November 18, 2014

To: The Robert G Bethel Joint Committee on Home and Community Based Services and Kan-Care Oversight

From: Joan Kelley, Legal guardian, Stakeholder, and Vice-President, KNI Parent Guardian Group

Re: Systemic Solutions, Supreme Court Ruling and Guidance

Good morning Chairman, and members of the Committee,
Thank you for your ongoing commitment to oversee the Kansas system serving our most vulnerable.

Reforms
Early reforms to appalling, isolated institutional conditions were necessary and properly motivated by the need to create a system of supports, responding to the diverse needs of the entire spectrum of people with Intellectual and Developmental Disabilities (I/DD). These reforms set the stage for decades of deinstitutionalization, yet have resulted currently, in an aftermath of deaths, abuse and systemic deficiencies that we sought to eliminate through such reforms. We as a State, decided 20 years ago to put into place commendable reforms. However, now appalling conditions have widely surfaced in community settings across our nation, leaving some to question the price of "progress."
See: Abuse 2014 document, submitted to the Joint Committee, August 12, 2014

Accountability
While robust oversight is often promised, the 2011 KNI Legislative Post audit gave insight into systemic deficiencies that ideally, would be re-designed to adequately protect our most defenseless citizens.

Since the State of Kansas does not track certain safety outcomes, there is, according to the 2011 Legislative Post Audit, no way to compare safety in community with that of facilities like the Kansas Neurological Institute. KNI currently provides a continuum of care for the state's most vulnerable, operating under stricter Federal guidelines and regulations. Quoting from the Post Audit:

"We couldn't compare abuse, neglect or exploitation statistics because the data aren't readily available for the community. (SRS) has a Kansas Protection Report Center which receives calls on allegations of abuse, neglect, and exploitation (critical incidents) for adults and children. Staff within the Division of Community Supports and Services screens and investigates those reports dealing with individuals with developmental disabilities living in the community.

Although the Division collects the data, it doesn't maintain it in a way to produce abuse and neglect statistics for adults with developmental disabilities living in the community (e.g. number of alleged and confirmed critical incidents). While

each of the 27 CDDO regions also report critical incident data back to (SRS), we didn't feel comfortable relying on that data without further work. As a result, we couldn't compare safety outcomes for KNI residents with individuals living in the community."

There is a compelling need for both community-based programs and centralized care, according to the 1999 Supreme Court Olmstead ruling. States need to operate a range of services to meet the diverse requirements of persons with disabilities and their families.

Olmstead

A majority of Justices in Olmstead recognized an ongoing role for publicly and privately- operated institutions:

"We emphasize that nothing in the Americans with Disabilities Act or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187

The plurality opinion in Olmstead stated:
"Each disabled person is entitled to treatment in the most integrated setting possible for that person - recognizing on a case-by-case basis, that setting may be an institution." 119 S. Ct. at 2189.

The Olmstead decision supports facility-based (institutional) care for those individuals whose severe impairments require the close care found in such settings.

"Unjustified isolation, we hold, is properly regarding as discrimination based on disability. But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand." 119 S. Ct. at 2185.

Provisions clarified above by the Supreme Court Justices are often omitted, thereby misconstruing the Olmstead Decision as an integration "mandate" for community placement only, and sadly, has led to numerous civil rights violations of the weakest members of our society.

Quality of Care
Accusations that residents of our State ICF-ID facilities are "isolated" ignore the Person Centered system that has been implemented at KNI for over ten years.

By comparison, staff rationing and alarmingly high Community staff turnover rates creates isolation as well as an environment for unreported abuse. Diminishing incentive to retain quality staff is reflected in the pervasive, stagnant wage crisis in an underfunded system.

Forcing limited admissions to state facilities exacerbates facility costs, instead of creatively utilizing the safety net available to assist families in crisis, maximizing the potential of a centralized campus. On the KNI campus of homes, dedicated staff serve those with the most profound, cognitive impairments, **and provide ancillary services** that support those living in the community, assisting them to remain in their communities. **Attached: Characteristics of KNI**

The direct correlation between staff turnover and abuse has not been adequately addressed. High staff turnover adds to the complex issues of training, cost of such ongoing training, and inconsistent care, where client most significantly suffers.

These disparities bring into question the integrity of claims that our fragile ones are and will be "well cared for" in a community of scattered homes with inadequate oversight.

In conjunction with the University of Minnesota's Research and Training Center on Community Living, the need for monitoring and data collection of Direct Support Workers is a critical first step to sound policy-making for long term sustainability. **Attached: The Need for Monitoring the Long-Term Care Direct Service Workforce and Recommendations for Data Collection, February 2009**

Prepared by the National Direct Service Workforce Resource Center
www.dswresourcecenter.org

Excerpts: U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy

"THE SUPPLY OF DIRECT SUPPORT PROFESSIONALS SERVING INDIVIDUALS WITH INTELLECTUAL DISABILITIES AND OTHER DEVELOPMENTAL DISABILITIES:

REPORT TO CONGRESS January 2006 Wages and Turnover differences in institutional vs community in HHS Report to Congress, 2006

TABLE 5. DSP Wages and Turnover Differences for Community vs. Institutional

Public Institution	Community Services
1979 Starting Wage	
$4.01	$3.49
1990 Average wage	
$8.72	$5.97
1998-2002 Average wage	

$11.67	$8.68

Turnover

Public Institutions	Community Services
28%	50%
(KNI: 15%)	(KS Communities: 60%)

I have included additional critical information, but will honor time limits and close.

On behalf of those voiceless individuals unable to be here and advocate for themselves, I close by respectfully imploring this Committee: Let us consider these things, as well as take the high road, showing compassion by truly serving those who most need our assistance and voice, both in the community and in State facilities.

Respectfully submitted,

Joan Kelley

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KANSAS NEUROLOGICAL INSTITUTE

Our mission is to support each person who lives at KNI to have a meaningful life.
We will accomplish this by:

- Ensuring well-being
- Providing opportunities for choice
- Promoting personal relationships
- Encouraging participation in the community
- Recognizing individuality

KNI strives to provide services in a person-centered manner in order to meet and exceed the expectations of the people who live here and of their family members and guardians.

1. **Characteristics and the needs of the people who live at KNI.**
    - All need 24-hour support and intensive support from direct support professionals
    - 82% have profound disabilities; most others have severe disabilities
    - All are adults (ages 18 to 74)
    - 60% over the of age 50; 85% over the age of 40
    - Median length of stay at KNI 35 years; 90% have lived at KNI for 10+ years
    - 50% are unable to walk
    - 78% are unable to speak
    - 80% are incontinent or unable to use the toilet without assistance
    - 71% have seizures or a history of seizures
    - 28% unable to eat by mouth; receive nutrition via tubes
    - 8% have tracheostomies
    - 21% are prescribed psychotropic medications
    - 32% require specialized behavior support services
    - Over 90 admissions to acute care hospitals in 2013
    - Over 119 admissions to KNI Medical Unit in 2013
    - Over 1.8 million nursing interventions in 2013
    - Great need for assistive technology (personalized seating systems and other equipment)
    - 78% have supported employment positions (1-2 hours/week to several hours/day)

2. **Staffing at KNI**
    - Budgeted in FY 2015 for 473.2 FTE staff (approximately 450 filled)
    - 313 FTE Direct Support (home staff & frontline supervisors, employment, advocacy, etc.)
    - 58.7 FTE Medical/Clinical (medical, nursing, therapies)
    - 85.5 FTE Program Support (facilities & maintenance, business, HR, training, etc.)
    - 16.0 FTE Administrative
    - 310 hours training for Direct Support Professionals in 1st year of employment
    - All Direct Support Professionals trained as Certified Nurse Assistants & Certified Medication Aides (over 105 hours of training) reducing the number of LPNs needed.
    - Turnover rate of 15% in direct support positions
    - Direct Support Professional average pay--$12.76 per hour
    - Physician on-call 24/7
    - Nurses on site 24/7
    - Dentist on staff

3. **Outreach services provided by KNI**
    - Wheelchair clinic served approximately 280 people from the community in FY 2014
    - Assistive Technology department served 300 people from the community in FY 2014
    - Dental services served 111 people from the community in FY 2014
    - Behavior support and Medical services provided to 35 people from the community in FY 2014
    - Training support through on-line training packages & on-site training
    - Philosophy of meeting needs in home communities & increasing community capacity
    - Partner with community agencies for Harvesters food distribution, blood drives, United Way, Project Topeka, classroom space, soccer fields, etc.

