PRACA POGLĄDOWA

# MANAGING THE COST OF SERVICES FOR PEOPLE WITH DISABILITIES: INTERNATIONAL APPROACH. PART II: OHIO, UNITED STATES

## Zarządzanie wydatkami na opiekę osób z niepełnosprawnościami. Podejście międzynarodowe. Część II: Ohio, Stany Zjednoczone

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### Abstract

**Introduction:** Four years of managing a housing network for people with disabilities prompted a rethinking of the financial management of the services offered. Clients with different needs require diverse professional staff for their home care. Emergency situations require that professionals offering assistance maintain the highest level of education possible. Financial resources often limit the quality of care for people with disabilities. **Method:** This paper is based on a literature search and on professional experience (Dana Pugh) in the management of a housing program for people with disabilities in Cleveland, Ohio (USA). **Findings:** In Poland, people with disabilities usually live with their families, and specialized services are offered outside their place of living. However, community housing is being developed to resemble the family home. In the United States, individuals with disabilities often live in housing with specialized basic assistance. To improve living conditions, we suggest stratifying different levels of care to offer specialized services relative to the needs of residents at each level. **Discussion:** An international approach to the care of people with disabilities allows for a comparison of different methods of service delivery, depending on financial resources, community traditions, and the professional knowledge of care providers. The authors suggest a specific model of service that promotes a high quality of professional knowledge despite financial constraints.

### Streszczenie

**Wstęp:** Cztery lata zarządzania siecią mieszkaniową przeznaczoną dla osób niepełnosprawnych skłoniły do ponownego przemyślenia sposobu zarządzania finansami dotyczącymi oferowanych usług. Klienci o różnych potrzebach wymagają zróżnicowanego, profesjonalnego personelu do opieki domowej. Sytuacje nadzwyczajne obligują specjalistów oferujących pomoc do utrzymywania możliwie najwyższego poziomu wykształcenia. Zasoby finansowe często ograniczają jakość opieki nad osobami niepełnosprawnymi. **Metoda:** Artykuł powstał w oparciu o kwerendę literatury oraz doświadczenie zawodowe (Dana Pugh) w zarządzaniu siecią domów opieki dla osób niepełnosprawnych w Cleveland w stanie Ohio (USA). **Wyniki:** W Polsce osoby niepełnosprawne mieszkają przeważnie z rodziną, a specjalistyczne usługi świadczone są poza miejscem zamieszkania. Tworzy się jednak budownictwo wspólnotowe na wzór domu rodzinnego. W Stanach Zjednoczonych osoby niepełnosprawne często mieszkają w placówkach mieszkalnych korzystających ze specjalistycznej podstawowej pomocy. Aby poprawić warunki życia, sugerujemy stratyfikację różnych poziomów opieki w celu zaoferowania specjalistycznych usług dostosowanych do potrzeb mieszkańców na każdym poziomie. **Dyskusja:** Międzynarodowe podejście do opieki nad osobami niepełnosprawnymi pozwala na porównanie różnych metod świadczenia usług, w zależności od zasobów finansowych, tradycji społecznych i wiedzy zawodowej świadczeniodawców. Autorzy proponują specyficzny model świadczenia usług, promujący wysoką jakość wiedzy zawodowej w warunkach ograniczeń finansowych.

**Keywords:** veterans; services; financial management; social work; residential care

**Słowa kluczowe:** weterani wojskowi; usługi; zarządzanie finansami; praca socjalna; domy opieki

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## Introduction

This is the second of two articles concerning an international approach to managing the costs of services supporting people with disabilities. The goal of this work is to compare how different countries deal with the problem of the increasing cost of services for the most vulnerable groups. Various models of service provision, either proposed or already in place, consider the diverse needs of people with different levels of disability. We believe that offering more options in the system of care can be advantageous for people who need assistance. In Part I of this work, we presented a comprehensive look at healthcare and housing for people with disabilities in Poland. Here, we suggest a solution to the problem based on a model developed in Cleveland, Ohio (USA). Research methods and the theoretical background are described in Part I.

