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Improving Professional Caregiving in the United States

Challenges and Opportunities

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COMMUNITY & STATE

Many people in the United States require assistance to live independent, self-determined lives. Policymakers and advocacy organizations agree – people are happier, healthier, and their care is less expensive when they can live in the community as opposed to an institutional setting.

The care delivery system in the United States is increasingly structured around this premise. Services that support people as they live in the community are a growing percentage of overall healthcare expenditures. In 2013, for the first time, home and community-based services (HCBS) constituted the majority (51%) of long term services and supports (LTSS) spending. The remaining 49% was attributed to institutional services such as nursing facilities. This shift demonstrates the ongoing trend in the rebalancing of LTSS from institutions to the community. In fiscal year 2014, HCBS spending increased to 53.1%.[1]

The majority of LTSS are provided by unpaid caregivers. Informal caregivers - largely uncompensated - provided $470 billion in care in 2013.[2] This unpaid care ranges from assistance getting to doctor appointments or paying bills to more intensive care such as support with bathing or wound care.

As a person's daily care needs become more extensive, they often require paid LTSS delivered by direct service workers (DSWs). There are many types of DSWs, but generally, DSWs are individuals who provide personal assistance to individuals accessing LTSS with a wide range of functional needs. This work can take place in institutional settings, but is largely delivered in group homes and/or in individuals' homes. The work can be part time or full time and can also vary in intensity and skills required.

The demand for DSWs currently outpaces the supply of individuals working in the profession.[3,4,5] Additionally, the number of informal caregivers in the United States is expected to decline, increasing the importance of paid LTSS services delivered by DSWs.[6] Meeting current and future demand will require a deeper understanding of the challenges facing DSWs today that cause individuals to leave the profession or prevent otherwise interested individuals from entering the DSW workforce in the first place. It will also require developing innovative solutions.

The business case for addressing the challenges facing the DSW profession is inextricably linked to the argument for shifting to community-based care; investing in DSWs improves the overall quality of care and supports delivered in community settings, therefore, shifting cost away from the acute and institutional settings and bending the overall cost trend for LTSS.

The LTSS Landscape

Over the last twenty years, an increasing number of individuals are receiving support in their homes and community, in part, to states' obligations under the Supreme Court's Olmstead decision which found that the unjustified institutionalization of persons with disabilities violates the Americans with Disabilities Act (ADA) and an increased desire by individuals and federal regulators to expand community-based options for those in need of LTSS. LTSS require coordination across multiple providers including community based organizations and agencies. The community-based, whole-person approach allows individuals to live in the least restrictive setting while helping to control costs.

Historically, states have used fee-for-service (FFS) Medicaid to deliver LTSS (institutional and HCBS). Recently, states have begun moving these benefits and populations to managed care:

> By the end of 2016
>
> **19 STATES**
>
> had implemented a managed LTSS program.
> That is **more than triple** the number 10 years ago.[7]

- Many states have integrated behavioral health benefits into managed care contracts and included individuals with severe mental illness (SMI) into managed care.
- In several states individuals with ID/DD receive some of their Medicaid benefits through a managed care organization. While waiver services have often been among the last benefits to move to managed care, a handful of states have moved or are contemplating waiver benefit integration into managed care.

[1]CMS Truven https://www.medicaid.gov/medicaid/ltss/downloads/ltss-expenditures-2014.pdf

[2]Reinhard, et. al. Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain. AARP Public Policy Institute.

[3]Bureau of Labor Statistics, Fastest growing occupations. https://www.bls.gov/news.release/ecopro.t05.htm;

[4]2016 Caregiver Recruiting Survey Results https://providers.careinhomes.com/downloads/2016-Recruiting-Survey-Results.pdf?

[5]The New York Times, "A Shortage of Caregivers". February 26, 2014. https://newoldage.blogs.nytimes.com/2014/02/26/a-shortage-of-caregivers/?_r=0

[6]Reinhard, et. al. Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain. AARP Public Policy Institute.

[7]AZ, CA, DE, FL, HI, IA, IL, KS, MA, MI, MN, NC, NJ, NM, NY, RI, TN, TX, and WI, http://nasuad.org/sites/nasuad/files/State%20Medicaid%20Integration%20Tracker%20December%202016_0.pdf

Individuals Who Work with a DSW

Last year, the National Advisory Board of UnitedHealthcare Community & State published two papers[8] that outlined the need for a standard quality framework for individuals accessing LTSS. Since improved caregiving will help achieve the quality standards outlined in the quality frameworks, a focus on caregiving is a logical continuation of that framework. It is the unanimous opinion of the National Advisory Board that the quality of life and health care for those accessing LTSS is largely dependent on the performance of DSWs – more than any other health care professional. Further, the Board believes that the perceived level of professional value of DSWs is reflective of the cultural commitment to meet the needs of individuals accessing LTSS.