4. **How family members and guardians feel about the services provided to their loved ones at KNI**
    - Transition to community services is available to all guardians who desire it
    - Few have been interested in giving serious consideration to a transfer to community service system
    - Annual survey of guardians in 2013 showed overall satisfaction with supports rated 4.8 on a scale of 1-5

5. **KNI provides person-centered supports that enhance a person's quality of life**
    - People at KNI live in unique homes, typically in groups of 7-8 compatible people
    - People have generally shared their homes with the same group of people for many years & experience continuity and security
    - People have opportunities to establish daily routines, opportunities for privacy, opportunities to be with family , friends and people they like
    - The current populations at KNI (146) contrasts with the "licensed capacity established for a 1970s institutional model (454) and makes a vastly better quality of life possible
    - People have frequent opportunities to participate & interact in the community (shopping, social & recreational events, employment, family contact, etc.)
    - People have access to the staffing & transportation that promote access to the community
    - People are employed & earn money they can spend on items and activities that are important to them

6. **The cost of services at KNI includes many expenses that are not included in Home & Community Based Services rates such as:**
    - Primary medical care (Medical staff & 24/7 on-call physician)
    - 24 hour on-site nursing care
    - Services in KNI's Medical Unit to reduce need for ER and acute care services
    - Dental services (for people living at KNI & through outreach services)
    - Service coordination (Targeted Case Management)
    - Transportation, including lift vehicles
    - Food or nutritional formula for those who do not eat by mouth
    - Customized assistive technology services (wheelchairs & assistive technology—for people living at KNI & through outreach services)
    - Highly accessible physical environments with specialized tubs, lift equipment and other environmental modifications
    - Occupational and physical therapy services
    - Adult disposable briefs
    - Housing, utilities and maintenance
    - Medication

- Services from medical specialists (optometry, podiatry, seizure clinic)
- Dietitian services, particularly for those who do not eat by mouth
- Home furnishings
- More highly trained and better paid direct support staff

The Need for Monitoring the Long-Term Care Direct Service Workforce and Recommendations for Data Collection

February 2009

Prepared by the National Direct Service Workforce Resource Center
www.dswresourcecenter.org

PHI

University of Minnesota Research and Training Center on Community Living

The Lewin Group

Westchester Consulting

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Acknowledgments: The primary authors of this paper are Steve Edelstein, National Policy Director at PHI, Dorie Seavey, Director of Policy Research at PHI, and Sheryl Larson, Senior Research Associate at the University of Minnesota Research and Training Center on Community Living. Several other members of the technical assistance team at the DSW Resource Center are gratefully acknowledged (Carrie Blakeway and Bernadette Wright at The Lewin Group and Sue Flanagan at Westchester Consulting). In addition, helpful feedback was received from several federal partners of the DSW Resource Center, including the Center for Medicare and Medicaid Services, Department of Labor, Office of the Assistant Secretary for Planning and Evaluation, Office on Disability, and the National Center for Health Statistics. Finally, the paper benefited from in-depth comments from officials in 13 states who are involved with workforce development initiatives relating to the direct service workforce. **(see Appendix D).**

The Direct Service Workforce Resource Center

The National Direct Service Workforce Resource Center was created by the Centers for Medicare and Medicaid Services in 2006 to respond to the large and growing shortage of workers who provide direct care and personal assistance to individuals who need long-term supports and services in the United States. The Resource Center supports efforts to improve recruitment and retention of workers who assist people with disabilities and older adults to live independently and with dignity in the community. This includes direct support professionals, personal care attendants, personal assistance providers, home care aides, home health aides, and others.

The Resource Center offers:

- A comprehensive online searchable database (www.dswresourcecenter.org) of resources, research, best practices, and policy briefs related to improving recruitment and retention of DSWs
- Access to information, resources, and advice from a diverse and experienced team of direct service workforce policy professionals through a national toll-free telephone number (1-877-822-2647)
- Individualized, in-depth technical assistance for selected State Medicaid Agencies

The technical assistance providers include:

- The Lewin Group
- Institute for the Future of Aging Services
- PHI (formerly the Paraprofessional Healthcare Institute)
- Research and Training Center on Community Living, University of Minnesota
- Westchester Consulting

Executive Summary

Around the country, states are grappling with how to meet the escalating demand for long-term care (LTC) services and supports while at the same time re-orienting their long-term care service delivery systems toward home- and community-based settings and away from institutional ones. A growing number of states are realizing that a commensurate emphasis on workforce policy is key to achieving the twin goals of increasing the volume of services provided and offering care in the least restrictive settings possible.

LTC services and supports are by their nature extremely labor intensive, assisting individuals with the most intimate self-care tasks, and other activities of daily living (ADLs) and instrumental activities of daily living (IADL).* Direct service workers—a paid workforce currently totaling about three million nationwide—constitute the main input or "factor of production" into these services and supports. But this workforce shows classic signs of workforce instability, including high turnover and vacancy rates. Policymakers need to recognize the increasingly essential role that paid aides and caregivers play in LTC, their particular needs and circumstances as low-wage workers, and the unique character of home- and community-based services, including their often part-time and episodic nature.

As more and more states launch efforts to improve workforce quality and stability, policymakers are hampered by a lack of ongoing, reliable state-based information about their direct service workforce. State LTC service delivery systems have management information systems (MIS) that account for and reimburse services delivered, and these can often be used to obtain information on the consumers served, units of service provided, and expenditures. But these systems are rarely set up to gather and report on basic information about the direct service workforce that could be used by state policymakers to assess how their state's workforce is changing or improving, and where the challenges lie.

This White Paper proposes that states collect a minimum data set of information on their direct service workforce across LTC settings that includes three basic elements : (1) numbers of direct service workers (full time and part time), (2) stability of workforce (turnover and vacancies), and (3) average compensation of workers (wages and benefits). The paper argues that this information is essential for states to know in order to assess the magnitude of their workforce issues, design appropriate policy responses, and, finally, assess the impact of new policies and/or trends over time.

These recommendations have been developed by CMS's Direct Service Workforce Center Resource Center, an historic collaborative effort of the nation's key workforce experts who span service systems for individuals of all ages with physical, developmental, or intellectual disabilities, and with chronic illnesses and end-of-life care needs. They are informed by the Resource Center's experience providing in-depth technical assistance to 15 states and general assistance to a dozen more states, in order to help them strengthen their direct service workforces.

**ADLs refer to activities such bathing, dressing, eating, toileting, transferring, and walking across the room. IADLs refer to activities needed to remain independent such as shopping for groceries, preparing hot meals, using the telephone, taking medications, and managing money.*

1. Long-Term Care Systems Change and The Role Of Workforce

Around the country, states are grappling with how to meet the increasing demand for long-term care (LTC) services and supports while at the same time re-orienting their LTC service delivery systems toward home- and community-based settings and away from institutional ones, such as nursing facilities. Tackling these two issues has led many states to embark on reforming the fragmented structure of their LTC systems, a structure that has been fostered by siloed funding, the accretion of multiple waiver programs, and low levels of inter-agency and inter-departmental communication and coordination.

Moving towards a long-term care system that is comprehensive, cohesive, and sustainable requires action on several key fronts. State policy leaders are beginning to realize that workforce is one of those fronts, and that, in fact, the twin goals of rebalancing and meeting expanding demand for LTC services and supports cannot be accomplished without a commensurate workforce policy.

The Role of Workforce

LTC services and supports are, by their nature, extremely labor intensive, and involve assisting individuals with the most intimate of self-care tasks and other activities of daily living (ADLs) and instrumental activities of daily living (IADLs).[1] * Direct service workers (DSWs)—a paid workforce currently totaling about 3 million nationwide—constitute the main input or "factor of production" into these publicly provided services and supports.

While the extreme dependence of these services and supports on DSWs is perhaps obvious, three fundamental but changed realities are becoming increasingly apparent:

- **The LTC system cannot continue to rely on a steady supply of women with few other employment opportunities.** Today's underlying demographics are strikingly different from the labor supply conditions that existed from the 1960s to the early 1990s when increasing numbers of females were entering the labor force. At the beginning of the current decade, the absolute size of this cohort began to contract. The old workforce paradigm viewed this workforce as largely disposable, and turnover as an unavoidable cost of doing business. But the structural "supply" change underway shifts the workforce calculus to a focus on retention and a consideration of the costs that turnover exacts in terms of replacement, additional training, lost productivity, and even lost revenues.
- **Relatives, spouses and other family caregivers currently provide the majority of support to persons with disabilities of all ages, but they are aging along with the rest of the population and our family caregiving system is increasingly stressed.** As these informal caregivers age, they are at increasing risk of needing supports themselves, and are less likely to continue to be able to provide unpaid supports at the same rate as they have in recent decades.[1] Furthermore, growing caregiving responsibilities are pressuring more women to retire early or move from full-time to part-time work.[2] According to health experts, the adverse health impacts of overburdened caregivers now constitute an emergent public health issue.[3]

** ADLs refer to activities such bathing, dressing, eating, toileting, transferring, and walking across the room. IADLs refer to activities needed to remain independent such as shopping for groceries, preparing hot meals, using the telephone, taking medications, and managing money.*

- **States are moving toward developing highly decentralized service delivery systems in which workforce holds the key to quality assurance**, that is, to ensuring the quality of care provided in hundreds of thousands of private and congregate homes. While provider licensure, regulatory standards, and quality management programs, including tracking and monitoring systems, can play important roles, investing in and supporting the quality and stability of the direct service workforce could not be more important to ensuring service quality and the well-being of consumers.

In sum, successful recruitment and retention of DSWs is not only essential to producing the volume of services demanded but it is also the most effective quality lever that policymakers have at their disposal.

State of the Direct Service Workforce

The problematic state of the nation's direct service workforce is an issue receiving growing attention. This workforce shows classic signs of workforce instability, including high turnover and vacancy rates. At its roots, this instability stems from the fact that LTC service delivery and reimbursement systems were designed for a different time, an era in which women were entering the labor force in increasing numbers, family caregivers were more available, and institutional care dominated public programs and paid services generally. Policymakers need to recognize the essential role that paid aides and caregivers play in LTC, their particular needs and circumstances as low-wage workers, and the unique character of home- and community-based services (HCBS), including their often part-time and episodic nature.

