The home must finalize its report to DHS within 30 and provide the following information:

- Additional detail about the incident.
- The results of the incident investigation.
- Action taken to protect the health, safety and well-being of the individual.
- A description of the corrective action taken in response to an incident and to prevent recurrence of the incident.
- The person responsible for implementing the corrective action.
- The date the corrective action was implemented or is to be implemented.[380]

All community homes are required to have written grievance procedures for individuals, individual's families, advocates and staff persons, that assure investigation and resolution of complaints.[381] Both community homes and live sharing homes are required provide procedures for individuals to resolve differences and make choices so the one individual's exercise of their rights does not infringe upon another individual's rights.[382]

Financial Integrity

In every waiver application submitted by ODP to Medicaid there is a question about maintaining financial integrity:

> Describe the methods that are employed to ensure the integrity of payments that have been made for waiver services, including: (a) requirements concerning the independent audit of provider agencies; (b) the financial audit program that the state conducts to ensure the integrity of provider billings for Medicaid payment of waiver services, including the methods, scope and frequency of audits; and, (c) the agency (or agencies) responsible for conducting the financial audit program.[383]

Pennsylvania's responses identify multiple ways in which this occurs through various entities. Of particular interest to providers in the Quality Assessment and Improvement (QA&I) process. Conduced on a three-year cycle,

> ODP compares paid claims data to provider records such as time sheets and reports of services rendered for a random selection of claims from the previous fiscal year across all participants served. . . . This is a desk review comparing a provider's records to a report of paid claims from PROMISe, the state's Medicaid Management

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[380] 55 Pa.Code §§ 6400.18(i) and (j); 6500.20(i) and (j).
[381] 55 Pa.Code §§ 6400.23.
[382] 55 Pa. Code §§ 6500.33 and 6500.33.
[383] Application for 1915(c) HCBS Waiver: PA.0593.R03.05 - Nov 01, 2023 (as of Nov 01, 2023), 239.

> Information System. ODP reviews for consistency of day and time between the documentation and the claim as well as documentation supporting the number of units billed.
>
> The providers identified in the monitoring sample each year will have claims reviewed for a 95% confidence interval with a 5% margin of error by randomly selecting claims from the previous fiscal year across all participants served.[384]

If an individual or their representative believes that a provider is committing fraud, such as billing for services not rendered, complaints may be made to DHS via their MA Provider Compliance Hotline.[385] Additionally, suspected Medicaid fraud and abuse can be reported to the U.S. Health and Human Services Office of Inspector General hotline.[386]

All nonprofit organizations in Pennsylvania (except those receiving less than $100,000 in gross annual contribution) are required to conduct annual financial reviews or audits for purposes of their authorization to solicit funds.[387] This is in addition to the requirements of the U.S. Internal Revenue non-profit organization rules, and ODP and Medicaid fraud and abuse protections.

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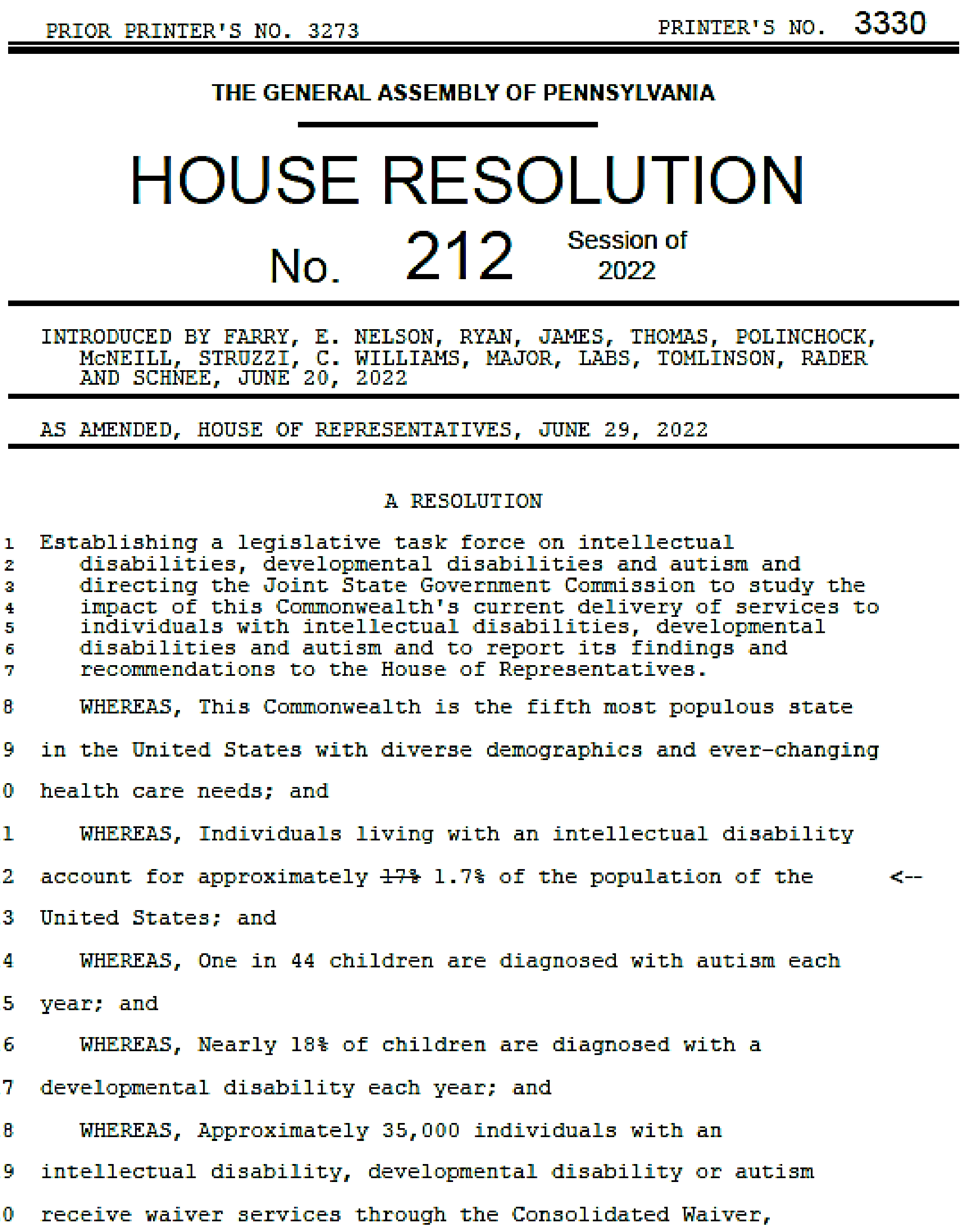
[384] *Ibid*., 240.