Because of their often-complex health needs, individuals needing LTSS have unique service utilization patterns that differ significantly from the general and Medicaid-specific populations.

Individuals of all ages – elderly and non-elderly -– with intellectual and developmental disabilities, physical disabilities, behavioral health diagnoses (e.g., dementia), spinal cord or traumatic brain injuries, and/or disabling chronic conditions – all require LTSS. Elderly adults with disabilities are the primary beneficiaries of LTSS and are costly to the entire Medicaid program. They are part of a larger eligibility category commonly referred to as aged, blind, and disabled (ABD). While not all of the ABD population is in need of LTSS, they have an increased risk of becoming dependent and are the most expensive population served by Medicaid. This eligibility group comprises less than one-third of Medicaid beneficiaries but two-thirds of Medicaid spending.[9]

We recognize that the needs of these individuals are highly variable and complex. Addressing them as a whole, as we must in this paper, presents the danger of missing important nuances. Nonetheless, we have attempted to extrapolate the key commonalities to propose solutions that can improve caregiving for the entire spectrum of LTSS recipients.

CASE STUDY:
Gary Sullivan, National Advisory Board Member
(In his own words)

MY CONDITION: I am a 76-year-old married male who was diagnosed with a very rare form of muscular dystrophy at age 35. I have been confined to a wheelchair for 41 years and I would classify myself as a functional quadriplegic. I need assistance with all my activities of daily living which include: showering, grooming, toileting, dressing, ambulating, and eating. I also need to be turned several times during the night after going to bed. All of the foregoing assistance is necessary 7 days and 7 nights every week.

My wife is 75 years old, works part-time 3 days per week as a preschool teacher (necessary for the budget) and assists me 3 nights per week and all other times when a DSW is not here. I am extremely fortunate to have a healthy wife who is physically strong for her age. We live in a two-bedroom apartment. Our bedroom has twin beds with me in one bed and my wife or the DSW in the other. My wife sleeps in the 2nd bedroom in order to get some respite when she is not on duty.

THE ROLE OF THE DSW IN MY LIFE: When my wife is not on duty, the DSW is the first person I see in the morning and the last person I see before going to bed. She wakes me up in the morning, shows me my morning medications and after I confirm that it is correct, administers it to me. She then determines what I would like for breakfast and then prepares it. After preparing it, she feeds it to me. She then assists me with necessary toileting while still in bed. (I can only use urinals and bedpans). She then assists me with brushing my teeth, shaving and any other grooming/bathing tasks. She then asks me what I would like to wear for the day and assists me in getting dressed.

After I am dressed she uses a sliding board to transfer me into my wheelchair. She then puts the finishing touches on grooming (brushes hair, etc.). Once in my wheelchair I am usually “good to go” for the rest of the day unless I need to go to the bathroom, eat or do something that necessitates raising my arms or any other physical activity. The DSW then tidies up and goes home. The “morning routine” usually takes 3 – 4 hours. I have a total of 56 hours of home care per week.

Again, when my wife is not on duty, the DSW arrives around 10 PM and prepares me for bedtime. As she does in the morning, she administers my evening medication. She then transfers me from my wheelchair to my bed. She undresses me and assists with brushing my teeth. On occasion I watch television for a period of time and she then prepares me for sleep. This is a rather detailed process because when I am in a given position I am unable to change that position. On a normal night she will turn me 4 – 5 times. On a rough night she will turn me or change my position 8 – 10 times. At the appointed time in the morning, she will wake me up and go through the above referenced “morning routine.”

[8]uhc.com/NABQuality
[9]Medicaid and Long-Term Services and Supports: A Primer Kaiser Family Foundation.

A good DSW is distinguished by various characteristics rather than skills. Her ability to listen, understand, and execute detailed instructions correctly is critical, both for comfort and safety. She is characterized by her detailed care, delicacy and painstaking attention to duty... In a word, she is fastidious. An example of this is where the ordinary DSW feels triumphant to get her charge from the bed into the wheelchair alive; whereas a good DSW concerns herself with eliminating any fear possessed by her charge during the transfer and then ensures maximum comfort by eliminating clothing wrinkles and making sure that her charge is sitting comfortably in all respects. This very same attitude is even more important when placing her charge in bed, ensuring that the spreadsheet used for turning is wrinkle free and that her charge is situated properly for maximum comfort. A good DSW comes to work on time, every time and is free of conflict and other distractions. She focuses acutely on her charge and understands fully the awesome responsibility she has in being the makeweight for a person with one or more disabilities living a comfortable, enjoyable life, to the extent possible. A bad DSW could come to work anywhere from 10 minutes to a half hour after her appointed time and can act unprofessionally. Thus, rather than providing aid he or she becomes an additional burden to her charge.