Despite the high degree of similarity between the types of tasks performed by the vast majority of DSWs as well as the skills required to perform those tasks, the direct service workforce is segmented into several different subgroups, in part mirroring the siloed nature of LTC service delivery systems and funding streams. Four main groups can be distinguished: (1) nursing facility aides, (2) direct support professionals, (3) personal and home care aides, and (4) home health aides. Among the recent national highlights for each of these groups are the following:

Nursing facility aides

- DSWs working in nursing facilities currently total about 656,000 and are now far outnumbered by DSWs working in HCBS.[4] DSWs working in nursing facilities continue to have the highest rate of turnover of any group of DSWs, averaging about 66 percent nationally.[5]
- The nursing facility direct-service workforce is increasingly non-white (about 52 percent). Nationally, about a fifth of this workforce is foreign born but in high-immigration, large states such as Florida, New York, and California, the percentage of the DSW nursing facility workforce that is foreign born ranges from 38 percent to 63 percent.[6]
- The wages and benefits received by nursing facility aides are on average higher than those received by their counterparts in non-institutional settings.[7] But still, in 2007 nearly 50 percent of aides have household incomes under 200 percent of the federal poverty level.[8]

Direct support professionals (DSPs)

- Direct support professionals (DSPs) provide services and supports to individuals with developmental and intellectual disabilities, substance abuse challenges, and serious and persistent mental health issues.

- The majority of DSPs work in home and community settings, including in in-home services, supported living arrangements, and small group homes. This decentralization of community support services has greatly increased the challenges faced by DSPs in fulfilling their roles compared to when DSPs worked primarily in congregate care settings and institutions. Today, DSPs are called on to provide medication supports, implement behavioral plans, teach new self-care skills, design and implement augmentative communication systems, support friendships and self determination, and provide a wide range of other sophisticated supports that require substantial skills, judgment, and personal accountability.[9]
- De-institutionalization *per se* has not solved recruitment and retention problems for DSPs. Average wages for DSPs in private sector community services for persons with developmental disabilities range from $7.30 to $15.18, with a mean of $8.68.[10]

Personal and home care aides (PHCAs)

- PHCAs provide services and supports to older individuals and people with physical disabilities.
- Like DSPs, PHCAs face growing challenges in fulfilling their roles and increasing responsibilities for care requiring greater skill and judgment. The tasks performed by PCHAs range from companionship and help with IADLs such as shopping, transportation, meal preparation, and light housekeeping, to assistance with ADL /self-care activities. PHCAs increasingly provide services to nursing facility-eligible consumers in home- and community-based settings. Like DSPs, PHCAs typically work under conditions that offer little supervision and access to professional consultation, although many of the tasks performed are not considered skilled or health maintenance activities.
- A growing number of PHCAs are "independent providers," meaning that they are directly employed by consumers and not by agencies. Often these arrangements are part of Medicaid programs that allow for consumer direction and permit the payment of family members, friends, and neighbors. The work of more than 400,000 independent providers is now organized under state- or county-based public authorities.[11]
- Nationally, the median age of PHCAs is 44, and increasing numbers of these aides are working full-time full-year. About a fifth of PHCAs live in households with incomes below the federal poverty level, and over 40 percent of PHCA households receive some kind of public assistance.[12]

Home health aides (HHAs)

- Home health aides (HHAs) typically are employed by Medicare-certified home health agencies and deliver more clinically-oriented services under the supervision of a Registered Nurse or Physical Therapist.
- Until recently, HHAs were the core of the traditional home- and community-based workforce serving older individuals. However, in 1997, in response to rapid growth of home care expenditures in the prior decade, Congress moved to reign in Medicare home care spending and establish a new prospective payment reimbursement system. These changes had major repercussions in the home care industry causing a significant contraction in the number of Medicare-certified agencies and a corresponding reduction in the HHA workforce.[13] At the same time, LTC service delivery systems began to shift to increasingly rely on PHCAs and non-agency based consumer-directed arrangements.

- In contrast to the last decade, demand for HHAs is predicted to increase significantly in the near future. According to the U.S. Bureau of Labor Statistics, HHAs are now the third fastest growing occupation in the economy, projected to increase by nearly 50 percent over the decade ending in 2016.[14] In part, this demand reflects the growing need for DSWs who can attend to home-based consumers whose conditions are debilitating enough that they meet Medicaid eligibility criteria for nursing-facility admission. In addition, individuals who are not financially eligible for Medicaid but who have similar support needs are increasingly hiring HHAs privately, often at pay scales that are higher than those offered under Medicaid program.

Leading Issues and Trends

While the direct-service workforce is segmented, several overarching issues and trends play fundamental roles in shaping this workforce as a whole and the policy discussions surrounding it:

National Surveys Showing the Downsides of Direct Service Work

1. According to a recent tabulation by **Forbes Magazine**, the personal and home care occupation qualifies as one of the 25 worst paid jobs in America, ranking just above cashiers and under parking lot attendants.
2. The **Substance Abuse and Mental Health Services Administration** recently reported that, among all workers in the U.S., personal care workers experience the highest rates of depression lasting two weeks or longer.
3. Work-related injuries are very common in long-term care. According to the latest **Survey of Occupational Injuries and Illnesses**, in 2007, the nursing aide occupation had the highest incidence rate of injuries and illnesses of any occupation, exceeding that of construction laborers, tractor-trailer truck drivers, roofers, and welders. All types of nursing and residential care facilities reported injury and illness rates that are 2 to 2.5 times those for service-producing industries in general.

Sources: *Paul Maidment (June 4, 2007) "America's Best and Worst Paying Jobs," Forbes Magazine;* Substance Abuse and Mental Health Services Administration, Office of Applied Studies. (October 11, 2007). *The NSDUH Report: Depression among Adults Employed Full-Time, by Occupational Category.* Rockville, MD; Bureau of Labor Statistics, U.S. Department of Labor (November 2008) *"Nonfatal Occupational Injuries and Illnesses Requiring Days Away from Work, 2006" and (October 2008) "2007 Survey of Occupational Injuries & Illnesses: Summary Estimates Chart Package."*

1. **Compensation levels for home- and community-based direct service jobs continue to fall behind other occupations with comparable low levels of training requirements.** National occupational wage data provides strong evidence about the problematic state of DSW wages and benefits, both in an absolute sense and relative to the wages of other low-skilled occupations.[15] Recruiting and retaining skilled and experienced workers could become more difficult if DSW jobs do not become more competitively attractive. Given that the barriers to qualification tend to be so low, direct service work may increasingly be relegated to those without more marketable job skills and training.[16]
2. **Chronically high rates of workforce instability.** For nearly the last decade, the vast majority of states have reported shortages of DSWs generally, high turnover and vacancy rates, lack of qualified staff, and difficulty retaining workers.[17] In home care, turnover typically ranges from 40 to 50 percent annually and in nursing facility care, the national average is roughly 66 percent.[18] While there have been no national studies of DSP turnover in the

last decade, smaller scale state and local studies indicate turnover rates of about 50 percent in settings that employ DSPs.[19] An unstable workforce can compromise both access to services and the quality of services received. Staff instability and turnover also are expensive, resulting in financial burdens for both agency–based LTC providers as well as state and federal governments which foot a large part of the bill for these services.[20]

3. **Shift in employment of DSWs toward home- and community-based settings and away from institutions.** Recently, the size of the nation's home- and community-based workforce surpassed the nation's nursing facility workforce population for the first time.[21] This is a significant milestone that highlights the rebalancing of service delivery systems towards home- and community-based settings. For workers, this shift means that they are working more independently, with much less support from co-workers or supervisors, and that they are called on to exercise more professional judgment to solve everyday challenges that arise.
4. **Challenge of trying to rebalance toward less attractive DSW jobs.** In many states, there is still a significant discrepancy between the compensation standards (i.e., wages and benefits) offered in institutional direct service jobs and comparable home- and community-based positions. Wages for DSWs in nursing facilities and state institutions for individuals with intellectual and developmental disabilities tend to be at least 25 percent higher than wages for those working in home and community settings, and employer-provided health insurance and other benefits are more available in non-home care settings.
   These compensation discrepancies exist despite findings in many states that at least as many people with the most significant support needs live in small community settings as live in institutions. Lack of parity impedes workforce rebalancing efforts because it decreases the relative attractiveness of direct service work in non-institutional settings. The table below illustrates some of the national differences between compensation for DSWs in nursing facilities and large institutions versus in-home and community settings.
5. **Emphasis on expanding the consumer-directed workforce and supporting family caregivers.** One avenue that state policymakers have been pursuing in order to address workforce shortages is to draw out non-traditional DSWs—so-called "independent providers"—who generally are not affiliated with provider agencies. Many independent providers have been informal caregivers such as family members, neighbors, and friends. State and federal policy attention to family caregivers also has increased significantly in recent years. Between 2004 and 2008, 21 states passed a total of 30 bills with caregiver-related provisions. Five federal bills related to family caregiving were enacted in the 109th Congress, and 28 bills were introduced in the 110th Congress. The most common legislative strategies have been: caregiver tax incentives, family and medical leave policies, and respite care provisions.[22]

DSW COMPENSATION IN HCBS IS TYPICALLY LOWER THAN IN INSTITUTIONAL SETTINGS

Labor Force Participation, Compensation & Poverty	DSPs in Large Institutions	Aides in Nursing Facilities	DSWs in HCBS Settings
Compensation			
• Average hourly wage rate	$13.17	$10.61	$8.74
• Paid sick time	N.A.	65%	45%
• With employer-based health care coverage	~61%*	58%	39%
Labor force participation			
• Percent working full-time full-year	~59%*	54%	46%
Poverty (based on family income)	~14%*	16%	22%

N.A. = not available.

