



## **PHI NATIONAL POLICY AGENDA: Consumer Direction and Family Caregiving**

### **Problem**

Over the last decade, our long-term care system has undergone profound changes. Due to changes in consumer preference and public policy, increasing numbers of consumers are choosing to receive services in their own homes and other community-based settings. Workforce demographics bear this out—there are now more long-term care workers in home and community-based settings than in nursing homes and other institutional settings.

But the shift has involved more than a change in venue—many consumers wish to have greater control over how services are provided and who provides them. Through new consumer-directed programs, people are identifying and hiring their own workers to provide personal assistance services. In some cases, these workers are family members.

The practice of paying family members to provide personal assistance services is blurring the line between family and paid caregiving, underscoring the need for a more holistic approach to caregiving policy. Though typically treated as separate worlds, in reality, family and paid caregiving are intertwined, supplementing and substituting for one another over the course of the ever-changing needs of those with disabilities or chronic illnesses.

As our country moves toward a decentralized model of service delivery much greater responsibility is being placed on consumers for meeting their own needs and on workers for managing their own work lives. Greater infrastructure is required to help both be successful.

### **Solutions**

Many states use fiscal intermediaries to handle payroll functions for self-directing consumers. But intermediaries can assume additional functions to promote efficient service delivery, quality care for consumers, and quality jobs for workers.



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**It is time for a new paradigm – one that integrates and supports both informal and formal care under a single overarching policy agenda. With the increasing reliance on home and community-based services, particularly under consumer-directed programs, developing an appropriate support system for consumers, family caregivers, and paid workers is a critical first step.**

**To support the needs of consumer, workers and family caregivers, PHI recommends that policymakers take the following actions:**

- **Promote the development of a multifaceted intermediary infrastructure** to support consumers and workers in consumer-directed programs and family caregivers. Services and supports should include:
  - **Web-based registries** to support matches between consumers and workers;
  - **Programs and resources to assist consumers in their role as employer/supervisor** –e.g., training in recruiting, hiring, and supervising their staff;
  - **Training programs, information and tools for caregivers—both paid and unpaid**—who are providing and coordinating care;
  - **Linkages for workers** to employment supports, social services and other programs as well as access to pooled benefits;
  - **Resources for families** learning to manage and provide care including a family caregiver assessment to determine the needs and capabilities of families members in assuming these roles ;
  - **Access to emergency back-up services** when regular workers are not available as well as connections to respite and other support services for family caregivers; and
  - **“One-stop” agency structure or single points of entry** with trained staff to assist consumers and families to identify the resources they need and that promote operational efficiencies and support service delivery.

PHI ([www.PHInational.org](http://www.PHInational.org)) works to improve the lives of people who need home and residential care—and the lives of the workers who provide that care. Using our workplace and policy expertise, we help consumers, workers and employers improve long-term services and supports by creating quality direct-care jobs. Our goal is to ensure caring, stable relationships between consumers and workers, so that both may live with dignity, respect, and independence. For more information on the PHI national policy agenda, contact Steve Edelstein, Director of National Policy, at [sedelstein@PHInational.org](mailto:sedelstein@PHInational.org) or 718.402.7413.