The Direct Service Worker Profession

DSWs play a critical role in delivering care and supports necessary for people to live the lives they want as independently as possible. They can be the first to notice warning signs of sickness, decline or trouble for those they serve. They are entrusted to provide support for people of all ages with a variety of needs. Their work is not glamorous, but is often fundamental to maintaining health, independence and emotional wellbeing for those they provide care.

> There are roughly **2 million** home care workers delivering services across the country.
>
> Roughly **90%** are women, with a median age of 45, and more than half are people of color.

In addition, more than half of these individuals do not have any formal education beyond high school. Home care workers earn a median hourly wage of $10.11,[10] as a result one in four DSWs live below the federal poverty line.[11]

In America's market-driven economy, as the demand for workers in a particular industry increases, wages within that field will increase to attract more workers. However, wages for DSWs are comparatively low and have remained so despite increasing demand for workers. The wage pressures are a result of the way wages are set for the profession. Medicaid is the largest payer of LTSS in the United States; therefore, the majority of DSW wages are set by the Medicaid agency in a given state. Each state sets payment rates within the Medicaid program, either directly or negotiated through managed care organizations, for all participating provider types, from surgeons to home health aides. Due to the significant cost of Medicaid to state budgets, provider rates are constantly under pressure to remain as low as possible (while meeting the federal definition of "adequate") and are often targeted for cuts when state budgets require balancing.[12,13] Due to this structure, wages for DSWs remain largely stagnant and actually erode over time. Alternative jobs such as retail, food service and even private-pay LTSS are market-driven; with wages increasing in recent years as demand for workers has increased, creating a greater difference in pay compared to Medicaid LTSS and an attractive choice for the workforce.

DSWs have very difficult jobs. They perform work that is incredibly taxing, both physically and emotionally and require a level of personal involvement with their clients that no other profession requires. They are often isolated, with little interaction with colleagues and little support.

There are three general categories of DSWs – personal care aides, home health aides, and nursing assistants. The individuals working in each category play a crucial role in the delivery of services within programs that support people in need of LTSS and provide personal care and companionship. These tasks can include but are not limited to: bathing, shopping, homemaking, running errands, and light housekeeping tasks. While some tasks are standard throughout all three DSW categories, they differ in job responsibilities, required education and licensure levels.

Personal care aides (PCA): Generally provide non-medical services to assist people in conducting activities of daily living – such as dressing, eating and bathing. This category can be further broken down by the number and complexity of activities of daily living with which they assist their client. For example, the services of the DSW who care for a fully ambulatory elderly adult requiring minor assistance may be classified as "companion care" whereas the services of the DSW, who cares for a functionally quadriplegic adult who uses a wheelchair, are far more complex and intense.

[10]Bureau of Labor Statistics, U.S. Department of Labor, Occupational Outlook Handbook, 2016-17 Edition, Home Health Aides, on the Internet at https://www.bls.gov/ooh/healthcare/home-health-aides.htm

[11]http://phinational.org/sites/phinational.org/files/phi-home-care-workers-key-facts.pdf

[12]CMS, Coverage of Direct Service Workforce Continuing Education and Training within Medicaid Policy and Rate Setting: A Toolkit for State Medicaid Agencies. Available at https://www.medicaid.gov/medicaid/ltss/downloads/workforce/dsw-training-rates-toolkit.pdf

[13]For example, Oklahoma in 2017: "Drastic cuts could be coming for Medicaid patients in Oklahoma". Available at http://kfor.com/2017/04/11/drastic-cuts-could-be-coming-for-medicaid-patients-in-oklahoma/

Home health aides: Typically provide support with activities of daily living as well as basic medical care such as simple dressing changes and checking of vital signs. With appropriate training, home health aides can also give massages and assist with braces and mobility devices. States usually require individuals pass a certification exam to work as a home health aide; vocational schools and community colleges often offer training and certification programs for those aspiring to become home health aides.

Nursing assistants: In many cases, those working as nursing assistants are Certified Nursing Assistants (CNAs) and have passed a certification and training process that includes the home health aide certification as well as clinical components. In addition to assisting with activities that personal care aides and home health aides provide, CNAs can also check vital signs, change dressings, clean catheters, control infections, and administer treatments under the supervision of a Registered Nurse (RN) or Nurse Practitioner (NP).

CASE STUDY:
Professional Direct Service Worker Katy Kinard
(In her own words)

MY PROFESSIONAL JOURNEY: I've been a paid caregiver since 2002, so 15 years. For a college summer job, I worked with a 7-year old, Maddie,[14] with cerebral palsy through an agency that mostly specialized in elderly (late-life) care. They started asking if I'd like to be a fill-in caregiver for older adults, and so I did, and I loved it! I realized that it comes more naturally for me than working with children.