* *Figure is for all DSWs in Residential Care Facilities (without nursing), an industry that includes many community-based, non-institutional settings as well as large institutions. Therefore, for DSPs in large institutions, the labor force participation and health care coverage statistics probably understate the true figures while the poverty statistic probably overstates the true figure.*

Sources: *PHI analysis of Current Population Survey 2006, and 2006 data from Occupational Employment Survey of the Bureau of Labor Statistics, U.S. Department of Labor; Larson et al. (2007) "Staffing patterns, characteristics and outcomes in large state residential facilities in 2006" in Prouty et al. (Eds.) Residential services for persons with developmental disabilities, Table 1.34; Institute for Women's Policy Research (2007) Women and Paid Sick Days, Fact Sheet #B254a.*

6. **Growing economic development potential of the direct service workforce.**[23] In every state, direct service jobs constitute the employment core of the long-term care industry, and typically these jobs are not only at the top of the list of the fastest growing occupations but also among the jobs expected to add the most new positions. Given the sheer numbers of these occupations today as well as their tremendous expected growth, the economic case for improving the quality of these jobs is becoming increasingly compelling, particularly at a time when states are seeking to stem job loss, stabilize low income families, and revitalize communities in the face of the current economic downturn.

2. State Efforts to Improve Workforce Are Growing But Policymakers Lack Essential Workforce Information for Making Sound Policy

Most states appear to be at the earliest stages of designing comprehensive and systematic approaches to workforce development for long-term care. However, signs of an explicit focus on workforce policy are emerging at the state level around the country. Examples of state-based policy initiatives and efforts include the following:[24]

- Workforce commissions and studies.
- Interagency structures to coordinate and set LTC policy and direction.
- Wage and benefit initiatives such as wage pass-throughs, wage floors, wage and hour protection, living wages, health insurance coverage initiatives for DSWs, and collective bargaining under public authorities for independent providers.
- Reform of reimbursement and procurement systems to create incentives for quality care and quality jobs.
- Statewide training and credentialing initiatives to address the problem of variable training standards by identifying core competencies and skills, and creating competency-based state training systems with certificate and/or certification components.
- State support for selection tools to assist providers in reducing early turnover using realistic job previews and other human resource strategies.
- Engagement of state public workforce development system with LTC providers in order to address worker shortages, improve recruitment and retention, create improved training and career path infrastructure, and galvanize multi-employer partnerships that can marshal new resources for systems change.[25]

While increasing numbers of states are taking steps to launch efforts to improve workforce quality and stability, for these initiatives to be truly effective, state policymakers need basic workforce information that will allow them to:

- Assess the magnitude of the identified workforce problem,
- Design appropriate policy responses, and
- Evaluate and assess the impact of new policies or simply trends over time.

But policymakers are hampered by a lack of ongoing, reliable state-based information about their direct service workforce. As a recent report by the federal Health Resources and Services Administration concluded: "existing data systems—which were designed for other purposes—cannot support systematic assessments of any [LTC] industry component: individual workers, individual facilities, classes of workers, classes of facilities, people receiving services, people needing services, organizations financing services, or policymakers overseeing the various systems."[26]

In general, there tends to be better workforce data available for nursing facilities and other institutions at the state level than for workers in home- and community-based settings. There are several reasons for this, including: greater federal reporting requirements for nursing facilities and institutions; the large numbers of disparate and often small non-institutional providers; with the exception of certified home health agencies, the lack of cost reporting requirements for HCBS providers; and, finally, the lack of standard job titles or job categories for services and supports delivered in non-institutional settings.

National and state estimates of employment and wages for a set of occupations containing the vast majority of DSWs are available through the Occupational Employment Statistics program, a federal-state cooperative program between the

Bureau of Labor Statistics and State Workforce Agencies that conducts a semi-annual mail survey of employers.[13]While the OES estimates for direct-service related occupations can be useful in suggesting broad changes in state employment and wages for several key DSW occupational categories, several features of the underlying occupational and industry classification schemes are problematic, limiting the use of this data for workforce planning or development purposes.[28]

States may have demographic data that can be used to paint the broad brushstrokes of their "care gap" situation—such as shrinking pools of traditional caregivers, declining numbers of working-age people, and occupational projections for various DSW jobs. However, the vast majority of states do not have access to basic quantitative information that describes the state of the workforce in place to deliver services and supports to people with various kinds of disabilities. Nor do they have the data needed to support a comprehensive workforce strategy across service settings. Instead, various program, agency, and departmental "silos" collect their data independently, and even then, workforce data is rarely a dedicated focus, contributing to an ad hoc or disjointed approach.

> ***"State planners and policymakers do not have adequate data and information with which to assess the adequacy of the long-term care paraprofessional workforce. They are being pummeled with cries for help from nursing homes and home health agencies having difficulty recruiting workers. They hear horror stories of unscrupulous individuals taking advantage of frail senior citizens. They are beginning to realize that they do not have enough information either to design appropriate responses to these situations or to evaluate the ad hoc responses they have implemented to address these and other problems."***
>
> *2004 Report from the Health Resources and Services Administration, US Department of Health and Human Services. Available at: http://bhpr.hrsa.gov/healthworkforce/reports/nursing/nurseaides/chap15.htm.*

3. The Case for A Minimum Data Set On Workforce

The regular collection of basic workforce information, and its injection into the workforce development policy, will allow state policymakers to meet five important objectives:

- To create a baseline against which the progress of workforce initiatives, including systemic interventions to improve workforce outcomes, can be measured.
- To inform policy formulation regarding workforce initiatives.
- To help identify and set long-term priorities for LTC reform and systems change.
- To promote integrated planning and coordinated approaches for LTC and comparability of data across programs to assist in the assessment and evaluation of adopted policy initiatives.
- To compare state progress with the progress of other states or with overall national performance, assuming cross-state collaboration to develop a common framework for effective collection, analysis, and use of DSW workforce data.

There are several important areas of policy development where workforce information can play a critical role. For example:

Evaluating the impact of wage and benefit initiatives. A state legislature that has implemented wage pass-throughs or COLAs for specified groups of DSWs might want to know how wage and benefit levels have changed for these workers. To our knowledge, no state in the country collects DSW wage and benefit data across long-term care sectors.

Estimating the cost of establishing a wage floor for DSWs. A state legislature wishing to improve DSW compensation by creating a wage floor to be paid to workers providing services under publicly financed programs would need to know how much the wage floor would be likely to cost. Essential to this calculation is an estimate of the number of workers who would be affected and information about current average wage rates.

Gauging progress in creating the workforce capacity to meet service delivery rebalancing goals. A state that has established specific rebalancing goals with respect to numbers of people served in different settings may want to monitor how its home- and community-based workforce has been expanding relative to its institutional workforce (*i.e.*, the workforce employed in nursing facilities and larger ICF-MRs), in addition to examining the number of people served in institutional and community settings. It may also wish to know the size of its independent provider workforce serving consumers in consumer-directed programs, and how that workforce has been expanding relative to agency-based workers.

Conducting workforce needs assessment to meet increased demand for services. A state may wish to estimate the number of additional workers that it needs to attract to home-and community-based settings in order to meet, say, a 25 percent increase in demand for service units over a certain time period, such as the next three years. Conducting this kind of assessment can inform recruitment and retention efforts, payment policy discussions about the compensation levels necessary to attract additional workers, and plans for expanding training capacity and infrastructure.

Assessing trends in workforce turnover and its related costs. A state may wish to know whether the rate of direct staff turnover in a certain segment of its long-term care system has improved over the last five years. It also may be interested in estimating the public share of the direct cost of turnover in its facilities in order to estimate the costs and benefits of creating a Medicaid rate enhancement for LTC employers that lower their turnover rates.

Evaluating the need to expand health insurance coverage for DSWs. Several states have identified expanding health insurance coverage for DSWs as a priority, because research indicates that such coverage can play a powerful role in improving recruitment and retention, and also because of pressure to extend health insurance to paid caregivers who undergird publicly funded health care systems, such as Medicaid long-term care services.

Several states already have taken steps to implement statewide data collection about their direct service workforces:[29] For example:

- **Kansas** has implemented a nursing facility reimbursement method under the state's Medicaid program that provides a rate enhancement for facilities that demonstrate lower direct care staff turnover, higher retention, and greater continuity of care. Similarly, **Oklahoma's** new Focus on Excellence Program for nursing facilities provides an incentive-based scoring system that offers enhanced rates based on several performance measures, including turnover and retention for DSWs. In addition, the Program's website allows users to rate each nursing facility by their turnover and retention rates for DSWs.
- **North Carolina** collects statewide data on turnover across all direct service settings and uses this benchmark information to assess the performance of providers receiving special licensure status under the state's voluntary NC NOVA (New Organizational Vision Award) program. NC NOVA is a "raise-the-bar" program that sets best-practice criteria and expectations pertaining to enhancing recruitment and retention for DSWs.

- **New Mexico** has a statewide web-based data collection and reporting system for developmental disabilities services that tracks the training received by DSWs, supervisors, and case managers as well as provider turnover and retention.[30] Employers use the database as a planning tool and the state uses it to generate compliance reports for recertification as well as a tool for identifying weaknesses and strengths in the state's training infrastructure. Workers can use the database to generate portable certificates for successfully completed training.

4. Recommended Elements of A Minimum Data Set On Workforce

Over the last three years, the Direct Service Workforce Resource Center, a CMS-funded initiative, has had a unique opportunity to provide assistance to states on workforce issues related to long-term care. Through a competitive application process, 15 states have been selected (five per round in three rounds) to receive intensive technical assistance, and an additional 11 states have received short-term general assistance.

The technical assistance provided through these rounds has drawn upon teams of workforce experts that cut across the workforce fields of aging, developmental and physical disabilities, and chronic mental illness. Many of the applications for assistance identified workforce data collection as a major need.