[385] "Reporting Suspected MA Fraud & Abuse," *Department of Human Services*, accessed February 15, 2024, https://www.dhs.pa.gov/about/Fraud-And-Abuse/Pages/MA-Fraud-and-Abuse---General-Information.aspx.

[386] "Submit a Hotline Complaint," *Office of Inspector General*, accessed February 15, 2024, https://oig.hhs.gov/fraud/report-fraud/.

[387] "Information for Charitable Organizations," *Pennsylvania Department of State*, accessed February 15, 2024, https://www.dos.pa.gov/BusinessCharities/Charities/Resources/Pages/Information-for-Charitable-Organizations.aspx.



PRIOR PRINTER'S NO. 3273 PRINTER'S NO. 3330

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 212 Session of 2022

INTRODUCED BY FARRY, E. NELSON, RYAN, JAMES, THOMAS, POLINCHOCK, McNEILL, STRUZZI, C. WILLIAMS, MAJOR, LABS, TOMLINSON, RADER AND SCHNEE, JUNE 20, 2022

AS AMENDED, HOUSE OF REPRESENTATIVES, JUNE 29, 2022

A RESOLUTION

Establishing a legislative task force on intellectual disabilities, developmental disabilities and autism and directing the Joint State Government Commission to study the impact of this Commonwealth's current delivery of services to individuals with intellectual disabilities, developmental disabilities and autism and to report its findings and recommendations to the House of Representatives.

WHEREAS, This Commonwealth is the fifth most populous state in the United States with diverse demographics and ever-changing health care needs; and

WHEREAS, Individuals living with an intellectual disability account for approximately ~~17%~~ 1.7% of the population of the United States; and <--

WHEREAS, One in 44 children are diagnosed with autism each year; and

WHEREAS, Nearly 18% of children are diagnosed with a developmental disability each year; and

WHEREAS, Approximately 35,000 individuals with an intellectual disability, developmental disability or autism receive waiver services through the Consolidated Waiver, Community Living Waiver, Adult Autism Waiver and the Person/Family Directed Support Waiver; and

WHEREAS, This Commonwealth has created ~~an integrated~~ A MULTIFACETED system for individuals with intellectual disabilities, developmental disabilities and autism; and <--

WHEREAS, Individuals who have an intellectual disability, developmental disability or autism are in need of additional services in their community; and

WHEREAS, Individuals and their families should have a choice of options, including the choice to REASONABLY decline a placement they do not believe to be appropriate, for individuals in need; therefore be it <--

RESOLVED, That the House of Representatives establish a legislative task force on services provided to individuals with intellectual disabilities, developmental disabilities and autism; and be it further

RESOLVED, That the task force be comprised of four members of the House of Representatives appointed by the Speaker of the House of Representatives, two members recommended by the Majority Leader of the House of Representatives and two members recommended by the Minority Leader of the House of Representatives; and be it further

RESOLVED, That the House of Representatives direct the Joint State Government Commission to assist the task force and conduct a study on the impact of this Commonwealth's current needs and system capacity for providing opportunities for individuals with intellectual disabilities, developmental disabilities and autism in this Commonwealth; and be it further

RESOLVED, That the Joint State Government Commission, as part of its study, establish an advisory committee consisting of the following members:

(1) A representative recommended by the Department of Human Services, Office of Developmental Programs.