When I refer to my profession I personally call myself "caregiver". If a different name is used, I have to explain to others what I mean anyway, and I end up having to say "caregiver" to help them finally understand, so being politically correct or having a more prominent-sounding name almost ends up looking worse, because at the end of the conversation, it makes it seem like I was somehow ashamed to say "caregiver."

MY CURRENT CLIENTS: I primarily work with one individual who hired me directly through the state's Medicaid Managed Care program. This individual has significant functional limitations and requires substantial support for dressing, bathing, etc. It used to be that I'd have 3-4 pieced-together part-time clients on a regular basis. I technically still work with Maddie one day every three weeks, but it's more like a little-sister-big-sister thing to keep up the friendship.

FAVORITE PART OF MY JOB: My favorite part is physically doing tasks that I can see are making a tangible difference in someone's comfort level and quality of life. It doesn't feel like work to me but rather, the joy one might get from volunteer work, only I have the added bonus of getting paid! I also get great satisfaction in true friendships with my clients, and some of this stems from idolizing my grandparents when I was younger/ wanting their approval and friendship...those kinds of self-reflections.

MY BIGGEST CHALLENGES: I would say personality conflicts in general have been the most difficult, because sometimes the lines get blurred between "worker" and "good friend"... and both parties are liable to feel hurt and misunderstood at times. I think I can improve this by remembering my main role is being a paid worker for their needs, not my emotional ones.

I also think the biggest challenge in being a long-term caregiver is being an hourly worker without salary, health benefits, and paid leave. I have other jobs to supplement this, but I'm not sure caregiving can be a career for me moving forward if I stay unmarried, getting older on one income.

My current job is very physically demanding. It's a big difference from companion care. The pay scale should vary based on companion care vs. hands-on physical labor and increased due to the extent of activities. Mental exhaustion is no less important than physical exhaustion.

MOST VALUABLE TRAINING: Life-saving training is most important. Otherwise, my most valuable training has been from the individuals themselves communicating clearly what they prefer throughout their daily schedule.

In times past, this has not been communicated clearly, and notes from other caregivers have been my saving grace and most helpful "training:" (e.g., Ms. J does not like her coffee served to her with breakfast. She expects it served after her meal."). Training for someone's personality is just as important, in my opinion. I started keeping notes about preferences and keeping it in the caregiver folder. It saves frustration and sanity for both parties, as clients do not like "re-training" caregivers when it comes to pre-expected preferences they don't like to voice.

If agencies would encourage these notes to be kept up in the caregiver folder and new workers persuaded to study this before the first day on the job, including pet peeves, arguments, etc., it would eliminate premature firing (or quitting) and would bond the caregiver/client relationship sooner.

14 This individual's name has been changed

The Challenge: The Direct Service Worker Shortage

The problem is, at its heart, a simple one. There are not enough qualified DSWs and the demand continues to grow. The reasons for this shortage are numerous and complex.

> From 2005 to 2015, the DSW workforce doubled from
> **700,000** to over
> **1.4 million**[15]

The majority of that growth was in personal care aides. From 2014-2024, the demand for DSWs is expected to grow by 633,100 jobs, more than any other single occupation.[16]

However, a number of factors are contributing to a shortage of qualified individuals entering the profession. As the national unemployment rate has dipped below 5% there are currently multiple, more desirable alternatives for workers – such as opportunities in the retail and fast food industries which provide similar, and sometimes higher, pay for less stressful work.

As mentioned above, the job is demanding and wages are low, making it difficult to attract and retain highly qualified individuals. Due to the shortage and more attractive alternatives available the workforce, the overall quality of the DSW workforce is eroding as less qualified individuals are hired to meet needs – therefore, further contributing to the shortage. Recurrent failure, imbedded in the industry's core structure, to provide adequate wages, benefits, training, clear role delineation, and career pathways has reflected poorly on the public image and perception of these positions and has contributed to the stigmatization of the DSW. Addressing the DSW shortage will require solving for each of these factors and removing the stigma of the DSW profession.

To create strategies to improve the quality of the DSW experience, it is important to document the key challenges. These challenges can be broken down into two categories: challenges for the DSWs and challenges for the individual in need of support. The difficulties inherent in the DSW profession exacerbate shortages in the workforce. The challenges to individuals cause gaps in coverage and unnecessary hardship.

The explosion of demand cannot (and should not) be curbed, so solutions need to operate under the presumption that it will continue. Therefore, it is important to focus solutions on impact factors other than the rising demand.