Data Components

Drawing from this rich experience with state-based policy formulation and program implementation for workforce, we propose the following minimum dataset on the direct service workforce to be collected statewide by major groupings of LTC settings. We suggest creating three types of workforce indicator variables: (1) those that count sheer workforce capacity as indicated by numbers of workers providing services within particular settings, (2) variables indicating the stability of the direct service workforce (turnover and vacancies), and finally, since the terms of compensation are so highly correlated with recruitment and retention, (3) variables that proxy for the average terms of compensation for DSWs.

The specific indicators we propose are the following:

Workforce volume	Workforce stability	Worker compensation
• Number of full-time workers • Number of part-time workers	• Turnover rate • Vacancy rate	• Average hourly wage • Benefits (health insurance, paid time off)

These three sets of indicators—workforce volume, stability, and compensation—correspond to the most problematic aspects of the current direct service workforce, and the workforce dimensions that most compromise state objectives concerning rebalancing and increasing the volume of services.

- Understanding the distribution of **numbers of workers** across settings and programs and trends over time is essential to determining where public resources might be most usefully injected in order to create sufficient capacity to meet the accelerating demand for services.
- Measures of **workforce stability**, particularly over time, are nothing less than a critical "outcome" indicating whether the investments that state government is making in workforce are producing the desired results in terms of lowering vacancy and turnover rates, and improving retention.

Workforce stability is also a key indicator of the quality of services and supports received by consumers, and can be used over time along with other measures to monitor quality assurance.

- Finally, **compensation** indicators give us vital information about how direct service jobs are keeping up with other low-wage jobs, and also changes in the relative compensation status of different types of direct service occupations. Over the long term, the competitive attractiveness of home- and community-based direct service jobs will precondition the capacity for successful rebalancing.

Appendix A presents more detail on the definitions of the data elements and suggests methods for calculating the indicator variables. **Appendix C** presents a list of additional variables beyond the essential ones specified here that would allow for more fine-grained analysis of workforce issues (*e.g.,* hours worked, retention).

LTC Settings to Be Covered

It is essential that workforce data collection efforts span the entire gamut of publicly supported LTC settings, and that data be collected for major groupings of these settings. Compared to twenty years ago, the LTC industry consists of a much more complex mix of overlapping services, settings, and provider employers. While taking into account this entire mix is challenging, each of the settings plays a critical role in the makeup of state-based service delivery systems. Furthermore, from a consumer and worker perspective, many of the settings are interrelated or connected. In addition, the relative importance and needs of different settings can shift over time, with commensurate workforce implications.

For example, many states have now launched nursing facility transition programs which are increasing demand for home-based placements but also for placements in assisted living residences and residential care homes (group-living arrangements that provide room, board, and personal care). But in many states, group settings that provide housing and supportive services do not have sufficient capacity—either in terms of physical infrastructure or workforce capacity—to accommodate increased demand. In sum, workforce data collection systems need to be implemented that allow administrators and policymakers to see how the direct service workforce is deployed across the spectrum of LTC settings, and to identify changes over time.

While states commonly use different definitions and terminology to describe their various LTC settings and providers, generic categories of settings and provider/employers can be distinguished. These common categories are presented in the chart below.

The Continuum of LTC Settings

INSTITUTIONAL SETTINGS		HOME AND COMMUNITY-BASED SETTINGS						
		Community Residential		Supports to Individuals and Families			Non-Residential Community Supports	
Nursing facility & residential rehabilita-tion	State operated institutions & large private institutions	24-hr residential supports & services	Less than 24-hr residential supports & services	Home health care services	Personal care services (agency-directed)	Personal care services (consumer directed)	Day programs, & reha-bilitative or medical supports	Job or vocational services
(e.g., SNFs, ICFs)	*(e.g., ICF-MR, residences with 16 or more people, residential rehababilita-tion)*	*(e.g., group home, hospice, sup-ported living rangement, supervised living facil-ity, assisted living)*	*(e.g., semi-independent living services)*				*(e.g., day services for seniors, adult day programs, reha-bilitation for working age adults)*	*(e.g., supported employ-ment, work crews, sheltered work-shops, job training)*

Operationalizing Statewide Data Collection

There are a number of options for operationalizing a system for collecting statewide workforce data (see **Appendix B** for a brief description of these options). The first step is to inventory what is already knowable from a state's current data collection and management information systems, including information that can be gleaned from required cost reporting, quality management, and claims processing systems. Data and reports available from provider associations and research institutes should also be examined. Consideration should be given to expanding or augmenting existing reporting requirements and surveys in order to capture the needed workforce information.

Assuming that information on all six indicators is incomplete across all provider settings, one option is to require that providers receiving public reimbursement annually submit a simple, standardized "Workforce Report" containing their actual data for the six recommended variables. Linking the timely completion of such reporting to a reimbursement or contracting period may be advisable. Another option is to use a survey sampling strategy to derive reasonable estimates of the six indicators for each major group of long-term care settings. This would require administering a survey to a representative sample of providers in each setting.

Capturing workforce data on consumer-directed programs will require special consideration. CMS requires states to have Financial Management Services (FMS) (*i.e.*, Government or Vendor Fiscal/Employer Agent, Agency with Choice) available to consumers using consumer-directed services. These entities could prepare information on numbers of workers payrolled, hours worked, and wages and benefits paid by consumer-employers. Estimating turnover and vacancy rates for independent providers directly employed by consumers will require either consumer surveys or, when FMS entities are in operation, some kind of tabulation of unduplicated counts of independent providers by consumer.

Recommended State Minimum Dataset on Workforce for LTC Systems Change

Overarching LTC systems objective

To ensure a stable, competent direct service workforce that:

- Delivers a high quality of care and supports quality of life for people receiving services and supports
- Is sufficient to meet the growing demand for services
- Is deployed across a full continuum of LTC settings consistent with the needs and preferences of LTC consumers.

Goals of the state minimum dataset on workforce

- To monitor progress of workforce initiatives
- To inform policy formulation
- To help identify and set priorities for long-term planning
- To promote system-wide coordination and planning for LTC programs using comparable data
- To compare state progress with the progress of other states or with overall national performance, assuming cross-state collaboration to develop a common framework for effective collection, analysis, and use of DSW workforce data.

Components

- Workforce volume
  - Number of full-time workers
  - Number of part-time workers
- Workforce stability
  - Turnover rate
  - Vacancy rate
- Workforce compensation
  - *Average hourly wage*
  - *Benefits (health insurance and paid time off)*

5. CONCLUSION

LTC systems change and rebalancing have significant workforce implications. Drawing on evidence-based tools, strategies, and policy practices for improving the direct service workforce, many states are beginning to address these implications and show promising signs of increased activity to improve recruitment and retention. In the last several years, projects such as the Better Jobs Better Care initiative, and CMS Real Choice Systems Change, CMS DSW Demonstration Grants, and CMS DSW Resource Center have shown a number of workforce interventions to be effective in stabilizing and strengthening the direct service workforce.

But while workforce improvement initiatives in LTC are increasing, state policymakers are often hampered by a lack of on-going, reliable state-based information about their direct service workforces. What they need is the hard data to help them do three things: accurately identify the gaps in their systems, choose and employ the most appropriate tools to address these gaps, and measure the effectiveness of their efforts over time.

In sum, ***having data on basic workforce indicator variables has become an essential ingredient of sound LTC policymaking***. The challenge offered by this White Paper is for states to *voluntarily* expand their data collection on public long-term care programs to include the tracking and monitoring of key direct service workforce

vital signs. We envision not an additional layer of federally-imposed data collection requirements, but ideally cross-state collaborations, perhaps with federal support, to develop common frameworks for effective data collection, analysis, and use of direct service workforce data.

While states may have concerns about the cost of undertaking additional data collection, our hope is that the examples provided by current state efforts as well as cross-state peer learning and collaboration will help states find cost effective ways to gather this critical information. The costs of data collection and monitoring should be compared to the benefits of creating the capacity to monitor key DSW workforce indicators that are key to more effective policy formulation for long-term care. The ultimate objective of these efforts is to ensure the development of a stable, competent direct service workforce—one that can deliver high-quality services and supports to consumers, and be sufficient to meet the growing demand for services, particularly in home and community settings.

GUIDE TO APPENDICES

Appendix A describes the elements of the recommended state minimum data set.

Appendix B provides options for implementing statewide workforce data collection.

Appendix C describes additional data elements for states to consider collecting.

Appendix D provides annotated comments from state officials invited to review this paper.

APPENDIX A: Elements of State Minimum Data Set on The DSW Workforce

The table below describes the recommended statewide data elements to be collected and suggested calculations for key measures of DSW workforce volume, stability, and compensation.