The number of adults with disabilities in Ohio reaches 28% [1]. They are affected by many health problems in more significant ways than those without any disability. Here are some numbers: 49% of all individuals with disabilities have depression, compared to 14% of those without disability; 45% of those with disability have obesity compared to 34% of those without disability who have obesity; 31% of those with disability smoke compared to 14% of those without disability who smoke; 17% of those with disability have diabetes compared to 8% of those without disability who have diabetes; and 12% of those with disability have heart disease compared to 4% of those without disability who have heart disease [1]. Disability-related healthcare costs in Ohio reach $35 billion per year [1], accounting for 37% of the state's health care spending, or $17,732 per person with a disability. These are significant numbers that require public attention.

The common approach to social policies is to treat a group of people as having the same characteristics or conditions. However, in each field of public health there is often a stratification of group members according to the severity or complexity of their needs. For example, in social work, it has become more common to apply a person-centered evaluation of the social determinants of health. We have learned that the context of the environment in which we were born and live is important for our bio-psycho-social evaluation and required treatment. As a result, the screening of social determinants of health has become an important tool in defining the scope of necessary care.

In the field of addiction, we use levels of care defined by ASAM (American Society of Addiction Medicine) criteria [2]. In the Veterans Health Administration, patient acuity is determined according to the PACT (Patient Aligned Care Team) "Primary Care" Social Work Practice Model. Each established acuity or care level verifies the intensity and complexity of care required for evaluated patients [3]. These levels of care, depending on the complexity of needs, serve several purposes. First, the level of care defines the severity of problems that need to be addressed. Second, it dictates the most appropriate services to meet the needs of a patient. As a result, it establishes the degree of education and experience of professionals that are necessary to address the health challenges of a patient. Such stratification allows for the economically optimal use of scarce institutional and human resources in patient care. We propose a system of care that is based on the idea of different needs of care for various groups of people with disabilities.

In Poland, there are several levels of public resources for the care of disabled individuals. Most of them date back to before 1989, when all public services were run by the government. Since 2010, the Social Insurance Institution (ZUS) has used the Barthel Index (or modified Barthel scale) to evaluate Activities of Daily Living. Depending on the Barthel Index score, people with disabilities receive different levels of public support [4].

One approach to decreasing the cost of services in Poland is to have a separate organization offering specialized assistance, where a person can be referred for a service. The main difference between the models in the US and Poland is the location of services in relation to housing. In Poland, people with disabilities can be referred to services outside their place of living, whereas in the US, services can be located within the place where they live. Below, we will discuss how to help people with disabilities in their homes, based on the belief that many would benefit from in-home services that do not require travel.

## Case of group homes in Cleveland, Ohio

In this paper, we propose a system of care that can both decrease the cost of services and, at the same time, increase the professionalism of staff in healthcare provider homes for people with disabilities, with a particular focus on individuals with developmental disabilities. We will focus on formal care for people with severe disabilities, as a majority of them (about 60%) receive such treatment, while the rest rely on informal care from family and friends [5]. The paradigm of the proposed model is to offer the same housing standard to all clients. However, residents with higher needs can be offered higher-standard services that are already factored into the cost of housing. Our model is based on a system located in Greater Cleveland, Ohio, called The H.O.P.E. (Helping Other People Elevate) Network. This is a healthcare agency that is certified and licensed by the Ohio Department of Developmental Disabilities (DODD). The H.O.P.E. Network provides direct support, including but not limited to the promotion of health and the management of diseases/disorders, medication administration, cooking, housekeeping, toileting, bathing/showering, transportation, and social support for members of the community diagnosed with developmental disabilities (e.g. Attention-Deficit/Hyperactivity Disorder, Autism Spectrum Disorder, Cerebral Palsy, Fragile X Syndrome, Intellectual Disability, Language Disorders, Learning Disorders, Tourette syndrome) and acquired disabilities (e.g. as a result of violence or combat, see below for an example involving veterans). Many of our clients are dually diagnosed with psychiatric and/or substance use disorders. To provide the above-listed services, we hire Direct Support Professionals (DSP), paraprofessionals who receive eight hours of DSP training, as required and provided by the DODD. Although well-intentioned and equally ambitious, the structure and plan set forth by the DODD is systematically flawed and, as such, works in direct opposition to the goals shared by clients and the state of Ohio.