CMS has documented additional factors that exacerbate the issue:[17,18]

> **Recruitment, Vacancies, and Turnover:** High rates of turnover affect quality of service as they create additional cost and a gap in service. The estimated cost of training a new worker is $4,872.
>
> **Training and Education:** State training requirements are lax and disparate. This leads to varying levels of training and competencies in the DSW workforce.
>
> **Competitive Wages and Benefits:** Despite the enormous growth in demand, DSW wages have actually declined over the past decade (the national average is just over $10 per hour, but in some markets it is considerably less). Jobs with similar wages (e.g. fast food, hospitality) are less demanding, and therefore recruiting for DSW positions is very difficult. The majority of DSWs currently do not receive employment benefits.
>
> **DSW Career Paths:** DSW positions do not have a clear growth trajectory into higher wage, more desirable jobs.
>
> **Isolation of DSWs:** DSW positions are often isolating. Workers do not have natural interaction with co-workers and supervisors, yet they face extremely trying circumstances.

These factors exacerbate the increased demand and help lead to both shortages and a reduction in quality. They also make it more difficult to insist that DSWs undergo rigorous pre-qualifications (such as pre-employment training), since those can be an expensive barrier to entry to the profession.

Challenges for Individuals Served by DSWs

The people who are most affected by shortages and reductions in quality are people DSWs serve. The variations in quality and the demand have incredible downstream impacts on quality of life and costs.

[15]http://phinational.org/sites/phinational.org/files/phi-home-care-workers-key-facts.pdf

[16]Ibid.

[17]Coverage of Direct Service Workforce Training within Medicaid Policy and Rate Setting, A Toolkit

[18]A Synthesis of Direct Service Workforce Demographics and Challenges Across Intellectual/Developmental Disabilities, Aging, Physical Disabilities, and Behavioral Health (Hewitt et al., 2008).

CASE STUDY:
Gary Sullivan, National Advisory Board Member
(In his own words)

"Incredibly, here's the timeline I must inform my new employee of:

1. **I hire her and complete all of the paperwork today, November 2.**
2. **I must tell her that she probably will not be able to start work (at the earliest) until November 14. I also tell her that she will be paid on a biweekly basis.**
3. **If everyone has done their job properly (which means I must stay on top of just about everybody in the process) and she is able to start on November 14, and further, she works all of her assigned hours during that pay period (November 13 – November 26), her timesheet will be submitted on November 28 and she will be paid for the first time on December 12.**

Yes, you read that right. I hired her on November 2, she started work on November 14, and was paid for the first time on December 12. I am sure that you can readily see that there are great and long lines at my door trying to get a job as my DSW."

Agency vs. Self-Directed Models

Individuals can find a DSW through one of two models – through an agency or on their own (often referred to as "Self Direction" or "Consumer Direction").

In the agency model, the agency receives payment for services delivered from the payer and is the employer of the DSW. The agency is responsible for hiring (including conducting appropriate background checks), training, and scheduling the DSW and is also responsible to provide back-up workers in the event a regularly-scheduled DSW is unable to meet their appointment. While in the agency model the agency manages much of the administrative burden of sourcing a DSW, there can be challenges regarding continuity of service and lack of transparency and flexibility for the individual.

Individuals who choose the self-directed model have more flexibility in finding a DSW and can target those workers that are qualified to meet their unique needs. But self-directed individuals also face additional burdens. If they find and hire the DSW themselves, they are considered the employer of record, but they often face challenges in finding, securing, training, managing and handling administrative needs for a DSW. To find a DSW, many individuals have to use traditional job websites (such as Craigslist or Care.com) that are not tailored to their needs. They then hope that they receive applications from qualified applicants, but there are no guarantees.

Even after someone has found a qualified DSW, there are significant hurdles to overcome. In many cases, the DSW must pass a background check, have a current First Aid/ CPR certification, have two different forms of identification acceptable for I-9 purposes, sign an Service Agreement which exculpates multiple parties from liability for anything that may happen to her/him during the employment period, and agree that she/he will abide by all of the rules of the engagement.

In addition to these administrative challenges, individuals looking to hire DSWs sometimes struggle with relational difficulties of having an employee conduct very personal tasks for them. Having duties related to bathing, toileting, and other intimate tasks create a workplace dynamic between employer and employee that can often strain the relationship. DSWs also have to navigate family dynamics that can prove to be tense. All of these factors complicate the relationship and make the job even more demanding.

Pathways to Improvements

Managed Care Organizations (MCOs) can play a crucial role in improving the effectiveness of direct service. As one observer wrote, the movement into less acute settings and whole person, inter-disciplinary care, "creates an opportunity to upgrade the skills and increase the responsibilities of pre-baccalaureate workers to improve both the nature of the jobs and the performance of the healthcare system."[19]

MCOs offer the ability to develop strategies reliant on greater volume and resources (financial, technological, expertise). MCOs also have experience leveraging integrated care teams in their health plan operations. DSWs can be a critical part of these care teams, as they have a unique insight into changes in the members' health. The experience of coordinating these teams positions health plans for finding opportunities to better engage DSW into care strategies.