1. WORKFORCE VOLUME	
Data elements to collect	A. Number of DSWs currently employed, by setting and job title B. Number of DSWs employed full-time (35 hours or more per week), by setting and job title C. Number of DSWs employed part-time (less than 35 hours per week), by setting and job title
Recommended calculations	D. Total number of DSWs currently employed in each setting E. Total number of DSWs currently employed in each job title F. Percent of all DSWs employed full-time, by setting and job title G. Percent of all DSWs employed part-time, by setting and job title
2. WORKFORCE STABILITY	
Data elements to collect	A. Total number of separations (i.e., workers who left their position for any reason—voluntary or involuntary--excluding promotions) over a 12-month period B. Average number of DSWs employed calculated over a 12-month period, by setting and job title C. Number of vacant positions on a particular date, by setting and job title D. Number of DSW workers employed on a particular date, by setting and job title
Recommended calculations	E. Average annual turnover rate, by setting and job title (2a/2b) F. Average vacancy rate, by setting and job title (2c/(2c+2d))
3. WORKFORCE COMPENSATION	
Data elements to collect	A. Average hourly wage paid to DSWs, by setting and job title B. Number of DSWs without health insurance from any source, by setting and job title C. Number of DSWs enrolled in employer-provided health insurance, by setting and job title D. Number of DSWs with paid sick or vacation leave, by setting and job title
Recommended calculations	E. Average DSW hourly wage, by setting and job title (3a) F. Percentage of DSWs with no health insurance coverage from any source, by setting and job title (3b/1a) G. Percentage of DSWs with employer-provided health insurance, by setting and job title (3c/1a) H. Percentage of DSWs with paid sick or vacation leave, by setting and job title (3d/1a)

APPENDIX B: Options for Implementing Statewide Workforce Data Collection

States already face numerous federal reporting requirements relating to LTC (for example, OSCAR reporting for nursing facilities, and CMS Forms 64 and 372 for Medicaid waivers). In addition, states partner with the federal government to conduct several establishment surveys, such as the U.S. Bureau of Labor Statistics (BLS) Occupational Employment Statistics (OES) survey, the National Compensation Survey (NCS), and the BLS Job Openings and Labor Turnover Survey (JOLTS). These reporting requirements and surveys impact at the provider level where there are also state reporting requirements, such as required cost reports and other financial reporting.

Given the reporting burden already carried by states and LTC employers, making the most of existing data collection efforts is critical. However, to the extent that information on key workforce vital signs are not available to policymakers, consideration should be given to the costs and benefits of taking steps to either expand existing data collection systems or to create new ones in order to produce the information that policymakers need in order to make effective workforce development policy for LTC systems.

While it is beyond the scope of this White Paper to suggest specific state-level instruments, we briefly describe below approaches that could be taken to determine optimal data collection strategies. Much of the data we recommend collecting would require expanded establishment surveys or reporting and possibly analysis of state administrative records. As a result, additional costs will likely be associated with these data collection recommendations. These costs should be compared with the benefits of creating the capacity to monitor key DSW workforce indicators that can assist with more effective policy formulation for long-term care.

I. Data collection methodologies

The data collection recommendations described in this White Paper may be met in a variety of ways. Some possible methods are briefly described here.

A. Create an inventory of already knowable workforce indicators at the state level and consider expanded reporting and surveys, building on existing data collection efforts
   Identify what indicators are already knowable from existing state data collection and management information systems, including information that can be gleaned from required cost reporting, and claims processing, quality assurance systems, and administrative records. Also review data or reports available from provider associations and research institutes that collect such information routinely or periodically. Consider augmented reporting and enhanced survey instruments, building on existing data collection efforts, in order to collect the data necessary to calculate key workforce indicators.
B. Census approach within states
   Design a required standardized "Workforce Report" to be submitted annually by all providers receiving public reimbursement. Provide, if possible, for sub-state tabulations.
C. Sampling approach within states
   Design a "Workforce Report" that will allow for the measurement of key workforce indicators and then determine an appropriate sampling frame of employers. Dimensions along which the sample could be stratified include: the LTC population group served (*e.g.,* aging vs. persons with developmental disabilities), the service type (*e.g.,* ADLs vs IADLs), and the setting (*e.g.,* nursing facilities vs. in-home care).

II. Collecting information on independent providers in consumer-directed programs

Capturing workforce data on consumer-directed programs will require special consideration. CMS requires that states have Financial Management Services available for consumers using consumer-directed services. These entities could theoretically provide information on compensation, numbers of workers and some information on workers' compensation insurance activities (this will vary by type of FMS used). Estimating turnover and vacancy rates for independent providers directly employed by consumers will require either consumer surveys or, when intermediaries exist, some kind of tabulation of unduplicated counts of providers by consumer.

III. Collecting information across populations, service types, settings, and job titles

Regardless of which strategy is used, we recommend that states work toward developing an ongoing reporting system that collects and shares the core workforce data elements broadly. Comprehensive systems will include each of the listed population groups, service types and setting types, and will allow for comparisons to be made across population groups, service types and setting types. When sample sizes are insufficient to allow reliable estimates for subpopulations, service types or service settings, the reporting system should at least indicate the which populations, service types or service settings were included or excluded from the data collection effort.

A. Population groups receiving LTC supports

1. Individuals with conditions due to aging and/or chronic medical conditions
2. Individuals with physical disabilities
3. Individuals with intellectual and developmental disabilities
4. Individuals with chronic mental health and substance abuse conditions
5. Other (specify)

B. LTC service types

1. Medical supports and rehabilitation
2. Supports for activities of daily living (eating, dressing, toileting, transferring, mobility)
3. Supports for instrumental activities of daily living (meal preparation, shopping, housework, money
4. management, medication management)
5. Habilitation (supports for communication, learning, self-direction including supervision, and economic self-sufficiency)

C. LTC settings

1. Institutional (including nursing homes, ICFs, state operated institutions, and private institutions with 16 or more residents including ICFs-MR)
2. Community residential (24-hour or less than 24-hour supports in places with 15 or fewer people with disabilities living together)
3. In-home (home health care services, personal care services) agency directed
4. In-home (personal care services) consumer directed
5. Non-residential community supports (adult day services, rehabilitative services, and medical supports)
6. Non-residential community supports (job and vocational services)

IV. Job titles to include and duplicated

Job titles will vary across settings and by state. We recommend that states count workers identified in four broad categories: nursing facility aides, direct support professionals, personal and home care aids, and home health aides, using the definitions outlined in this paper (see Section I). If these job titles are not applicable or do not adequately capture the job categories used, states should look across settings, programs and disability populations to identify the most common job titles used in their state for workers providing direct supports and services to people with disabilities.

States should note that counts of DSWs are unlikely to be unduplicated counts because some workers work for multiple employers. Even with duplicates, however, these counts will provide states with a close estimate of worker volume and allow states to track volume over time. It may be possible to obtain an unduplicated count of DSWs providing LTC support and services under Medicaid or other publicly funded services if DSWs are assigned a unique identifier across employers and programs.

V. Comparability with other data collection programs

When new or augmented data collection systems are designed, consideration should be given to building in comparability with existing data programs, including those used by the BLS. For example, the basic coding for direct service occupations and industries used in the SOC (Standard Occupational Classification) and the NAICS (North American Industry Classification System) can be utilized but then expanded to a finer level of detail in order to address the limitations summarized in note 29 to this White Paper.

APPENDIX C: Additional Data Elements to Consider Collecting

I. Additional Volume Variables

- Hours worked
  - Average number of hour of hours worked per week, by setting and job title
  - Average number of part-time DSWs, by setting and job title, who work less than 20 hours, and 20 to 35 hours, per week
- Frontline supervisors

Frontline supervisors are individuals whose primary responsibility is the supervision of direct service staff, although they may also perform direct service tasks but at less than 50% of their hours.

  - Number of people employed as frontline supervisors, by setting
  - Average number of DSWs under the supervision of supervisors, by setting
  - Number of people who left frontline supervisors positions in the past 12 months, by setting
  - Number of vacant frontline supervisor positions, by setting
- Changes in the demand for DSWs
  - Changes in actual and projected numbers of eligible LTC consumers or support recipients
  - Ratio of DSWs to consumers/recipients in various public LTC programs

II. Additional Stability Variables

- Turnover
  - Rate of turnover among new workers (*i.e.,* employees with less than 3-6 months tenure), by job title and setting
  - Percent of leavers who left within 6 months after hire, by job title and setting
  - Rate of voluntary turnover and rate of involuntary turnover, by job title and setting
- Retention
  - Average provider retention rate (by setting), measured as state average of provider retention rates (by setting and job title), and calculated as the number of DSWs employed by a provider for at least 12 months divided by number of DSWs on payroll (either at the time numerator is determined or on last day of fiscal year)

III. Additional Compensation Variables

- Wages
  - Average entry-level wage per hour paid to DSWs, by setting and job title
  - Average wage per hour paid to DSWs with 1+ years of tenure by setting and job title

- Health Insurance
  - Number of DSWs who are eligible for employer-provided insurance, both for self and dependents.
- Retirement benefits
  - Number of DSWs with access to employer-sponsored retirement plans, by job title and setting
- Disability benefits
  - Number of DSWs with short-term disability insurance policy for which their employer pays at least a part of the premium, by job title and setting

IV. Other Workforce-Related Variables of Interest

- Entry training for DSWs
  - Number of DSWs completing state training requirements for CNAs or HHAs working in certified provider organizations
  - Number of DSWs completing state training requirements for workers not covered by federal OBRA requirements
    (*e.g.*, personal care assistants, home care aides, aides working in assisted living facilities)
  - Number of DSWs completing state training requirements for DSWs in Medicaid consumer-directed programs
  - Number of DSWs completing state training requirements for universal core curriculum
- Career ladder advancement programs
  - Number of DSWs completing DOL Apprenticeship Program for CNAs, HHA, and/or DSPs
  - Number of DSWs participating in state-sanctioned career ladder initiatives or training enhancement programs
  - Number of DSWs completing state required training for specialty aide positions
    (*e.g.*, medication aide, geriatric aides, senior aide)
- Training for supervisors
  - Number of supervisors completing state-sanctioned supervisory training for nurse supervisors/managers
  - Number of consumers completing state-sanctioned training for consumers directing their own workers (in consumer direction programs) (*e.g.*, "consumer as employer" training)
- Injury rates
  - Numbers of worker comp claims filed, by relevant occupational codes and setting

APPENDIX D: Annotated Comments from State Reviewers

In the summer 2008, The DSW Resource Center team circulated a draft of this report to all the state agencies receiving technical assistance from the Center. These agencies are a mix of State Medicaid Agencies, State Units on Aging, and different state Offices of Disabilities. We asked for their feedback on the report and to comment on the potential usefullness of the set of data we recommend for collection. Fourteen individuals from thirteen states provided written comments, which we incorporated into the report and appendices. What follows is a summary of the state reviewers' overall comments by state:

AZ Knowing the number of workers and turnover rates would be useful for the reasons stated. Some of this data would be useful for employers too. Some provider agencies wonder about rates being paid for other services and fairness of different rates, and knowing turnover rates at other agencies might help them see that there are ways to reduce turnover.