(2) A representative recommended by the Department of Labor and Industry, Office of Vocational Rehabilitation.

(3) A representative from the autism advocacy community OR A SELF-ADVOCATE FROM THE AUTISM COMMUNITY.

(4) Two relatives who have a loved one receiving ~~waiver service.~~ HOME AND COMMUNITY-BASED WAIVER SERVICES OR ARE THEMSELVES RECEIVING WAIVER SERVICES, WITH AT LEAST ONE BEING THE PARENT OR GUARDIAN OF AN INDIVIDUAL.

(5) Two relatives of individuals WHO ARE ON THE WAITING LIST FOR SERVICES or individuals who THEMSELVES are on the waiting list for services~~.~~, WITH AT LEAST ONE BEING THE PARENT OR GUARDIAN OF AN INDIVIDUAL.

(6) A representative of an organization that offers community participation supports.

(7) A representative from the Rehabilitation and Community Providers Association.

(8) A representative from Pennsylvania Advocacy and Resources for Autism and Intellectual Disabilities.

(9) A representative from a community or campus setting.

(10) A physician who is a member of the Pennsylvania Psychiatric Society who has experience treating individuals with intellectual disabilities, DEVELOPMENTAL DISABILITIES AND AUTISM.

(11) A representative recommended by the Pennsylvania Association of County Administrators of Mental Health and Developmental Services.

(12) Any other representatives from other organizations

that are deemed appropriate by the Joint State Government Commission;

and be it further

RESOLVED, That the study examine the impact of this Commonwealth's current delivery system available to individuals with intellectual disabilities, developmental disabilities and autism; and be it further

RESOLVED, That the study examine the efficiency, uniformity and best practices of the administration of services through the county system, QUALITY OF LIFE OUTCOMES, including waiver services, waiting lists and transitional protocols~~;~~ OF MOVING INTO AND OUT OF ONE WAIVER OR PROGRAM TO ANOTHER OR TRANSITIONING OUT OF HIGH SCHOOL; and be it further

RESOLVED, That the Joint State Government Commission study how current Federal and State laws and regulations impact and limit supports and services; and be it further

RESOLVED, That the study examine collaborations ~~with~~ BETWEEN the Department of Human Services, managed care organizations and providers, including reimbursement rate settings, DIRECT SUPPORT PROFESSIONALS, OTHER funding sources and how providers collaborate to serve individuals with intellectual disabilities, developmental disabilities and autism; and be it further

RESOLVED, That the Joint State Government Commission study the opportunities for ~~integrated~~ job coaching, community participation supports, including for individuals who cannot go ~~into the community~~ OR CHOOSE NOT TO GO INTO THE COMMUNITY BECAUSE OF UNDERLYING ISSUES, and additional programs offered through the Office of Vocational Rehabilitation OR THE EMPLOYMENT FIRST COMMISSION; and be it further

RESOLVED, That the Joint State Government Commission study this Commonwealth's current treatment needs, including network capacity to treat and care for high acuity individuals, individuals with complex medical needs in addition to intellectual disabilities and individuals who need special care and assistance with intensive behavioral health issues, INCLUDING, WHEN APPROPRIATE, PROVIDER REFERRAL, ADMISSION AND DISCHARGE PRACTICES; and be it further <--

RESOLVED, That the study examine all available living settings, including intermediate care facilities, community homes, ~~State centers, lifeshare,~~ SERVICES WITHIN FAMILY HOMES, STATE CENTERS, LIFESHARING, independent living with assistance, farmhouse settings, campus settings and any other innovative residential services available to individuals living with intellectual disabilities, developmental disabilities and autism; and be it further <--

RESOLVED, That the study include barriers and obstacles in transportation for individuals living in the home or receiving community-based services for jobs, medical appointments and peer-to-peer groups; and be it further

RESOLVED, That the study examine workforce issues, direct support professionals, SUPPORTS COORDINATORS and other behavioral HEALTH OR MENTAL HEALTH specialists or health care practitioners who assist with the provision of services; and be it further <-- <--

RESOLVED, That the Joint State Government Commission examine providers who have ceased operations since the beginning of the COVID-19 pandemic; and be it further

RESOLVED, That the Joint State Government Commission solicit input from representatives and advocates from all aspects of the sector and continuum of care to assist the Joint State

Government Commission with its findings and recommendations in the report; and be it further

RESOLVED, That the Joint State Government Commission issue a report with its findings and recommendations no later than ~~June 1, 2023,~~ 18 MONTHS AFTER THE ADOPTION OF THIS RESOLUTION to all <-- <-- of the following:

(1) The chair and minority chair of the Health and Human Services Committee of the Senate.

(2) The chair and minority chair of the Human Services Committee of the House of Representatives.