As discussed further below, there is also evidence to suggest that improved caregiving and better coordination with care coordinators within managed care plans results in significant medical cost savings.

[19]Part of the Solution: Pre-Baccalaureate Healthcare Workers in a Time of Health System Change, Metropolitan Policy Program at Brookings, July 2014

Below is a list of solutions health plans can institute to improve the overall quality of support for those they serve. These solutions can be divided into two categories:

- Efforts that would improve the competency and effectiveness of available DSWs ; and
- Efforts that would make the individual experience of hiring a DSW better.

Tiered Competency-based Training

Core Competencies are a critical element of any effective workforce development program. Effective training can impact employee retention, job satisfaction, independence, relationships between workers and individuals, communication between medical personnel and DSWs (to the extent the individual receiving support wants and needs this communication), and it can lead to improved clinical outcomes. It can also further decrease employee absenteeism and acute conditions.[20]

State requirements for competency-based training for DSWs are highly variable. Below is an attempt to synthesize disparate state requirements:[21]

- 23 states have no training requirements of any kind (45%)
- 27 states leave the sufficiency of PCA training to the agency-employer (53%)
- 25 states specify required training hours for PCAs (49%); but, of these, 14 require no more than 40 hours of entry-level training
- About one-fourth of states have a state-sponsored PCA curriculum and/or certification.
- 10 states have no training requirements in any of their programs (20%)
- 7 states have training requirements for PCAs in all programs, but they are not uniform (14%)
- 22 states have uniform training requirements for PCAs across all programs; only 5 specify detailed skills and a curriculum for PCAs. Also 4 of the 22 require PCAs to complete home health aide training

Though the training requirements are variable, CMS has published a list of key Core Competencies that the training should develop in DSWs:[22]

COMPETENCY	DESCRIPTION
Communication	The DSW recognizes communication as a core function of support and uses person first language and effective communication skills to establish a supportive and collaborative relationship
Facilitation of Individualized Services	Provides person-centered services to support participant's preferences, strengths, interests and goals, and participates in multidisciplinary teams
Crisis Prevention and Intervention	DSW identifies potential risks, crisis situations and/or behaviors, and uses appropriate procedures to de-escalate the situations
Dignity of Risk	DSW demonstrates respect for the individual's autonomy and self-determination (or "dignity") to make choices for himself or herself.
Safety	DSW understand ways to support a participant to be safe and adhere to procedures necessary to maintain a safe environment
Professionalism and Ethics	DSW demonstrates professionalism by respecting participant rights in accordance with relevant ethical standards and legal protections
Participant Empowerment	DSW supports the participant to lead a self-determined life by providing information necessary to make informed decisions and advocate on his or her own behalf, when needed
Advocacy	DSW understands diverse challenges and is able to identify and use effective strategies to overcome them
Supporting Health and Wellness	DSW assists the participant and supports the development of skills to maintain health and wellness in all areas of his or her life
Interpersonal and Family Relationships	DSW engages in support that recognizes, respects and values the role of family and social relationships as an essential component of quality of life and community living

[20]Larson, Lakin, Bruininks, 1998.

[21]DirectCourse Course Catalog CPAC State by State Training Requirements. April, 2016

[22]Road Map of Core Competencies for the Direct Service Workforce

COMPETENCY	DESCRIPTION
Community and Service Networking	DSW is familiar with formal and informal supports available in his or her community and skilled in assisting the participant to identify and gain access to such supports
Cultural Competency	DSW engages in support that recognizes and values diverse worldviews and experiences and is capable of adopting supports to the unique needs of participants in a culturally competent way
Education, Training and Self-development	DSW identifies and seeks opportunities for profession development, education and training as appropriate to the participant and reflecting emerging evidence based practices

Notably, while Medicaid funds cannot be used for recruitment or initial training of DSWs, they can be used to pay for continuing education of DSWs. MCOs managing LTSS contracts can facilitate agency and state usage of these funds to help train DSWs in the key competencies necessary to be an effective DSW. For example, in Vermont's self-directed program individuals and their workers can design and submit individualized requests for training.[23] Better training in these core competencies could reduce overall costs by reducing preventable medical utilization.

Better Alignment with Health Plans

MCOs are responsible for improving quality of care and reducing costs. To do this, they must create care teams with multiple capabilities that can address all of the needs of their members. The focal point of those teams is frequently a "Care Coordinator."

Care Coordinators assist members with obtaining the proper services at the proper time. They help individuals to sequence their care in a way that results in better quality of life and better medical outcomes. They also attempt to avoid acute health incidents by offering preventive solutions before hospitalization is required. When hospitalizations are needed, the Care Coordinators play a critical role in supporting successful transitions back to the community to reduce chances of re-admission to the hospitals. Care Coordinators rely on data from medical claims, health risk assessments, and direct communication with the members in order to inform their care plans. While they communicate with DSWs, communication practices are not standardized and the benefit of that communication is not fully understood.