DC The paper makes a logical and sensible case for the importance of states collecting data on the direct service workforce, but states may pause initially due to obvious work, cost and collaboration necessary to operationalize and implement. The paper would be useful to the District of Columbia in that it validates what some policy makers are aware of and may be helpful to other policy makers regarding the challenges ahead should they opt to implement.

FL This paper will go a long way to raise awareness about the direct support workforce within our state. Simply defining the DSW profession (including division into subgroups) is helpful.

LA The data recommended in the paper would be helpful and, in fact, we are in the process of trying to collect most of this data from our long term care providers. This is a useful baseline. We have one or more study groups or stakeholder groups attempting to call attention to and/or address DSW workforce issues and the paper should certainly be shared with them. We are also trying to raise the issue with state workforce officials who tend to focus more on shortage issues with healthcare "professionals" and the paper may help.

NH The proposed data would be extremely helpful and would be particularly useful in our current efforts to build a case around improving the workforce and enhancing wages and benefits. The legislature responds better to good data rather than anecdotes, although the stories help put a face to the data. We respond to issues based on anecdotes and it would be better to have good data to inform our actions. This paper does a very good job of defining the workforce. I particularly found the chart on the Continuum of LTC settings to be helpful.

NJ-1 The information in the paper related to the challenges facing the LTC system should open anyone's eyes on the importance of this information. Legislators and other governing bodies need to see data demonstrating the significance of the issues we face in order for necessary funding to be allocated and policies to be created. Collecting the proposed information will help state departments, agencies, and individuals present their cases. In addition to this, qualitative data related to the strain caregiving has on families, and in turn the general workforce and economy, is also important to present as it extends the crisis beyond the field of human services.

The data collection recommendations are extremely useful especially as states recognize quantitative data as necessary to the development, implementation and sustainability of workforce development initiatives. We have been piloting a Career Path for DSPs and collecting information to display the effectiveness of training and mentoring, tied to increased competency and salary based incentives, in improving skills, increasing the professionalization and decreasing the turn-over of DSPs in the state. Future statewide implementation will allow us to collect additional data related to its effectiveness and help us to gather information necessary to improving the process. The recommendations in this paper will be useful in the determining what data to collect and ways to utilize this data to set priorities and create policy.

NJ-2 The paper will be a useful tool in beginning the discourse of change within states for policy decisions on the LTC system and for strengthening the direct care workforce. We believe that the concept and content of the proposed state minimum data sets included in the paper are an excellent foundation for enacting meaningful data collection standards in states.

NY The background section of the paper provides a very good overview of the current issues that relate to supply and demand for nursing facility aides, direct support professionals who serve persons with developmental disabilities, personal and home care aides, and home health aides. That information alone is a positive addition to the discussions we're having within the New York State service system for persons with developmental disabilities, and I'm sure will also be of benefit to other states.

Regarding the recommendations for collection of a minimum data set on workforce information, the challenge is not so much to get all stakeholders to agree that more information about the status of the direct support workforce is needed. The challenge is to work through the mechanics of instituting data collection among providers of various sizes and with varied service delivery patterns.

OH This paper will be EXTREMELY useful in my state as we have been legislatively charged to address this very issue and have developed work teams at the state level to identify the problems and develop solutions. Having the data recommended in this paper would absolutely be useful. Because there is NOTHING out there, this is a great start. The "quality" assurance statements are key to the paper's effectiveness.

PA This paper would be useful as a statewide approach for common data collection. The feasibility of implementing the recommendations could be helped by federal incentives for completing the information, such as some form of reduced cost for health care.

SC The paper makes a convincing case for the importance of collecting data on the direct service workforce. Implementation of the recommendations could provide the necessary data to justify the funding/expenditures needed to facilitate collaboration among Health and Human services agencies, Department of Education and Labor, Technical Schools, provider groups and others.

TX The entire document will be a very useful planning tool for Texas. Two topics will be particularly useful for Texas and other states. First, providing states with a starting point regarding which data to collect (i.e., minimum data set) is very useful. With respect to a minimum data set, the DSW Resource Center Team made an excellent decision to suggest a set of minimum data to collect as well as additional data elements to consider collecting. Second, citing examples of states which have developed statewide data collection efforts is also useful.

Having the data recommended would be very useful for Texas. Texas, like many other states, only has anecdotal evidence that vacancy and turnover rates are high. In addition to the examples cited in the paper, having knowledge about workforce volume, stability, and compensation will also help with decisions regarding legislative appropriations. Especially helpful are the examples given where workforce information can play a critical role in policy development. These examples help the reader make the connection between the need to collect data and the benefits of having the data available when developing policy.

VT The paper makes a convincing case. The statistics you cite about the current and projected market of direct care workers really hammers home the urgency of action.

WI This report's recommendations will enable statewide health care stakeholders to capture more information for a fuller picture and be able to collect and analyze supply, demand, and distribution data for direct service workers in order to help ensure that in the future, we have a diverse workforce that is appropriate and sufficient in number for addressing the care needs of the public. The only challenge for implementation may be the adequate resources necessary to implement such a project of data collection.

ENDNOTES

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2 Johnson, Richard W. and Anthony T. Lo Sasso (Fall 2006) "The Impact of Elder Care on Women's Labor Supply," *Inquiry* Vol. 43, pp. 195-210. Available at: http://www.inquiryjournal.org.

3 Talley, Ronda C. and John E. Crews (February 2007) "Framing the Public Health of Caregiving," *American Journal of Public Health* Vol. 97, No. 2, pp. 224-228. Available at: http://www.ajph.org/content/vol97/issue2.

4 See the U.S. Department of Labor, Bureau of Labor Statistics (December 2007) *2006-16 National Employment Matrix, detailed occupation by industry.* Available at: http://www.bls.gov/emp/empoils.htm.

5 American Health Care Association (July 2008) Report of Findings 2007 AHCA Survey Nursing Staff Vacancy and Turnover in Nursing Facilities, Washington, DC: AHCA. Available at: http://www.ahcancal.org/research_data/staffing/Documents/Vacancy_Turnover_Survey2007.pdf. .

6 PHI analysis of 2008 March Supplement of the Current Population Survey, U.S. Census Bureau.

7 PHI (forthcoming, Spring 2009) *Who Are Direct-Care Workers?*, Facts 3, Bronx, NY: PHI.

8 PHI (forthcoming, Spring 2009) Who Are Direct-Care Workers?, Facts 3, Bronx, NY: PHI.

9 U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy (January 2006) The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities: Report to Congress. Available at: http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.htm#changing. Hoge, M.A., Morris, J.A., Stuart, G.W., Daniels, A.S., Huey, L.Y., Adamns, N. (2007) An Action Plan for Behavioral Health Workforce Development, Cincinnati, OH: The Annapolis Coalition on the Behavioral Health Workforce.

10 Larson, Hewitt & Knobloch (2005); Amy Hewitt *et al.* (November 2007) *Direct Support Professional Work Group Report*, North Carolina Commission for Mental Health, Developmental Disabilities, and Substance Abuse.

11 Dorie Seavey and Vera Salter (October 2006) *Paying for Quality Care: State and Local Strategies for Improving Wages and Benefits for Personal Care Assistants.* Policy Report #2006-18, Washington, DC: AARP Public Policy Institute, pp. 17-19. Available at: http://assets.aarp.org/rgcenter/il/2006_18_care.pdf.

12 PHI (forthcoming, Spring 2009) *Who Are Direct-Care Workers?*, Facts 3, Bronx, NY: PHI.

13 Korbin Liu et al. (July 2003) Agency Closings and Changes in Medicare Home Health Use: 1996-1999, Washington, DC: U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy. Available at: http://aspe.hhs.gov/daltcp/reports/closings.htm.

14 PHI (April 2008) *Occupational Projections for Direct-Care Workers 2006-2016*, PHI Facts 1, Bronx, NY: PHI. Available at: http://www.directcareclearinghouse.org/download/BLSfactSheet4-10-08.pdf.

15 Median hourly wages for personal and home care aides increased by 9.4% from 2002 to 2006 (mean annual income in 2006 of $18,180). Here are rates of increase in wages over the same period for comparable earning jobs, some of which arguably involve less demanding work than that performed by DSWs: crossing guards 12.8% ($22,270); security guards 12.5% ($23,620); hairdressers, hairstylists & cosmetologists 12.4% ($24,550); manicurists & pedicurists 10.8% ($21,280); retail salespersons 11.6% ($23,940).

16 H. Stephen Kaye *et al.* (2006) "The Personal Assistance Workforce: Trends in Supply and Demand," *Health Affairs*, Vol. 25, No. 4, pp. 1113-1120.