## Educational needs of direct support professionals

The phenomenon of comorbidity among psychiatric disorders is very well known. Simonoff et al. [6] reported that "among individuals with autism spectrum disorder (ASD), some 70% have at least one comorbid disorder (most commonly social anxiety disorder), and over 40% have two or more such disorders." As such, comorbidity among individuals with developmental disabilities is more "the rule than the exception thereof" [7].

Typically, clients with developmental disabilities should be linked with case management, social workers, or psychologists and psychiatrists. Among developmentally disabled clients, there is an increased potential for more severe and longer-term psychopathological symptomatology, necessitating greater access to professional mental health services. However, despite the severity of these problems, access to mental healthcare services is not significantly greater

According to the DODD criteria for training, the Direct Support Professional (DSP) is expected to have a high school diploma or general equivalency diploma and a clean criminal background. These criteria include a course in CPR and First Aid, an eight-hour training detailing the DODD's policies and procedures directly related to the provision of support services, and, when appropriate to the needs of one or more individual clients, a two-day course in medication administration [8]. These criteria afford many citizens, particularly those for whom advanced education has been elusive, much-needed access to upward mobility via the healthcare professions. However, it can be easily argued that such limited training subsequently limits DSPs' preparedness for attending to problems commonly experienced by the populations they serve.

To suggest that there are no DSPs with outstanding professionalism and high-level healthcare-related expertise would be sheer fallacy. However, outliers notwithstanding, DSPs are undertrained and underprepared when faced with issues such as hallucinations, delusions, mania, homicidality, and suicidality, none of which are uncommon. A study conducted by Lunsky [9] found that one-third of a sample (*N* = 98) of individuals with intellectual disabilities reported experiences of suicidality. Further, it was concluded that "this population is vulnerable to physiological, psychological, social, economic, and environmental correlates associated with suicide risk" [9]. However, the National Action Alliance for Suicide Prevention [10] asserts that "proximity to families, caregivers, and providers" should render suicide, for individuals with developmental disabilities, a "never event." As stated above, the quality of care is often limited by the prospect of only three days of training, and this standard of care is difficult to maintain. The COVID-19 pandemic has left in its wake a hiring crisis that has further decimated the pool of optimal DSP candidates.

Professionals working with vulnerable populations need to be trained in evidence-based practices and understand how the field of helping professions is evolving in response to changes in society. Below, we present a health issue that has gained significant recognition in recent years and a practice that acknowledges the role of trauma in people's lives. Both these topics are significant in the care of people with disabilities.

## Veterans with traumatic brain injury

In 2018, Yi et al. [11] published a study that linked a lifetime history of Traumatic Brain Injury (TBI) to current disability among Ohio adults. They found a significant relationship between a history of TBI and the development of serious health problems and disability within the large group studied. TBI is often described as a silent epidemic, frequently leading to disability [12]. The first large studies concerning TBI were conducted in military settings, including the Veterans' Administration (VA). TBI has come to be known as the "signature injury"' of the Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) conflicts [13]. Contemporary literature indicates that approximately 12% to 16% of veterans sustained a TBI during their deployment. Service members disproportionately return from deployment diagnosed with both a history of mTBI (m for mild) and current Post-Traumatic Stress Disorder (PTSD). Although extensive literature exists on the neuropsychological factors associated with TBI and PTSD as separate experiences, there is a dearth of research exploring their combined effects [12]. A study conducted by Combs et al. [13] revealed that the comorbid experience of TBI and PTSD results in greater and more severe cognitive deficits than PTSD alone. Given the potential for DSPs to encounter service members with histories of these experiences and associated diagnoses, it is imperative that agencies effectively recruit and appropriately compensate personnel with expertise related to a trauma-informed care approach to service provision. Neither the current level of training nor the associated rate of pay adequately support agencies' efforts to recruit or retain personnel appropriately qualified to attend to this level of client need.