We believe that better communication between DSWs and Care Coordinators, essentially making DSWs part of the larger care team, will help prevent acute conditions and hospitalizations. For instance, a DSW could inform a Care Coordinator that a member is refusing to eat and showing signs of depression. The Care Coordinator could then explore the possibility of getting a behavioral health professional to see the member before the condition gets worse.

There are several ways to establish a line of communication between Care Coordinators and DSWs. DSWs could be provided with training to inform them of the assistance a care coordinator can provide. Further, DSWs could be provided with contact information or a web-based portal to pass along critical information about the patient's well-being. Training of both DSWs and Care Coordinators should reflect the importance of the linkage between them. Under this model, the DSW would not replace or distance the individual from the care planning process within the care team and all members of the care team, including the DSW, would collaborate with the individual in any decision-making.

UnitedHealthcare has pursued a pilot improving line of sight between Care Teams and DSWs in New Mexico with Addus HomeCare, Inc. through our New Mexico Health Plan. That pilot is not mature enough to report on outcomes, but communication between the DSWs and Care Teams has been successful. The financial outcomes associated with similar pilots are discussed below.

Enhanced Directories

Individuals who choose self-direction have limited options for finding a DSW. CMS recently recommended open registries[24] as there are many job boards and directories that compile applicants for DSW positions. However, those boards are often limited in their usefulness to individuals. The information on the board is often out of date (because DSWs who register quickly find another job) or insufficient (because it does not provide enough information on a DSWs qualifications). This creates a mismatch between the need and the available workforce, and creates additional lag time between when a DSW leaves employment and when a new one is found.

In order to provide more substantial assistance to those seeking a DSW, directories need to be enhanced with more personalized services. For example, both members and DSW

[23]Department of Disabilities, Aging, and Independent Living: Division of Disability and Aging Services. Handbook for People Who Self-or Family-Manage Medicaid Waiver Services. Available at: http://www.ddas.vermont.gov/ddas-publications/publications-dds/publications-dds-documents/dds-publications-other/dds-pub-other-handbook-self-family-manage-medicaid

[24]https://www.medicaid.gov/federal-policy-guidance/downloads/cib080316.pdf

candidates should be called and interviewed when they register. Their needs and qualifications should be matched, and the member should be provided with (ideally) several candidates that fit his or her needs. In addition, information should be continually updated so that applicants that are no longer interested are removed from the directory.

An enhanced directory will also help attract new workers. Currently, DSWs who work in the field often have to actively seek relevant postings. A better interface will make it easier for willing DSWs to find more hours, and thus keep them more engaged in the profession.

Peer Supports

DSWs often experience isolation while performing their incredibly emotionally taxing job. Many do not have any natural interactions with co-workers or managers to support them. A peer support program could help prevent isolation and depression. It could also be used as a training mechanism in which a peer naturally has opportunities to pass on key lessons in caring for individuals.

Improving Wages

As stated above, wages for DSWs have been stagnant for nearly a decade. CMS has identified several strategies to help increase DSW wages and benefits.[25] Those include

- Wage Pass-Through Legislation
- Rate Enhancements Linked to Provider Performance Goals
- Reform of Methods For Rebasing and Updating Reimbursement Rates

Wage pass-throughs are the most common means of stimulating increased DSW wages. Pass-through programs permit additional state Medicaid funds to be added to reimbursement rates and used for the sole purpose of being passed through to workers. The amount is calculated in one of two ways: either the amount of wage per hour is increased through the Medicaid reimbursement rate or providers are given a percentage of a specific rate increase. CMS reported in 2013 that, "A 1999 survey found that 10 of 16 states implementing wage pass-through programs used [the per hour] method with pass through amounts ranging from 50 cents to $2.14 per hour...[and] 6 of 16 states established wage pass through programs as a percentage of the increased reimbursement rate."

Pass-throughs create higher wages, which result in lower turnover and higher quality. One study found that workers who worked in the 20 states that had implemented pass-through programs earned as much as 12% more per hour than workers in states that had not implemented pass-through programs.[26] Another found that pass-throughs resulted in 3-4% increases in nurse aid hours.[27] In conjunction, CMS estimated that worker wages would have to increase by 10 to 22% in order to reach minimum adequate staffing levels in LTSS. Additionally, a pass-through program in Wyoming created an increase of average wages of over $3.00 over four years, resulting in a corresponding reduction of turnover rates from 52% to 32%.[28]

We believe that additional evidence would enhance the advocacy case for better wages by showing net savings.