17 For six years now, the National Survey of State Initiatives on the Long-Term Care Direct Care Workforce has found that the vast majority of states consider direct-care turnover and vacancies to be a serious issue. The percentage of states has varied from 88 percent in 1999 to 97% in 2007. For the latest survey, conducted in 2007, see PHI and the Direct Care Workers Association of North Carolina (forthcoming, Spring 2009), *Results of the 2007 National Survey of State Initiatives on the Long-Term Care Direct Care Workforce*. Prior years surveys can be found at: http://www.phinational.org/clearinghouse.

18 Dorie Seavey (October 2004) *The Cost of Frontline Turnover in Long-Term Care*, Better Jobs Better Care Report, Washington, DC: Institute for the Future of Aging Services, American Association of Homes and Services for the Aging; American Health Care Association (July 2008) *Report of Findings 2007 AHCA Survey Nursing Staff Vacancy and Turnover in Nursing Facilities*, Washington, DC: AHCA. Available at: http://www.ahcancal.org/research_data/staffing/Documents/Vacancy_Turnover_Survey2007.pdf.

19 U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy (January 2006) The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities: Report to Congress. Available at: http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.htm#changing.

20 Dorie Seavey (October 2004) *The Cost of Frontline Turnover in Long-Term Care*, Better Jobs Better Care Report, Washington, DC: Institute for the Future of Aging Services, American Association of Homes and Services for the Aging; U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy (January 2006) *The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities: Report to Congress*. Available at: http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.htm#changing.

21 PHI (April 2008) *Occupational Projections for Direct-Care Workers 2006-2016,* Facts 1, Bronx, NY: PHI. Available at: http://www.directcareclearinghouse.org/download/BLSfactSheet4-10-08.pdf.

22 Family Caregiver Alliance "Federal and State Caregiving Legislation." Available at: http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1848.

23 PHI (November 2008) *Eldercare/Disability Services: Untapped Engine for Job Creation and Economic Growth*, Facts 2, Bronx, NY: PHI. Available at: http://www.directcareclearinghouse.org/download/PHI%20FactSheetNo2.pdf. See also, PHI (April 2008) *Occupational Projections for Direct-Care Workers 2006-2016*, Facts 1, Bronx, NY: PHI. Available at: http://www.directcareclearinghouse.org/download/BLSfactSheet4-10-08.pdf.

24 For more information and examples of state-based initiatives, see: Dorie Seavey and Vera Salter (October 2006) *Paying for Quality Care: State and Local Strategies for Improving Wages and Benefits for Personal Care Assistants*, Policy Report #2006-18, Washington, DC: AARP Public Policy Institute, pp. 17-19. Available at: http://assets.aarp.org/rgcenter/il/2006_18_care.pdf. See also PHI and the Direct Care Workers Association of North Carolina (forthcoming, Spring 2009), *Results of the 2007 National Survey of State Initiatives on the Long-Term Care Direct Care Workforce*; and Amy Hewitt *et al.* (November 2007) *Direct Support Professional Work Group Report*, North Carolina Commission for Mental Health, Developmental Disabilities, and Substance Abuse.

25 Better Jobs Better Care (January 2006) *Engaging the Public Workforce Development System: Strategies for Investing in the Direct Care Workforce*, Issue Brief No. 6. Available at: http://www.bjbc.org/page.asp?pgID=180).

26 National Center for Health Workforce Analyses (February 2004) Nursing Aides, Home Health Aides, and Related Health Care Occupations—National and Local Workforce Shortages and Associated Data Needs, Bureau of Health Professions, Health Resources and Services Administration, US Department of Health and Human Services, Chapter 8. Available at: http://bhpr.hrsa.gov/healthworkforce/reports/nursing/nurseaides/chapt8.htm.

27 The three occupations usually identified as being related to the direct service workforce are: Nursing Aides, Orderlies and Attendants; Home Health Aides; and Personal and Home Care Aides. The occupation of Social and Human Service Assistants also is sometimes identified as including some DSWs.

28 In particular: a) The occupational definitions generally are out of date and/or mix DSWs with other workers who provide indirect services; b) Some of the industry classifications combine institutional and community LTC settings, reflecting an earlier era in which community-based settings were the exception not the norm; and c) The sampling frame of the OES survey has not kept up with important changes in the LTC industry: it excludes the hundreds of thousands of DSWs who today are self-employed or work as independent providers for private-pay consumers or under state Medicaid programs and waivers. Note: Under Medicaid programs, independent providers are directly employed by consumers (or jointly employed by consumers and a provider agency) and often employer-related fiscal and administrative responsibilities are handled by "Fiscal Agents" or "Employer Agents" and sometimes by public authorities.

29 PHI and the Direct Care Workers Association of North Carolina (forthcoming, Spring 2009), Results of the 2007 National Survey of State Initiatives on the Long-Term Care Direct Care Workforce.

30 See DSW-RC webinar presentation available at: http://www.dswresourcecenter.org/pdfs/NM%20Web%20Data%20Entry%20and%20Reporting%20System.ppt.

KANSAS NEUROLOGICAL INSTITUTE

Our mission is to support each person who lives at KNI to have a meaningful life.
We will accomplish this by:

- Ensuring well-being
- Providing opportunities for choice
- Promoting personal relationships
- Encouraging participation in the community
- Recognizing individuality

KNI strives to provide services in a person-centered manner in order to meet and exceed the expectations of the people who live here and of their family members and guardians.

1. **Characteristics and the needs of the people who live at KNI.**
    - All need 24-hour support and intensive support from direct support professionals
    - 82% have profound disabilities; most others have severe disabilities
    - All are adults (ages 18 to 74)
    - 60% over the of age 50; 85% over the age of 40
    - Median length of stay at KNI 35 years; 90% have lived at KNI for 10+ years
    - 50% are unable to walk
    - 78% are unable to speak
    - 80% are incontinent or unable to use the toilet without assistance
    - 71% have seizures or a history of seizures
    - 28% unable to eat by mouth; receive nutrition via tubes
    - 8% have tracheostomies
    - 21% are prescribed psychotropic medications
    - 32% require specialized behavior support services
    - Over 90 admissions to acute care hospitals in 2013
    - Over 119 admissions to KNI Medical Unit in 2013
    - Over 1.8 million nursing interventions in 2013
    - Great need for assistive technology (personalized seating systems and other equipment)
    - 78% have supported employment positions (1-2 hours/week to several hours/day)

2. **Staffing at KNI**
    - Budgeted in FY 2015 for 473.2 FTE staff (approximately 450 filled)
    - 313 FTE Direct Support (home staff & frontline supervisors, employment, advocacy, etc.)
    - 58.7 FTE Medical/Clinical (medical, nursing, therapies)
    - 85.5 FTE Program Support (facilities & maintenance, business, HR, training, etc.)
    - 16.0 FTE Administrative
    - 310 hours training for Direct Support Professionals in 1st year of employment
    - All Direct Support Professionals trained as Certified Nurse Assistants & Certified Medication Aides (over 105 hours of training) reducing the number of LPNs needed.
    - Turnover rate of 15% in direct support positions
    - Direct Support Professional average pay--$12.76 per hour
    - Physician on-call 24/7
    - Nurses on site 24/7
    - Dentist on staff

3. **Outreach services provided by KNI**
   - Wheelchair clinic served approximately 280 people from the community in FY 2014
   - Assistive Technology department served 300 people from the community in FY 2014
   - Dental services served 111 people from the community in FY 2014
   - Behavior support and Medical services provided to 35 people from the community in FY 2014
   - Training support through on-line training packages & on-site training
   - Philosophy of meeting needs in home communities & increasing community capacity
   - Partner with community agencies for Harvesters food distribution, blood drives, United Way, Project Topeka, classroom space, soccer fields, etc.

4. **How family members and guardians feel about the services provided to their loved ones at KNI**
   - Transition to community services is available to all guardians who desire it
   - Few have been interested in giving serious consideration to a transfer to community service system
   - Annual survey of guardians in 2013 showed overall satisfaction with supports rated 4.8 on a scale of 1-5

5. **KNI provides person-centered supports that enhance a person's quality of life**
   - People at KNI live in unique homes, typically in groups of 7-8 compatible people
   - People have generally shared their homes with the same group of people for many years & experience continuity and security
   - People have opportunities to establish daily routines, opportunities for privacy, opportunities to be with family , friends and people they like
   - The current populations at KNI (146) contrasts with the "licensed capacity established for a 1970s institutional model (454) and makes a vastly better quality of life possible
   - People have frequent opportunities to participate & interact in the community (shopping, social & recreational events, employment, family contact, etc.)
   - People have access to the staffing & transportation that promote access to the community
   - People are employed & earn money they can spend on items and activities that are important to them

6. **The cost of services at KNI includes many expenses that are not included in Home & Community Based Services rates such as:**
   - Primary medical care (Medical staff & 24/7 on-call physician)
   - 24 hour on-site nursing care
   - Services in KNI's Medical Unit to reduce need for ER and acute care services
   - Dental services (for people living at KNI & through outreach services)
   - Service coordination (Targeted Case Management)
   - Transportation, including lift vehicles
   - Food or nutritional formula for those who do not eat by mouth
   - Customized assistive technology services (wheelchairs & assistive technology—for people living at KNI & through outreach services)
   - Highly accessible physical environments with specialized tubs, lift equipment and other environmental modifications
   - Occupational and physical therapy services
   - Adult disposable briefs
   - Housing, utilities and maintenance
   - Medication

- Services from medical specialists (optometry, podiatry, seizure clinic)
- Dietitian services, particularly for those who do not eat by mouth
- Home furnishings
- More highly trained and better paid direct support staff