## Trauma-informed care

For more than two decades, the health and mental healthcare fields have advocated for a focus on trauma-informed care (TIC). Widely credited as the impetus for this movement, the Adverse Childhood Experiences (ACE) study began in 1995 and emphasized the important role played by psychological trauma experienced early in development as a determinant of physical and mental problems throughout the lifespan. The ACE study revealed an extraordinary propensity for early traumatic events and their subsequent negative impact on psychological and physical well-being, underscoring the necessity for TIC. In 2013, the Department of Developmental Disabilities (DODD) and Ohio Mental Health and Addiction Services (MHAS) created Ohio's Trauma-Informed Care Initiative to support TIC for services for people with disabilities [14].

Butler et al. [15] assert that TIC requires an understanding of "the involvement and impact of violence and victimization in the lives of most consumers of mental health, substance abuse, and other services." Further, it requires the application of "that understanding of designing service systems and providing services to accommodate the requirements and vulnerabilities of trauma survivors and to facilitate their participation in treatment" [15].

It is widely held that individuals with a developmental disability, particularly intellectual disability, are at significant risk of experiencing adverse life events, including abuse and trauma in childhood, above and beyond what is common among the general population [16]. These findings converge with the self-reports of HOPE Network clients as well as with the data included in the individual service plans associated with HOPE Network clients. Clients report experiences of sexual and other forms of domestic abuse, environmental and community violence, abject poverty, bullying, and racism and white supremacy. Consistent with the literature, HOPE Network clients are easily observed by trained professionals to express psychological trauma in myriad ways, including but not limited to altered arousal, outwardly directed aggressive behaviors, and suicidal ideation.

Given the prevalence of such detrimental experiences and the strong correlation with severely negative outcomes within this population, the need for trauma-informed care by Team Members who provide support for individuals with developmental disabilities is substantial and undeniable.

It is clear that there is a great need for a comprehensive reevaluation of direct support professionals' training criteria, which might afford people with developmental disabilities the quality of care necessary for optimal health and well-being. An individualized approach is recommended, as each person with developmental disabilities requires DSPs with varying levels of training. In an effort to provide levels of training appropriate to individuals without significantly stagnating the training process, a tier system, the Client-Caregiver Stratified Schedule of Services (C-CSSS), is recommended.

## Tier-based system related to position responsibility and compensation

Just as each individual client we encounter comes to us with a unique set of circumstances, so too do candidates for employment in the role of DSP. The resume-evaluation and interviewing processes reveal natural distinctions among candidates' levels of training, experience, and expertise.

An example of an effective three-tier system is as follows:

***Position Level 1 – Team Members have completed training, acquired exceptional experience, and developed exceptional expertise in the paraprofessional, healthcare, and/or mental healthcare fields.***

***Training:*** Team Members have completed formal academic and on-the-job training related to Direct Support Specialist (DSP), State Tested Nursing Assistant (STNA), Certified Nursing Assistant (CNA), and/or Home Health Aide (HHA) duties. Team Member's training includes a noted focus on trauma-informed care (TIC). Additionally, Team Members have completed accredited academic programs in one or more of the following or appropriately comparable fields; nursing, psychology, social work, occupational therapy, physical therapy, sociology and/or education.

***Experience:*** Team Members have two or more years of evidentiary experience performing the functions of DSP, STNA, CNA, or HHA in addition to one or more year of experience in one or more of the above-mentioned fields. This is confirmed by appropriate professional references.

***Expertise:*** Team Members have developed exceptional expertise in one or more of the above-mentioned paraprofessional and one or more of the professional fields. This may be evidenced qualitatively by a 2.5–3 score on a three-star rating scale relative to the interview process and/or verbal confirmation from one or more prior employer references.

***Associated intervention (beyond Level 2 and 3 interventions):***

- Provide clients with psychoeducation related to biopsychosocial health promotion, prevention, and patient-self-management.
- Assist clients with crisis management.
- Provide supportive counseling to assist clients and families with their adjustment to a diagnosis or disability.
- Perform the function of liaison between external healthcare professionals and clients.
- Provide supervision for staff on Position Levels 2 and 3.