Career Pathways

Another critical element of any effective workforce plan is developing a "career pathway." Career pathways are strategies to help workers develop credentials and skills that are not only relevant to their current job, but also position them for advancement in the future.[29] As CMS noted: "Linking wage increases to workers' advancement in training programs (i.e. career pathways, apprenticeships, credentialing, or certification programs) represents an important coordinated strategy that may be implemented on the state level."[30]

DSWs do not have an obvious career progression available to them and since they often are not required to obtain a significant certification, they do not have any credential that can be leveraged into a higher paying job. Indeed.com names customer service representatives, cashiers, retail sales associate, receptionist, and nursing assistant as potential career paths for DSWs. We believe that DSWs develop key skills that are applicable to other professions in the caregiving industry, particularly care coordinators, life coaches, customer and provider services representatives employed by insurance companies. In each of these roles, the health plans are looking for individuals who have an understanding and compassion for the individuals we serve. Creating a career path is one way of exhibiting culture change on top of higher wages.

The PATHS program at Texas A&M is a potentially promising model for developing career pathways within the DSW industry. The PATHS Certificate Program at Texas A&M University provides training to individuals with intellectual disabilities to

[25]Coverage of Direct Service Workforce Continuing Education and Training within Medicaid Policy and Rate Setting: A Toolkit for State Medicaid Agencies, August 2013
[26]Baughman and Smith
[27]Feng and colleagues
[28]Lynnch Fortune, Mikesell, & Walling, 2005, Sherard 2002
[29]DOL Career Pathways Toolkit: A Guide for System Development
[30]Coverage of Direct Service Workforce Continuing Education and Training within Medicaid Policy and Rate Setting: A Toolkit for State Medicaid Agencies, August 2013

become DSWs or child care professionals. This two semester certificate program prepares graduates for employment in a career serving people with disabilities or working with children.[31]

Health Plans should supplement agency and self-directed recruitment efforts by defining career pathways in the health care industry for DSWs. They should, where possible, seek to hire DSWs to higher paying positions, demonstrating the value of the experience as a DSW toward larger career goals.

The Benefits of Investing in the DSW Workforce – A Business Case

To bolster the argument for investment in the DSW workforce, it must be shown that improved caregiving results in improved quality and overall cost savings. More specifically, it must be shown that there is ultimately a return on investment through overall costs savings associated with keeping people out of hospitals and institutions and reducing turnover in the workforce.

There two key areas of cost that can be impacted by the solutions proposed in this paper: (1) recruitment, retention and turnover costs, and (2) medical cost savings based on improved services and better coordination with care teams. Evidence for cost savings based on improving the DSW is not fully developed, but there are significant indications that they would be substantial.

It is widely recognized that low wages result in greater turnover in the profession.[32,33] In addition, research indicates that even small increases in DSW salaries can lead to more effective recruiting and retention. Turnover increases costs and results in degradation of service quality. As CMS puts it: "High rates of worker turnover are a key barrier to the delivery of quality services. Consequences of the turnover of direct service workers are significant, as the estimated cost of hiring and training new workers is $4,872 per position and worker vacancy rates can result in increased stress on the remaining workforce."

A recently published study indicates that better trained DSWs results in substantial reductions in health care utilization.[34] The study found that California residents were less likely to utilize emergency or inpatient services after their DSWs received key training. The DSWs involved in the program were given CPR, first aid, infection control, and other training. The study showed that in the 136 residents with DSWs who received the training, emergency department visits declined by 24% in the first year following training and 41% in the following year. The 2,000 residents whose DSWs did not receive the training did not show declines.

We are not aware of a study exploring the impact of better coordination between DSWs and MCO care teams. However, our substantial experience in care coordination leads us to believe that the impact would be substantial. If care teams have access to qualitative information about members' health, it will allow them to intervene earlier and prevent acute incidents.

While the exact return on investment of increased wages will vary considerably we encourage states, DSW agencies, and MCOs to conduct rigorous financial analyses to determine the true cost of turnover.

[31]http://paths.tamu.edu/

[32]University of Minnesota (UMN), Research and Training Center on Community Living in partnership with The Lewin Group. (2006). CMS Direct Service Workforce Demonstration Promising Practices in Marketing, Recruitment and Selection Interventions. Retrieved from http://www.dswresourcecenter.org/tiki-download_file.php?fileId=11

[33]Wright, B. (2009). Strategies for improving DSW recruitment, retention, and quality: What we know about what works, what doesn't, and research gaps. National Direct Service Workforce Resource Center; The Lewin Group. Retrieved from http://www.dswresourcecenter.org/tiki-index.php?page=Reports see also Senecal, J. K., Livingston, J. A., & Reback, D. (2008). Legislative study of the direct care workforce in Vermont. Retrieved from http://dail.vermont.gov/dail-publications/publications-legis-studies/dcw-report-exec-summary

[34]Gorman, Kaiser Health News, 8/11

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