***Position Level 2 – Team Members have undergone some training and have experience and quantifiable expertise in the paraprofessional, healthcare, and/or mental healthcare fields.***

***Training:*** Team Members have undergone formal academic training at an introductory level or cursory on-the-job training related to DSP, STNA, CNA, or HHA duties. This may include training in other related fields such as nursing, psychology, social work, sociology, and/or education. Lastly, Team Members have completed all required training and received medication administration certification (med cert) relevant to that Team Member's assignment(s).

***Experience:*** Team Members have more than one month but less than two years of evidentiary experience performing the functions of DSP, STNA, CNA, or HHA. This is confirmed by appropriate professional references.

***Expertise:*** Team Members have developed general expertise in one or more of the fields of DSP, STNA, CNA, or HHA. This may be evidenced qualitatively by a 1.5–2.5 score on a three-star rating scale relative to the interview process and/or verbal confirmation from one or more prior employer references. Of additional note, Team Members with their own experience of disability, but who are able to perform designated work assignments, are acknowledged, to some degree, as experts.

***Associated intervention (beyond Level 3 interventions):***

- Assist clients with various activities of daily living (ADLs; bathing, food preparation, eating, hygiene, and grooming).
- Administer prescribed medication to assigned clients.

- Encourage and support clients in full community participation.

This may include having the appropriate driver's license or permit and providing transportation to and from client destinations.

***Position Level 3 – Team Members have no prior training, no experience in related fields, and no associated expertise.***

***Training:*** Team Members have never participated in DSP, State Tested Nursing Assistant (STNA), Certified Nursing Assistant (CNA), or Home Health Aide (HHA) training.

***Experience:*** Team Members have never been employed by DSP, STNA, CNA, or HHA agencies, and have not performed the functions of any of the above-mentioned positions.

***Expertise:*** Team Members have not developed any quantifiable expertise in relation to the paraprofessional, health, or mental healthcare fields. This may be evidenced qualitatively by a 0– 1.5 score on a three-star rating scale relative to the interview process and/or verbal confirmation from one or more prior employer references.

**Associated interventions:**

- Provide clients with camaraderie and companionship.
- Enable clients' independence.
- Offer continued encouragement and social support.

## Financial support by DODD

Obstacles abound when it comes to attracting and hiring personnel with training related to TIC. Professionals with training and experience in this area tend to request higher rates of pay than what is typical in the field in Ohio, which is $13.74 as of the writing of this article, according to ZipRecruiter [17]. However, it should be noted that the Ohio House has recently taken measures to increase pay rates, with DSP wages set to rise to $17 in 2024 and to $18 in 2025. While this is an appreciated step forward, it still falls short of the necessary wage levels suitable for personnel who have acquired the training and experience necessary to effectively recognize, appropriately attend to, and optimally support lower-functioning and more severely traumatized clients.

The strides taken by the Ohio House should be viewed as foundational in recognizing the need for improved pay across the field. However, this first step in assisting agencies in the development of a more economically attractive, more competent, and safer field, with appropriate for entry-level personnel, falls short of affording Team Members an average annual salary of $47,456, which according to ZipRecruiter [17] is also consistent with the low-average salaries of social workers in Ohio [17]. In order for Team Members' pay to meet the state's average rate of pay, Ohio needs to consider the more appropriate rate of $22 per hour for Level 2 Team Members. To attract highly trained, experienced, and expert candidates, compensation should align with each tier, with Level-1 personnel being offered the appropriately higher rate of $27 per hour.

These changes are essential for promoting a necessary overhaul and increasing the sustainability of a field that currently and systematically encourages high turnover by affording hourly rates that force heads of single-earner households to work in excess of forty hours weekly or take on multiple jobs to bring their annual pay to that of the state's average. It is the opinion of The HOPE Network that these increases will help reduce current and historical turnover rates, which can negatively impact clients, particularly those with attachment problems which are commonly subsequent to neglect and abuse during early development.

It would be socioeconomically irresponsible to delay such changes for much longer. A perpetual overtime-heavy workweek is unsustainable, both for personal self-care and the well-being of personnel. A lack of self-care, including but not limited to appropriate sleep, rest, relaxation, and rejuvenation, can only have a negative impact on clients. Given the vulnerability of this particular population, it would be unethical to continue the trend of underpaying personnel who provide services for members of the community with developmental disabilities.

## Financial support by legal system

The Americans with Disabilities Act (ADA) guarantees individuals with disabilities access to the same services provided by law enforcement as that provided to anyone else [18]. Exclusion, segregation, denial of same services, or discriminatory treatment of individuals with disabilities is not only unethical but illegal [16]. While the legislative power associated with the ADA is tangible in other settings, it continues to prove elusive in law enforcement "even when the communicative accommodations are relatively simple" [18]. This profound unwillingness or inability to respond to the needs of people in ways appropriate to their specific type and level of disabilities fuels negative outcomes when police interact with individuals with disabilities.

Police are routinely called upon to respond when individuals experience mental health crises. These stimulus-response situations often escalate into violence. Moreover, when the police encounter mental health conditions such as schizophrenia or Tourette's syndrome, the result is often arrest and/or brutalization [19], the ADA's protections notwithstanding.

It is noteworthy that the National Alliance on Mental Illness [10] asserts that "almost half of the people who die at the hand of police have some kind of disability." Hawkins [18] further notes that "like other cases of police shootings, much of the violence inflicted against people with disabilities is the result of law enforcement failing to communicate effectively and utilize de-escalation tactics." The likelihood of unnecessarily violent outcomes increases exponentially by intersectionality with ethnic-racial identity (ERI), class, gender, and LGBTQIAA+ status. In essence, members of any marginalized group are particularly vulnerable to police brutality [20].

For the above reasons and more, federal, and local legislation should focus on making funding available to agencies that oversee and provide support for individuals with developmental disabilities. As Benjamin

Franklin is credited with saying, “an ounce of prevention is worth a pound of cure.” Assuredly, taxpayers burdened by the costs of the plethora of police brutality and wrongful death lawsuits would agree.

The criminal justice and judicial systems continue to face long-term and often fatal challenges when it comes to the treatment of people with disabilities. Calls for defunding the police abound. One place where funding could be directed to benefit both sides of this argument is the DODD, for the purpose of appropriate payment to the current paraprofessionals and future professionals who are and would be the actual first responders to incidents involving members of the community with developmental disabilities. Improved training and increased pay would reduce the likelihood of police responses to individuals with developmental disabilities, including improperly fatal ones, as well as unnecessary and inappropriate judicial and carceral outcomes. With this in mind, a call to action is made to redirect funding from systems that legally abuse and murder people with developmental disabilities and toward a system dedicated to their support, restoration, and empowerment.

## International approach

Each country must address the needs of vulnerable populations because these groups usually need external assistance. People with disabilities often cannot meet their own needs. They require governmental support. In the US, there is ongoing research evaluating current policies and services for people with disabilities [21, 22], and calls for action to improve the system of care [23]. There is an inherent contradiction between the theoretical models of disability [24, 25] and the constraints of available resources and cost of services. It is interesting to compare how different countries – with their different histories of social services – take care of their vulnerable populations [26, 27]. These comparisons reveal differences in financial management [28], barriers to treatment, especially during a pandemic [29], and the dissemination of information on available support [30].

## Conclusions

Our comprehensive analysis of service care for people with disabilities in Poland showed that economic constraints on the system lead to a stratification of housing offers, where higher standards of services come at higher costs. People with disabilities might be able to choose less expensive housing with essential services, but such services are often located outside their place of living. These external services might be difficult to access, often involving long waiting times. Moreover, lower housing costs may correspond to less professional care provided by direct support staff.

In contrast, the case presentation of group housing in the US demonstrates the potential for a unified housing network that employs staff with different levels of education and expertise. Depending on their proficiency, they are available to all residents of the network, addressing any crisis that may arise, although their primary responsibility is to residents requiring their services based on individualized treatment planning. This model offers continuous and broad-ranging professional assistance within a single system of care.

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